THE INTEGRATION OF CONTENT OF DEVELOPMENTAL DISABILITIES IN CALIFORNIA STATE UNIVERSITY, SACRAMENTO, DIVISION OF SOCIAL WORK

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THE INTEGRATION OF CONTENT OF DEVELOPMENTAL DISABILITIES IN CALIFORNIA STATE UNIVERSITY, SACRAMENTO, DIVISION OF SOCIAL WORK

A Project

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Division of Social Work
Abstract

of

THE INTEGRATION OF CONTENT OF DEVELOPMENTAL DISABILITIES IN CALIFORNIA STATE UNIVERSITY, SACRAMENTO, DIVISION OF SOCIAL WORK

by

Jennifer Lee Joyner

The Council on Social Work Education (CSWE) prioritizes that content on diverse and oppressed populations be infused throughout the curriculum in accredited programs in Social Work. Studies conclude that there is a lack of information and content on social work services with persons with a developmental disability and their families in Graduate programs in Social Work across the United States. The population of persons with a developmental disability is steadily increasing as there are more infant and child diagnoses and prolonged life expectancy for adults with a developmental disability. This increase in the population and emerging area of aging persons with a developmental disability creates a demand for knowledgeable, competent, and culturally sensitive social workers to provide best practice services and meet the needs of these persons in a variety of social service settings. The primary purpose of this study was to explore the depth and breadth of curricula focused on content related to Social Work Practice with Persons with a Developmental Disability through surveying MSW II students at California State University, Sacramento. This project was designed to bring awareness to the lack of content on persons with a developmental disability in the graduate programs in Social
Work, and to gather the opinions and perspectives regarding the topic of developmental disabilities in the Master of Social Work program at California State University.

__________________________________, Committee Chair
David Demetral, PhD, LCSW

__________________________________
Date
DEDICATION

I dedicate this thesis to my loving and supportive family. To my wonderful parents, James and Janice Joyner, thank you for encouraging me to pursue my dreams and to follow my heart. You have both instilled the importance of an education and strong work ethic, and provided me with the opportunity to accomplish my educational and career goals. Thank you for loving me and believing in me every step of the way. To my beautiful sister and best friend, Katherine Rose Joyner, thank you for supporting me and putting up with me during the challenging times. You have always been there for me and have made it a mission to keep a smile on my face! To my awesome brother, Kevin Joyner, thank you for being you; you are a true joy! You are the inspiration behind this project, and my motivation to bring awareness to the growing community of persons with developmental disabilities, their families, and the need for competent and culturally knowledgeable social workers in this field. Every goal you accomplish and declare “I did it!” brings a smile to my face and motivates me to accomplish my own goals. I am so proud of the obstacles you have overcome in life and the young man you have become.

To my devoted grandmother, Lois Payne Hoover, thank you for the love you have always shown me. Grammie, you have always made your sweetheart feel special and remind me of the inner strength that I have to endure life’s challenges. I cherish the times I get to spend with you. To my wise grandfather; Robert Hoover, your passing at the beginning of the MSW program was devastating. You were such a strong influence in my life and I miss your words of wisdom. My fondest memory of you is when I graduated
from Sonoma State; you were so proud of me that you had tears in your eyes. Your love and pride for me has motivated me to put 100% into all I do. I know that you will be with me, sharing tears of joy when I graduate in May 2010 with my Masters in Social Work.

This thesis is dedicated to my family for their endless supply of love, support, smiles, and laughs that has made this a meaningful and enjoyable journey. I love you all very much and am grateful to have such an amazing family to celebrate this accomplishment with.
ACKNOWLEDGMENTS

I would like to express appreciation to my family and friends who have been supportive during my entire educational journey. Thank you for continually encouraging me during the hardest times, helping me keep a smile on my face, and challenging me to reach my full potential. It has made me a stronger person to have my loved ones cheering for me throughout this process and sharing this life-changing experience with me. I love and cherish you all and thank you for all the love and support you have shown to me over the years.

I would also like to acknowledge all my fellow colleagues who have travelled on this journey with me. The friendships and bonds that have been established have enriched our journey. The memories of time spent together will stay with me forever. It is difficult for others to truly understand our experience in the MSW program, and I am so grateful to have shared this incredible experience with all of you! I know that without all of you, I would not be where I am today. Thank you.

Lastly, I have been blessed by having the most knowledgeable and dedicated professors and field instructors to educate and support me on my journey in the field of social work, teaching me lessons that will help me throughout my lifetime. I am so grateful for their commitment to their students and their passion for the profession. I would like to express my appreciation to Dr. David Demetral for his endless knowledge and his amazing heart for his students. Dr. Demetral, you have been so supportive during the entire process of writing this thesis. Every time I came in for a consultation I left
feeling energized with renewed excitement because of your vast knowledge and passion in the field of developmental disabilities and social work. Thank you to my professors and field instructors for providing me with a solid foundation in which I know I will continue to grow and utilize the skills you have taught me.
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dedication</td>
<td>vi</td>
</tr>
<tr>
<td>Acknowledgments</td>
<td>viii</td>
</tr>
<tr>
<td>List of Tables</td>
<td>xiv</td>
</tr>
<tr>
<td>List of Figures</td>
<td>xvii</td>
</tr>
<tr>
<td><strong>Chapter</strong></td>
<td></td>
</tr>
<tr>
<td>1. INTRODUCTION</td>
<td>1</td>
</tr>
<tr>
<td>Background</td>
<td>2</td>
</tr>
<tr>
<td>Statement of the Problem</td>
<td>3</td>
</tr>
<tr>
<td>Purpose of the Study</td>
<td>4</td>
</tr>
<tr>
<td>Theoretical Framework</td>
<td>4</td>
</tr>
<tr>
<td>Definition of Terms</td>
<td>5</td>
</tr>
<tr>
<td>Assumptions</td>
<td>7</td>
</tr>
<tr>
<td>Justifications</td>
<td>7</td>
</tr>
<tr>
<td>Limitations</td>
<td>8</td>
</tr>
<tr>
<td>2. LITERATURE REVIEW</td>
<td>9</td>
</tr>
<tr>
<td>Overview of Developmental Disabilities</td>
<td>9</td>
</tr>
<tr>
<td>Prevalence of Disabilities in California</td>
<td>15</td>
</tr>
<tr>
<td>History of Developmental Disabilities</td>
<td>16</td>
</tr>
<tr>
<td>Institutionalization</td>
<td>17</td>
</tr>
</tbody>
</table>
4. FINDINGS ........................................................................................................59

Introduction........................................................................................................59

Participants’ Self-Reported Awareness and Knowledge Towards Providing Social Work Services to Persons with a Developmental Disability .....................59

Participants’ Previous Work Experience with Persons with a Developmental Disability ...........................................................................................................62

Depth and Breadth of Content Related to Persons with a Developmental Disability Integrated into Social Work Curriculum.........................................................62

Coverage on Major Policies in the Field of Developmental Disabilities in the Division of Social Work Policy Course........................................................................63

Coverage on Content of Diversity Issues Relating to Persons with a Developmental Disability in Diversity Course.................................................................65

Coverage on Critical Concepts in Human Behavior in the Social Environment .........................................................................................................................67

Coverage on Tools for Social Work Practice with Persons with a Developmental Disability ....................................................................................................72

Presentation of Content on Developmental Disabilities in Division of Social Work Curriculum..................................................................................................75

Participants’ Self-Reported Awareness and Knowledge and Previous Work with Persons with a Developmental Disability ......................................................79

Participants’ Self-Reported Awareness and Knowledge and Coverage of Individuals with Disabilities Education Act (IDEA), Section 504, and Americans with Disabilities Act in Policy Courses........................................83

Participants’ Self-Reported Knowledge and Awareness and Coverage on Diversity Issues with Persons with a Developmental Disability ................................89

Importance of Developmental Disabilities in the Social Work Program ........91
5. CONCLUSION ..........................................................................................................................95
Results from Study..................................................................................................................96
Recommendations..................................................................................................................98
Appendix A. Survey................................................................................................................102
Appendix B. Informed Consent...............................................................................................105
Appendix C. Outline of Essential Concepts to be Infused in Elective Course on
Advance Practice with Persons with a Developmental Disability ..........107
References.............................................................................................................................109
# LIST OF TABLES

![Page](#)

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Participants Self-Reported Awareness and Knowledge of Providing Services to Persons with a Developmental Disability</td>
<td>60</td>
</tr>
<tr>
<td>2.</td>
<td>Participants’ Previous Work With Persons With Developmental Disabilities</td>
<td>62</td>
</tr>
<tr>
<td>3.</td>
<td>Content Covered on Individuals with Disabilities Education Act in Policy Courses</td>
<td>64</td>
</tr>
<tr>
<td>4.</td>
<td>Content Covered on Section 504 in Policy Courses</td>
<td>65</td>
</tr>
<tr>
<td>5.</td>
<td>Content Covered Americans with Disabilities Act in Policy Courses</td>
<td>65</td>
</tr>
<tr>
<td>6.</td>
<td>Content on Persons with Development Disabilities in Diversity Courses</td>
<td>66</td>
</tr>
<tr>
<td>7.</td>
<td>Pre-natal Development Covered in Human Behavior and Social Environment Course</td>
<td>68</td>
</tr>
<tr>
<td>8.</td>
<td>Pre-natal Diagnosis Covered in Human Behavior and Social Environment Course</td>
<td>68</td>
</tr>
<tr>
<td>9.</td>
<td>Mental Retardation Covered in Human Behavior and Social Environment Course</td>
<td>69</td>
</tr>
<tr>
<td>10.</td>
<td>Cerebral Palsy Covered in Human Behavior and Social Environment Course</td>
<td>69</td>
</tr>
<tr>
<td>11.</td>
<td>Seizure Disorders Covered in Human Behavior</td>
<td>70</td>
</tr>
<tr>
<td>12.</td>
<td>Autism Spectrum Disorder Covered in Human Behavior</td>
<td>70</td>
</tr>
<tr>
<td>13.</td>
<td>Learning Disabilities Covered in Human Behavior</td>
<td>71</td>
</tr>
<tr>
<td>14.</td>
<td>Traumatic Brain Injury Covered in Human Behavior</td>
<td>71</td>
</tr>
<tr>
<td>15.</td>
<td>Coverage on Biopsychosocial Assessment with Persons with a Developmental Disability</td>
<td>73</td>
</tr>
</tbody>
</table>
16. Coverage on Mental Health Assessment with Persons with a Developmental Disability ................................................................. 73

17. Coverage on Counseling Strategies for Social Work with Persons with a Developmental Disability .................................................. 74

18. Clinical Case Management in Working with Persons with a Developmental Disability ........................................................................ 74

19. Professor Presented Content on Developmental Disabilities .......................................................... 76

20. Content on Developmental Disabilities Presented Through Readings .................. 76

21. Content on Developmental Disabilities Integrated Through Class Discussions .................................................................................. 77

22. Content on Developmental Disabilities Provided Through Student Presentations ........................................................................ 77

23. Content on Developmental Disabilities Integrated by Other Sources .................. 78

24. Content on Developmental Disabilities Presented Through the use of Multimedia ........................................................................ 78

25. Content on Developmental Disabilities Presented by a Guest Speaker .................. 79

26. Participants’ Self-Reported Awareness and Knowledge working with Persons with Developmental Disabilities and Previous Work Experience with Persons With a Developmental Disability .............................................................. 81

27. Chi-Square Tests for Table 26 .......................................................................................................................... 82

28. Awareness and Knowledge of Persons with a Developmental Disability and Coverage of Individuals with Disabilities Education Act in Policy Courses ...... 84

29. Chi-Square Tests for Table 28 .......................................................................................................................... 85

30. Awareness and Knowledge of Persons with Developmental Disabilities and Coverage of Section 504 in Policy Course ................................................................. 86

31. Chi-Square Tests for Table 30 .......................................................................................................................... 87
32. Awareness and Knowledge Working With Persons with a Developmental Disability and Coverage on American Disability Act in Policy Course..............88

33. Chi-Square Tests for Table 32 .............................................................................89

34. Awareness and Knowledge Working With Persons with a Developmental Disability and Coverage of Persons with Developmental Disability in Diversity Course ........................................................................................................90

35. Chi-Square Tests for Table 34 .............................................................................91
LIST OF FIGURES

<table>
<thead>
<tr>
<th></th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>The importance of multi-level practice with persons with a developmental</td>
<td>92</td>
</tr>
<tr>
<td></td>
<td>disability</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Developmental disabilities integrated into required courses</td>
<td>93</td>
</tr>
<tr>
<td>3</td>
<td>Students interested in elective course</td>
<td>94</td>
</tr>
</tbody>
</table>
Chapter 1
INTRODUCTION

Persons with a developmental disability utilize a variety of social services and come into contact with social workers in an array of settings. Developmental disabilities affect persons of all ages, race, ethnicities, and even sexual orientation. The term developmental disability encompasses a range of disabilities, which vary in limitations, strengths, and cognitive abilities. These individuals with developmental disabilities are all unique, thus call upon competent, trained professionals to support them throughout the life span in the mainstream community towards being educated and living in the least restrictive environment. Individuals with developmental disabilities and their families face obstacles and challenges that differ from other vulnerable and marginalized groups. The population of developmentally disabled adults and children is rapidly increasing as individuals with disabilities are living longer and more children are being diagnosed with autism, a specific developmental disability. Current statistics indicate that this population has increased 59.6% in between 2007 and 2008 in California alone (California Department of Developmental Services, 2008, p. 9). Though this population fits within the definition of marginalized groups in which social workers serve, the review of literature suggests the field of developmental disabilities lacks professional interest and support.

Having a special relationship with the population of developmental disabilities, this researcher was interested in making a meaningful stride in strengthening the liaison
between social work and the field of developmental disabilities. This researcher’s younger brother is diagnosed with Down syndrome, and since his birth, this researcher has been active in the field of developmental disabilities. Working in special education classes, taking college courses specializing in developmental disabilities and career opportunities, and working one on one with families with children with developmental disabilities in the community has opened this researcher to the need of social workers in the many stages and settings of an individual with developmental disability’s life. Knowing the prevalence and importance of social workers working with children and adults with developmental disabilities and their families, this researcher wanted to pursue a project that would evaluate and promote competence to ensure the service delivery of social workers to the developmentally disabled population and their families.

Background

The population of individuals with developmental disabilities is steadily growing and increasing in numbers. This increase in population growth is especially seen in the state of California. According to the California Department of Developmental Services (2008), the population of individuals with a developmental disability has increased 59.6% over the past decade. Studies illustrate that this population will continue to increase as the prevalence of childhood diagnoses sky rockets and individuals with developmental disabilities experience prolonged life expectancies.

Persons with a developmental disability have a deep history of discrimination and continue to experience stigmatization from the mainstream culture. In the past few
decades, legislation has enacted policies that protect the rights of persons with a developmental disability as well as provide a foundation in which these individuals can integrate into the society. Prior to the movements in the 1960s through mid 1970s, individuals with developmental disabilities were institutionalized and socially isolated from the rest of society. The enactment of the Lanterman Developmental Disabilities Services Act in 1969 into California law insured those persons with developmental disabilities and their families have a right and access to needed services and support to aid in living in the least restrictive environment in mainstream society (USC University Affiliated Program for the Department of Developmental Services, 2001).

Social workers are dedicated to serving oppressed and vulnerable populations as clearly stated in the Social Work Code of Ethics (National Association of Social Workers [NASW], 1996), thus including those with developmental disabilities. Therefore, it is imperative that social workers are sensitive, knowledgeable, and culturally competent of developmental disabilities and the current challenges and issues that they face throughout the life span. With the increasing population of developmental disabilities, social workers will be experiencing more contact with this population in a variety of social service settings.

Statement of the Problem

Studies have indicated that Master in Social Work programs are currently lacking in including content on developmental disabilities in the curriculum. This absence of educational opportunities on this disenfranchised population leads to social workers who
are ill equipped to effectively and efficiently serve these individuals and their families. With the vulnerabilities and uniqueness of this population, social workers should be prepared and knowledgeable in how to work with these individuals and their families.

Purpose of the Study

The purpose of this study is to determine the degree to which the social work curriculum, at California State University, Sacramento Master in Social Work program is preparing its students to be competent and confident in working with individuals with a developmental disability and their families. The benefit of understanding possible limitations of including content on developmental disabilities into the social work curriculum could open avenues for actively integrating discussions and knowledge about this population into previously existing social work courses. This would provide a well-rounded educational experience preparing social work students to be knowledgeable and confident in serving persons with developmental disabilities in any social service setting.

Theoretical Framework

Ecological Systems Theory provides the theoretical framework for this project. The Ecological Systems theoretical framework focuses on the interrelated multi-level systems that affect the development of the human being. Through the lens of this theoretical framework the relationships between the person and the environment are explored at all the levels: micro, meso, and macro. It examines the person in relation to her immediate environment (family and household), to her social networks (friends, school, work), and to the community or society (including laws and policies that govern
the person). The Ecological Systems theory reflects a holistic approach in understanding the person through the life span, as it examines all the factors, resources, and demands that affect the person. As discussed by Rothery (2008) “In any situation where we have to mobilize our resources to meet life’s demands, we perform a balancing act…We draw on our strengths and competencies to access resources and use them effectively to deal with the demands we face” (p. 106).

The Ecological Systems theoretical framework is the foundation for this project and an essential tool for social workers working with persons with a developmental disability and their families. Social workers need to have knowledge and awareness of the multiple systems that affect persons with a developmental disability, be properly equipped to utilize available resources to promote best practice techniques, and to empower the individuals and their families.

Definition of Terms

Developmental Disabilities

Developmental Disabilities refers to a disability that is attributable to mental retardation, cerebral palsy, epilepsy, autism, or disabling conditions found to be closely related to mental retardation or to require treatment similar to that required for individuals with mental retardation. The Developmental Disability shall originate before the age of eighteen, is likely to continue indefinitely, and constitutes a substantial disability. (D. Demetral, personal communication, November 5, 2009)
A ‘substantial disability’ is a condition which results in major impairment(s) of cognitive and/or social functioning, representing sufficient impairment to require interdisciplinary planning and coordination of special or generic services to assist the individual in achieving maximum potential; and the existence of significant functional limitation, as determined by the regional center, in three or more of the following areas of major life activity (Receptive and expressive language, Learning, Self-care, Mobility, Self-direction, Capacity for independent living, and Economic self-sufficiency). (D. Demetral, personal communication, November 5, 2009)

Institutionalization

Institutionalization refers to state hospitals and other facilities that were utilized to house thousands of persons with developmental disabilities prior to the mid-1970s (Mary, 1998).

Cultural Competency

Cultural competency refers to the social worker’s need to be knowledgeable of the populations they serve and sensitive to challenges and issues that they face. As stated in the Code of Ethics, social workers practice in areas of competence and consistently develop their professional expertise. (Hepworth, Rooney, Rooney, Strom-Gottfried, & Larsen, 2006, p. 15)
Marginalization

Marginalization refers to populations or groups who are socially identified as being powerless or of lower social standing (Rothery, 2008). Other terms used to define these populations are Oppressed, Vulnerable, or Disenfranchised.

Assumptions

This study is based on the assumption that the social work curriculum does not adequately address the topic of social work in the field of developmental disabilities. There is a shared assumption that the demand for competent and culturally sensitive social workers in the field of developmental disabilities is high, and that social workers will serve persons with a developmental disability and their families in an array of settings. Thus it is assumed that social work curriculum should integrate topics relative to developmental disabilities so that social work students will be properly equipped to efficiently serve this population.

Justifications

The justification of this study is to increase the competence level of graduate students in the social work program on the topic of developmental disabilities, so that they may efficiently and effectively work with clients with developmental disabilities and their families. The field of social work is diverse in its service delivery and despite which aspect of social work a graduate pursues the chances of having a client with developmental disabilities is likely. The topic of developmental disabilities is assumed to be overlooked in the Master program of Social Work and limited acknowledgement in its
curriculum as discussed in numerous research studies. Therefore it is important to assess California State University of Sacramento (CSUS) Social Work Program at the Masters level incorporation of developmental disabilities into the curriculum and the competence of second year students nearing graduation. The ultimate goal of this study is to identify the need and importance for material on developmental disabilities that can be accessible to professors in the Master in Social Work program to integrate the topic into core social work classes.

Limitations

This study focused on the integration of developmental disabilities in the curriculum at California State University, Sacramento (CSUS) Division of Social Work, Graduate Program. The extent to which the curriculum addressed developmental disabilities was determined through surveying the second year students (MSW II) in the Master of Social Work program. This project did not study other California State Universities or Universities of California Social Work programs. This project relied on the perspectives and self-reports of the voluntary participants of MSW II students at CSUS, Division of Social Work and did not seek out perspectives from alumni students.
Chapter 2
LITERATURE REVIEW

Overview of Developmental Disabilities

The term developmental disability serves as an umbrella for many types of mental disabilities and conditions. The concept of developmental disability has had a historical transformation as the perception and knowledge of professionals and society changed towards this population. Developmental disability can also be defined within the context of varying perspectives. As noted by Myers (2007), there are at least four frameworks in which one can define a disability: “psychological, economic, sociological, and political” (p. 96). In these perspectives, developmental disability has been defined as a social construct as well as a “key aspect of the human experience,” in which disability is the “result of personal and collective responses to difference” (Myers, 2007, p. 96). Definitions of developmental disability reflect perspectives, knowledge, and purpose. Therefore it is necessary to review the governing definitions of developmental disability in order to understand which members of society are included in this classification and to what purpose does this definition serve them.

The federal definition of developmental disability as defined by Federal Public Law 100-146 is defined as:

A severe, chronic disability of a person that:

1. Is attributable to a mental or physical impairment or combination of mental and physical impairments
2. Is manifested before the person attains the age of twenty-two years

3. Is likely to continue indefinitely

4. Results in substantial functional limitations in three or more of the following areas of major life activity, including the following:
   a. Self-care
   b. Receptive and expressive language
   c. Learning
   d. Mobility
   e. Self-direction
   f. Capacity for independent living
   g. Economic self-sufficiency

5. Reflects the person’s need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services that are lifelong or of an extended duration and are individually planned and coordinated.

(Disability Rights California, 1992, p. 1)

Developmental disabilities defined under the Federal Public Law provides a broad overview of a functional definition which provides individuals that fall into this definition with access to specified services. The federal definition does not specify conditions or diagnoses that qualify an individual to having a developmental disability, but rather remains general in its classification. Unlike federal Public Law 100-146, the State of
California has developed its own definition of developmental disability, which provides a more confined and specified focus in outlining the criteria.

The State of California also has an operational definition of developmental disabilities, which aids in the direction of necessary services to residents of California that fall under these categories. As stated and defined in California Welfare and Institutions Code (WIC) Section 4512, a developmental disability is:

A disability which originated before an individual attains age 18, continues, or can be expected to continue, indefinitely, and constitutes a substantial disability for that individual. As defined by the Director of Developmental Services, in consultation with the Superintendent of Public Instruction, this term shall include mental retardation, cerebral palsy, epilepsy, and autism. This term shall also include disabling conditions found to be closely related to mental retardation or to require treatment similar to that required for mentally retarded individuals, but shall not include other handicapping conditions that are solely physical in nature (Disability Rights California, 2009, ¶ 1).

California Welfare and Institutions Code Section 4512 also defines substantial disability as:

The existence of significant functional limitation in three or more of the following areas of major life activity, as determined by a regional center, and as appropriate to the age of the person:
1. Self-care,
2. Receptive and expressive language
3. Learning
4. Mobility
5. Self-direction
6. Capacity for independent living
7. Economic self-sufficiency. (Disability Rights California, 2009, ¶ 2)

For the purpose of this literature review a developmental disability will be used according to the following definition:

“Developmental Disability” refers to a disability that is attributable to mental retardation, cerebral palsy, epilepsy, autism, or disabling conditions found to be closely related to mental retardation or to require treatment similar to that required for individuals with mental retardation. The Developmental Disability shall originate before the age of eighteen, is likely to continue indefinitely, and constitutes a substantial disability. (D. Demetral, personal communication, November 5, 2009)

A “substantial disability” is a condition which results in major impairment(s) of cognitive and/or social functioning, representing sufficient impairment to require interdisciplinary planning and coordination of special or generic services to assist the individual in achieving maximum potential; and the existence of significant functional limitation, as determined by the regional center, in three or more of the
following areas of major life activity (Receptive and expressive language, Learning, Self-care, Mobility, Self-direction, Capacity for independent living, and Economic self-sufficiency). (D. Demetral, personal communication, November 5, 2009)

As illustrated in the California Welfare and Institutions Code Section 4512 and Demetral (personal communication, November 5, 2009), the term developmental disability encompasses the diagnoses or classifications of mental retardation, cerebral palsy, epilepsy, and autism. With a variety of diagnoses combined into one recognized population of individuals with developmental disabilities it is essential for social workers to understand the terms and disabilities in order to fully support and effectively serve this population.

Mental retardation is defined as a “condition of limited mental ability,” which is marked by lower IQ levels and difficulties in daily life functioning (Santrock, 2006). There are many forms of mental retardation classified as mild, moderate, severe, and profound. According to Santrock (2006), 89% of persons diagnosed with mental retardation have IQs of 55 to 70 which indicates mild mental retardation, six percent fall into the category of moderate mental retardation (IQs 40 to 54), approximately 3.5% are classified as having severe mental retardation (IQs 25 to 39), and less than one percent have IQs below 25, indicating profound mental retardation (Santrock, 2006). Mental retardation can have an organic cause or be caused by social and cultural factors. Forms of mental retardation that stem from social and cultural factors are determined when there
is no evidence of organic brain damage found (Santrock, 2006). Organic retardation, on the other hand, is caused by brain damage or is due to a genetic disorder, such as Down Syndrome. Down syndrome, or trisomy 21, is a genetic disorder where there is an extra copy of the 21st chromosome. This over expression of the 21st chromosome alters the course of development (National Association for Down Syndrome, 2009).

Cerebral Palsy is an encompassing term that is used to describe a group of chronic movement or posture disorders. These chronic movements or posture disorders are a result of the limited or lack of ability for the brain to control the muscles. There are four identified disorder of cerebral palsy: spastic (difficult or stiff movement), ataxic (loss of depth or perception and balance), athetoid/dyskinetic (uncontrolled or involuntary movements), and mixed which would include the presence of two or more of the disorders. Cerebral palsy can be caused by injury during the birthing process, though later damages to the brain have also been identified as causes (4MyChild, n.d.).

Epilepsy is characterized as a brain disorder in which groups of neurons located in the brain signal abnormally. This abnormal signaling of the nerve cells disrupts the normal function of the neurons resulting in unfamiliar sensations, emotions, and behaviors. This disruption of normal neural activity can also cause convulsions, muscle spasms, loss of consciousness, as well as occasional seizures. A person is only considered to have epilepsy after having two or more seizures (National Institute of Neurological Disorders and Stroke, 2009).
Autism Spectrum Disorders (ASD) refers to the broad continuum of functioning of persons diagnosed with autism and the impacts ASD has on an individual’s social and daily functioning. ASDs include the conditions of autism, Asperger, and Pervasive Development Disorder (PDD). Autism is characterized as a complex neurobiological disorder that results in impaired communication and relations with others. Autism is also associated with rigid, inflexible routines and schedules, and repetitive behaviors (Autism Speaks, 2009).

Prevalence of Disabilities in California

The population of developmentally disabled persons is steadily increasing. As stated by the California Department of Developmental Services (DDS) (2008), 146,237 individuals receive their services in the state of California. California DDS (2008) also reported an increase of 59.6% from January 1997 to January 2008. Within Sacramento County, the number of persons with developmental disabilities receiving services from Alta Regional Center is 16,483 as reported in October of 2008 (Alta California Regional Center, 2008). There are many factors that can be attributed to the consistent growth of this population, though two specific contributions have been identified in the literature.

One contributing factor is the increased awareness and diagnosis of autism in children. According to the Autism and Developmental Disabilities Monitoring Network Surveillance, the diagnosis of autism was a rarity before the 1990s, however has increased substantially causing an outbreak in concern. Studies conducted in 1985 estimated the prevalence of Autism to be 0.4 to every 1,000 children; today studies
estimate two to six out of every 1,000 children are diagnosed with Autism (Rice, 2007). Though this number appears to be high, the number of children affected by Autism may actually be even higher than estimated. As noted by Mandell, Wiggins, Carpenter, Daniels, DiGuiseppi, Durkin et al. (2009), ethnic minorities and medically underserved communities, are frequently misdiagnosed with conduct disorder or adjustment disorder rather than receiving a proper diagnosis of Autism. This misrepresentation of ethnic and underserved communities could account for a miscalculation of the actual number of persons diagnosed as developmentally disabled. This rapid increase in the prevalence of autism amongst children is an important factor that needs to be identified in examining the growth of the developmentally disabled population.

Although there are many speculations on factors that influence the increase in this specific population, one specific factor found in the literature is the prolonged life expectancy. As discussed by Kropf (1996), life expectancy rates for individuals with developmental disabilities have increased dramatically, especially seen in persons with Down syndrome, which have an increased life expectancy of thirty years. With an increase in childhood diagnoses and significant increases in life expectancy, the developmentally disabled population will continue to increase its numbers.

History of Developmental Disabilities

The topic of developmental disabilities has a rich and in depth history in the United States. Over the past century, there have been many historical milestones and movements that continue to shape the current state of developmental disabilities. The
history of developmental disabilities has not been extensively covered or shared. As stated by Fleischer and Zames (2001),

The reason that people with developmental disabilities are often thought to have had no history is really that they’ve had no recorded history. Only recently have there been any histories of disability. It’s been partly because society has denied that there was anything important to be learned… So, people with disabilities have followed the paths of people with color, and women of trying to reclaim what has long been lost. (p. 12)

The extensive history experienced by people with developmental disabilities needs to be heard in order to learn from the past and properly serve and uplift this minority group in the future. By examining the historical timeline of developmental disabilities one can see how the professional field of social work has become an important and key profession in serving this population in today’s array of settings.

Institutionalization

In the 1800s, persons with developmental disabilities were kept hidden from mainstream society. Housed amongst the homeless, deviant, and mentally ill, people with developmental disabilities were not viewed as functional members of society, and means of caretaking were confined to asylums, almshouses, schools for idiots, and institutions (Ferguson, 2004; Palley & Van Hollen, 2000; Trent, 1994.). The first institution designated for people with developmental disabilities was founded in 1848 by Samuel Gridley. The ideology behind this specialized institution for the blind and for others
following was to teach these children and adolescents a trade so that they could live as productive members in society (Pelka, 1997). The notion that individuals with developmental disabilities could be taught in a controlled environment and reintegrated into the community as productive members of society sought hope in the eyes of the public. This educational movement is believed to have begun in France in the late 18th century, and received momentum in the United States with the opening of specialized institutions to help this disadvantaged population (Malone, McKinsey, Thyer, & Straka, 2000; Trent, 1994).

With the increase in numbers of individuals at these institutions and the unsuccessful transitions of persons with disabilities into society, superintendents of these institutions were pushed to house individuals for life. This transformed how the institutionalization was perceived, as it once served as a hopeful avenue for parents and families of the developmentally disabled, it had now turned into a permanent placement away from the public communities providing minimal custodial care (Palley & Van Hollen, 2000; Trent, 1994). As discussed by Thorn, Pittman, Myers, and Slaughter (2009), these institutions served as a tool for segregation and isolated these individuals from communities. According to Palley and Van Hollen (2000), in 1865 there were only eight schools for children with developmental disabilities across the United States, but by 1876 there were thirty-four states that had established institutions housing at least 25,000 children with mental disabilities. These acts of isolation and institutionalization, according to Thorn et al. (2009), were based on the knowledge of treatments of the time.
However, in hindsight this best known treatment of the time caused emotional damage and internalized discrimination. The use of isolation and institutionalization did not prove to be effective and has caused emotional damage to some individuals as well as feeling devalued and disadvantaged (Martin, 2006).

The utilization of institutions fulfilled two purposes during this time. As depicted by Palley and Van Hollen (2000), institutions served to protect the developmentally disabled and to control them in order to protect society. These primary purposes reflect the ongoing debate on the perception of individuals with developmental disabilities, commonly referred to as the feeble minded, idiots, or mentally retarded during this time in history. In some accounts of this historical timeline, persons with these developmental disabilities were viewed as “innocent” and “child-like.” A shift in mainstream ideology and amongst professionals in the field led to a new perception of this population, which persuaded the expansion of institutions.

Once institutions were utilized for the “warehousing” of the poverty-stricken, mentally ill, and developmentally disabled, a shift in perception occurred amongst professionals that later translated into the rest of society (DeWeaver, 1983). People with developmental disabilities soon became viewed as a burden to society. As discussed by Turnbull and Turnbull (2000), families were often faulted for their child’s mental retardation or deficiencies and were insisted upon “surrendering” their burdensome child to the state’s institutions and the professionals in the field (p. 4). Giving birth or rearing a child with developmental disabilities almost became a shaming experience for families as
this shift in ideology took place. In a society rooted in values of independence and competition it was devastating for a middle class family to give birth to a dependent child (Brockley, 2004). With the “burden” of caring for a child with developmental disabilities and the societal pressures that were placed upon families, many parents opted to place their socially “undesirable” and feared child into the institutions, sometimes even concealing the child’s destiny. Eric Erickson, an internationally known developmental psychologist, and his wife gave birth to a child with Down syndrome in the 1940s and experienced the same fear and pressure. Consequently, Erickson and his wife placed their child in an institution, meanwhile covering up this process by sharing with the family that the child had died at birth (Pollack, 2007). During this time, it was assumed that the professionals held all the knowledge regarding the best treatments and placements for children and individuals with developmental disabilities. This high regard for limited accessible knowledge increased the power amongst professionals in the field, and led to a dangerous movement in the United States.

Eugenics Movement and Conditions of Institutions

The eugenics movement was born out of a Darwinism philosophy, most commonly noted as “survival of the fittest.” Societal efforts had confined most of its undesirable and deviant members into institutions. In attempts to properly serve these individuals, the focus of the institution was on minimal custodial care, which often lasted for the lifetime of the individual. Many professionals associated with the institutions at this time viewed persons with a developmental disability as a social burden and opted to
sterilize this population in attempts to “manage the human gene pool” as well as manage the increased population of “inmates” in the institutions (Pollack, 2007; Trent, 1994). In the U.S. Supreme Court in 1927, it was ruled constitutional to utilize forced sterilization on people with disabilities (Pelka, 1997). Consequently, this movement of social control had its most significant impact on the United States during 1890 to 1940 in which thousands of developmentally disabled men and women were forcibly sterilized.

The institutions provided minimal custodial care, utilized sterilization, and subjected its “inmates” to dangers and abuse. As discussed by Trent (1994), institutions in America were founded on the philosophy of moral treatment, in which individuals housed in the facilities were to be treated with kindness, never to be abused, and only restrained to prevent harm to the individual or others. This commitment to moral treatment dwindled as the size of institutions and population of residents increased. The term institutionalization can have a negative connotation attached to it due to the nature of abuse, neglect, and trauma many residents underwent. As discussed by Pelka (1997), residents of the institution obtained little to no education, faced physical and verbal abuse by staff and other residents, and often became patients of medical experiments. Klein and Strully (2000) addressed personal accounts of the terrible conditions individuals with developmental disabilities faced during their decades of institutionalization. “Residents were subjected to physical, sexual, and emotional mistreatment; barbaric punishment that included prolonged periods of isolation, withholding of food, and physical beatings; and a humiliating lack of privacy for even the most private activities” (Klein & Strully, 2000, p.
Living in institutions posed numerous threats to its residents with developmental disabilities and integrated these horrific practices of abuse and punishment into its daily routines. In a letter from Charles Wilbur, a founder of the Association of Medical Officers of American Institutions for Idiotic and Feeble-Minded Persons, to W.H.C. Smith, Superintendent of Beverly Farms, a private facility, concerns about the institutions were discussed. As quoted by Trent (1994), the letter written in 1909 stated “Very few insane are cured or Feeble minded benefited by the institutions, not because it is not possible but by the way they are managed by the Public. God help the Defectives of the land as man is failing to make much effort” (p. 97). Suspicions of the conditions and effectiveness of the institutions began to rise in spurts leading to the historical milestone in developmental disabilities known as deinstitutionalization.

Deinstitutionalization

The institutions in the United States began to face critical problems. With increasing residents, many institutions became overcrowded posing more risks of abuse for its residents. During the war, funding for these institutions was often cut leading to residents starving to death. The filthy and overcrowded institutions soon became exposed by the media. Photographs captured the poor living conditions that existed behind the walls, and stories of abuse and neglect began to spread throughout the communities. Despite many efforts to expose the horrifying risks of the institutions, there were still approximately 228,500 people living in state institutions in 1967 (Pelka, 1997). Exposing the poor conditions and trauma that were being experienced by residents within the
institution left many parents across the nation concerned for the future of their child with a developmental disability.

With the rise in activity amongst parents advocating on behalf of their children and the rest of the population of individuals with developmental disabilities, the move to deinstitutionalization became more probable. As noted by Pelka (1997), there were significant court cases that served as a milestone for the beginning of deinstitutionalization, Halderman v. Pennhurst State School and Hospital (1978) and New York ARC v. Rockefeller (1973). In these cases, federal judges ruled, “the conditions prevailing at institutions for people with developmental disabilities were so cruel as to be unconstitutional and that people with developmental disabilities had a right to a life in the community” (Pelka, 1997, p. 94). These court rulings were a breakthrough in the history of developmental disabilities as it was now unconstitutional to “warehouse” individuals with developmental disabilities.

In 1961, President Kennedy appointed a Presidential Panel on Mental Retardation with its members being experts in the field including the founder of National Association for Retarded Children, Elizabeth. Boggs, who represented the parents’ perspective (Pelka, 1997). The President’s Panel on Mental Retardation offered a report in 1962 that requested a variety of living arrangements and group homes that would allow individuals with developmental disabilities to live within the community. With significant strides taken towards deinstitutionalization, new terms such as normalization, mainstreaming, and community inclusion were brought to the forefront.
Three Waves of Movements in Developmental Disabilities

*Professional Movement*

In the 19th century and early decades of the 20th century, developmental disabilities were included in the medical field. It was the professionals in this field that held the knowledge and power in the movement of developmental disabilities. This stage in the history of developmental disabilities is viewed as the first wave of the disability movement, spearheaded by the professionals (Wehmeyer, Bersani, & Gagne, 2000). It was the professionals that moved mental retardation into its own field separate from medicine, psychology, and education and it was those professionals that became experts in this newly founded field (Wehmeyer et al., 2000). The professionalism movement marked a time in history where developmental disability was perceived as a societal problem that needed to be fixed or to the extreme, eliminated (Trent, 1994). Medical professionals dominated the field of developmental disability during this time, which left many individuals with developmental disabilities and their parents and families powerless.

*Parent Movement*

Before this phenomenon, parents were isolated in raising their developmentally disabled child and in dealing with the fears, societal pressures, and life changing decisions with regard to their child’s well-being. Parents were pushed disregard their own input and trust the professionals in the field who often recommended institutionalizing
the child. Lacking other parents to turn to during these tough times, many endured the troubles and pain alone.

Parents of developmentally disabled children have played an important and influential role in advocating for the rights of their children which is marked as the Second Wave in the disability movement, known as the parent movement. As stated by Abeson and Davis (2000), current opportunities for the developmentally disabled are “the direct result of the diligent and thoughtful work of the parents who, as they organized, gave birth to what became a national movement” (p. 19). This national movement is a large portion of the history of developmental disabilities for it served as a foundation for further progress and accomplishments in the field. The parents’ commitment to their children and the rest of the developmentally disabled population has led to many triumphs in the progression of developmental disabilities.

It took the courage and determination of one mother of a mentally retarded child to plant the seed of this national phenomenon. In 1894, this mother placed an ad in the paper searching for other parents and children such as herself, calling for parents to band together and fight for their children (Castles, 2004). This small act of courage in a time surrounded by fear led to the creation of one of the most powerful organization formerly known as the National Association for Retarded Children (NARC), and now referred to as the National Association for Retarded Citizens (NARC). Parents formed the ARC in 1950 with its mission to:
secure for all people with mental retardation the opportunity to choose and realize
their goals of where and how they learn, live, work, and play, and to reduce the
incidence of and limit the consequence of mental retardation through education,
research, advocacy and the support of families, friends, and community. (Pelka,
1997, p. 22)

The NARC grew rapidly gaining over a thousand members in its first year. By
1975, there were approximately 1,700 state and local chapters throughout the United
States with over 218,000 members (Abeson & Davis, 2000, p. 20). Together these
members strived for creating more opportunities and a better image for their children and
future children born into the United States with developmental disabilities. This idea is
reflected in the following quote made by the President’s Committee on Mental
Retardation in 1977 in regard to the parents’ movement; “It required parents to bring their
problem into the open and to challenge both the traditional image of mental defect and
the rejection and discrimination practiced by society against them” (Abeson & Davis,
2000, p. 19). Parents and families with members with developmental disabilities took a
risk to strive for a better acceptance amongst the public for persons with a developmental
disability. Together, the NARC along with another parent movement organization known
as United Cerebral Palsy (UCP) fought and lobbied for social justice and equality for the
developmentally disabled. NARC and UCP have had a significant impact on the
expansion of local, state, and federal programs that serve persons with developmental
disabilities and their families (Pelka, 1997). The motivation and determination of parents
of developmentally disabled children across the United States has led to an advancement and accessibility of services as well as recognizing persons with developmental disabilities as citizens with fundamental rights. Today, parents continue to advocate for their own children as well as the rest of the developmentally disabled population, thus continuing on the legacy of the powerful and courageous parent movement.

*Self-Advocacy Movement*

The Third Wave of the Developmental Disability movement is marked as the self-advocacy movement. According to Wehmeyer et al. (2000), there were multiple components that led to the self-advocacy movement, though the highlighted factor was the founding of the term self-determination. The concept of self-determination was introduced to the developmental disability movement in the 1970s, when parents and professionals together recognized that many individuals with developmental disabilities could advocate for themselves and make their own voices heard (Wehmeyer et al., 2000). This concept and recognition of self-determination by parents and professionals coupled with the normalization and community integration advancements opened up the avenue for individuals with developmental disabilities to take control over their own lives and have their voices heard. It was this enlightening movement that led to the principle that people with developmental disabilities are their own best advocates (Pelka, 1997).

This self-advocacy movement began in small strides where many individuals advocated for themselves and for friends on personal matters. These individuals moving into the community from the institutions united with each other in “loosely organized”
groups for the purpose of educating and advocating for each other as newly integrated members in the community (Pelka, 1997). These smaller advocacy groups combined with many individuals with developmental disabilities grew into highly organized self-advocacy groups that moved from advocating on a personal level to tackling important issues on a macro level that affected the developmental disability population as a whole. Today there are over 700 self-advocacy groups across the country, in which some of its high positioned leaders are individuals with developmental disabilities (Pelka, 1997; Wehmeyer et al., 2000).

This self-advocacy movement in the field of developmental disabilities has played an important role in overcoming the stereotypes of the previous decades. As discussed by Wehmeyer et al. (2000), persons with developmental disabilities are now perceived as capable and competent members of society that need to be shown respect and treated with dignity. The self-advocacy movement has provided many individuals with developmental disabilities a chance to exert control over their own lives and have their voices heard on a macro level. According to Shoultz (n.d.), this movement has allotted many individuals with developmental disabilities a chance to practice multiple self-advocating skills such as: “learning how to be assertive, how to participate in public forums, how to present in front of audiences, and how to support one another” (p. 1). This Third Wave of the Developmental Disability movement, the self-advocacy movement, has gained momentum over the past three decades and continues to make significant strides in the current state.
Class Action Law Suits and Public Law

The Developmental Disability movement gained momentum through the rulings of significant court cases. The outcomes of these historical milestones have led to the implementation of Public Laws that recognize and protect the rights of persons with developmental disabilities.

A class action suit, Wyatt v. Stickney, proved to be a landmark in the historical movement of developmental disabilities. Occurring in 1972, Wyatt filed a class action suit for the patients in Alabama’s state institutions for the mentally impaired, which advocated for their right to adequate treatments and care (Harvard Law Review, 1973; Taylor, 2001). The ruling of this court case proclaimed that patients of Alabama State Institutions have a “constitutional right to the least restrictive circumstances necessary to achieve the purposes of habilitation” (Taylor, 2001, p. 16). The rulings in this court case proved victorious in the Developmental Disability movement as it was used to argue a similar class action suit in New York ARC v. Rockefeller in 1973 (Pelka, 1997). Other federal court cases including O’Connor v. Donaldson in 1975 and Halderman v. Pennhurst in 1978, along with Wyatt v. Stickney concluded that the institutionalization of individuals with developmental disabilities without hope of progression with treatment or education was unconstitutional (Pelka, 1997). The class action suit of Wyatt v. Stickney and its impact on the federal level, legally ensured individuals with developmental disabilities the right to a habilitating environment.
Brown v. Board of Education of Topeka, United States Supreme Court case of 1954 is considered as a noteworthy decision in American history (LaNear & Frattura, 2007). This historical case challenged the segregation of students based on color and addressed the need for equal educational opportunity for all school-aged children and adolescents. The Supreme Court ruled that segregated schools based on color was unconstitutional and did not provide equal opportunities (San Francisco State University Disability Programs and Resource Center, 2006). As discussed by LaNear and Frattura (2007), though this court case was pivotal around racial inequalities it served as a legal foundation for the equal educational opportunities amongst all students, which includes those with developmental disabilities. The arguments presented by Brown in this historical case have been referenced in proceeding judicial decisions in regards to the rights of students with developmental disabilities (LaNear & Frattura, 2007). LaNear and Frattura (2007) do argue the historical significance of Brown v. Board of Education in regards to the current dual system of education, where desegregation and inclusion is still an ongoing process. Brown v. Board of Education did provide a legal starting point for the equal opportunity for education amongst all students, however its implementation and success is under scrutiny decades later.

The next milestone in the Developmental Disability movement was the passage of the Education For All Handicapped Children Act, Public Law 94-142, which built upon the legal foundation put forth through Brown v. Board of Education, and progressing disability rights law suits, Mills v. Board of Education (1972) and PARC (Pennsylvania
Association for Retarded Children v. Pennsylvania (1972) (Fleischer & Zames, 2001; Pelka, 1997). Public Law 94-142 required all public schools to provide students with disabilities, including developmental disabilities, “free appropriate public education” and to do so in the “least restrictive” settings or an “integrated environment” (Pardini, 2002; San Francisco State University Disability Programs and Resource Center, 2006). Altshuler (2007) explains that prior to the enactment of this law, there were over one million children with disabilities that were excluded from the public school system, and over half of children with disabilities received inadequate schooling. Public Law 94-142 was renamed to Individuals with Disabilities Education Act (IDEA) in 1990, and has been amended and reauthorized since. IDEA is a federal law that oversees the implementation of state and public agencies that provide early intervention, special education, and other services to children with disabilities at no cost to parents (Altshuler, 2007). IDEA outlines “comprehensive procedural requirements, such as written notice, due process hearings, access to records, and right to counsel, permitting parental or guardian challenges to an IEP in order to ensure that parents play a pivotal role in the child’s education” (Fleischer & Zames, 2001, p. 184).

Section 504 under the Rehabilitation Act of 1973 is an important legislation in the Developmental Disability movement for it protects the rights of individuals with disabilities that participate in programs and activities that receive federal funding. It is stated in Section 504 that:
No otherwise qualified individual with a disability in the United States… shall solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance. (U.S. Department of Education, 2007, p. 4)

According to the U.S. Department of Education (2007), under the provisions of Section 504, public school districts are required to provide free appropriate education to all qualified students with identified disabilities, despite the severity of the disability.

Free Appropriate Public Education (FAPE) is an educational program under IDEA that provides individualized education to specifically meet the unique needs of a child from preschool to the age of 21. Through FAPE, schools are required to provide individualized education to meet the needs of its students and any disabilities they may have. In order to properly provide the needed services to the student, an Individualized Education Program (IEP) is developed (Altshuler, 2007).

The IEP is a mandated program for the school systems, under the IDEA and FAPE, in order to ensure the rights of students with developmental disabilities to appropriate educational services. Each IEP is created around the unique needs of the student receiving special services and allows for parental involvement throughout the special education process (Altshuler, 2007).

The following components are required in the IEP:
1. A statement of students’ present level of educational functioning and how the disability impacts their ability to progress within the general curriculum

2. A statement of measurable annual goals and short term objectives that address the students’ educational needs that result from their identified disability

3. An outline of the specific special education services, related service, supplemental services, and program modifications that will be made in order to achieve the measurable annual goals, including their frequency, duration and location

4. Any modifications in standardized testing, and how students will be appropriately assessed for educational progress

5. A statement of how students progress toward the annual goals will be measured and how their parents will be regularly informed

6. When students reach the age of fourteen (and older), a statement of transitional service needs and agency linkages. (Altshuler, 2007, pp. 27-28)

The Developmental Disabilities Assistance and Bill of Rights Act (Public Law 94-103) of 1975 is the only law that explicitly supports individuals with developmental disabilities and their families (Turnbull, Stowe, Agosta, Turnbull, Schrandt, & Muller, 2007). The P.L. 94-103 served as a “bill of rights” for the population with developmental disabilities and was a funding source for many services (Strock-Lynskey & Keller, 2007, p. 115). When the Developmental Disabilities Assistance and Bill of Rights was enacted
into law it initially withheld funding to institutions that did not follow the outlined
criteria, such as to provide suitable treatments and services to its residents with
developmental disabilities (Pelka, 2007). Turnbull et al. (2007) discuss the goals of P.L.
94-103 as to strengthen families with members with developmental disabilities with
supports, services, and assistance.

The American with Disabilities Act (ADA) was enacted into law on July 26, 1990
by President George W. Bush to prohibit discrimination on the basis of disability in many
areas to ensure equal opportunities for all. This is a monumental act in history, for it is
the first time full legal citizenship to Americans with disabilities is legally acknowledged
and recognized (San Francisco State University Disability Programs and Resource
Center, 2006). The specified sections outlined in the ADA include: employment, state
and local government, public accommodations, commercial facilities, transportation, and
telecommunications (U.S. Department of Justice, 2005). This recent milestone in the
developmental disability movement strives to fulfill four policy goals, as illustrated by
Ne’eman (2009), “equality of opportunity, full participation, independent living, and
economic self-sufficiency” (p. 113). Equal opportunity as defined in the disability rights
movement is the “equal chance to access the full scope of what society has to offer,
regardless of his/her starting position in life or particular characteristics” (Ne’eman,

The history of the development of these policies and public laws are important for
social workers to understand because they created the need for mainstreaming,
normalization, and individualized educational plans (IEP) which incorporates the profession of social work. The move from institutionalization towards community integration opened the avenue for professional social workers to work in the field of developmental disabilities. As case managers, supporters, and advocates, social workers have been in the front line of this transition. It is important in the profession of social work to understand the policies and public laws that affect the populations that social workers are serving to efficiently meet their needs and support them on reaching their highest potentials.

Lanterman Act and Regional Centers

The Lanterman Developmental Disabilities Services Act (Lanterman Act) was enacted into California law in 1969 and outlines the rights and responsibilities of persons with a developmental disability and develops agencies that provide services to assist with support (USC University Affiliated Program for the Department of Developmental Services, 2001). In 1963, only about 5% of the population of persons with a developmental disability were being served by the State of California (Golden Gate Regional Center, n.d.b). A study was conducted to redefine the responsibilities of the State of California for serving the population of persons with a developmental disability based on the notion that families were unable to provide for their loved ones care and needed services and needed state support (Golden Gate Regional Center, n.d.b). This study interviewed 100 parents and surveyed more than 1,200 parents to identify what parents with children with a developmental disability needed from the State of California.
The themes that came from the interviews and surveys were that parents needed community residential care and counseling (Golden Gate Center, n.d.b). Thus, statewide agencies were created in response to the voices of the parent movement and continue to respond to the voices of the self advocacy movement to serve persons with a developmental disability and their families through coordinating and providing necessary services to keep these individuals in the community and out of state hospitals.

The idea of California Regional Centers was introduced in 1965, where it was defined in Assembly Bill 691 to be “regional diagnostic, counseling and service centers for mentally retarded persons and their families” (¶ 20). This bill required the State of California to expand its responsibility to this population by serving them from the time a person is diagnosed with needing special care rather than waiting until they are admitted to a state hospital (Golden Gate Center, n.d.b). The idea of regional centers accompanied the movements towards deinstitutionalization, thus setting up support in the community, offering other residential opportunities and settings for persons with a developmental disability and their families, meanwhile promoting integration into communities and public society.

Agencies that provide services and support under the Lanterman Act are the California Regional Centers. In the early years of the implementation of the Lanterman Act, there were only seven California Regional Centers serving this population. Currently, there are 21 regional centers serving persons with a developmental disability statewide. The California Regional Centers fulfill many roles and responsibilities in
providing services. These include the following: outreach to identify persons that may need services along with assessment and evaluation to determine those that qualify for those services, counseling for persons that are at high risk for having a baby with a developmental disability, early intervention services, development of Individual Program Plan (IPP), service coordination of individualized services that support individuals with reaching their goals as defined in the IPP and promote community integration, and provide advocacy to ensure the protection of the rights of persons with a developmental disability (Golden Gate Regional Center, n.d.a).

Services Offered and Provided to Persons with a Developmental Disability

Persons with a developmental disability are supported through an array of services to meet the unique and individualized needs to promote growth towards highest potential and level of functioning. Services that are most commonly utilized by persons with a developmental disability include: physical therapy, occupational therapy, speech/vision/hearing therapy, adaptive behavioral skills training, community living skills, independent living skills, self advocacy skills, and educational skills and support services.

Developmental Disabilities and Impact on Families

Families with a member having a developmental disability can have a significant impact on the whole family unit as well as its other members. Each member has a different experience, though literature indicates common themes that parents and siblings share with other families when having a child or sibling diagnosed with a developmental
disability. The most common theme that is thread through family systems when there is a child with a developmental disability is stress. Parents and siblings of a child with a developmental disability have a lot of emotions to sort through as they try to understand the disability and the resources available, grieve the loss of having a typical functioning child or sibling, and change the family dynamics and routines to accommodate the child with a developmental disability.

Guralnick (2000) outlines four stressors that impact the family unit, and emphasizes the importance of maneuvering through these stressors so that it does not impact the developing child with a developmental disability. This is not to minimize the other stressors that are not directly related to the child with a developmental disability, rather that these are common stressors faced by families in the early stages of learning of their child’s diagnosis. The four common stressors that have been identified in families with a child with a developmental disability are: deciphering needs based on abundant information, family and interpersonal distress, resource needs, and threats to self-confidence in parenting abilities (Guralnick, 2000).

A huge stressor occurs upon hearing that the child has a diagnosis of a developmental disability. All members of the family react differently to hearing this news as they try to grieve the loss and accept and love the child they have. This can create tension and stress in the family unit as each member copes with the news differently. The overwhelming information can also be stressful for parents as they try and sort through professional opinions and literature to seek out the best interventions and therapies for
their child’s specific needs. Finding services and resources that match the family can also create more stress upon the family unit. As the family unit faces distress and deals with strong emotions, it is reported that many will retract from the social environment and become more isolated. The family also faces a shift as it changes routines, schedules, and other structures to accommodate the special needs of the child. This can cause the added stress of finances when a parent has to transfer time and energy away from the work force and towards the child (Guralnick, 2000).

The last stressor the Guralnick (2000) discusses is the perceived threat to the confidence in parenting that is felt through the other three identified stressors. “These three classes of stressors threaten the very essence of sound parenting—that is, the ability to maintain a sense of control, confidence, and mastery over the persistent and often surprising parenting challenges” (Guralnick, 2000, p. 39). The parents can become overwhelmed with the new challenges and needs that their child with a developmental disability needs, and may feel their parenting skills are threatened when they cannot efficiently meet those needs without resources and services.

Plant and Sanders (2007) conducted a study that predicted the levels of stress of parental caregivers and found that the level of difficulty of providing care to the child with a developmental disability was the best indicator for the level of stress a parent felt. This research did not support previous studies and assumptions that the level of severity of the disability indicated the level of stress for a parent caregiver. Though the level of severity of the disability can affect the level of difficulty of care-giving, it is not the sole
indicator of stress. It does appear that the perceived difficulty of the care giving can create insecurities and lack of confidence in parental abilities. This feeling of failing can have negative effects on the parent, the marriage, the child with a developmental disability, other children in the family unit, and the family unit as a whole.

The impact of the stressors on and within the family unit can affect the development of the child with a developmental disability. Guralnick (2000) emphasizes the importance of dealing with these stressors through services and resources provided through early intervention to decrease the risk for further complications in the development of the child with a developmental disability. Stressors can halt the development of parent-child transactions, can limit the parent’s ability to seek out resources and services that will aid with development, and can cause the family unit to isolate from their social support network restricting the child’s experiences (Guralnick, 2000). These stressors can also put a strain on the marriage or partnership.

Hatton, Emerson, Graham, Blacher, and Llewellyn (2009) conducted a study to understand the changes in family composition when having a child with a developmental disability. Findings indicated that rates of separation after the child’s birth were higher among families who had a child with a developmental disability, though rates were also higher in maternal re-partnering in these families. The findings appeared to balance out, though this separation and re-partnering serves as added stress on the family unit and can impact the development of the child with special needs.
Guralnick (2000) emphasizes the impact stressors on the family unit can ultimately have on the child’s intellectual development during the first five years of life, as it can result in IQ declines of 8-12 points (Guralnick, 2000). The stressors discussed are commonly felt in families with a child with a developmental disability. There are services and resources readily available for parents and the family to access to alleviate some of the stress and to work productively in caring for the developing child, meeting their special needs. Each family unit navigates through these stressors on their own unique path, in which they can find a sense of confidence, purpose, meaning, and hope for the future of their child.

Understanding the effects a child with a developmental disability can have on a family is important for social workers that with these families. Since the common stressors families face can have negative effects on the child and on the family composition, it is important for the social worker to understand these stressors and work with the family to establish necessary supports and resources to alleviate some of the stress.

Siblings play an important role in the family unit, and also experience common themes that are prevalent in other families with a child with a developmental disability. Carsillo (2006) outlined the common themes that are present with siblings without a disability when in a family with a sibling with a developmental disability. These themes include feelings of neglect from their parents or other family members, fearing to upset the parents by asking questions, feeling embarrassed in public or around social networks.
when with the sibling with a developmental disability, and fearful of the unknown around
the parameters of the disability as parents overestimate the sibling’s understanding of the
diagnosis. The stressors that affect the parents and the family unit also impact the
siblings. Oftentimes siblings may feel ashamed of having these feelings because they
know there sibling needs the extra care and attention. In order to understand the real
feelings of siblings, *The Sibling Slam Book: What It’s Really Like to Have a Brother or
Sister With Special Needs* was created by Don Meyer (2005), who runs Sibshops or focus
group for siblings, to present the voices of the siblings in families with a child with a
developmental disability. All participants were in there teenage years; the multiple
responses to the questions reflected the strong, profound, and at times incompatible
emotions that were felt as a sibling to a brother or sister with a developmental disability.

Common themes in the responses to “Do you think being a sib has affected your
personality? How?” included feelings of being mature and growing up fast as many
siblings took on the caregiver role at a young age. This also brought on feelings of
worrying excessively about their sibling and being defensive towards those who are
insensitive towards persons with a developmental disability. These themes are illustrated
in the following quotes:

“I think I’m a stronger person for having a sister with special needs. I’ve had to
stand up for more things-for both my sister and myself-than I would have if she
wasn’t in my life”; “Because I had to comprehend my sister’s limitations and be
considerate of her differences and needs, I subconsciously played the role of carer
when we were at the same primary school. I made sure she was okay, worried when she didn’t have friends to play with, and checked to see if she had taken her medicines...". (Meyer, 2005, p. 50)

Many of these siblings have different experiences and responses to having a sibling with a developmental disability, though all of them were able to learn life lessons through their role as a sibling. Developing characteristics of patience, understanding, acceptance, and unconditional love were common and some were grateful for meeting new people with disabilities and those who worked with their siblings. Siblings also had the common response of never giving up because their siblings with a developmental disability never stop trying despite the limitations and obstacles placed before them. Lauren O., aged 16 stated, “Normal is just a cycle on the washing machine. No one is the same; we all have differences and excel in different areas” (Meyer, 2005, p. 132).

Siblings play a crucial role in the family unit and have important perspectives on growing up with a sibling with a developmental disability. Though these feelings and emotions can be complex and complicated, it is reassuring for siblings to know that there are other kids and teenagers that are going through the same experiences.

It is beneficial for the social worker to work with all members of the family of the person with a developmental disability. Siblings can often be overlooked when the family is seeking services, though they play an important role in the family and are experiencing some of their own stressors. The siblings need services and resources as well, which is a
reason why SibShops were created to serve as a support group for siblings with a brother or sister with a developmental disability.

Social Work Practice with Persons with a Developmental Disability

Social work practice with persons with a developmental disability does not operate in an isolated field. Whether the social worker is with Child Protective Services (CPS), Adult Protective Services (APS), Child Welfare, Educational Social Work, Clinical Social Work, Drug and Alcohol Social Work, Gerontology or Hospice Social Work, or an array of other settings it is important to know about multi-level practice with persons with a developmental disability and their families because they will be seeking services in one or all of these areas. Thus, the need for all social work students to understand the legal, social, human behavioral, biological, and social justice advocacy positions for this population are critical.

DeWeaver (as cited in Gourdine and Sanders, 2003) addresses the multiple roles of the social work profession in working with persons with a developmental disability and their families. These roles include: “evaluating clients, counseling parents of clients, discharge planning, planners, advocates, protection professionals, providers of direct services or case managers, consultants, resources developers” (Gourdine & Sanders, 2003, p. 213). The roles the professional social worker fulfills can be viewed on a continuum throughout the lifespan of the individual with the developmental disability. With the increase in early child diagnoses and the prolonged life expectancies of persons with a developmental disability, social workers will be needed in all stages of the life
development, such as early intervention and the increasing field of gerontology amongst the population of developmental disabilities.

**Early Intervention**

Early intervention services were created through the enactment of P.L. 99-457, and is specifically outlined in Part C of IDEA, in which this social system was designed to provide support and services to infants and toddlers with disabilities and their families, spanning from birth to three years of age (Guralnick, 2000; Malone et al., 2000). Guralink (2000) summarizes the multiple factors that emerged to form an efficient model and early intervention system. These factors include:

- dramatically increasing knowledge of the capacities of infants and toddlers,
- emerging developmental models emphasizing the importance of family patterns of interaction regulating child outcomes, and behavioral and neurobiological research emphasizing the disproportionate influence of the first few years of life and the plasticity of development during that period. (p. 43)

It was recognized that it is crucial to intervene during this small window of time of development and make the best use out of it. Parents of infants and young children with a developmental disability needed the resources, services, and support to enhance their child’s overall development. Thus, the implementation of early intervention services was created to help families with their newborn or young child with a developmental disability through an array of services and resources to alleviate the stress and empower and support the parents in managing the complexity of the situations.
Social workers serving families through early intervention services need to be equipped with knowledge and techniques that will be effective in empowering the family rather than overwhelming the unit, and provide supports and resources to help the developing infant and young child with a developmental disability reach important developmental milestones. Roskenkoetter, Hains, and Dogaru (2007) discuss techniques that are effective for social workers practicing in the area of early intervention. Amongst these techniques, the need for focusing on parental strengths and family involvement in service planning was highlighted. Block and Block (2002) agree that family involvement is crucial in early intervention as current trends now focus around a family-driven mode. In this approach, the social worker serves as a facilitator and collaborator in a partnership with the family, supporting the family in determining the best services and resources for their infant or young child with a developmental disability. This approach differs from previous models as the social worker does not provide the “expert” advice to the parent, but rather develops a reciprocal dialogue in which services, resources, research, and professional knowledge of development can be discussed.

Developmental Disabilities and the Aging Population

The life expectancy of persons with a developmental disability has increased over the past two decades creating an emerging population of aging persons with developmental disabilities. This trend has been referred to as the “invisible elderly” or the “little known group,” as this population of persons aging with developmental disabilities had previously received little acknowledgement in services (Doka & Lavin, 2003, p.
Doka and Lavin (2003) reported that the population of persons with a developmental disability rarely survived into the latter part of their life span. This trend has changed with the impacts of deinstitutionalization and increased awareness and knowledge in the medical realm in treating persons with a developmental disability. Sheets (2005) reports that Americans aged sixty years and older with an intellectual or developmental disability currently account for approximately 526,000 persons, and 600,000 persons aged 60 years and older are diagnosed with cerebral palsy. In a report presented to the 2005 White House Conference on Aging by Alan Factor, the Associate Director of Rehabilitation Research and Training Center on Aging with Developmental Disabilities, it was estimated that the mean age of death for persons with developmental disabilities increased from 19 years of age during the 1930s to 66 years in 1993; a reported increase of 247% (Factor, 2004, p. 1). Factor (2004) estimated that in the year 2000, persons with a developmental disability aged 60 years or older accounted for 641,161 in the United States. This number has been projected to reach 1.2 million in the year of 2030. Aging persons with a developmental disability are now experiencing similar life expectancies as the non disabled populations, which is consequently causing a competition for services (Parish & Lutwick, 2005).

The aging population faces many new obstacles as their life expectancy increases. Cognitive abilities, physical health, support systems, and experiences of loss complicate the later part of the life span. Rapid declines in overall functioning coupled with declines in external resources, specifically social supports, creates a “difficult paradox in later
life” for persons with a developmental disability (Doka & Lavin, 2003). Doka and Lavin (2003) report that declines in cognitive abilities and overall physical health are “accentuated in persons with a developmental disability” which can be more restrictive with fewer services and resources available for support (p. 136).

The demand for social workers in the field of gerontology has never been higher. With the aging generation of the “baby boomers” coupled with increased life expectancy of persons with a developmental disability, studies have indicated a crucial need for social workers with specialized training or knowledge in the realm of gerontology and developmental disabilities. Parish and Lutwick (2005) highlight the importance of NASW policy statements on the implementation of services to aging persons with a developmental disability, as it emphasizes the importance to provide services that are “respectful, appropriate, and directed by individuals with disabilities” (p. 352). Social workers work with persons with a developmental disability and their families throughout their life span; therefore, social workers need to be knowledgeable and competent as this population they serve faces new challenges and obstacles in later life, so that they may allocate and provide appropriate services that are directed by their consumers.

Teitelman and O’Neill (2001) reported that social workers in the field, even those working with older adults, have received minimal training and education in the domain of gerontology. Parish and Lutwick (2005) recommends that social work education addresses the necessary competencies and knowledge required to effectively serve persons with a developmental disability and their families, with an emphasis on how to
support families and the individual during the “end-of-caregiving transition” (p. 353). Doka and Lavin (2003) suggest significant changes in educating professionals working with aging persons with a developmental disability and making changes in social programs and policies to efficiently meet the needs of this emerging group. With the increased longevity of persons with a developmental disability, there is a greater need for competent social workers in the field of gerontology and developmental disabilities to effectively meet the individuals and families where they are at and appropriately guide and connect them to services that will continue to support and respect the individual during the later stages of life.

Social Work Education and Integration of Content on Developmental Disabilities

Persons with a developmental disability and their families have very unique needs and concerns that need to be properly and effectively addressed in the field of social work. As illustrated, individuals with developmental disabilities and their families are a vulnerable population that seeks an array of social services during their life span. It is necessary to provide this rapidly growing population with culturally sensitive and knowledgeable social workers that can effectively meet their special concerns and needs during each significant milestone and transitional period. The CWSE requires that MSW programs provide curriculum that covers content on disability. Gouradine and Sanders (2003) address the lack in standardized requirements for integrating this content into the curriculum, which consequently leads to the inadequate coverage of this vulnerable population. Deweaver and Kropf (1992) also emphasize this lack of an educational
standard for including content on developmental disabilities into the program, and refer to this population as “a forgotten minority in education” (p. 36).

As discussed by Olney (2000), when content on developmental disabilities and effective ways of working with these individuals is left out of the curriculum, professionals entering the field are ill equipped with knowledge and skills to support these people. Mary (1998) also identifies this current wave of social workers as unprepared and unmotivated to serve this disenfranchised population, which has in the past decade been a high priority in the field. The commitment to the Social Work *Code of Ethics* has been weak as the priority has shifted towards a clinical approach.

Russo-Gleicher (2008) discusses the need for Master in Social Work programs to reemphasize social justice and advocacy and to fulfill the role of promoting opportunities for students to develop knowledge and interest in serving the developmentally disabled population. It is crucial for social work students to be exposed to developmental disabilities so that they can develop cultural sensitivity and knowledge and work towards cultural competence. As studied by Rimmerman, Hozmi, and Duvdevany (2000), contact and exposure to individuals with developmental disabilities aids the able bodied student in developing an attitude towards the whole population. It provides an opportunity for the able bodied student to overcome unconscious rejection toward the person with developmental disability and reflect on the anxieties, fears, and stigma that may be present within the student (Rimmerman et al., 2000).
Literature covering the inclusion of developmental disabilities within social work and other service-oriented educational programs highlights the lack of coverage resulting in social workers and other professionals insecure and uncertain of how to serve this population. Findings produced by Liese, Clevenger, and Hanley (1999) conclude that around 80% of all MSW programs surveyed place the least emphasis on developmental disability content, with less than 20% strongly emphasizing its content. Through studies, Russo-Gleicher (2008) has concluded findings that curriculum content covering developmental disabilities is nearly absent in MSW programs across the country.

Solutions for Integrating Developmental Disabilities into the Curriculum

The recognition of the lack of content of developmental disabilities in the MSW programs has led to studies on identifying ways of reintegrating this subject back into the curriculum. In the qualitative study conducted by Russo-Gleicher (2008), themes submerged in solutions for bringing content on developmental disabilities to the social work students. The overall solution interweaved throughout the themes was to integrate developmental disabilities into all social work core courses (HBSE, Diversity, Practice, Policy, and Research courses) through the utilization of case studies, role playing, guest speakers from professionals in the field, current issues, policies and legislations historically and currently affecting the population, application to theories, or research studies that have added to the knowledge in the field (Russo-Gleicher, 2008). This theme was also presented by Deweaver and Kropf (1992) in which an infusion model in which content on developmental disabilities would be integrated into existing Human Behavior
in the Social Environment courses. Even though a thorough overview of developmental disability content would require its own course, Kropf (1996) suggests that older people with developmental disabilities should be combined in gerontology courses or discussed with topics regarding the aging population. This solution implies that the overall content on developmental disabilities be broken down into parts that can be infused with other topics up for discussion in MSW required courses.

Literature also focuses on reintroducing University Affiliated Programs (UAP) to address the growing population of developmental disabilities and the need for confident and knowledgeable social workers to serve these individuals and their families. As stated by Mary (1998), “university affiliated programs were developed during Kennedy’s presidency to prevail over the tremendous shortage of professionals educated and trained to serve persons with developmental disabilities” (p. 254). As explained by Liese et al. (1999), UAP has been approved by the Developmental Disabilities Assistance and Bill of Rights Act of 1994 to assist communities and states to effectively serve and meet the needs of individuals with developmental disabilities and their families. UAP task force has also worked alongside CWSE to develop curriculum designed to bring developmental disability content to the “‘mainstream’ in social work education” (Liese et al., 1999, p. 65). Though the utilization of UAPs has made significant strides, the implementation of UAPs to Master in Social Work Programs has currently not been successful.
Literature Foundation For Project

The Master in Social Work Programs do not currently have an educational standard for integrating content on developmental disabilities into the program which has ultimately led to a lack of coverage on this marginalized population. This population is facing an influx in numbers in which the demand for trained, knowledgeable, and confident social workers is needed. In order to be effective working with this population, social workers need to develop an understanding what the definition of a developmental disability means, the policies and legalities that affect this population, diversity issues, human development, ethical considerations, social justice issues, best practice techniques, resources available, and other pertinent issues that directly and indirectly affect this population and their families. The purpose of this project is to determine if California State University, Sacramento Division of Social Work, Master program has effectively integrated content on developmental disabilities into the curriculum as well as survey the second year students to determine their self reported knowledge and confidence in providing social work services to persons with a developmental disability and their families.
Chapter 3

METHODS

Study Design

This study design was an exploratory research design. An exploratory design is utilized to explore an area of interest that has not been fully researched; so that the researcher can develop focused ideas that can be further explained in future research (Krueger & Neuman, 2006). The primary purpose of this study was to explore the extent to which the Division of Social Work at Sacramento State University incorporated persons with developmental disabilities and relative topics to the field of advanced social work practice. Research indicates that MSW programs across the country lack content and instruction on educating graduate students on persons with a developmental disability. This study was designed to gather the opinions and perspectives of the Master of Social Work students in their second year (MSW II) at Sacramento State University on the depth and breadth of content of persons with developmental disabilities in the curriculum as well as the overall importance of addressing this population in the social work program. The curriculum under observation will be of the core social work courses (Practice, Policy, Human Behavior in the Social Environment, Research, and Diversity) and other electives. This researcher utilized quantitative and some qualitative questions in the developed survey. The focus was on whether essential content on developmental disabilities has been covered in specified courses of the social work program, to explore the level of knowledge that these voluntary student participants had of persons with
developmental disabilities, and to explore the perceived importance of integrating content of developmental disabilities into the program or creating an elective course for Social Work Practice with Persons with a Developmental Disability.

Sampling

This researcher utilized non-random, purposive sampling; focusing on second year Master students in the Graduate School of Social Work at Sacramento State University. Non-random purposive sampling focuses on specific criterion in which all participants that fit this criterion are sought out, and no eligible participants are excluded (Krueger & Neuman, 2006). This researcher sought out these student participants through permission from professors in the Division of Social Work, Graduate Program, to offer their students the opportunity to voluntarily participate in this study. All the surveys were distributed in classes geared towards second year students. The sample size in this study amounted to 68 voluntary participants (N=68) out of 74 possible participants in the selected courses. This sample size is 54% of the reported 125 MSW II students.

Measurement Instrument

This researcher presented the purpose of this study to all eligible student participants in preapproved Graduate Social Work courses by the Committee for the Protection of Human Subjects Division of Social Work. These courses had to be selected and approved by the Committee before the study could be conducted. This researcher stated that this survey was deemed no risk to its participants, and was exploring the opinions of the students. A survey was developed by this researcher to serve as a tool for
measurement in identifying the coverage in core social work courses, as well as electives, of topics related to persons with developmental disabilities, self-rated knowledge of developmental disabilities, and to highlight the student’s perspectives on importance of developmental disabilities in core classes or creating an elective for deeper coverage (see Appendix A). This survey consisted of 10 questions. The students that wished to participate were instructed to fill out the survey to the best of their knowledge.

Data Collection Procedure

This researcher administered informed consent forms to all MSW II students in selected Graduate School of Social Work courses (see Appendix B). The informed consent explained the voluntary nature of participation in this survey. Students that wished to participate in the study read and signed the informed consent. All consent forms were obtained and stored in its’ own envelope. After all informed consents were collected, the survey was administered. This survey was collected and placed in a separate envelope to ensure confidentiality, which were later stored in a locked file cabinet at this researcher’s residence.

Protection of Human Subjects

The parameters of this project and the study were submitted and approved by the Committee for the Protection of Human Subjects from the Division of Social Work. This study was deemed no risk by the Committee (Human Subjects Approval #: 09-10-048). All participating MSW II students in selected courses received an informed consent form that explained the nature of this study, and the measures that were taken by this
researcher to keep all information obtained confidential. This researcher collected the informed consents before administering the survey, and kept both documents in separate envelopes to ensure the privacy of all subjects. These documents were stored in a locked cabinet at this researcher’s residence. Only this researcher and her thesis advisor Dr. Demetral had access to these completed surveys. Upon completion of this study, all documents were destroyed.

Statistical Analysis Plan

The data obtained by this researcher through content analysis on the course outlines and completed surveys was analyzed using the statistical package, Statistical Package for the Social Sciences (SPSS). Cross tabulations, frequency distributions, and bivariate analyses were used to understand the extent to which courses of social work in graduate studies address the topic of developmental disabilities. This information was presented through graphs and tables created with SPSS.

Limitations

There have been several limitations identified in this research study. This researcher was not able to access a survey sample that included all MSW II students in the Graduate School of Social Work at California State University, Sacramento, but rather received a sample that represented 54% of the reported 125 second-year students. This obstacle occurred as this researcher did not receive approval to survey all second-year practice courses, which is a required course for all MSW II students. Therefore, this researcher had obtained a smaller sample size of 68 completed surveys by only surveying
a sample of students who were in courses in which this researcher received approval. This researcher was limited to surveying approved courses that were geared towards second year students. There was a small sample of voluntary participants that were not MSW II students, but rather MSW students in the three-year program, or MSW students in the accelerated one-year program. The survey developed by this researcher asked specific questions that targeted whether or not specified information was covered in identified questions. Through feedback from the voluntary participants, this researcher noted that many participants identified that material encompassing social work practice with persons with a developmental disability was covered though not in the specific courses that this researcher was targeting. With this knowledge, this researcher believes that the data obtained through the surveys may not accurately reflect the material that is covered in core social work courses.
Chapter 4
FINDINGS
Introduction

This chapter presents the findings that were collected from the 68 completed surveys. The data was compiled together in tables and pie charts to illustrate the frequencies and relationships between variables with the collected data. In this chapter, the researcher will summarize the findings and discuss the implications of the results.

Participants’ Self-Reported Awareness and Knowledge Towards Providing Social Work Services to Persons with a Developmental Disability

There were 68 participants that completed the survey in this study. These participants were asked to rate their current awareness and knowledge of providing social work services to persons with a developmental disability. The definition of a developmental disability was provided on the survey for a clear, uniformed definition. The participants were to rate themselves using a Likert scale, indicating none, minimal, average, above average, or extensive awareness and knowledge (see Table 1). Among these 68 participants, only 2.9% rated themselves of having no awareness and knowledge, 36.8% indicated minimal awareness and knowledge, 32.4% indicated average awareness and knowledge, 19.1% rated themselves as above average awareness and knowledge, and 8.8% self-rated having extensive awareness and knowledge of providing social work services to persons with a developmental disability. The emerging themes from the data indicate that the majority of the social work student participants in their second year of the Graduate School of Social Work had minimal to average
knowledge and awareness of providing social work services to persons with a developmental disability.

Table 1

*Participants’ Self-Reported Awareness and Knowledge of Providing Services to Persons with a Developmental Disability*

<table>
<thead>
<tr>
<th>Self-Reported Awareness</th>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>2</td>
<td>2.9</td>
<td>2.9</td>
<td>2.9</td>
</tr>
<tr>
<td>Minimal</td>
<td>25</td>
<td>36.8</td>
<td>36.8</td>
<td>39.7</td>
</tr>
<tr>
<td>Average</td>
<td>22</td>
<td>32.4</td>
<td>32.4</td>
<td>72.1</td>
</tr>
<tr>
<td>Above Average</td>
<td>13</td>
<td>19.1</td>
<td>19.1</td>
<td>91.2</td>
</tr>
<tr>
<td>Extensive</td>
<td>6</td>
<td>8.8</td>
<td>8.8</td>
<td>100.0</td>
</tr>
<tr>
<td>Total</td>
<td>68</td>
<td>100.0</td>
<td>100.0</td>
<td></td>
</tr>
</tbody>
</table>

The combined percentage of 69.2% of students reporting average or minimal awareness and knowledge working with persons with a developmental disability is a concerning figure. The literature indicates a decline of competent and knowledgeable social workers in the realm of developmental disabilities due to the lack of content of this topic in social work curriculum. The data of this study suggests a similar trend in the Division of Social Work, Graduate program at California State University, Sacramento (CSUS). Literature focuses on the need for competent social workers prepared to serve
individuals with a developmental disability and their families throughout the stages of their life. This demand for competent social workers does not reflect the supply of social workers that is graduating in 2010 from CSUS.

This researcher did note the statistics of student participants that did report having an above average or extensive knowledge and competence of social services and the population with a developmental disability. The combined percentage of 27.8% does illustrate that there is a small portion of students that feel they are competent and confident in providing social work services to persons with a developmental disability and their families. The data does beg the question of what makes these social work students report above average and extensive knowledge in providing social work services to this population. Are these social work students equipped with the knowledge, policies, and understanding of the critical biopsychosocial issues that affect persons with a developmental disability and their families and have they developed the essential skills to work with the population throughout the stages of the life span? The answer to this question may not be clear. The findings from the data suggest that these social work students did not obtain significant knowledge relating to critical biopsychosocial issues and may even be lacking awareness of important policies that shape the lives and families of persons with a developmental disability. Therefore, it appears that student participants that rated themselves as having above average or extensive knowledge and awareness had reported previous work experience with persons with a developmental disability,
knowing someone with a developmental disability, or having a relative with a developmental disability.

Participants’ Previous Work Experience with Persons with a Developmental Disability

The survey gathered information in regards to previous work experience with persons with a developmental disability. Among the participants surveyed, 73.5% had previous experience with persons with a developmental disability (see Table 2). This experience was indicated to be from work, internships, volunteering, relationships, or personal family members.

Table 2

*Participants’ Previous Work with Persons with Developmental Disabilities*

<table>
<thead>
<tr>
<th>Previous Work With Persons With a Developmental Disability</th>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>18</td>
<td>26.5</td>
<td>26.5</td>
<td>26.5</td>
</tr>
<tr>
<td>Yes</td>
<td>50</td>
<td>73.5</td>
<td>73.5</td>
<td>100.0</td>
</tr>
<tr>
<td>Total</td>
<td>68</td>
<td>100.0</td>
<td>100.0</td>
<td></td>
</tr>
</tbody>
</table>

Depth and Breadth of Content Related to Persons with a Developmental Disability Integrated into Social Work Curriculum

It was noted through literature reviews that topics relating to persons with a developmental disability may receive minimal to no coverage in social work curriculum. These findings are applicable to the majority of social work schools across the United
States. This research study was designed to gather the perspectives from the students on the integration of content related to the field of developmental disabilities into Sacramento State University, Division of Social Work, Graduate program core courses. For the purpose of this study, these core courses include: Practice, Policy, Diversity, and Human Behavior in the Social Environment. This survey evaluated coverage of content and methods of presentation. This researcher used frequency distributions to analyze the data and to determine the percentage of topics relating to the field of developmental disabilities.

Coverage on Major Policies in the Field of Developmental Disabilities in the Division of Social Work Policy Course

Data was collected on whether major policies affecting persons with a developmental disability was covered in policy courses in the Division of Social Work, Graduate Program at Sacramento State University. The survey identified three major policies: Public Law 94-142 (Education of All Handicapped Children Act now known as Individuals with Disabilities Education Act (IDEA), Section 504 [Pub. L. 93-112][29 U.S.C. 794], and American with Disabilities Act of 1990. Participants were asked to indicate if there was coverage on each of these policies in their social work policy course. Results indicate that out of 68 participants, only 32.4% received content on IDEA (see Table 3) and 16.2% indicated coverage on Section 504 (see Table 4) in policy courses at the Graduate level in the Division of Social Work. Findings conclude that information and content on Americans with Disabilities Act (see Table 5) was adequately covered in policy courses, with 73.5% of student participants reporting coverage.
It was noted by this researcher that participants indicated that they marked “yes” that there was content on these policies, though it was not specifically covered in policy courses. Some participants stated that they had received information on these policies in their practice courses, while some others stated that their knowledge came from undergraduate courses or knowledge from outside sources. Therefore, this researcher believes these results do not directly reflect the presence of content in policy courses, but rather the participants’ current or prior obtained knowledge.

Table 3

*Content Covered on Individuals with Disabilities Education Act in Policy Courses*

<table>
<thead>
<tr>
<th>Coverage on Content</th>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>46</td>
<td>67.6</td>
<td>67.6</td>
<td>67.6</td>
</tr>
<tr>
<td>Yes</td>
<td>22</td>
<td>32.4</td>
<td>32.4</td>
<td>100.0</td>
</tr>
<tr>
<td>Total</td>
<td>68</td>
<td>100.0</td>
<td>100.0</td>
<td></td>
</tr>
</tbody>
</table>
Table 4

*Content Covered on Section 504 in Policy Courses*

<table>
<thead>
<tr>
<th>Coverage on Content</th>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>57</td>
<td>83.8</td>
<td>83.8</td>
<td>83.8</td>
</tr>
<tr>
<td>Yes</td>
<td>11</td>
<td>16.2</td>
<td>16.2</td>
<td>100.0</td>
</tr>
<tr>
<td>Total</td>
<td>68</td>
<td>100.0</td>
<td>100.0</td>
<td></td>
</tr>
</tbody>
</table>

Table 5

*Content Covered Americans with Disabilities Act in Policy Courses*

<table>
<thead>
<tr>
<th>Coverage on Content</th>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>18</td>
<td>26.5</td>
<td>26.5</td>
<td>26.5</td>
</tr>
<tr>
<td>Yes</td>
<td>50</td>
<td>73.5</td>
<td>73.5</td>
<td>100.0</td>
</tr>
<tr>
<td>Total</td>
<td>68</td>
<td>100.0</td>
<td>100.0</td>
<td></td>
</tr>
</tbody>
</table>

Coverage on Content of Diversity Issues Relating to Persons with a Developmental Disability in Diversity Course

There are many diversity issues that face the population of persons with a developmental disability. This is an oppressed and marginalized population that deserves coverage in diversity related courses for the experiences of oppression, stigma, patronization, infantilization, and disenfranchisement of persons with a developmental
disability in our culture. Participants were asked to indicate whether content in diversity course covered diversity issues pertinent to persons with a developmental disability. This survey allowed participants to communicate whether it was covered, not covered, or if there was some coverage in the diversity course. Results suggest that 41.2% of the participants had diversity issues relating to persons with developmental disabilities covered in their diversity course, 29.4% reported some coverage, and 29.4% implied there was no content on diversity issues with persons with developmental disabilities in diversity (see Table 6).

Table 6

<table>
<thead>
<tr>
<th>Coverage of Content</th>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>20</td>
<td>29.4</td>
<td>29.4</td>
<td>29.4</td>
</tr>
<tr>
<td>Yes</td>
<td>28</td>
<td>41.2</td>
<td>41.2</td>
<td>70.6</td>
</tr>
<tr>
<td>Some Coverage</td>
<td>20</td>
<td>29.4</td>
<td>29.4</td>
<td>100.0</td>
</tr>
<tr>
<td>Total</td>
<td>68</td>
<td>100.0</td>
<td>100.0</td>
<td></td>
</tr>
</tbody>
</table>

Findings suggest that 29.4% of the student participants received no coverage on diversity issues relating to the population with developmental disabilities in their core class of diversity. This statistic reflects the growing trend presented in the literature in regards to social work curriculum that neglects introducing and integrating content of developmental disabilities into the courses. Diversity courses are focused on the
oppression, stigma, and disenfranchisement of groups of people and also calls for social workers to face their own values and stereotypes towards various oppressed populations. The results of the analyzed data reflect a prominent attitude in the society that has persisted throughout history in which the lives of persons with developmental disabilities are devalued and less of a priority. Neglecting content on diversity issues as they relate to persons with a developmental disability and their families is violating the commitment to the Social Work Code of Ethics and perpetuating a repetition of attitudes that were identified in the history of developmental disabilities.

Coverage on Critical Concepts in Human Behavior in the Social Environment

This survey addressed the coverage of content that focuses on critical bio-psycho-social issues that are important in providing social work services to persons with a developmental disability. The survey listed eight topics (Pre-natal development, Pre-natal diagnosis, mental retardation, cerebral palsy, seizure disorders, autism spectrum disorders, learning disabilities, and traumatic brain injury) and the participant was instructed to check the topics that were covered in their Human Behavior and Social Environment class. This researcher utilized frequency distributions to determine the percentage of coverage of each topic (see Tables 7-14). Findings indicate that 17.6% noted content on pre-natal development, 5.9% reported content on pre-natal diagnosis, 14.7% received content on mental retardation, 4.4% indicated content on cerebral palsy and content on seizure disorders, 14.7% reported content on autism spectrum disorders, 32.4% indicated receiving content on learning disabilities, and 17.6% noted content on
traumatic brain injury. Some participants indicated on the survey that they received information on the specified content from undergraduate social work courses; therefore these numbers could indicate a potentially smaller percentage than is already reflected.

Table 7

*Pre-natal Development Covered in Human Behavior and Social Environment Course*

<table>
<thead>
<tr>
<th>Coverage on Content</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>12</td>
<td>17.6</td>
</tr>
<tr>
<td>No</td>
<td>56</td>
<td>82.4</td>
</tr>
<tr>
<td>Total</td>
<td>68</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Table 8

*Pre-natal Diagnosis Covered in Human Behavior and Social Environment Course*

<table>
<thead>
<tr>
<th>Coverage on Content</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>4</td>
<td>5.9</td>
</tr>
<tr>
<td>No</td>
<td>64</td>
<td>94.1</td>
</tr>
<tr>
<td>Total</td>
<td>68</td>
<td>100.0</td>
</tr>
</tbody>
</table>
Table 9

*Mental Retardation Covered in Human Behavior and Social Environment Course*

<table>
<thead>
<tr>
<th>Coverage on Content</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>10</td>
<td>14.7</td>
</tr>
<tr>
<td>No</td>
<td>58</td>
<td>85.3</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>68</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>

Table 10

*Cerebral Palsy Covered in Human Behavior and Social Environment Course*

<table>
<thead>
<tr>
<th>Coverage on Content</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>3</td>
<td>4.4</td>
</tr>
<tr>
<td>No</td>
<td>65</td>
<td>95.6</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>68</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>
Table 11

*Seizure Disorders Covered in Human Behavior*

<table>
<thead>
<tr>
<th>Coverage on Content</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>3</td>
<td>4.4</td>
</tr>
<tr>
<td>No</td>
<td>65</td>
<td>95.6</td>
</tr>
<tr>
<td>Total</td>
<td>68</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Table 12

*Autism Spectrum Disorder Covered in Human Behavior*

<table>
<thead>
<tr>
<th>Coverage on Content</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>10</td>
<td>14.7</td>
</tr>
<tr>
<td>No</td>
<td>58</td>
<td>85.3</td>
</tr>
<tr>
<td>Total</td>
<td>68</td>
<td>100.0</td>
</tr>
</tbody>
</table>
Table 13

Learning Disabilities Covered in Human Behavior

<table>
<thead>
<tr>
<th>Coverage on Content</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>22</td>
<td>32.4</td>
</tr>
<tr>
<td>No</td>
<td>46</td>
<td>67.6</td>
</tr>
<tr>
<td>Total</td>
<td>68</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Table 14

Traumatic Brain Injury Covered in Human Behavior

<table>
<thead>
<tr>
<th>Coverage on Content</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>12</td>
<td>17.6</td>
</tr>
<tr>
<td>No</td>
<td>56</td>
<td>82.4</td>
</tr>
<tr>
<td>Total</td>
<td>68</td>
<td>100.0</td>
</tr>
</tbody>
</table>

These findings indicate that only a very small portion of the social work participants have been presented with critical issues that are pertinent for biopsychosocial assessments with persons with a developmental disability. These results do not support the prior findings of social work students that rated themselves of having above average and extensive knowledge and awareness, as the same percentage is not present in these findings relating to biopsychosocial concepts. The assumption is raised that those
students whom indicated higher levels of awareness and confidence in providing social work services with persons with a developmental disability are either not equipped with understanding of critical biospsychosocial concepts or have obtained this knowledge elsewhere.

Coverage on Tools for Social Work Practice with Persons with a Developmental Disability

The Graduate level of social work curriculum provides students with the opportunity to learn about essential tools and skills that are necessary in the field and integrate these tools/skills into their practice. This survey inquired about the coverage of social work tools that assist in provision of social services to persons with a developmental disability. These tools included the following: biopsychosocial assessment, mental health assessment, counseling strategies, and clinical case management geared towards working with persons with a developmental disability and their families. The results of the collected data indicate that 44.1% of the participants received information on biopsychosocial assessments working with children, adolescents, and adults suspected of having a developmental delay (see Table 15), whereas only 17.6% reported learning about mental health assessments for persons with a developmental disability (see Table 16). Data also shows that 33.8% noted receiving education on counseling strategies for persons with a developmental disability and their families (see Table 17), and 54.4% indicated receiving information on clinical case management with this population (see Table 18).
Table 15

_Coverage on Biopsychosocial Assessment with Persons with a Developmental Disability_

<table>
<thead>
<tr>
<th>Coverage on Content</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>30</td>
<td>44.1</td>
</tr>
<tr>
<td>No</td>
<td>38</td>
<td>55.9</td>
</tr>
<tr>
<td>Total</td>
<td>68</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Table 16

_Coverage on Mental Health Assessment with Persons with a Developmental Disability_

<table>
<thead>
<tr>
<th>Coverage on Content</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>12</td>
<td>17.6</td>
</tr>
<tr>
<td>No</td>
<td>56</td>
<td>82.4</td>
</tr>
<tr>
<td>Total</td>
<td>68</td>
<td>100.0</td>
</tr>
</tbody>
</table>
Table 17

**Coverage on Counseling Strategies for Social Work with Persons with a Developmental Disability**

<table>
<thead>
<tr>
<th>Coverage on Content</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>23</td>
<td>33.8</td>
</tr>
<tr>
<td>No</td>
<td>45</td>
<td>66.2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>68</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>

Table 18

**Clinical Case Management in Working with Persons with a Developmental Disability**

<table>
<thead>
<tr>
<th>Coverage on Content</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>37</td>
<td>54.4</td>
</tr>
<tr>
<td>No</td>
<td>31</td>
<td>45.6</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>68</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>

It is assumed that the listed tools for social work practice are integrated into the social work curriculum and weaved throughout the core classes that have been identified. Therefore, the findings indicate that when these tools are presented in the academic setting, there is a chance that it will include these tools in working with persons with a developmental disability. For instance, when learning about the biopsychosocial assessment, the analyzed data suggests that there is a 44.1% chance that students will
learn how to utilize this assessment for children, adolescents, and adults suspected of having a developmental delay. The findings indicate that 54.4% of the student participants had received education in some form regarding clinical case management in working with persons with a developmental disability, however only 33.8% received education on counseling strategies, and even fewer, 17.6% received education on mental health assessments with persons with a developmental disability.

Presentation of Content on Developmental Disabilities in Division of Social Work Curriculum

Student participants were asked to indicate how they received information on developmental disabilities. Findings suggest that 58.8% of students reported receiving information from professors (see Table 19), 60.3% indicate gaining information through readings (see Table 20), and 51.5% reported topics on developmental disabilities were brought up during class discussion (see Table 21). Other categories on the survey included: student presentations, 14.7% (see Table 22); other sources, 2.9% (see Table 23); multimedia, 20.6% (see Table 24); and information presented by a guest speaker, 13.2% (see Table 25).
Table 19

*Professor Presented Content on Developmental Disabilities*

<table>
<thead>
<tr>
<th>Coverage on Content</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>40</td>
<td>58.8</td>
</tr>
<tr>
<td>No</td>
<td>28</td>
<td>41.2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>68</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>

Table 20

*Content on Developmental Disabilities Presented Through Readings*

<table>
<thead>
<tr>
<th>Coverage on Content</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>41</td>
<td>60.3</td>
</tr>
<tr>
<td>No</td>
<td>27</td>
<td>39.7</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>68</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>
Table 21

*Content on Developmental Disabilities Integrated Through Class Discussions*

<table>
<thead>
<tr>
<th>Coverage on Content</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>35</td>
<td>51.5</td>
</tr>
<tr>
<td>No</td>
<td>33</td>
<td>48.5</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>68</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>

Table 22

*Content on Developmental Disabilities Provided Through Student Presentations*

<table>
<thead>
<tr>
<th>Coverage on Content</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>10</td>
<td>14.7</td>
</tr>
<tr>
<td>No</td>
<td>58</td>
<td>85.3</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>68</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>
Table 23

*Content on Developmental Disabilities Integrated by Other Sources*

<table>
<thead>
<tr>
<th>Coverage on Content</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>2</td>
<td>2.9</td>
</tr>
<tr>
<td>No</td>
<td>66</td>
<td>97.1</td>
</tr>
<tr>
<td>Total</td>
<td>68</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Table 24

*Content on Developmental Disabilities Presented Through the use of Multimedia*

<table>
<thead>
<tr>
<th>Coverage on Content</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>14</td>
<td>20.6</td>
</tr>
<tr>
<td>No</td>
<td>54</td>
<td>79.4</td>
</tr>
<tr>
<td>Total</td>
<td>68</td>
<td>100.0</td>
</tr>
</tbody>
</table>
Table 25

*Content on Developmental Disabilities Presented by a Guest Speaker*

<table>
<thead>
<tr>
<th>Coverage on Content</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>9</td>
<td>13.2</td>
</tr>
<tr>
<td>No</td>
<td>59</td>
<td>86.8</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>68</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>

These findings indicate that a large portion of content on developmental disabilities was presented to the participants by the professor, through readings, and also generated through class discussions. Therefore, it appears that the amount of coverage on social work services and persons with a developmental disability depended on the professor’s knowledge and understanding of this topic, as well as relative reading materials and knowledgeable students that could generate educating class discussions.

**Participants’ Self-Reported Awareness and Knowledge and Previous Work with Persons with a Developmental Disability**

A correlation between the two variables of participants’ self-reported awareness and knowledge and previous work experience with persons with a developmental disability was explored. The cross-tabulation table depicts the interdependent relationship between the two variables, participants’ self-reported level of knowledge and awareness and previous experiences with persons with a developmental disability (see Table 26). This statistical analysis was utilized to determine if there was indeed a relationship
between student participant’s self-reported awareness and knowledge of persons with a developmental disability with previous experience with this population. This table indicates that approximately 52% of the participants rated their awareness and knowledge average, above average, or extensive and also had previous experience working with persons with a developmental disability. There was only an approximate 9% of participants that reported average or above average that did not have any previous work experience with persons with a developmental disability. The table reports that approximately 22% of the participants had reported previous work experience and rated no or minimal knowledge and awareness. Results indicate that there is a statistical significance between these two variables of self-rated knowledge and awareness of persons with a developmental disability and previous work experience with this population (r=.057). It appears that level of self-reported awareness and knowledge in providing social work services to this population is dependent on the amount of previous work experience.
Table 26

Participants’ Self-Reported Awareness and Knowledge working with Persons with Developmental Disabilities and Previous Work Experience with Persons With a Developmental Disability

<table>
<thead>
<tr>
<th>Awareness and knowledge working with persons with developmental disabilities</th>
<th>None</th>
<th>Minimal</th>
<th>Average</th>
<th>Average</th>
<th>Extensive</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Previous Work With Persons With Developmental Disabilities</td>
<td>No</td>
<td>1</td>
<td>11</td>
<td>5</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Yes</td>
<td>1</td>
<td>14</td>
<td>17</td>
<td>12</td>
<td>6</td>
<td>50</td>
</tr>
<tr>
<td>Total</td>
<td>2</td>
<td>25</td>
<td>22</td>
<td>13</td>
<td>6</td>
<td>68</td>
</tr>
</tbody>
</table>
Table 27

*Chi-Square Tests for Table 26*

<table>
<thead>
<tr>
<th></th>
<th>Value</th>
<th>df</th>
<th>Asymp. Sig. (2-sided)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pearson Chi-Square</td>
<td>9.189a</td>
<td>4</td>
<td>.057</td>
</tr>
<tr>
<td>Likelihood Ratio</td>
<td>10.895</td>
<td>4</td>
<td>.028</td>
</tr>
<tr>
<td>Linear-by-Linear Assoc</td>
<td>8.686</td>
<td>1</td>
<td>.003</td>
</tr>
<tr>
<td>N of Valid Cases</td>
<td>68</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

This association between the two identified variables could describe a possible correlation between a social work student’s reported awareness and knowledge working with persons with a developmental disability and previous work experience with this population. It was important to determine whether or not the same association exists between reported knowledge and awareness and the presence of developmental disabilities in the social work curriculum. Therefore, it was important to explore the correlation between the student participant’s self reported knowledge and awareness of providing social services to persons with a developmental disability and the coverage of major policies that affect the lives of persons with a developmental disability and their families.
Participants’ Self-Reported Awareness and Knowledge and Coverage of Individuals with Disabilities Education Act (IDEA), Section 504, and Americans with Disabilities Act in Policy Courses

The results presented in the cross tabulation table indicate that participants’ self-reported knowledge of providing social services to persons with a developmental disability is not correlated with receiving education on IDEA, a major policy affecting the population of persons with developmental disabilities. The analyzed data shows that approximately 22% of the participants reported having average, above average, or extensive knowledge and awareness and also reported receiving information on IDEA in their policy course (see Table 28).
Table 28

Awareness and Knowledge of Persons with a Developmental Disability and Coverage of Individuals with Disabilities Education Act in Policy Courses

| Awareness and Knowledge working with persons with developmental disabilities | Covered Individuals with Disabilities Education Act in Policy courses |
|---|---|---|
| | No | Yes | Total |
| None | 2 | 0 | 2 |
| Minimal | 19 | 6 | 25 |
| Average | 16 | 6 | 22 |
| Above Average | 7 | 6 | 13 |
| Extensive | 2 | 4 | 6 |
| Total | 46 | 22 | 68 |
Table 29

*Chi-Square Tests for Table 28*

<table>
<thead>
<tr>
<th>Test</th>
<th>Value</th>
<th>df</th>
<th>Asymp. Sig. (2-sided)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pearson Chi-Square</td>
<td>6.372^a</td>
<td>4</td>
<td>.173</td>
</tr>
<tr>
<td>Likelihood Ratio</td>
<td>6.693</td>
<td>4</td>
<td>.153</td>
</tr>
<tr>
<td>Linear-by-Linear Association</td>
<td>5.574</td>
<td>1</td>
<td>.018</td>
</tr>
<tr>
<td>N of Valid Cases</td>
<td>68</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

^a. 5 cells (50.0%) have expected count less than 5. The minimum expected count is .65.

The results point out that very few of the participants reported learning about Section 504 in their policy courses. The data implies that approximately 10% of the participants who reported average, above average, or extensive awareness also reported having received coverage on Section 504 (see Table 30).
Table 30

*Awareness and Knowledge of Persons with Developmental Disabilities and Coverage of Section 504 in Policy Course*

| Awareness and knowledge working with persons with developmental disabilities | Covered Section 504 in Policy courses |
|---|---|---|
| | No | Yes | Total |
| None | 2 | 0 | 2 |
| Minimal | 21 | 4 | 25 |
| Average | 20 | 2 | 22 |
| Above Average | 11 | 2 | 13 |
| Extensive | 3 | 3 | 6 |
| Total | 57 | 11 | 68 |
Table 31

*Chi-Square Tests for Table 30*

<table>
<thead>
<tr>
<th>Test</th>
<th>Value</th>
<th>df</th>
<th>Asymp. Sig. (2-sided)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pearson Chi-Square</td>
<td>6.269a</td>
<td>4</td>
<td>.180</td>
</tr>
<tr>
<td>Likelihood Ratio</td>
<td>5.324</td>
<td>4</td>
<td>.256</td>
</tr>
<tr>
<td>Linear-by-Linear Association</td>
<td>2.249</td>
<td>1</td>
<td>.134</td>
</tr>
</tbody>
</table>

N of Valid Cases 68

a. 6 cells (60.0%) have expected count less than 5. The minimum expected count is .32.

The analyzed data indicates that participants were more likely to receive coverage on the Americans With Disabilities Act (ADA) in their policy courses. The participants who reported average, above average, or extensive awareness and knowledge of persons with developmental disabilities and received coverage on ADA accounted for approximately 49% of the participants.
Table 32

*Awareness and Knowledge Working With Persons with a Developmental Disability and Coverage on American Disability Act in Policy Course*

<table>
<thead>
<tr>
<th>Awareness and knowledge working with persons with developmental disabilities</th>
<th>None</th>
<th>Minimal</th>
<th>Average</th>
<th>Above Average</th>
<th>Extensive</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No</td>
<td>Yes</td>
<td>Total</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Minimal</td>
<td>9</td>
<td>16</td>
<td>25</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Average</td>
<td>5</td>
<td>17</td>
<td>22</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Above Average</td>
<td>2</td>
<td>11</td>
<td>13</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extensive</td>
<td>1</td>
<td>5</td>
<td>6</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>18</td>
<td>50</td>
<td>68</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 33

*Chi-Square Tests for Table 32*

<table>
<thead>
<tr>
<th></th>
<th>Value</th>
<th>df</th>
<th>Asymp. Sig. (2-sided)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pearson Chi-Square</td>
<td>3.011a</td>
<td>4</td>
<td>.556</td>
</tr>
<tr>
<td>Likelihood Ratio</td>
<td>3.002</td>
<td>4</td>
<td>.557</td>
</tr>
<tr>
<td>N of Valid Cases</td>
<td>68</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

a. 5 cells (50.0%) have expected count less than 5. The minimum expected count is .53.

Participants’ Self-Reported Knowledge and Awareness and Coverage on Diversity Issues with Persons with a Developmental Disability

Cross-tabulation analysis was utilized to determine if there was a strong association between participants’ self-reported knowledge and awareness of persons with a developmental disability and the coverage of diversity issues that affect the lives of persons and their families in this population. There were approximately 29% of participants who reported average, above average, and extensive awareness and also indicated coverage on content on persons with a developmental disability in diversity courses. The results also indicate that those participants who self-reported average, above average, or extensive knowledge and awareness and reported no coverage on topics relating to developmental disabilities in diversity courses accounted for approximately 16%. The results indicate that there is not a significant relationship between these two variables.
Table 34

*Awareness and Knowledge Working With Persons with a Developmental Disability and Coverage of Persons with Developmental Disability in Diversity Course*

<table>
<thead>
<tr>
<th>Awareness and knowledge working with persons with developmental disabilities</th>
<th>None</th>
<th>Yes</th>
<th>Some Coverage</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Minimal</td>
<td>7</td>
<td>8</td>
<td>10</td>
<td>25</td>
</tr>
<tr>
<td>Average</td>
<td>7</td>
<td>11</td>
<td>4</td>
<td>22</td>
</tr>
<tr>
<td>Above Average</td>
<td>3</td>
<td>6</td>
<td>4</td>
<td>13</td>
</tr>
<tr>
<td>Extensive</td>
<td>1</td>
<td>3</td>
<td>2</td>
<td>6</td>
</tr>
</tbody>
</table>

Total 20 28 20 68
Table 35

*Chi-Square Tests for Table 34*

<table>
<thead>
<tr>
<th></th>
<th>Value</th>
<th>df</th>
<th>Asymp. Sig. (2-sided)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pearson Chi-Square</td>
<td>8.424a</td>
<td>8</td>
<td>.393</td>
</tr>
<tr>
<td>Likelihood Ratio</td>
<td>8.651</td>
<td>8</td>
<td>.373</td>
</tr>
<tr>
<td>Linear-by-Linear</td>
<td>.384</td>
<td>1</td>
<td>.535</td>
</tr>
</tbody>
</table>

Association

N of Valid Cases 68

---

a. 8 cells (53.3%) have expected count less than 5. The minimum expected count is .59.

Importance of Developmental Disabilities in the Social Work Program

The survey gathered the perspectives of the participants on the importance of having content on developmental disabilities in the Master of Social Work Program. The participants were asked to rate their opinions (1-Strongly Disagree to 7-Strongly Agree) on the statement that “it is critical for social work students to learn about multi-level practice with persons with a developmental disability in the MSW programs.” A frequency distribution was used to determine the overall opinions from the MSW II students, and an overwhelming approximately 62% strongly agreed with this statement (see Figure 1). The entire sample of the student participants shared the opinion that it is important for all social work students to learn about multi-level approach in working with persons with a developmental disability.
Figure 1. The importance of multi-level practice with persons with a developmental disability.

The data from the survey also indicates that the majority of the student participants believed that content on persons with a developmental disability should be integrated into the required courses in the Division of Social Work, which include: Practice, Policy, Diversity, Human Behavior in the Social Environment, and Research. Approximately 55 out of the 68 participants strongly agreed (indicating 6 or 7) to this statement, as indicated by the responses on the Likert-scale (1-Strongly Disagree to 7-Strongly Agree) (see Figure 2).
Since there is currently no elective offered in the MSW program at CSUS that focuses on social work practice with persons with a developmental disability, this researcher thought it would be important to poll the students to explore if there was interest in this topic. The data concluded that 50 out of the 68 participants stated “yes” they would take the elective if given the opportunity (see Figure 3).
Figure 3. Students interested in elective course.
Chapter 5

CONCLUSION

The field of developmental disabilities has expansively grown and undergone significant transformation in recent history. From institutionalization towards community integration, this historically important progressive transition has placed social workers at the front line for serving persons with developmental disabilities and their families. Social workers serve an essential role for individuals with disabilities and their families throughout important milestones during the life stages. Social workers will serve persons with developmental disabilities in array of settings. Thus, it is essential that social workers are adequately educated in the field of developmental disabilities so that they may be confident and competent working with this population.

The review of literature suggests that there is lack of content on developmental disabilities in the Graduate level of Social Work programs across the United States. It has been hypothesized that the lack of content is due to the lack of faculty and student interest. This hypothesis was presented by Liese et al. (1999) who reported that 80% of all MSW programs surveyed placed least emphasis on developmental disability content. On the contrary, the growth of this population is creating a demand for knowledgeable and culturally sensitive social workers to efficiently meet the needs of these individuals and their families. The demand for social workers in the field of developmental disabilities has never been higher as research indicates an increase in early childhood diagnoses and, at the other end, prolonged life expectancies. There are some social
workers who would not choose to work with this population, though there is no longer a choice that can be made. Persons with developmental disabilities will be clients in a variety of agencies throughout their life journey and will be depending on competent social workers to meet their needs, serve them efficiently, and to be culturally sensitive and knowledgeable to the individual with the developmental disability.

Results from Study

The primary purpose of this study was to explore the extent to which the Division of Social Work at Sacramento State University incorporated persons with developmental disabilities and relative topics to the field of advanced social work practice. This study was designed to gather the opinions and perspectives of the Master of Social Work students in their second year (MSW II) at Sacramento State University on the depth and breadth of content of persons with developmental disabilities in the curriculum as well as the overall importance of addressing this population in the social work program.

This researcher studied the knowledge and confidence second year students in the Master Program of Social Work at California State University, Sacramento (CSUS) reported in working with persons with a developmental disability and their families. This study used cross tabulations to analyze whether awareness, knowledge, and confidence in working with persons with a developmental disability was correlated with previous work experience with this population or whether it was directly correlated with the content on developmental disabilities that is implemented into the curriculum in the Division of Social Work, Graduate Program, at CSUS. The results indicate that higher self-reported
knowledge and confidence in working with this population is correlated with previous work experience not from knowledge presented and obtained from the curriculum and overall program. Thus, social work students who did not come into the program with prior work experience with persons with a developmental disability or did not have an internship in the field of developmental disabilities lacked knowledge and awareness as well as confidence with working with this population.

The findings of this study reflect the overall themes presented in the literature review. There is a consensus amongst the literature that there is an overall deficiency in social work curriculum in regards to addressing developmental disabilities, reflected in the data obtained from this study. This assumption from the literature was reflected in this study, as the data obtained reflected a limited inclusion of developmental disabilities in the curriculum in the Division of Social Work, Masters Program, at California State University, Sacramento.

The findings of this study indicate an essential need for social work students to be educated on persons with developmental disabilities. The literature emphasizes the importance of integrating content on developmental disabilities into the social work program in order to prepare the graduating students for future work with this population, so that these new social workers are not ill equipped. The literature review discussed the notion presented by Rimmerman et al. (2000) that social work students need the opportunity to be exposed to the idea of working with persons with a developmental disability in order to work through the fear, anxiety, or stigma they may carry towards
this population. With the proper education and the opportunity to explore preconceived beliefs about persons with a developmental disability, social work students can develop the awareness, knowledge, cultural sensitivity, and confidence to provide efficient case-management, counseling, or other needed services.

The second year Master of Social Work students were also surveyed to explore the reported importance of including content on developmental disabilities into the curriculum. The findings reflected a shocking concurrence that approximately 88% of the student participants thought it is important to integrate the topic of developmental disabilities and relating content into the required courses in the MSW program. In addition, all but one of the participants agreed that it is critical for all social work students to learn about multi-level practice with persons with a developmental disability in the MSW program. The data suggests that there is strong interest amongst the social work students at CSUS to receive more of an education on social work practice with persons with a developmental disability.

Recommendations

The need for confident and competent social workers has never been higher in the field of developmental disabilities as the population continues to increase. It is a necessity that social work students receive an education that will prepare them for working with this population of persons with a developmental disability and their families. With this increased demand it is essential that accredited Schools of Social Work generate competent and culturally sensitive workers into the field that will be prepared to work
with any person with a developmental disability that they come in contact with in any setting they are working in.

The findings of this project present the opinions of the students that the field of developmental disabilities is an important topic of study. All the participants agreed that all social work students should be educated on social work practice with persons with a developmental disability. Therefore, it is recommended that content on developmental disabilities be fully integrated into core social work courses, including the following: Practice, Policy, Diversity, Human Behavior in the Social Environment, and Research. Through these courses, social work students can develop an overall understanding of the essential content that will aide in the development of a knowledgeable, confident, and culturally sensitive social worker. This includes, though is not limited to: definition of a developmental disability, the important milestones in the developmental process, the major policies that affect a person with a developmental disability and their families, obstacles and experiences of oppression or stigma, understanding the importance of the self-advocacy movement, critical biopsychosocial concepts as they pertain to persons with a developmental disability, understand common experiences and feelings parents and siblings share, and common ethical considerations that a social worker may face when working with this population. By incorporating class discussion around issues that affect individuals with a developmental disability and their families it can stimulate interest in this population for those who are not aware of the increase in this population or the opportunities that are in this field.
It is also recommended that an elective course be offered to MSW students for those who strive to learn more about social work practice with persons with a developmental disability. An outline of essential concepts in the field of developmental disabilities has been created to serve as a structure for the development of a future elective for Advanced Social Work Practice with Persons with a Developmental Disability (Appendix C). Content relating to developmental disabilities has been nearly absent, or minimal at best in MSW programs across the nation as indicated in the literature review. With the increase in the population of development disabilities and the demand for competent and confident social workers in this field, it is a great opportunity to bring this topic off the back burner and reignite the coverage of this special population. The development of this elective course is important and necessary for the preparation of social workers entering the current field of social services.
APPENDICES
APPENDIX A

Survey

“Developmental Disability” refers to a disability that is attributable to mental retardation, cerebral palsy, epilepsy, autism, or disabling conditions found to be closely related to mental retardation or to require treatment similar to that required for individuals with mental retardation. The Developmental Disability shall originate before the age of 18, is likely to continue indefinitely, and constitutes a substantial disability.

A “substantial disability” is a condition which results in major impairment(s) of cognitive and/or social functioning, representing sufficient impairment to require interdisciplinary planning and coordination of special or generic services to assist the individual in achieving maximum potential; and the existence of significant functional limitations, as determined by the regional center, in three or more of the following areas of major life activity (Receptive and expressive language, Learning, Self-care, Mobility, Self-direction, Capacity for independent living, and Economic self-sufficiency.)

1. Given the above definition of a person with a developmental disability, how would you rate your current awareness and knowledge of providing social work services to persons with a developmental disability:

   ______ None ______ Minimal ______ Average ______ Above average
   ______ Extensive

2. Have you previously worked with persons with a developmental disability?

   ______ Yes ______ No
   (if yes, please specify how long and in what capacity: ________________________________
   ____________________________________________________________________________
   ____________________________________________________________________________
   ____________________________________________________________________________
   ____________________________________________________________________________

3. In your policy class(es) in the Division of Social Work, did you cover the following major policies that impact the lives of person’s with a developmental disability?

   Public Law 94-142 (Education of All Handicapped Children Act) also known as, Individuals with Disabilities Education Act (IDEA): _____ Yes _____ No
Section 504. [Pub. L. 93-112][29 U.S.C. 794]: _____Yes     _____No

Americans with Disabilities Act of 1990: _____Yes     _____No

4. Was there content on the issues of oppression, stigma, patronization, infantilization, and disenfranchisement of persons with a developmental disability in our culture covered in your diversity class (SWRK 202)? _____Yes     _____No     _____Some coverage

5. In your Human Behavior and Social Environment course (SWRK 235A), did you cover the following critical bio-psycho-social concepts that pertain to social work with persons with a developmental disability:

   _____pre-natal development               _____seizure disorders
   _____pre-natal diagnosis                 _____autism spectrum disorders
   _____mental retardation                   _____learning disabilities
   _____cerebral palsy                       _____traumatic brain injury

6. In your practice class(es) SWRK 204A/B/C/D, did you receive information on the following:
   _____bio-psycho-social assessment with children adolescents, and adults suspected of having a developmental delay.
   _____mental health assessment(s) of children and adults with a developmental disability
   _____counseling strategies for persons with a range of developmental disabilities.
   _____clinical case management (i.e.-advocacy, brokerage, linkage, coaching, ect.)

7. Please indicate how topics relating to persons with a developmental disability (as highlighted in Questions #3, 4, 5, and 6) were presented to you in your courses in the Division of Social Work:

   _____Professor                           _____Multimedia
   _____Readings                            _____Discussion
   _____Student Presentation(s)             _____Guest Speaker
   _____Other/Please specify: ___________________________________________
8. I think it is critical for all social work students to learn about multi-level practice with persons with a developmental disabilities in their MSW programs:

    1  2  3  4  5  6
    7

Strongly Disagree
Strongly Agree

9. Should content on persons with developmental disabilities be integrated into required courses in the Division of Social Work, MSW program?

    1  2  3  4  5  6
    7

Strongly Disagree
Strongly Agree

10. If given the opportunity, would you take an elective course that focused on social work practice with persons with a developmental disability?

    Yes          No
APPENDIX B

Informed Consent

Attachment 1: Consent to Participate in Research
You are invited to participate in a research study that will be conducted by Jennifer Joyner, a Master of Social Work student at the Division of Social Work, California State University, Sacramento. This study will explore the presence, perceived importance, and knowledge of developmental disabilities in course content of accredited California State Universities, and Universities of California Graduate Schools of Social Work. This researcher is interested in your opinion as an MSW II student at CSUS to the knowledge and exposure you have gained on working with Persons with a Developmental Disability thus far in the program.

Procedures:
After reviewing this form and agreeing to participate in this study, sign and date the form. All consent forms will be collected and stored together. After receiving the signed informed consent form, a survey will be administered. This survey will take five to ten minutes to complete. Upon completion, this researcher will collect the survey.

Risks:
There are no identified risks for participating in this study.

Benefits:
The research gained through analyzing course outlines and surveys will show the extent to which the topic of developmental disabilities is covered in California State Universities and Universities of California, Graduate Schools of Social Work. A “best practice model” will be developed based on the findings in content and surveys for California State University, Sacramento. This research can be beneficial for Directors and Professors of Social Work Programs in the development of course content for graduate social work students.

Confidentiality:
All information is confidential. This researcher will keep the informed consent forms and completed surveys separate to protect the identity of participants. The collection of surveys and informed consents will be kept confidential and securely locked in a cabinet at this researcher’s home. This researcher’s thesis advisor will have access to completed surveys. The final research report will not include any identifying information that will link the content with its source.

Contact Information: If you have any questions you may contact the researcher, Jennifer Joyner at jennifer7joyner@gmail.com/
Or, if you need further information, you may contact the researcher’s thesis advisor: David Demetral, Ph.D., & LCSW
C/o California State University, Sacramento demetral@csus.edu
(Attachment 1 continued)
Consent to Participate as a Research Subject

I have read the descriptive information on the Research Participation cover letter. I understand that my participation is completely voluntary. My signature or initials indicate that I have received a copy of the Research Participation cover letter and I agree to participate in the study.

Signature or Initials: ____________________________________________
Date: ________________
APPENDIX C

Outline of Essential Concepts to be Infused in Elective Course on Advance Practice with Persons with a Developmental Disability

I. Overview of Developmental Disability
   A. Federal Definition
   B. California State Definition
   C. Description of Developmental Disabilities
      i. Autism and PPD
      ii. Epilepsy
      iii. Cerebral Palsy
      iv. Down syndrome
      v. Fragile X syndrome
   D. Description of population trends and statistics

II. History of Developmental Disabilities
    A. Institutionalization
    B. Eugenics
    C. Deinstitutionalization
    D. Three Waves of Movements: Professional, Parent, and Self-advocacy

III. Class Action Law Suits and Public Law
    A. Wyatt v. Stickney
    B. Brown v. Board of Education
    C. Americans With Disabilities Act
    D. Public Law 94-142-Education of All Handicapped Children Act
    E. Public Law 504
    F. IPP and IEP

IV. Lanterman Act
    A. Overview of Lanterman Act
    B. Individualized Assessment and Services

V. Regional Centers
    A. Overview of 21 regional Centers
    B. Mission, Purpose, and Function of the Regional Centers
    C. Vendor system-purchasing of services

VI. Services Offered and Provided to Individuals with Developmental Disabilities: Multi-Disciplinary Assessment on Treatment
    i. Physical therapy
    ii. Occupational therapy
    iii. Speech/hearing/vision therapy
    iv. Adaptive behavioral skills training
v. Community living skills
vi. Life skills
vii. Self advocacy skills
viii. Educational and life skills training

VII. Developmental Disabilities and Impact on Families
A. Effects on parents
B. Effects on siblings

VIII. Early Intervention and High Risk Prenatally

IX. Developmental Disabilities and the School Aged Child
i. Special Education
ii. Inclusion and Mainstreaming

X. Developmental Disabilities and the transition from Adolescence to Adulthood
i. Sexuality and Sex Education
ii. IEP and Preparation for Transition

XI. Developmental Disabilities and the Aging Population
i. Death, Grief, and Loss

XII. Best Practices in the Field of Developmental Disabilities
A. Person-Centered Planning
B. Individualized Assessment and Planning
C. Self Advocacy
D. Empowerment and Autonomy
E. Advocacy and Political Action

XIII. Current Issues Facing Developmental Disabilities
A. Mental Health system
   i. Dual Diagnoses
B. Criminal Justice System
   i. Domestic Violence
   ii. Competency to Stand Trial
   iii. Commitments
   iv. Diversion
C. Education
D. Medical Care

XIV. Social Work and Developmental Disabilities
A. Bio-Medical-Practice and Ethical Considerations
B. Social Services Across the Life Span
REFERENCES


Klein, J., & Strully, J. (2000). From unit D to the community: A dream to fulfill. In M. Wehmeyer, & J. Patton (Eds.), *Mental retardation in the 21st century* (pp. 3-17). Austin, TX: Pro-Ed.


