THE COMMUNITY SERVICE NEEDS OF INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES AND MENTAL ILLNESS FROM THE PERSPECTIVE OF THE MENTAL HEALTH PROFESSIONAL.

By

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ABSTRACT

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The purpose of this research was to examine the community service needs of individuals with developmental disabilities (DD) and severe mental illness (SMI). The level of success among individuals with DD/SMI within community settings largely depends on their level of functioning, adaptive behaviors, and needs being met. The DD/SMI population is in jeopardy of having decreased opportunities for community integration and an increased likelihood for psychiatric hospitalization due to unmet needs. Within the community service system, individuals with DD/SMI are challenging to serve as most systems relegate services to either developmental disabilities or mental illness programs. However, individuals with DD/SMI require a combination of services from both units for individuals with developmental disabilities and mental illness to support them successfully in the community. A review of the literature shows a very limited knowledge base for the DD/SMI population. The literature was reviewed for information on the community service needs, systems of care, and practice interventions for the DD/SMI population. Some emerging trends in practice were identified as well with family and care giver supports, peer to peer supports, self-directed supports, and gentle teaching. Systems theory was also utilized to provide a theoretical framework for the community service needs of individuals with DD/SMI. The present research utilized qualitative research methods of grounded theory approach, interviews, and focus groups to gather exploratory data from mental health professionals about the community services needs of individuals with DD/SMI. Findings
indicated the need for 1) staffing supports and other supportive services, 2) having access to services or service provision, 3) suggestions for a new service structure, 4) having a support person who the DD/SMI person knows well, 5) identifying barriers to accessing services, and 6) a lack of understanding about people with DD/SMI. The discussion includes a more detailed and exploratory review of the study findings and what can be learned from the observations and knowledge of the participants. A blended systems-grounded theory is presented to illustrate the study’s findings and provide connections to the community service needs of individuals with DD/SMI. Finally, the conclusion of the study includes the implications of the study findings in regards to practice, policy, and research. A discussion about the limitations and strengths of the present research, as well as recommendations for future research is also presented.
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TABLE OF CONTENTS

LIST OF TABLES ................................................................................................................................. x

LIST OF FIGURES ................................................................................................................................. xi

CHAPTER 1: INTRODUCTION & BACKGROUND .................................................................................. 1
  Key Terminology ................................................................................................................................. 2
    Developmental disabilities (DD) ........................................................................................................ 2
    Severe mental illness (SMI) ................................................................................................................ 4
  Prevalence of DD/SMI ......................................................................................................................... 5
  Historical Background of DD/ID, SMI, & DD/SMI ........................................................................... 6
    Social and political influences .......................................................................................................... 6
      DD/ID ............................................................................................................................................... 6
      SMI .............................................................................................................................................. 13
      DD/SMI ....................................................................................................................................... 20
        American’s with Disabilities Act (1990) .................................................................................... 21
        Medicaid ............................................................................................................................... 22
    Economic influences ...................................................................................................................... 27
      DD/ID ............................................................................................................................................... 27
      SMI ............................................................................................................................................... 29
      DD/SMI ....................................................................................................................................... 32
  Problem to be Addressed .................................................................................................................... 33

CHAPTER 2: LITERATURE REVIEW .................................................................................................... 35
  Approach to Literature Review Search ............................................................................................. 37
  Theoretical Orientation of Research .................................................................................................. 37
    Systems theory ............................................................................................................................... 37
  Community Service Needs of DD/SMI ............................................................................................... 42
  Systems of Care .................................................................................................................................. 48
  DD/SMI Intervention/Programs from Research ............................................................................... 51
    Multidisciplinary team approaches ................................................................................................. 52
    Assertive community treatment (ACT) ............................................................................................. 55
    Dialectical behavior therapy (DBT) ................................................................................................. 63
    Cognitive behavioral therapy (CBT) ................................................................................................. 65
  Emerging Trends in Practice .............................................................................................................. 67
    Family and caregiver supports ....................................................................................................... 67
    Peer to peer or peer mentor supports ............................................................................................. 68
    Self-directed or participant directed services ................................................................................ 68
    Gentle teaching ............................................................................................................................ 69
  Gaps in Literature Review for DD/SMI ............................................................................................. 70
  Mental Health Professional’s Perspectives on Community Services ............................................... 73
  Summary ......................................................................................................................................... 75
CHAPTER 3: METHODS

Research Question .................................................................76
Qualitative Approach .............................................................77
  Grounded theory .................................................................77
Sampling ......................................................................................82
  Participants .............................................................................82
  Limitations of sample ...........................................................84
Research Protocol .....................................................................85
  Interviews ...............................................................................85
  Focus groups ..........................................................................86
  Participant incentives ............................................................87
  Data collection methods .........................................................87
  Trustworthiness of data ........................................................87
  Confidentiality .........................................................................88
  Reflexivity statement ............................................................89
Analysis .....................................................................................89
  Corbin & Strauss (2008) coding .................................................90
  Sensitivity ..............................................................................91
  Code book .............................................................................92
  Theory development .............................................................92

CHAPTER 4: RESULTS.................................................................94

Research Question .....................................................................94
Participants ................................................................................94
Demographics ..........................................................................94
Findings ......................................................................................95
Primary Themes .........................................................................96
  Theme 1: Staffing supports and other supportive services .......96
    Staffing supports ..................................................................97
      Staffing as a supportive service ........................................97
      Concern of maintaining consistent staffing ....................97
    Other supportive services .................................................98
      Psychiatric services .........................................................98
      Employment .....................................................................99
      Social opportunities ........................................................99
  Theme 2: Having access to services or service provision .......100
    Not receiving services; don’t know what is available ..........100
    Outpatient model of service delivery ..................................101
    Attention to DD due to political influences .......................101
  Theme 3: Suggesting a new structure of services .................102
  Theme 4: Having a support person who knows them well ......103
    Role of case manager/supports coordinator .....................103
    Family or other natural supports ......................................104
    Functions of support person .............................................105
  Theme 5: Identified barriers to accessing services ..............106
    Funding and insurance issues ............................................106
APPENDIX F: Literature Search Results for Practice Modalities for DD/ID, SMI and DD/SMI Populations

REFERENCES
LIST OF TABLES

Table 1: Michigan Waiver Programs ...........................................................................................................24
Table 2: Mandatory vs. Optional Medicaid Services ......................................................................................26
Table 3: Background Information of Sample (Interviews & Focus Groups Combined) ..............................94
Table 4: Main Finding Themes for Study ......................................................................................................96
Table 5: Literature Search Results for Practice Modalities for DD/ID, SMI and DD/SMI Populations .................................................................................................................................177
LIST OF FIGURES

Figure 1: Traditional Residential Continuum .................................................................10
Figure 2: Systems Theory Framework for Community Service Needs of DD/SMI Population ...40
Figure 3: Theoretical Path for Community Service Needs of Individuals with DD/SMI ..........42
Figure 4: Blended Systems-Grounded Theory Model for Community Services for DD/SMI Population ...............................................................................................................119
CHAPTER 1: INTRODUCTION & BACKGROUND

In the United States there is a movement towards increasing the rights and liberties of individuals with developmental disabilities (DD) and severe mental illness (SMI). The movement towards increasing self-determination for the DD and SMI populations began with the Mental Retardation and Community Mental Health Construction Act in 1963. During the same year, President John F. Kennedy, in addressing Congress (February 5, 1963) stated:

We as a Nation have long neglected the mentally ill and the mentally retarded. This neglect must end, if our Nation is to live up to its own standards of compassion and dignity and achieve the maximum use of its manpower. (Fletcher, Loschen, Stavrakaki, & First, 2007, p. 1)

Since that time, individuals with DD and SMI have transitioned from state-run institutions to community-based services. The level of success among individuals with DD and SMI within community settings largely depends on their level of functioning and adaptive behaviors. At present, there is a growing recognition of individuals who are dually diagnosed with both a developmental disability and severe mental illness (DD/SMI). They are in jeopardy of having decreased opportunities for community integration and an increased likelihood for psychiatric hospitalization due to unmet needs (Hemmings & Al-Sheikh, 2013; Lunsky, Bradley, Durbin, Keogl, & Canrinus, 2006; Slayter, 2007). Within the community service system, individuals with DD/SMI are challenging to serve as most systems relegate services to either developmental disabilities or mental illness (Davis, Barnhill, & Saeed, 2008; Ervin, Williams, & Merrick, 2015). The service systems are separate. However, individuals with DD/SMI require a combination of services from both units for individuals with developmental disabilities and mental illness to support them successfully in the community (Barnhill, 2008; Chan, Hudson, & Vulic, 2004; Hemmings & Al-Sheikh, 2013). Individuals with DD/SMI need services that encompass structure, care pathways, training, flexibility, resources, an evidence-base,
multidisciplinary focus, personalized/individualized supports, access to information, and a focus on long-term care management for both disorders (Davis et al., 2008; Hemmings & Al-Sheikh, 2013). At present, many service systems are not adequately set up to meet the needs of the DD/SMI population because they are limited to one area, DD or SMI, and there is insufficient flexibility to work across both venues (Davis et al., 2008; Ervin, Williams, & Merrick, 2015).

Another issue that exists is the limited information available pertaining to what the community service needs of the DD/SMI population really are. To assist in bridging this gap, this study will focus on the primary research question of, **What are the community service needs of individuals with DD/SMI from the perspective of the mental health professional?**

To assist inconceptualizing the community service needs of the DD/SMI population, definitions of key terminology (ie. DD and SMI) along with information in regards to the prevalence of DD/ID, SMI, and DD/SMI in the United States, will be provided. An overview of the historical aspects of the DD/ID, SMI, and DD/SMI populations from the social, political, and economic influences that have existed over time will also be presented. Finally, the community service needs of the DD/SMI population will be examined.

**Key Terminology**

**Developmental disabilities (DD).** To begin, it is important to understand how each of the key terms is defined within the professional literature. Developmental disabilities (DD) are defined in several ways. According to the Michigan Mental Health Code (1996), developmental disabilities are defined as a severe, chronic condition that meets all of the following:

- Is attributable to a mental or physical impairment or a combination of mental and physical impairments,
- Is manifested before the individual is 22 years old,
- Is likely to continue indefinitely,
- Results in substantial functional limitations in 3 or more of the following areas of major life activity: 1) self-care, 2) receptive and expressive language, 3) learning,
According to the *American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders* (APA, 2013), many developmental disabilities are now classified as neurodevelopmental disorders. This includes intellectual disabilities, language disorders, speech sound disorders, childhood-onset fluency disorder, social communication disorder, autism spectrum disorder, specific learning disorder, and motor disorders (APA, 2013). The category of developmental disabilities also includes such medical conditions as traumatic brain injury (TBI) and cerebral palsy (CP). Mental retardation, now referred to as intellectual disability (ID) in the DSM-V (APA, 2013), is the most commonly occurring DD at this time with an approximate prevalence of 1-3% of the U.S. population having this diagnosis (APA, 2013; Keigher, 2000; Lehotkay, Varisco, Deriaz, & Carminati, 2009).

Severity of ID is dependent on the individual’s abilities in “intellectual and adaptive functioning deficits in conceptual, social, and practical domains” (APA, 2013, p. 33). Deficits in intellectual functioning can manifest as difficulties with reasoning, problem solving, planning, abstract thinking, judgement, academic learning, and learning from experience (APA, 2013, p. 33). Deficits in adaptive functioning result in the individual lacking skills to meet standards of personal independence and social responsibility and can be seen in such areas as communication, independent living, and social participation (APA, 2013, p. 33). Severity of ID ranges from mild, moderate, severe, and profound depending on the individual’s ability to perform tasks in each of the previously noted areas (APA, 2013). According to Lehotkay and colleagues (2009), the prevalence of mild ID accounts for 80%, moderate ID accounts for 12%, severe ID accounts for 7%, and profound ID accounts for 1% of the 3% of the population with ID diagnoses (p. 106).
Severe mental illness (SMI). Severe mental illness (SMI) is defined in terms of a brain disorder as well as limitations in daily functioning. The data presented by the National Institute for Mental Health (NIMH) (2010) from the National Survey on Drug Use and Health (NSDUH), defines SMI as:

- A mental, behavioral, or emotional disorder (excluding developmental and substance use disorders),
- Diagnosable currently or within the past year,
- Of sufficient duration to meet diagnostic criteria specified within the 4th edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV-TR),
- Resulting in serious functional impairment, which substantially interferes with or limits one or more major life activities. (NIMH, 2010)

Severe mental illness is also an umbrella term that encompasses several diagnoses in the DSM-5 (APA, 2013). These diagnoses include schizophrenia spectrum and other psychotic disorders, bipolar and related disorders, depressive disorders, anxiety disorders, obsessive-compulsive and related disorders, trauma and stressor related disorders, and personality disorders (APA, 2013).

It is estimated that SMI conditions affect 6% of the U.S. population and account for 15% of the global burden of disease (Pinninti, Fisher, Thompson, & Steer, 2010, p. 337). Individuals with SMI can experience many interruptions in their life due to severity of symptomatology. According to Kuehn (2011), in 2009, an estimated 5% of the U.S. population experienced an SMI condition which interfered with daily life activities (p. 27). Within the 5% who experienced an SMI condition, only 60.2% of those individuals received treatment for their condition (Kuehn, 2011, p. 27). Individuals with SMI also have disproportionate rates of interaction with the criminal justice system in comparison to the general population (Cohen, 2005; Swartz & Lurigio, 2007). According to Cohen (2005), approximately 42-50% of individuals with SMI will come in contact with the criminal justice system at some point in their life. Steadman and colleagues (2009) indicate a high occurrence of SMI in jail populations, with a prevalence of 14.5% to 31%
within inmate populations. Therefore, criminal justice institutions have become major providers of mental health services for individuals with SMI. According to Swartz and Lurigio (2007) the Los Angeles County jail system serves approximately 3,300 of its 21,000 detainees with psychiatric services daily. As such it has become one of the three largest psychiatric facilities in the country, followed by Cook County Jail in Chicago and Rikers Island Jail in New York (Swartz & Lurigio, 2007, p. 582).

**Prevalence of DD/SMI**

Individuals with DD/SMI are largely unrecognized and unaddressed in the field of mental health practice and research (Ervin, Williams, & Merrick, 2015; Hurley et al., 2003). At present, the terminology of “dual diagnosis” almost exclusively refers to individuals with severe mental illness (SMI) and co-occurring substance abuse (SA) disorders within the research literature about mental health services (Drake et al., 2001).

After reviewing the data available in the research literature for individuals with DD/SMI diagnoses, it appears that there is little consensus on the prevalence at this time. According to Shedlack and Chapman (2004), adults diagnosed with a DD are 10-39% more likely to exhibit features of SMI than adults in the general population (p. 7). The prevalence of SMI diagnoses range from 10% to 80% in the DD/ID population (Antonacci, Manuel, & Davis, 2008; Benson, 2004; Cooper et al., 2007; Ghafoori, Ratanasiripong, & Holladay, 2010; Glick & Zigler, 1995; Gustafsson & Sonnander, 2004; Hurley, Folstein, & Lam, 2003; Saeed, Ouellette-Kuntz, Stuart, & Burge, 2003). According to Ervin, Williams, and Merrick (2015) the National Core Indicator (NCI) project surveyed more than 30,000 adults with intellectual and developmental disabilities over a three year period of time ending in 2012. From that study, the occurrence of mental illness in individuals with DD/ID was between 33% to 35% (Ervin, Williams, & Merrick, 2015).
Among the dually diagnosed DD/SMI population, several SMI conditions are commonly associated with DD. These diagnoses included schizophrenia (Antonacci, Manuel, & Davis, 2008; Chan, Hudson, & Vulic, 2004; Hassiotis et al., 1999; Lehotkey et al., 2009), personality disorders (Chan, Hudson, & Vulic, 2004; Hassiotis et al., 1999; Lehotkey et al., 2009), affective disorders (Antonacci, Manuel, & Davis, 2008; Chan, Hudson, & Vulic, 2004; Ervin, Williams, & Merrick, 2015; Hassiotis et al., 1999), psychotic disorders (Chan, Hudson, & Vulic, 2004), anti-social personality disorder (Hassiotis et al., 1999), post-traumatic stress disorder (Chan, Hudson, & Vulic, 2004), somatic disorders (Lehotkey et al., 2009), and anxiety disorders (Antonacci, Manuel, & Davis, 2008; Chan, Hudson, & Vulic, 2004; Ervin, Williams, & Merrick, 2015).

**Historical Background of DD/ID, SMI, & DD/SMI**

To better conceptualize the community service needs of individuals with DD/SMI, a review of the historical impacts of social, political, and economic influences for the DD/ID, SMI, and DD/SMI populations since the deinstitutionalization movement to present day will be presented. The evolution of these areas over time will help to inform this research moving forward.

**Social and political influences.** Many social and political influences have occurred over time to impact the changes in community services for individuals with DD/ID, SMI, and DD/SMI. Some of the biggest contributors to the adaptation of services and supports in the community will be reviewed to help illustrate the differences of the DD/ID and SMI population in this area, as well as highlighting where similarities exist.

**DD/ID.** Up until 1963, the majority of individuals with developmental disabilities (DD) were placed in institutions or mental hospitals to separate them from “normally” developed and functioning community members (Covey, 1998). In 1963, two pieces of legislation helped to
bring the movement of deinstitutionalization to fruition; the Mental Retardation Facilities and Community Mental Health Center Construction Act (MRF-CMHC Act) and the Developmental Disabilities Assistance and Bill of Rights Act (DD Act).

The MRFCMH Act (1963) provided funds for establishing services that individuals were currently receiving in institutions and moved them into a community setting (Johnson & Traustadottir, 2005; Palley & Van Hollen, 2000). These services included residential housing, structured day program or vocational training, psychiatry, and involvement in the community of residence (Johnson & Traustadottir, 2005).

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act) was a pivotal policy for individuals with DD/ID as it was the first piece of legislation specifically directed at the DD/ID population. The DD Act was originally authorized in 1963, and most recently reauthorized in 2000 with the target focus of meeting the needs of the 4.5 million individuals with developmental disabilities in the U.S. (Work World, 2012). More specifically, the:

- DD Act ensures that individuals with developmental disabilities participate fully in their communities through full integration and inclusion in the economic, political, social, cultural, religious and educational sectors of our society. The DD Act further ensures that individuals with developmental disabilities and their families participate in the design of and have access to culturally competent services, supports and other assistance and opportunities that promote independence, productivity, integration and inclusion in the community. (Work World, 2012)

The DD Act was created to address the eight areas of employment, education, child care, health, housing, transportation, recreation, and quality assurance for individuals with DD/ID within the community (Work World, 2012).

Since its inception in 1963, the DD Act has been amended several times to add further supports. These amendments were fueled by gaps recognized by advocacy groups and clinicians on behalf of the DD/ID population. Amendments to the DD Act led to the creation of State
Developmental Disabilities Council’s (i.e. DD Council), University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD), and Protection and Advocacy (P & A) organizations (McGinty, Worthington, & Dennison, 2008; Work World, 2012).

State institution populations peaked in the mid-1950s with more than a half million residents. Following the passage of the 1963 Community Mental Health Construction Act and the DD Act, the population of State hospitals decreased by 45% from 504,604 to 275,995 (Bachrach, 1976, p. 9). Research indicates residents moved into communities where there was a heavy reliance on families of DD/ID, nursing homes, other residential facilities, and widespread use of psychoactive medications (Deb & Holmes, 1998; Bachrach, 1976). Psychopharmacology continues to be a resource for individuals with DD/ID to maintain community placements, increase abilities to function socially, and prevent psychiatric hospitalizations (Bhaumik, Watson, Devrapriam, Raju, & Tin, 2009; Shedlack, Hennen, Magee, & Cheron, 2005).

Supportive philosophies of the Normalization Principle and the Least Restrictive Environment (LRE) also empowered DD/ID individuals with moving to the community setting (Brodwin, Tellez, & Brodwin, 2002; Krieg, 2001; Roos, 1976). The normalization principle was advocated for by a number of organizations including the National Association for Retarded Children (NARC), Association of Retarded Citizens, American Civil Liberties Union (ACLU), the Council for Exceptional Children (CEC), and the American Psychiatric Association (APA) (Brodwin et al., 2002; Roos, 1976). The Normalization Principle was started in Denmark by a group of parents with children or loved ones with developmental disabilities (The Arc, 2011). The major tenets of the Normalization Principle were as follows:

1. A normal rhythm of the day (eating, sleeping);
2. A normal routine (living, work, school);
3. A normal rhythm of year (holidays);
4. Normal developmental experiences;
5. The chance to make choices;
6. The right to live heterosexually (not segregated into "men only" or "women only" accommodations);
7. A normal economic standard;
8. The right to live work and play in normal communities. (The Arc, 2011)

In 1974, President Nixon in support of the Normalization Principle issued Executive Order 11776 reaffirming the national goal of returning about one-third of the 200,000 people with mental retardation in public institutions to community residential placements (The Arc, 2011). Amendments to the Social Security Act authorized residential care in Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) and established the Supplemental Security Income program to directly benefit individuals with DD/ID who could not support themselves financially (Logan & Chung, 2001; The Arc, 2011).

Deinstitutionalization led to a “continuum model of services” and advocated for the least restrictive environments (LRE) for DD/ID individuals within the community (Johnson & Traustadottir, 2005, p. 93). The least restrictive environment pertained to all aspects of an individual’s life. Residential placement was one of the highest priorities for LRE (Johnson & Traustadottir, 2005). The deinstitutionalization movement assisted individuals in leaving segregated environments (institutions) for integrated environments (communities). To meet the needs of so many individuals, community placements began to be rank ordered as to their level of integration and restrictiveness to meet the needs of the DD/ID in community settings (Johnson & Traustadottir, 2005). Characteristically, the placements with the most intensive services also tended to be the most restricted and segregated, while the least intensive services were more integrated and supportive of independence (Johnson & Traustadottir, 2005; Thorn, Pittman, Myers, & Slaughter, 2009). Upon movement out of the institution, individuals with DD/ID were
placed in settings along the traditional residential continuum, as illustrated in Figure 1 (Johnson & Traustadottir, 2005).

Figure 1: Traditional Residential Continuum

<table>
<thead>
<tr>
<th>Public Institutions</th>
<th>Community ICF/IID</th>
<th>Foster Care</th>
<th>Independent Living</th>
</tr>
</thead>
<tbody>
<tr>
<td>Most restrictive…</td>
<td>…Least restrictive</td>
<td>…Least integrated</td>
<td>…Most integrated</td>
</tr>
<tr>
<td>Least normalized…</td>
<td>…Most normalized</td>
<td>…Most intensive services</td>
<td>…Least intensive services</td>
</tr>
</tbody>
</table>

*ICF/IID refers to Intermediate Care Facilities for Individuals with Intellectual Disabilities.

(Johnson & Traustadottir, 2005, p. 97)

Public institutions were the most restrictive and least integrated settings at the time. An institution was defined as “a large (16 or more residents) state residential facility in which people with intellectual disabilities were cut off or segregated from society” (Johnson & Traustadottir, 2005, p. 96). Public institutions have been called by several names including State hospitals, training schools, and development centers (Braddock & Heller, 1985; Goffman, 1961; Grob, 1994; Johnson & Traustadottir, 2005). The major characteristics of public institutions are shared by what Goffman (1961) refers to as “total institutions.” Total institutions are defined as “a place of residence and work where a large number of like-suited individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life” (Goffman, 1961, p. xiii).
Community was defined as “a facility or home located in ordinary housing or a residential neighborhood” (Johnson & Traustadottir, 2005, p. 96). Between the two extremes of public institutions and independent living were nursing homes and private institutions, community Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID), group homes, foster care, and semi-independent living (Johnson & Traustadottir, 2005).

The ICF/IID program was established in 1971 as an optional Medicaid benefit under the Social Security Act (CMMS, 2015). Institutions and small community facilities (typically 6-15 persons) were funded by the ICF/IID program (Johnson & Traustadottir, 2005, p. 97). In 2009, the ICF/IID program was funding 7,400 facilities which housed approximately 129,000 individuals with DD/ID (CMMS, 2015). For ICF/IID facilities to be reimbursed by Medicaid, they had to comply with federal standards in regards to “management, client protections, facility staffing, active treatment services, client behavior and facility practices, health care services, physical environment and dietetic services” (CMMS, 2015).

ICF/IID facilities were commonly used as residential placements for individuals with severe and profound levels of ID. According to the Center for Medicaid and Medicare Services (CMMS) (2015), in 1993, 82% of individuals in ICF/IID facilities were diagnosed with severe and profound ID; with 19% of individuals with severe ID, and 53% of individuals in the profound range of ID. In the future, they may also serve as defacto nursing homes, as the ICF/IID population continues to age and younger DD/ID individuals choose other residential living options (CMMS, 2015; Strydom et al., 2010).

The further progression of integrated community services was supported by Home and Community Based Service (HCBS) waivers. HCBS waivers were funded through Medicaid to provide individuals with severe needs with services within the community. This included
individuals with ICF/IID levels of care (Lakin, Doljanac, Byun, Standcliffe, & Taub, 2008). The creation of the HCBS waiver program provided individuals who had been relegated to institutions based on their unique needs the opportunity to move into the community with similar levels of support (Lakin et al., 2008; Rizzolo, Friedman, Lulinski-Norris, & Braddock, 2013). According to Amaral (2010), individuals with DD/ID and the aging populations were most often targeted for waivers. From 1992 to 2000, the number of DD/ID individuals receiving Home and Community Based Services (HCBS) increased from 57,627 to 287,759, showing an increase of 399% overall and an average yearly increase of 23% (Amaral, 2010).

Community integration was also aided by the recent change in many community services to self-determination (SD) models of practice, also known as self-directed care. The SD model functions as a “cash and carry” program for DD/ID individuals through Community Mental Health Centers (Alakeson, 2008). The premise of the program is to provide the individual with the level of eligible funding so they can be provided with finances to choose the services they need from the agency they wish to work with (Heller, Arnold, van Heuman, McBride, & Factor, 2012). Self-directed care is an emerging trend in the area of DD/ID at present. The slower implementation of self-directed care for individuals with DD/ID is likely related to the level of paternalism present in society in regards to this population, as well as the population’s ability to comprehend the program and acquire needed services (Lakin et al., 2008; Thorn et al., 2009).

Another trend in residential placement of individuals with DD/ID since deinstitutionalization is that of the individual returning to live with their family of origin (Deb & Holmes, 1998). Due to the lack of advanced planning and supports within the community, families were left to fill the gap for individuals with DD/ID when they were discharged from institutional settings (Deb & Holms, 1998; Wright, Avirappattu, & LaFuze, 1999). In these
instances, families often paid for services out of pocket for their loved one. The financial burden of paying for formal care for loved ones has contributed to financial strain and for some burnout of family members who can comprise natural supports (Deb & Holms, 1998; Wright, Avirappatu, & LaFuze, 1999).

According to the Center on Human Policy’s *The Community Imperative* declaration, 183 organizations have supported the rights of individuals with disabilities to live in the community since 2004 (Johnson & Traustadottir, 2005, p. 102). Residential placement trends support this opinion, as evidenced by a 67% decline in populations within U.S. institutions from 1980 to 2003 (Lakin et al., 2004). Further support of this movement is evidenced by the closure of State run institutions across the U.S. From 1960 to 2002, 168 institutions for individuals with intellectual disabilities were closed (Lakin et al., 2004). By 2003, eight states (Alaska, Hawaii, Maine, New Hampshire, New Mexico, Rhode Island, Vermont, and West Virginia) and the District of Columbia had closed all state run institutions (Lakin et al., 2004). In 2005, all of the institutions in England were also closed (Johnson & Traustadottir, 2005).

**SMI.** For individuals with mental illness, their journey and experience of the expansion of community services from institutions has been unique in many ways. In the past, many individuals with SMI were also supported in institutional settings or state run hospital facilities as they were seen as the premiere facility to offer mental health treatment (Grob, 1994). From 1875 to 1955, the number of institutions increased in the U.S. from sixty to 265, with an average resident population of more than half a million individuals (Grob, 1994). Over time, the perception of institutional settings as ideal for providing treatment and care has eroded and the perspective has shifted from them being viewed as “solutions” to mental health issues to “problems” (Grob, 1994).
Unlike individuals with DD/ID who typically have lifelong conditions, individuals with SMI can have conditions that are variable in duration from episodic, short-term, or long-term in nature. Throughout history, many believed that SMI conditions could be cured based on the duration of symptoms (Grob, 1994). For individuals with chronic conditions, many mental hospitals would discharge those who failed to improve with their treatments or show signs of recovery (Grob, 1994). Subsequently, this led to many individuals with SMI having unmet needs and a lack of community services available to address them (Grob, 1994).

During the 1940’s to 1950’s the development and introduction of a variety of therapies were implemented to further the innovation of treatment in institutional and mental hospital settings. The advent of psychotropic medications, milieu therapy, electroshock, psychosurgery, and psychotherapy appeared to show some promise in the treatment of individuals with SMI and led to the transition of a “therapeutic culture” within facilities (Grob, 1994). The therapeutic culture and use of multidisciplinary teams led to the realization that authoritarian institutional settings created dependence and needed to foster more democratic structures to include the person in more of their treatment. The hospital settings over time appeared to be incorporating elements of empowerment for those they supported by including them more holistically in treatment (Grob, 1994).

With the use of innovative therapies and approaches to help restore people to their communities came several policies to help create and support SMI individuals within the community setting. In 1954, the Community Mental Health Services Act became law in the state of New York (Grob, 1994). The law helped to influence other states, including California to re-examine their mental health systems and begin to shift funds from institutional and custodial care to community services and outpatient clinics. According to Grob (1994), the 1950’s were a time
of rapid growth for outpatient clinics and mental hygiene services in schools, courts, and social service agencies (p. 236).

Advocacy for individuals with SMI appears to have started somewhat later than for individuals with DD/ID, with grassroots efforts beginning in the late 1960’s. The movement began with small groups in California, New York, Massachusetts, and Kansas (Grob, 1994). Early advocates for individuals with SMI conditions included Dorothea Dix, Judi Chamberlin, Howie the Harp, Sally Zinman, and Sue and Dennis Budd (Braddock & Heller, 1985; Grob, 1983; Unzicker, 2012). These individuals led others to displays of “civil disobedience” such as chaining themselves to the gates of mental hospitals, protesting the American Psychiatric Association meetings and conferences, and liberating “inmates” of mental hospitals (Braddock & Heller, 1985; Grob, 1983; Unzicker, 2012). Advocacy groups for individuals with SMI formed later with such groups as the National Alliance on Mental Illness (NAMI) in 1979, National Association of Psychiatric Survivors in the 1970’s, and the National Association for Rights Protection and Advocacy (NARPA) in 1980. These advocacy groups helped to influence federal programs through the National Institute on Mental Health (NIMH) and also the Substance Abuse and Mental Health Services Administration (SAMSHA) (Unzicker, 2012).

The 1963 Mental Retardation Facilities and Community Mental Health Center Act (MRF-CMHC) was also a catalyst to individual’s moving from institutions into the community. One of the primary goals of the legislation was to replace custodial care provided in institutional settings with therapeutic centers within communities (Grob, 1994). Unfortunately, the lack of “administrative regulations, standards, and procedures” to specify the legislation’s purpose and intent led to many short-comings that did not benefit the SMI population (Grob, 1994, p. 259). These included the struggles between bureaucracies in determining the guidelines of the
legislation, the omission of mental hospitals, and the lack of community staff and resources to meet the populations needs (Grob, 1994). Further barriers included the independence of the CMHC’s and their ability to determine the services and supports offered, which frequently did not meet the needs of individuals with severe and persistent mental illness (Grob, 1994).

While the time period following the 1963 CMHC Act saw a reduction in institutional settings, not all individuals moved to living in the community. The federal programs of Social Security, Medicaid, and Medicare assisted many individuals in moving from one custodial care facility to another. Many of the individuals living in institutional settings were aging and in need of further care. According to Grob (1994), in 1962 the residents of institutional settings that were sixty-five years or older was 153,309 out of 504,604 (p. 266). By 1972, the number of residents over the age of sixty-five residing in institutional settings was reduced to 78,479 out of 274,837 (Grob, 1994). This reduction is not evidence of aging individuals moving into the community, but actually the transfer of care from institutional settings to nursing home facilities with the assistance of funding from Medicaid and Medicare (Grob, 1994).

The reduction of populations from institutions and mental hospitals was also supported by movement of individuals back into the community into a variety of settings and living situations. Individuals often moved in with family members, went to half-way houses, obtained housing within the community in an Adult Foster Care home (AFC), or may have become homeless (Grob, 1994; Johnson & Traustadottir, 2005). Due to the lack of advanced planning and supports within the community, families were left to fill the gap for individuals with SMI when they were discharged from institutional settings (Cunningham, McKenzie, & Fries-Taylor, 2006; Deb & Holmes, 1998; Grob, 1994). This was more prominent for individuals with SMI, as they were often not eligible for Medicaid and therefore not eligible for many community services
which were subsequently funded by Medicaid funds (Deb & Holmes, 1998; Cunningham, McKenzie, & Fries-Taylor, 2006). In these instances, families often paid for services out of pocket for their loved one. The financial burden of paying for formal care for loved ones has contributed to financial strain and often burnout of many family members as natural resources (Deb & Holms, 1998; Wright, Avirappatu, & LaFuze, 1999). As such, Krieg (2001) has indicated the SMI population had high levels of unmet needs which can lead to negative consequences of homelessness, interaction with the criminal justice system, drug abuse, and prostitution. It is estimated that approximately 25% of individuals living homeless on the streets of the U.S. have a diagnosis of SMI (Grob, 1994).

During the 1970’s to 1980’s several political and legislative movements were evident to assist with the SMI population gaining better access to services within the community. These included the expansion of mental health law in 1975, President Carter’s creation of the Commission on Mental Health (1977), and the 1980 Mental Health Systems Act (Grob, 1994). The beginning of the 1980’s and the election of Ronald Reagan to the Presidency changed the focus from the expansion of services in the field of mental health, to the reduction of economic federal expenditures. In 1981, the Omnibus Budget Reconciliation Act was signed into law, which provided block grants to states for mental health services and substance abuse (Grob, 1994). The legislation not only reduced federal spending, but also reversed three decades of leadership in mental health from the federal level and returned it to the states (Grob, 1994).

The SMI’s population needs also shifted over time, with a subgroup of individuals growing up in the community versus within an institutional setting. This was primarily a group of young adults with chronic conditions (Grob, 1994). Grob (1994) indicates people with SMI were rarely admitted to mental hospitals for extended stays, had similar reactions to authority as
their same aged peers, often responded with aggressiveness, volatility, and noncompliance, and
generally fell into the categories of schizophrenia, affective disorders, or borderline personality
disorders (Grob, 1994, p. 296). A further hindrance for this group was their lack of functional
and adaptive skills and addition of substance abuse issues of alcoholism and drug abuse (Grob,
1994). This group became high utilizers of services in frequenting emergency and psychiatric
wards of general hospitals for brief stays or other inpatient and outpatient facilities (Grob, 1994).
Many could also be found in correctional institutions (Grob, 1994).

Community integration for individuals with SMI conditions was not fully supported in
the past, and continues to have its barriers in the present. Society’s treatment of individuals with
SMI was characterized by “emotional problems or disturbance caused by
environmental/situational stress and to involve depression, tension, fearfulness, anxiety,
erratic/unpredictable behavior, and instability” (Caruso & Hodapp, 1988, p. 121). According to
Krieg (2001), research also indicates several negative consequences for communities with large
concentrations of SMI individuals after deinstitutionalization. These included “heavy littering,
frequent public urination and defecation, indecent exposure, obscene gestures, increased
shoplifting, decreased tourism, increased prostitution, suicide and threatened suicide, and lack of
physical health care” (Krieg, 2001, p. 372).

At present, SMI individuals may have a mental illness that will affect them for the
duration of their life contributing to “poor utilization of community-based treatments which
result in marginalized lifestyles for many, including low levels of employment and high levels of
homelessness and engagement in criminal activities” (Robertson, Pearson, & Gibb, 1996; Stein,
1999; Weisman, Lamberti, & Price, 2004 as cited in Cosden, Ellens, Schnell, & Yamini-Diouf,
2005, p. 199). Most often the individual with SMI will seek out assistive services while in crisis
for psychiatric issues, homelessness, substance abuse, or interaction with the criminal justice system (Cunningham et al., 2006; Slayter, 2007; Umb-Carlsson & Jansson, 2009). In those instances the individual with SMI is most likely to engage in short term assistance from a community agency to ameliorate the crisis, or be referred to psychiatric services for consultation and medication stabilization (SAMSHA, 2012; Shedlack et al., 2005). The use of medication therapy to address such SMI diagnoses as major depression, bipolar disorder, and schizophrenia, have greatly assisted the SMI population in reducing psychiatric symptom levels within shorter periods of time (SAMSHA, 2012; Shedlack et al., 2005).

The use of the recovery model of practice has also aided with treatment. The recovery model incorporates stages of change (engagement, persuasion, active treatment, and relapse prevention) into the therapeutic approach with individuals with SMI and/or substance abuse needs (Mueser, Noordsy, Drake, & Fox, 2003). According to Mueser and colleagues (2003):

The rehabilitation and recovery promoting function of case management is aimed mainly at improving overall psychosocial functioning and developing a sense of positive self-esteem and self-worth. Such a focus is critical to helping clients develop the belief that they are capable of changing their lives, and creating positive lives worth living without substances. (p. 102)

A therapeutic strategy commonly used to support SMI individuals within the recovery model is the approach of motivational interviewing (MI). Motivational interviewing is defined as “a set of therapeutic strategies designed to help clients understand the impact of substance abuse on their lives in their own terms” (Mueser, Noordsy, Drake, & Fox, 2003, p. 108). Motivational interviewing can be utilized within individual, family, or group therapy environments (Mueser, Noordsy, Drake, & Fox, 2003).

Over time varying treatments and approaches have been researched and developed to help better meet the needs of the SMI population in the community, with several reaching the
rigor of becoming evidence-based practices. These approaches include Assertive Community Treatment (ACT), Dialectical Behavior Therapy (DBT), Cognitive Behavioral Social Skills Training, Critical Time Intervention, Pathways’ Housing First Program, Acceptance and Commitment Therapy, Adolescent Coping with Depression, Critical Time Intervention, Double Trouble in Recovery, ICCD Clubhouse Model, Modified Therapeutic Community for Persons with Co-Occurring Disorders, Multi-Systemic Therapy with Psychiatric Supports, Partners in Care, Pathways Housing First Program, Psycho-Educational Multifamily Groups, Teen Screen, Interpersonal Psychotherapy for Adolescents, and the Wellness Recovery Action Plan (SAMHSA-NREPP, 2011).

**DD/SMI.** While many differences exist in the social and political influences of individuals with DD/ID and SMI diagnoses, there are a few similarities in regards to the community service needs. First, both populations benefited and struggled in regards to the outcomes of different forms of legislation (Grob, 1994; Johnson & Traustadottir, 2005). While the purpose and intent of such legislation as the Mental Retardation and Community Mental Health Centers Construction Act (1963) were to move individuals into the community, the lack of available community services to meet the population’s needs at the time created barriers to that success. The responsiveness of the community service system was seen over time with the realization that the supports available were not meeting the needs of the DD/ID, SMI, and DD/SMI populations, and other forms of treatment and support being promoted by several advocacy groups.

Second, both the DD/ID and SMI populations shared a reliance on nursing home facilities following the deinstitutionalization movement and CMHC Act of 1963 (Bachrach, 1976; Deb & Holmes, 1998; Grob 1994). Both had populations that were aging and in need of ongoing
custodial care that was not able to be met at the time in the community setting (Bachrach, 1976, Grob, 1994). The lack of more intense service options in the community for the aging populations further illustrates the lack of supports for the DD/ID, SMI and DD/SMI populations throughout history.

Third, the advent of new psychiatric medications assisted both populations in decreasing psychiatric symptoms and therefore contributed to their ability to live more successfully in the community (Grob, 1994; Krieg, 2001; SAMSHA, 2012; Shedlack et al., 2005). The creation of new psychiatric medications aided the DD/ID, SMI, and DD/SMI populations to move from more restrictive environments and into the community setting.

Finally, both populations relied heavily on their families for support and care after being discharged from institutional settings when community services were not yet adequately established (Grob, 1994; Bachrach, 1776; Freedman & Capobianco-Boyer, 2000). For both the DD/ID and SMI populations, the creation of community services to meet their unique needs has been a slow process over time. In the past decade, the expansion of self-determination services for both populations has led to more choice and empowerment of the individuals about which services and supports they choose and how they are implemented (Freedman & Capobianco-Boyer, 2000).

Currently there are no comprehensive federal policies that specifically target the DD/SMI population. Of the existing policies, the Americans with Disabilities Act (1990) and Medicaid policy are the most inclusive of the DD/SMI population in regards to promoting community services.

_American’s with Disabilities Act (1990)._ The Americans with Disabilities Act (1990) has been one of the most expansive pieces of legislation in addressing discrimination among
individuals with disabilities (both DD and SMI) in the United States. The Americans with Disabilities Act (ADA) prohibits discrimination against people with disabilities in employment, transportation, public accommodation, communications, and governmental activities (Cohen, 2005; Kiuhara & Huefner, 2008; Oyez & Koenig, 1998; Mechanic, Bilder, & McAlpine, 2002; Noe, 1997; U.S. Department of Labor, 2012). The ADA has assisted the DD/ID, SMI, and DD/SMI populations with increased placement of individuals from institutions into the community, with increased opportunities for employment through accommodations of environments and needed equipment, and also job training support that was absent prior to the legislation (Cohen, 2005; Mechanic, Bilder, & McAlpine, 2002; Kiuhara & Huefner, 2008; Oyez & Koenig, 1998; Noe, 1997).

The Americans with Disabilities Act (1990) promoted the customization of services for individuals (ie. access to services and employment), the responsiveness from community services (ie. addressing discrimination and expansion of services), and aided in the empowerment of individuals with disabilities to have full access to their communities like their non-disabled peers.

Medicaid. The availability of Medicaid funding facilitated movement of DD/ID and SMI individuals from institutional to community based settings (Amaral, 2010; Day, 2006; Kitchner, Hernandez, Ng, & Harrington, 2006; Walker & Osterhaus, 2010). At present, Medicaid provides health care coverage for approximately 8.8 million individuals with disabilities in the United States (Medicaid.gov, 2012). In the past, and into present day, Medicaid has been a major source of funding for individuals with DD/ID and SMI within Community Mental Health Centers across the country (Verdier & Barrett, 2008). Some of the major impacts of Medicaid providing community services will be reviewed.
Community Mental Health Centers are funded through federal and state appropriations of Medicaid funds (Walker & Osterhaus, 2010). These funds are available in several forms, including a variety of Medicaid waivers known as Home and Community Based Service (HCBS) waivers (Kitchener et al., 2006; Rizzolo, Friedman, Lulinski-Norris, & Braddock, 2013; Walker & Osterhaus, 2010). The HCBS waivers are overseen by the federal Centers for Medicaid and Medicare Services (CMMS) (Walker & Osterhaus, 2010). From 1992 to 2000, the number of DD/ID individuals receiving Home and Community Based Services (HCBS) increased from 57,627 to 287,759, showing an increase of 399% overall and an average yearly increase of 23% (Amaral, 2010).

While states receive federal funding for waiver programs, each state is able to create their own waivers to fit the needs of their populations. This allows for variability among states in regards to the number of waivers provided and the services provided under each waiver (Medicaid.gov, 2012). For example, the State of Michigan currently has four waiver programs which include the MI Choice Renewal, MI Waiver for Children with SED, MI Children’s Waiver Program, and MI Habilitations Supports Waiver (Medicaid.gov, 2012). Each of the waiver programs offers a combination of services to meet the needs of the designated populations (Refer to Table 1).
### Table 1: Michigan Waiver Programs

<table>
<thead>
<tr>
<th>Name</th>
<th>Target Population</th>
<th>Services</th>
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<tbody>
<tr>
<td>MI Choice Renewal</td>
<td>Individuals 65 yrs - no max age, disabled ages 18-64</td>
<td>Provides adult day health, homemaker, personal care, specialized medical equipment and supplies, fiscal intermediary, goods and services, chore, community living supports, counseling, environmental accessibility adaptations, home delivered meals, non-medical transportation, nursing facility transition, PERS, private duty nursing, residential services, and training for aged individuals.</td>
</tr>
<tr>
<td>MI Waiver for Children with SED</td>
<td>Individuals w/mental illness SED ages 0-19</td>
<td>Provides respite, child therapeutic foster care, community living supports, community transition, family home care training, family support and training, therapeutic activities, therapeutic overnight camping, and wraparound for individuals with mental illness.</td>
</tr>
<tr>
<td>MI Children’s Waiver Program</td>
<td>Individuals w/autism, MR, DD ages 0-17</td>
<td>Provides respite, enhanced transportation, fiscal intermediary, community living supports, environmental accessibility adaptations and specialized medical equipment and supplies, home care training-family, home care training-non-family, and specialty service for individuals with autism.</td>
</tr>
<tr>
<td>MI Habilitations Support Waiver</td>
<td>Individuals w/DD ages 0 - no max age</td>
<td>Provides out-of-home non-vocational habilitation, prevocational services, respite, supported employment, supports coordination, enhanced medical equipment and supplies, enhanced pharmacy, goods and services, community living supports, environmental modifications, family training, PERS, and private duty nursing.</td>
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(Medicaid.gov, 2012)

Each state is responsible for establishing and administering their own Medicaid programs and determines the type, amount, duration, and scope of services within the broad federal guidelines for waivers (Day, 2006; Medicaid.gov, 2012; Well, 2003). This allows states the...
ability to adapt or revise services recommended by Medicaid to meet the needs of the individuals they support.

States are required to provide “mandatory services” as specified by federal guidelines, but can choose to provide other services known as “optional benefits” through the Medicaid Program (Day, 2006; Medicaid.gov, 2012; Well, 2003). Table 2 outlines the services considered mandatory and optional under Medicaid policy. This is an area where community services could further be adapted to become more customized, responsive, and empowering to the needs of the DD/SMI population.

In reviewing the services offered, the majority of services that would benefit the long-term care needs of individuals with DD/ID, SMI, and DD/SMI are located under the “optional” services section. These services include occupational therapy, speech and language services, preventive and rehabilitative services, case management, intermediate care facilities for the ID, and HCBS waiver services (Day, 2006; Medicaid.gov, 2012; Well, 2003). Team approaches that incorporate a number of the optional services have been established as evidence based practices (EBP) for DD and SMI populations, and work continues to progress in building them as EBP for the DD/SMI population (Hackerman, Schmidt, Dyson, Hovermale, & Gallucci, 2006; King, Jordan, Mazurek, Earle, Earle, & Runham, 2009; Martin et al., 2005; Oliver et al., 2005; Sakdalan, Shaw, & Collier, 2010). The combination of multidisciplinary professionals to support individuals in the community has been proven to reduce the occurrence of psychiatric hospitalization, increase quality of life and family inclusion, and to reduce the interactions with the criminal justice system for DD and SMI populations (Davis et al., 2008; Hackerman, Schmidt, Dyson, Hovermale, & Gallucci, 2006). If the “optional” services that pertain to these multidisciplinary team approaches were to be reduced or discontinued, that could threaten the
funding of effective practice approaches for the DD/ID, SMI and potentially the DD/SMI population in the future.

Table 2: Mandatory vs. Optional Medicaid Services

<table>
<thead>
<tr>
<th>Type</th>
<th>Service</th>
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<tbody>
<tr>
<td>Mandatory</td>
<td>Inpatient hospital services; outpatient hospital services; Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) services; nursing facility services; home health services; physician services; rural health clinic services; federally qualified health center services; laboratory and X-ray services; family planning services; nurse midwife services; certified pediatric and family nurse practitioner services; freestanding birth center services; transportation to medical care; tobacco cessation counseling for pregnant women; tobacco cessation</td>
</tr>
<tr>
<td>Optional</td>
<td>Prescription drugs; clinic services; physical therapy; occupational therapy; speech, hearing and language disorder services; respiratory care services; other diagnostic, screening, preventive and rehabilitative services; podiatry services; optometry services; dental services; dentures; prosthetics; eyeglasses; chiropractic services; other practitioner services; private duty nursing services; personal Care; hospice; case management; services for individuals age 65 or older in an Institution for Mental Disease (IMD); services in an intermediate care facility for the intellectually disabled; State plan Home and Community Based Services- 1915(i); Self-Directed Personal Assistance Services- 1915(j); Community First Choice Option- 1915(k); other services approved by the Secretary; TB Related Services, Inpatient psychiatric services for individuals under age 21</td>
</tr>
</tbody>
</table>

(Day, 2006; Medicaid.gov, 2012; Well, 2003)

Medicaid services also provide funding for the Ticket to Work program enacted in 1999. This program expanded Medicaid coverage to individuals with disabilities whose incomes were too high to qualify for SSI (Bond, Xie, & Drake, 2007; Cook et al., 2006; Waynor & Pratt, 2011). Many people with DD/ID and SMI conditions are able to work and earn a living, but by choosing to do so make an income too large for them to be typically eligible for Medicaid services (Cook et al., 2006; Waynor & Pratt, 2011). According to Waynor and Pratt (2011), “the literature has consistently found that fear of losing benefits is one of the most intractable barriers
to employment for persons with disabilities” (p. 73). The Ticket to Work program provides support for these individuals who are able to work but perhaps work for businesses that do not provide health insurance, the individual works too few hours to be eligible for private insurance, or the insurance available is not broad enough to provide for the individual’s needs (Cook et al., 2006; Day, 2006; Well, 2003). This also means that for individuals with DD/ID, SMI, and DD/SMI conditions they cannot afford needed medications, and will be unable to access clinical treatment and community supports as their wages increase (Day, 2006). According to Hackerman et al. (2006), employment has been a benchmark indicator of stability and advancement for patients with DD/SMI (p. 20). Therefore the continued support of the Ticket to Work program would further assist the DD/SMI population toward stability in their lives, in both mental health and financial areas.

**Economic influences.** The availability of resources and the funds to support community services for individuals with DD/SMI is an ongoing issue within the community service system with budgetary constraints. This has also been an issue throughout history for individuals with DD/ID, SMI, and DD/SMI in accessing resources and services to adequately meet their needs in the community. Some of the major impacts to community services will be reviewed here in greater depth.

**DD/ID.** Currently, the primary funding source for community services for the DD/ID population is Medicaid. Medicaid funds are dispersed from the federal level to the individual states. During the fiscal year of 2010, Medicaid had 66,695,156 individuals enrolled and receiving health care services (Medicaid.gov, 2012). In 2010, Medicaid paid out total funds in the amount of $383,495,367,018 for those individuals, with the federal government paying for 67.79% and state funds paying for 32.21% (Medicaid.gov, 2012). The statistics from 2010 are a
major increase over time from the data available for 2006 which indicates Medicaid enrollment at 59,928,867, expenses of $299,021,981,879, with the federal government paying for 57.04% and states paying for 42.96% (Medicaid.gov, 2012). Enrollment in Medicaid continues to rise in the U.S. as the present number of enrollees is 71,754,506 nationally, with 2,289,337 enrollees being represented within Michigan (Medicaid.gov, 2016).

In examining these statistics further it becomes evident that the economic climate of the United States has greatly affected individual’s needs for access to health care. It also appears the role of funding for Medicaid services has changed as well, with the federal government taking on paying for larger portions of this program over time (Medicaid.gov, 2012; Verdier & Barrett, 2008). According to Verdier and Barrett (2008), the “increased use of Medicaid as a funding source for mental health services has led to greater scrutiny of state Medicaid funding arrangements” and increased scrutiny by the federal Centers for Medicaid and Medicare Services (CMMS) in attempting to reduce services such as rehabilitation services and targeted case management (p. 1205).

Through CMHC’s, Medicaid funds are dispersed in several ways. For the DD/ID population, services are often funded through the Home and Community Based Services (HCBS) waivers, as mentioned previously. According to Rizzolo and colleagues (2013), the “Medicaid program funded over 75% of all publicly funded long-term supports for individuals with intellectual and developmental disabilities in the U.S. in fiscal year 2009” (p. 1). Since the HCBS waiver was first authorized in 1981, the number of participants has grown from 1,379 to 572, 493 in 2009 (Rizzolo et al., 2013). In 2009, a total of $25.1 billion dollars was spent to support DD/ID individuals nationwide through the HCBS waiver program. Of the services available to support DD/ID individuals, the three largest utilized in 2009 were residential
habilitation services ($12.4 billion or 53%), day habilitation ($4.5 billion or 19%), and companion/homemaker/chore/personal assistance/supported living ($2.7 billion or 11%) (Rizzolo et al., 2013). The average cost per person receiving services through the HCBS waiver program is approximately $34,813 annually, according to research conducted by Rizzolo and colleagues (2013).

There is also a trend within the field of community services for DD/ID individuals in regards to Self-Determination (SD) and forms of support waivers. In a comparison of states that utilized both a comprehensive (ie. HCBS) and supports waivers, Rizzolo and colleagues (2013) found that supports waivers were roughly 20% of the average cost of comprehensive waivers. Supports waivers have come into fruition as states attempt to reduce the average per person cost by addressing changes to their service systems (Rizzolo et al., 2013). This has included such options as “eliminating the cost of 24-hour residential care in the support waiver, utilizing natural supports provided by family caregivers, maximizing federal reimbursement for services previously paid for solely by state and local dollars, and addressing the growing waiting list for services in the states” (Rizzolo et al., 2013, p. 11). Self-determination options also promote the customization and empowerment of individuals in regards to community services.

**SMI.** In comparison to individuals with DD/ID, individuals with SMI conditions receive funding and support from a variety of sources. Like individuals with DD/ID, SMI individuals also receive benefits from entitlement programs such as Social Security Disability Insurance (SSDI), Social Security Income (SSI), Medicaid, Medicare, and Affordable Care Act plans such as the Healthy Michigan Plans (HMP) (Bond, Xie, & Drake, 2007; Bush, Drake, Xie, McHugo, & Haslett, 2009; Cook et al, 2006; Mechanic, Bilder, McAlpine, 2002; & Michigan.gov, 2016). They also earn income from competitive employment, in the form of part-time and full time
According to several research studies, individuals with SMI conditions are the fastest growing and largest proportionate group receiving SSDI and SSI benefits in the United States (Bond, Xie, & Drake, 2007; Cook et al., 2006; Mechanic, Bilder, & McAlpine, 2002). Characteristically, the SMI population also continues to receive Social Security benefits for longer periods of time than any other group of recipients (Cook et al., 2006; Gao, Schmidt, Gill, & Pratt, 2011). The SSDI program “provides support to individuals of working age who have paid a specified amount of Social Security tax and subsequently are determined to be eligible because of a disability” (Bond, Xie, & Drake, 2007, p. 1412). Beneficiaries of the SSDI program are able to work for a trial period without any impact on their benefits. After the trial period is complete, then beneficiaries are subject to losing their SSDI benefits, a phenomenon known as “falling off the cliff” (Bond, Xie, & Drake, 2007, p. 1412). Individuals eligible for SSDI are also automatically eligible for Medicare after a two year period of time (Bond, Xie, & Drake, 2007).

In comparison, the SSI program provides income assistance to individuals with a disability who do not have an established or substantial work history (Bond, Xie, & Drake, 2007). Eligibility for the SSI program is “based on income and resources, in addition to establishing that the disability is severe enough to render the person unable to work for at least 12 months (Bond, Xie, & Drake, 2007, p. 1412). Unlike the SSDI program, SSI beneficiaries can earn income without losing their benefits, with the criteria that the SSI payment is reduced by $1 for every $2 in earned income (Bond, Xie, & Drake, 2007). For individuals eligible for SSI, they are also automatically eligible for Medicaid at the time of approval (Bond, Xie, & Drake, 2007). Beneficiaries of both SSDI and SSI may be fearful of losing their benefits and
associated health insurance, and therefore these programs can become deterrents to obtaining competitive community employment and earning income (Bond, Xie, & Drake, 2007; Cook et al., 2006).

Employment for individuals with SMI is another key area for earning income and support. Amongst individuals with an SMI diagnosis, the unemployment rate continues to be high, with numbers ranging from 32 to 61% (Cook et al., 2006; Mechanic, Bilder, & McAlpine, 2002). The average unemployment rate for the general population is approximately 18% (Cook et al., 2006; Mechanic, Bilder, & McAlpine, 2002). According to Bush and colleagues (2009), for individuals who “develop independent vocational lives outside of the mental health system they decrease their use of the mental health system” as long term impacts of employment (p. 1029). Individuals also reported that being employed enabled them to handle their diagnostic symptoms better and to leave the mental health system (Bush, Drake, Xie, McHugo, & Haslett, 2009).

The advent of the Affordable Care Act (2010), or potentially better known as “Obama Care,” has also assisted individuals with SMI to access health insurance and mental health services better. In Michigan, the Affordable Care Act (2010) has led to the Healthy Michigan Plan (HMP) which is a waiver that was approved by the Centers for Medicaid and Medicare (CMMS) for implementation on April 1, 2014 (Michigan Department of Health & Human Services, 2016). The purpose of the HMP was to provide Michigan residents with affordable health care coverage (Michigan Department of Health & Human Services, 2016). Individuals are eligible for the HMP if they meet the following criteria:

- Are age 19-64
- Have income at or below 133% of the federal poverty level ($16,000 for a single person or $33,000 for a family of four)
- Do not qualify for or are not enrolled in Medicare
- Do not qualify for or are not enrolled in other Medicaid programs
- Are not pregnant at the time of application
- Are residents of Michigan. (Michigan Department of Health & Human Services, 2016)

Currently, the HMP has a total of 590,464 beneficiaries receiving services and supports with approximately 51% being female and 49% being male (Michigan Department of Health & Human Services, 2016). The largest age group receiving HMP benefits at this time is individuals between the ages of 25 to 34 years old (159,372 enrollees), making up 27% of the total enrolled (Michigan Department of Health & Human Services, 2016).

Healthy Michigan Plan (HMP) has also assisted SMI individuals with accessing mental health and substance use treatment services that they may not have been able to access previously. The HMP is being implemented at various community agencies including Community Mental Health Centers across the state of Michigan at this time (Michigan Department of Health & Human Services, 2016).

With the HMP’s income eligibility criteria, it could potentially assist individuals with SMI to receive health coverage benefits if they were cut off of Medicaid for earning too much income from employment, which was previously stated as a concern from research presented by Bond and colleagues (2007), and Cook and colleagues (2006). Healthy Michigan Plan (HMP) appears to provide coverage for individuals that would have potentially been in a “gap” of either earning too much income to be eligible for Medicaid, but not being able to maintain employment full time to receive health coverage benefits through an employer.

**DD/SMI.** After reviewing the major impacts for individuals with DD/ID and SMI, it would appear that addressing the potential economic issues for the DD/SMI population would include such elements as entitlement programs such as Medicaid, Medicare, SSI, SSDI, and opportunities for employment could be advantageous to creating community services to meet the
populations’ unique needs. Inclusion of the Healthy Michigan Plan (HMP) may also be beneficial in meeting the needs of the DD/SMI population.

**Problem to be Addressed**

Given the dearth of research to guide services development for individuals with DD/SMI, it is possible that their unmet needs can lead to poorer outcomes such as increased psychiatric hospitalizations or incarceration. Another possibility may be that individuals receive little or no care for their mental health disorder. There is a strong need for knowledge drawn from empirical research that can be used to influence the development and structure of community based services for the people with DD/SMI. Throughout history the community service needs of individuals with DD/ID and SMI have adapted and/or expanded based on many influences from the social, political, and economic influences. A summary of these occurrences will be reviewed in regards to the experiences of individuals with DD/ID and SMI, as well as common themes for the DD/SMI population.

For individuals with a dual diagnosis of DD/SMI, having access to community services that are supportive of their unique needs is vital to their success. At present, the challenges to the helping process include the structure of services (DD/ID and SMI program separation), the accessibility of services based on eligibility criteria, and the provision of services (i.e. are the services available the “right fit” for DD/SMI individuals). Further challenges are presented in the form of interventions that have not been subjected to an empirically rigorous evaluation process to determine which forms of approach are best practices for individuals with DD/SMI conditions. Furthermore, there is also a need for better articulation of the needs of individuals with DD/SMI within the community for a more comprehensive understanding of support needs.
The literature review section will provide further information on the status of recent and current research in regards to the DD/SMI population.
CHAPTER 2: LITERATURE REVIEW

As the primary research question of the study is determining the community service needs of individuals with DD/SMI from the mental health perspective, the literature review section will focus on the research available in this area. The research available was quite limited in general. The majority of the research available was in relation to interventions and program evaluations of supports for individuals with DD/SMI.

Research regarding individuals who have been diagnosed with DD/SMI continues to be a newly emerging area. The lack of comprehensive research about individuals with DD/SMI has many consequences for the field of mental health. First, without a research base, practitioners may lack assessment tools to accurately identify individuals with DD/SMI conditions. Second, when an individual is diagnosed with DD/SMI, insufficient research could mean interventions used may not be subjected to sufficient empirical evaluation for this population. Third, the lack of evidence-based treatment interventions could further compound negative outcomes for the DD/SMI population in the form of increased psychiatric hospitalizations, homelessness, drug use, unemployment, victimization of crime, and incarceration (Slayter, 2007). For social workers to practice effectively with the DD/SMI population they are required to educate themselves about the needs of the population. If a comprehensive research base is not available to provide that education, then social workers could be functioning less effectively in their practice.

This section will be covering a variety of topics to outline the available literature to support individuals with DD/SMI. The document begins with an overview of the NASW Code of Ethics and the responsibility of practitioners when engaging in supporting populations with limited research available to inform practice. The theoretical orientation of this research will be
presented and how it organizes the community service needs of individuals with DD/SMI. Systems of care will also be reviewed for various populations that could be replicated or adapted to meet the needs of the DD/SMI population. The approach taken to search and review the available literature will also be presented with supportive documentation available in appendix F.

The available research was searched using relevant key terms in regards to DD/ID, SMI and DD/SMI to find the existing research. Among the search, eight articles were found in regards to interventions or program evaluations for these key areas. Five were directly related to interventions for individuals with DD/SMI. These articles will be outlined further with the relevant information presented to the topic. During the literature review, several emerging trends in practice were found including family and care-giver supports, peer to peer and peer mentor supports, self-directed or participant directed supports, and gentle teaching approaches. As the area of DD/SMI was quite limited, an analysis of available research and the gaps in that research will also be presented. Finally, the perspective of the mental health professional will be presented and its importance to the present research.

When working with an emerging practice area, the NASW Code of Ethics (2008) requires social workers to “exercise careful judgment and take responsible steps (including appropriate education, research, training, consultation, and supervision) to ensure the competence of their work and to protect clients from harm” (NASW, 2008, 1.04c). At this time, with the limited amount of research available regarding the DD/SMI population, this would indicate a vast majority of social workers interacting with clients of this population appear to be practicing with minimal information to inform intervention and treatment approaches.
Approach to Literature Review Search

Initially, the literature review process involved a broad search of several search engines and also organizations with an association with developmental disabilities, intellectual disabilities, severe mental illness, or dually diagnosed interventions (Refer to appendix F). First, the Michigan State University library was accessed to search the social science search engines. This included such search engines as PsychINFO, Med Line, ProQuest, Social Work Abstracts, and Wilson Select. As the information obtained from the search engines was limited in quantity in regards to programs and interventions for the DD/SMI population, the search was broadened to mental health organizations, advocacy groups, and well known research entities. These groups included the National Institute on Mental Health (NIMH), The Substance Abuse and Mental Health Services Administration (SAMHSA) - National Registry on Evidence-based Programs and Practices (NREPP), the National Association of the Dually Diagnosed (NADD), the National Alliance on Mental Illness (NAMI), and the U.S. National Institute of Health (i.e. ClinicalTrials.gov). Refer to appendix F for information on specific dates of searches, sources of searches, key terms used, and results found. After obtaining information on the areas of EBP, a narrower search was conducted with the library search engines to obtain more specific data on each program and intervention in greater depth.

Theoretical Orientation of Research

The theoretical orientation of this research incorporates elements of systems theory to inform the community service needs of the DD/SMI population.

Systems theory. Systems theory appears to have originated from Ludwig von Bertalanffy who illustrates this approach from a mathematical perspective (Bertalanffy, 1950). According to Bertalanffy (1950), considering a society or nation as a sum neglects to take into
consideration the smaller parts. Using such a collectivist conception of society can have consequences that impact the daily lives of those being considered a part of the whole that have different needs. As such, the present research is being supported by systems theory as a theoretical base due to the conceptualization of communities as systems and the varying elements that impact that system from differing levels on a regular basis to assist in identifying the needs of the DD/SMI population.

Bertalanffy (1950) defines a system as “a complex of interacting elements” (p. 143). In comparison Kirst-Ashman and Hull (2009) define a system as “a set of elements that forms an orderly, interrelated, and functional whole” (p. 10). The set of elements that make up the system must be interrelated and have some kind of mutual relationship of connection to one another (Bertalanffy, 1950; Kirst-Ashman & Hull, 2009). A person, a group, and even an organization can be considered a system, as long as it meets the standards outlined in the definitions above.

Robbins, Chatterjee, and Canda (2006) illustrate systems theory from the perspective of its many parts including the focal system, the subsystems, and the suprasystems. The focal system is the primary system of focus. The subsystems and suprasystem are defined by the focal system. Robbins, Chatterjee, and Canda (2006) define the subsystem as “a system that is part of the focal system and is smaller than and internal to the focal system” (p. 39). In relation, the suprasystem is the opposite of the subsystem, in that it is external to the focal system (Robbins, Chatterjee, & Canda, 2006). Another term used to describe the suprasystem is the environment.

Within this study, the focal system is specified as the community services for individuals with DD/SMI. The subsystems would include the DD/SMI population, and their families and other natural supports. The suprasystem, or environment, would include the macro level influences on the DD/SMI population. Such influences would include the Department of Health
and Human Services, as a primary policy and service setter; Social Security as a primary funding source of income; and finally Medicaid policy and services as set by state and federal legislative guidelines (ie. Center for Medicaid and Medicare Services).

According to Hasenfield (2010), human service organizations engage and interact with other systems and must constantly seek out and maintain legitimacy for the work that they do. This is accomplished through interactions with other systems in their environment, where they adopt and uphold moral systems and also cultural frames (Hasenfield, 2010). Some of the moral systems referred to by Hasenfield (2010) include “legislative bodies, government bureaucracies, regulatory agencies, professional associations, other human service organizations, various civic and political associations, and clients” (p. 14). According to Hasenfield (2010):

In this sense, human service organizations are archetypically “institutionalized organizations.” That is, their growth and survival depend less on the technical proficiency of their work with dominant cultural symbol and belief systems, that is, institutional rules (Meyer & Rowan, 1977). For human service organizations, the primary sources of these institutional rules are generally the state and the professions. Compliance with state policies and regulations provides the legal foundation for the organizations existence and is a prerequisite for the attainment of public funds. (p. 14-15)

Therefore, human service organizations can be considered highly dependent on the institutional environment for legitimacy and in turn for receiving funding and supports for services.

Within the present study, this perspective helps to illustrate the competing dynamics amongst community service systems from the varying levels of systems. As illustrated within figure 2, the community service needs of individuals with DD/SMI are impacted by the sub-system of people with DD/SMI and their natural supports and at the suprasystem level from primary policy makers such as the Department of Health and Human Services and Centers for Medicaid and Medicare Services.
Systems theory also encompasses other concepts that can help support the present study and approach to data collection. Some of these concepts include the dynamic of the system, the input and output of the system and homeostasis (Bertalanffy, 1950; Kirst-Ashman & Hull, 2009). A system is considered dynamic when it is having frequent and constant movement. For individuals with DD/SMI, the community service needs are a dynamic system in the way the services change and adapt based on the influences from policy makers and then translated impacts of service delivery to the individuals. The dynamics of the system are also utilized in forming individualized and customized services and supports to meet the DD/SMI population’s needs.

Two concepts that are also illustrated in this research are the input and output of the system. According to Kirst-Ashman and Hull (2009), the “input is energy, information, or
communication flow received from other systems; output is the same flow emitted from a system to the environment or to the other systems” (p. 10). According to Bertalanffy (1950), “transitions towards higher order presupposes a supply of energy, and energy is delivered continuously into the system only if the latter is an open system, taking energy from its environment” (p. 149). An example of input within the current research is the DD/SMI population seeking access to community services to get their needs met. An example of output from the current research would be the community service system (ie. focal system) communicating with other service providers or macro level policy makers (ie. suprasystem) like the Department of Health and Human Services (DHHS) regarding the needs of the DD/SMI population.

A final concept that helps to illustrate systems theory and its impact on the present research study is homeostasis. According to Kirst-Ashman and Hull (2009) the concept of homeostasis refers to the tendency for a system to maintain a relatively stable, constant state or equilibrium or balance” (p. 11). In examining the current community service system for individuals with DD/SMI, one may consider the system to be unbalanced or unable to achieve homeostasis. The community service system at present has not made changes to adapt to the needs of the DD/SMI population, and therefore has constant impacts of input on the system from such needs as psychiatric monitoring and possible hospitalization which translate into decreased opportunities for community integration (Brown, Brown, & Dibiasio, 2013; Hemmings & Al-Sheikh, 2013; Lunsky et al., 2006).

At present, the community service system relegates services for the DD/SMI population to either the DD or MI service systems. For the system to potentially achieve a state of homeostasis, the community service system may want to consider having the DD/SMI
population served jointly within DD and MI supports to possibly address the impacts on the system from individual needs going unmet. The relationship between the unmet needs of the DD/SMI population and systems theory is illustrated in figure 3 below.

Figure 3: Theoretical Path for the Community Service Needs of Individuals with DD/SMI

**Community Service Needs of DD/SMI**

Community services can be defined in several ways. For the purposes of this research, community services are those resources and support that individuals can access in the community through formal or informal means. Formal types of support are those accessed through agencies such as Community Mental Health Centers (CMHCs), Department of Health and Human Services (DHHS), Social Security Administration (SSA), etc. Informal types of supports include churches or religious affiliations, support groups, friends and family members.

The community service needs of the DD/SMI population are largely unknown at this time in part due to the limited research and knowledge development in this area. The needs can begin to be conceptualized by referring to the DD/ID and SMI literature as a point of reference. In regards to the needs from the DD/ID perspective, Rizzolo and colleagues (2013) examined 88 Medicaid HCBS waivers across 41 states and the District of Columbia to gain a better understanding of the services utilized. Across the 88 HCBS waivers, 1,300 services were offered
which could be categorized into 18 areas of support. These areas included the following services and supports:

- Residential habilitation
- Companion/homemaker/chore/personal assistance/supported living
- Adult day health
- Community transition supports
- Day habilitation
- Financial support services
- Care coordination
- Transportation
- Prevocational services
- Supported employment
- Assistive and medical technologies
- Health and professional services
- Respite
- Family training and counseling
- Individual goods and services
- Self-advocacy training
- Education, and recreation and leisure. (Rizzolo et al., 2013, p. 5)

The three most utilized services included residential habilitation, day habilitation, and companion/homemaker/personal assistance/supported living (Rizzolo et al., 2013). Residential habilitation refers to the “individually tailored supports that assist with the acquisition, retention, or improvement in skills related to living in the community” (Rizzolo, 2013, p. 5). This area also includes assistance with identifying and retaining housing in a least restrictive environment.

According to Rizzolo and colleagues (2013) day habilitation refers to the “assistance with acquisition, retention, or improvement in self-help, socialization and adaptive skills that takes place in a non-residential setting” (p. 9). Finally, the companion/homemaker/personal assistance/supported living service is aimed at assisting individuals to maintain living in their own home or within their family’s home (Rizzolo et al., 2013). Therefore, the community service needs of individuals with DD/SMI will likely include some level of support within each
of these three areas as well as within the other 15 categories based on the persons individualized care needs.

In examining the needs of individuals with SMI and DD/SMI, the literature indicates the need for services and supports that can assist with maintaining community living, monitoring psychiatric needs, and reducing interactions with the police and criminal justice entities (Hemmings & Al-Sheikh, 2013; Lunsky, Bradley, Durbin, Keogl, & Canrinus, 2006; Slayter, 2007). Therefore, the community service system should offer supports in the form of mental health therapists, case managers, and psychiatrists to assist with monitoring of psychiatric conditions and providing medication consultation and review. Case management can also assist with navigating community service systems and assisting the DD/SMI person with accessing supports at multiple agencies (Davis et al., 2008). Psychiatry services are also very important to assist with monitoring and treating psychiatric conditions through consultation and recommendations for possible medication therapy. Individuals with SMI also need effective therapeutic practice interventions to support them in the community. The SMI research base has several evidence based practices such as assertive community treatment (ACT), dialectical behavior therapy (DBT), and cognitive behavioral therapy (CBT) that should be considered (see appendix F) for therapeutic supports for individuals with DD/SMI. The approach of ACT may be very advantageous for the DD/SMI population as the approach incorporates a multidisciplinary team of supports to meet the individual’s needs (King et al., 2009). King and colleagues (2009) report the outcomes of ACT principles include “increasing client contact with support services, decreasing admissions to hospitals, reducing time spent in the hospital, improved accommodations, employment, and patient satisfaction” (p. 1). Therefore, a
combination of supportive services and practice interventions should be considered to meet the needs of the DD/SMI population in the community.

While both DD/ID and SMI conditions separately have several areas of evidence based practice (EBP) that have been proven to be effective areas of treatment, the area of DD/SMI brings special practice considerations for social workers to take under advisement (Davis et al., 2008). First, people with DD/ID are well known as their diagnoses usually require long-term care. Treatment interventions tend to assist individuals with obtaining and maintaining levels of functioning in regards to activities of daily living (ADL’s) and adaptive functioning (Thompson, et al., 2009). For individuals with DD/ID, this means they may be in services through formal agencies or informal supports for the majority of their life (Chan et al., 2004; Kaiser & McIntyre, 2010). This is especially true for individuals with reduced intellectual functioning (i.e. severe and profound ID) who have legal guardians and are deemed incapable of making major life decisions (Lee, 2011).

On the other hand, individuals with SMI have a broader range of duration of disorders from short-term and episodic to chronic and long-term. For those individuals with chronic and persistent SMI conditions, they may have a mental illness that will affect them for the duration of their life contributing to “poor utilization of community-based treatments which result in marginalized lifestyles for many, including possibly low levels of employment and high levels of homelessness and engagement in criminal activities” (Cosden, Ellens, Schnell, & Yamini-Diouf, 2005, p. 199).

According to Davis and colleagues (2008), for individuals with DD/SMI, treatment planning and implementation commonly involve “highly specialized, individualized programs that focus on long-term management of both disorders” (p. 205). To accommodate the needs of
the DD and SMI populations, community based services have to expand further to include case management services to assist with a variety of areas which include “coordinating links to community resources, prevention and outreach, patient advocacy, emergency and crisis care, hospitalization, discharge planning and coordination, and residential, family, and in-home services” (Davis et al., 2008, p. 206).

Second, the structure of programs for DD/SMI differs substantially from those specifically designed for individuals with DD or SMI individually. Programs and interventions for the DD/SMI population “need to accommodate the effects of cognitive, adaptive, and neurological deficits on the capacity of clinicians to differentiate mental disorders from severe challenging behaviors” (Davis et al., 2008, p. 206). For clinicians to develop effective interventions, they need to consider the complex needs of the DD/SMI population and the influence the DD/ID diagnosis can have in terms of “risk, precipitation, probability of relapse, treatment response and course of many mental disorders” (Davis et al., 2008, p. 206). Diagnostic issues in relation to individuals with DD/SMI have historically been linked to the separateness of the two systems (i.e. DD and MI) and the division of training of its professionals (Davis et al., 2008).

A third area of consideration is the need for well trained and experienced professionals to support the DD/SMI population as diagnostics can be complicated. Hurley and colleagues (2004) write that “individuals with ID are markedly under-served and unable to access proper psychiatric treatment because of atypical presentation, inability to sufficiently verbalize symptoms, and reliance on diagnostic criteria developed using intellectually normal individuals” (Hurley, Folstein, & Lam, 2003, p. 40). According to Lehotkay and colleagues (2009), the atypical presentation of SMI diagnoses in individuals with DD is more challenging to diagnose
as their signs and symptoms may not correlate with common diagnostic manuals such as the DSM-IV-TR (2000). The diagnostic process is further compromised by the “impaired communication skills, impoverished social skills, stress-induced disruption of information processing, pre-existing cognitive deficits, and maladaptive behaviors” that often present with individuals with a DD (Lehotkey et al., 2009, p. 106).

Another diagnostic issue is the occurrence of “diagnostic overshadowing” frequently interferes where the behavior or symptoms exhibited by the individual are seen as only characteristic to the SMI condition or the DD/ID condition (Antonacci et al., 2008; Chan et al., 2004; Hackerman et al., 2006; Hurley, Folstein, & Lam, 2003). For clinicians who have not been adequately trained to work with the DD/SMI population, diagnostic overshadowing can be problematic in identifying the correct diagnoses and effective treatments in the community setting. Further research conducted by Costello and colleagues (2007) in regards to education programs for DD/SMI populations for psychiatrists, psychologists, and primary care physicians in five countries indicates that the majority of professional groups responsible for providing mental health services receive minimal formal training. For clinicians working to support individuals with DD/SMI in the community, this further complicates their ability to effectively identify psychiatric symptoms for treatment, make recommendations for treatment, and support the needs of the DD/SMI population.

Clinicians have recognized that the occurrence of DD/SMI diagnoses present differently than solely DD, ID, and SMI conditions over time. This realization has spurred the development of additional resources in the field of mental health including the Diagnostic Manual – Intellectual Disability (DM-ID) (Fletcher et al., 2007), Contemporary Dual Diagnosis: MH/MR (Jacobson, Holburn, & Mulick, 2002a/b), Assessing Medical Issues Associated with
Behavioral/Psychiatric Problems in Persons with Intellectual Disability (Poindexter, 2005), and Integrated Treatment for Dual Disorders: A Guide to Effective Practice (Mueser, Noordsy, Drake, & Fox, 2003). The NADD also sponsors the official journal of research for individuals with ID/SMI, known as the Journal of Mental Health Research in Intellectual Disabilities.

According to Chan, Hudson, and Vulic (2004), the lack of research for the DD/SMI population has negatively affected the amount of support and service delivery available in mental health service systems for this population. The lack of support manifests in negative outcomes for the DD/SMI population including increased incidents of psychiatric hospitalizations, homelessness, substance abuse, and interaction with the criminal justice system (Chan, Hudson, & Vulic, 2004; Lunsky, Bradley, Durbin, Keogl, & Canrinus, 2006). For example, Lunsky and colleagues (2006) found that individuals with DD/SMI had longer lengths of stay in in-patient psychiatric hospitals than individuals without DD diagnoses. The DD/SMI population is typically younger, is more likely to live in more restrictive and dependent settings, and are less likely to get married or have children compared to individuals with an SMI diagnosis alone (Lunsky et al., 2006). Therefore, the DD/SMI population is in need of services and supports that assist with prevention of negative outcomes and assisting individuals with DD/SMI to live in the least restrictive environment possible.

**Systems of Care**

As the literature in regards to the community service needs of the DD/SMI population is limited, having a community service system available to meet their needs is unobtainable at this time. A strong community service system is needed to support the DD/SMI population and address the unmet needs and negative consequences of their symptomatology. As no system of care research is currently available for the DD/SMI population, a search of systems of care for a
variety of populations was conducted. The outcome of this search yielded several examples of systems of care with supportive services that could also be replicated and adapted to better serve the DD/SMI population.

The first system of care reviewed was in regards to youth with serious mental illness and the focus of reducing incarceration (Erickson, 2012). Within this study, Erickson (2012) indicates 160 systems of care (SOCs) have been implemented under the Substance Abuse and Mental Health Services Administration’s (SAMHSA) Center for Mental Health Services in response to the deficiencies of children’s mental health care. The SOCs utilize child and family team approaches to develop individualized plans of service, integrate community-based and mental health care supports, and intensive home-based services (Erickson, 2012, p. 409). One SOC program example provided was the Wraparound Milwaukee program which “uses multidisciplinary treatment teams, family involvement, and individualized care plans” (Erickson, 2012, p. 409). The program utilizes the Mobile Urgent Treatment Team which is a 24-hour crisis response team who intervene during times of family crisis situations to assist with prevention of the youth being removed from the home or inpatient psychiatric hospitalization (Erickson, 2012). A broad array of services is available within the Milwaukee Wraparound program due to a blend of funding from “child welfare, juvenile justice, Medicaid, and SSI” (Erickson, 2012, p. 409). Program outcomes have been quite positive and shown a 50% reduction in recidivism rates after one year, a 90% reduction in out-of-home placements, and a savings of $18,504 per youth serviced over other care models (Erickson, 2012).

Another example of an SOC presented by Erickson (2012) included the Robert Wood Johnson Foundation’s Reclaiming Futures Initiative which was designed to support collaboration between juvenile justice, social services, and services for families. The foundation “funds
programs that use comprehensive case management to coordinate individually tailored services for juvenile offenders with substance abuse histories using multiple systems of care” (Erickson, 2012, p. 410). Erickson (2012) indicates a national evaluation of 10 programs funded by the Robert Wood Johnson Foundation’s Reclaiming Futures Initiative show evidence of improvements to the areas of treatment delivery, cooperation amongst service providers, and involvement of families in treatment (p. 410).

The second system of care examined was in regards to mental health services for children, youth, and families across America (Miller, Blau, Christopher, & Jordan, 2012). Within their review of systems of care, Miller and colleagues (2012) present Project LAUNCH (Linking Actions for Unmet Needs in Children’s Health) (p. 573). Project LAUNCH is a SAMHSA funded grant program with a focus of promoting wellness of children ages birth to eight years “by addressing the physical, social, emotional, cognitive, and behavioral aspects of their development” (Miller et al., 2012, p. 573). The project aims to improve collaboration and coordination of child caring service systems through such means as:

Local communities promoting healthy social and emotional development by integrating mental-health informed practices into child-care centers and schools; primary care clinics; home visiting programs; and families. This includes increasing the use of screening and assessment for developmental and behavioral health issues across settings, and improving pathways to link children and families with appropriate services. (Miller, 2012, p. 573)

During the first three years of the initiative, some positive outcomes have been observed which have included bringing mental health consultation into early childhood education centers and health centers, educating over 10,000 community providers about issues related to behavioral health, and connecting 4,800 families to parent training programs (Miller, 2012).

The third system of care reviewed was in regards to rural care systems and tele-emergency services (Mueller, Potter, MacKinney, & Ward, 2014). Mueller and colleagues
define tele-emergency as “an immediate, real-time, interactive audio/video connection between an urban “hub” emergency department (ED) and a rural hospital” (p. 228). Tele-emergency services often involve consultation about diagnosis, treatment, requests for inpatients admission to the hospital, and case disposition (Mueller et al., 2014). Mueller and colleagues (2014) found that 95% of survey respondents indicated the tele-emergency service improved the quality of care within their facilities. Overall tele-emergency has shown to “increase access to high-quality, integrated, patient-centered care, especially in rural areas” (Mueller et al., 2014, p. 233).

Each of the systems of care presented offer services and supports that could be replicated or adapted to provide support for the DD/SMI population in meeting their needs. Systems of care which provide individualized plans of service, intensive case management, home-based services, and mental health support would assist in meeting the needs of the DD/SMI population. The inclusion of a Mobile Urgent Treatment Team, like the Wraparound Milwaukee program (Erickson, 2012), would also help in supporting individuals with DD/SMI in navigating crises in the family home and preventing out of home placement into psychiatric hospitals. The incorporation of tele-emergency services could also assist in navigating a crisis, if the system was set-up with therapists and psychiatrists as the “hub” vs. medical hospital settings as presented previously (Mueller et al., 2014). Finally, the inclusion of elements of Project LAUNCH (Miller et al., 2012) to assist with providing collaboration and coordination of services and supports for the DD/SMI population, as well as community education would be very helpful.

**DD/SMI Interventions/Programs from Research**

After conducting an extensive review of the literature eight research studies were located in regards to DD/SMI interventions and program evaluations. It appears that the amount of
information on practice interventions and programs for individuals with solely DD and SMI conditions is more vast than DD/SMI at this time.

Through search efforts five programs and interventions were located specific to the DD/SMI population with different intervention approaches that incorporate community services. The existing programs and interventions were: 1) the special needs clinic of the Johns Hopkins Bayview Medical Center (Hackerman, Schmidt, Dyson, Hovermale, & Gallucci, 2006), 2) assertive community treatment (ACT) (King, Jordan, Mazurek, Earle, Earle, & Runham, 2009; Martin et al., 2005; Oliver et al., 2005), 3) dialectical behavior therapy (DBT) (Brown, Milton, & Brown, 2013; Sakdalan, Shaw, & Collier, 2010), and 4) cognitive behavior therapy (CBT) (Ghafoori, Ratansiripong, & Holladay, 2010; Shedlack & Chapman, 2004).

**Multidisciplinary team approaches.** Hackerman and colleagues (2006) conducted a program evaluation for the Johns Hopkins Bayview Medical Center Special Needs Clinic (SNC) for individuals with DD/SMI to determine if the program that utilized a multidisciplinary approach was successful in supporting 210 patients.

The SNC program utilized a multidisciplinary team approach which included services and supports of case management, psychiatry, behavioral specialists, nurses, and occupational therapists. Intervention approaches utilized included medication management, therapy, and support groups (Hackerman et al., 2006). Theoretical orientations of interventions included insight-oriented and cognitive behavioral therapy. Evaluation data was reviewed for the time period between 1999 to 2004 in the form of record reviews. For the evaluation period, the SNC had 210 patients total, with 130 patients continuing to receive active treatment as of March of 2004 (Hackerman et al., 2006). Program outcomes included service utilization, clinic/provider characteristics, and outcomes such as primary medical care, psychiatric hospitalizations,
employment, and homelessness (Hackerman et al., 2006). Study results indicated the SNC showed positive outcomes for each area.

Hackerman and colleagues (2006) found the majority of participants were living in a family or natural support setting (65% lived with family, 27% lived in a group home, 7% lived independently with support services, and 1% lived with non-relatives). The majority of participants were between 18-29 years old (47%), with individuals ranging from 30-39 years (21%) the next largest proportionate age group. In regards to education, the majority of participants had a high school diploma or GED (66%), with individuals with less than a high school diploma (33%) represented as well. The majority of participants had some form of medical assistance insurance (47%), or utilized Medicare (27%) or private insurance (27%). Participants exhibited Axis I diagnoses (APA, 2000) of affective disorder (38%), autism spectrum disorder (14%), psychotic disorder (15%), impulse control disorder (12%), adjustment disorder (9%), anxiety disorder (6%), eating disorder (3%), and ADHD (3%). In regards to Axis II diagnoses, mild ID (42%) was most common, with moderate ID (24%), and severe/profound ID (11%). Also interesting to note, 32% of participants were able to sustain community employment, less than 5% were psychiatrically hospitalized, and less than 1% was incarcerated (Hackerman et al., 2006, p. 14-17)

Hackerman and colleagues (2006) recommended further research to understand the impacts of dual diagnosis of DD/ID with SMI conditions, and to assess service delivery systems to determine if they are meeting the needs of the DD/SMI population. Future goals for the SNC included identifying assessment tools for the DD/SMI population, effective behavioral interventions, integration of clinical services, and increased funding (Hackerman et al., 2006, p. 23).
A second program with a multidisciplinary team approach was conducted by Shedlack and Chapman (2004), to determine the effectiveness of social learning interventions with three individuals with DD/SMI in a psychiatric hospital program. The Developmental Disabilities Program at McLean Hospital is a teaching hospital of the Harvard Medical School. The program provides diagnosis and treatment of individuals with DD/SMI within its psychiatric partial hospital setting. The medical model is utilized in the program and provides a highly structured and comprehensive treatment for patients. Both cognitive and behavioral therapeutic interventions are utilized throughout the program. The primary focus of intervention involves a multi-modal approach with multidisciplinary teams (Shedlack & Chapman, 2004). Team members include a psychiatrist, two registered nurses, a licensed psychologist, clinical social worker, and secretary/art therapist. Patients participated in daily therapies in groups (illness management, problem and solutions, impulse control, social skills, stress management, and life skills), reinforcement-based contingency management interventions, and social learning interventions (self-instruction, problem solving, modeling, and relaxation) (Shedlack & Chapman, 2004, p. 11-12). The social learning approach emphasizes the use of bio-psycho-social assessment and skill deficit perspective. Admissions criteria to the program include:

- Being at least 18 years of age, mild/moderate mental retardation or borderline intellectual functioning, symptoms consistent with a DSM-IV Axis I psychiatric diagnosis, verbal communication skills, use of the toilet without assistance, adequate housing in place, and medical necessity/partial hospital level of care. (Shedlack & Chapman, 2004, p. 10).

Participants who met admissions criteria attended the program daily while continuing to live in their own home, group homes, or family homes. The length of time within the program was dependent upon psychiatric needs (Shedlack & Chapman, 2004).

Shedlack and Chapman (2004) utilized a qualitative approach to the study by conducting case studies of three participants’ experiences of involvement with the program. Research
design utilized an “AB design with a single target measure and no return to baseline” (Shedlack & Chapman, 2004, p. 19). Case studies utilized baseline measures at the time of admission and compared them to data at discharge from the program. One scale utilized for data collection was the Aberrant Behavior Checklist (ABC; Aman et al., 1985; Aman & Singh, 1986) (Shedlack & Chapman, 2004). Participant’s case notes in regards to participation in group therapies, reinforcement therapies, and social learning therapies were documented as well. Participants participated in the program for 2-3 months based on level of care at admission, and reductions in need to warrant discharge (Shedlack & Chapman, 2004).

Results from the three case studies indicated the use of social learning interventions as successful in the treatment of psychiatric symptoms in this population of DD/SMI (Shedlack & Chapman, 2004). Participants exhibited positive outcomes in “negative affect, compulsive verbalizations, and anxiety-related behaviors” (Shedlack & Chapman, 2004, p. 18). Future research recommendations focused on controlled experimental designs to determine the effectiveness of social learning interventions with the DD/SMI population (Shedlack & Chapman, 2004). Findings from Shedlack & Chapman (2004) further promote the need of individualized and customized services to support individuals with DD/SMI successfully in the community.

Assertive community treatment (ACT). Of the eight programs identified, three interventions involved the approach of ACT. The first program was implemented by King and colleagues (2009), where they evaluated a specialized Assertive Community Treatment (ACT) program for the dually diagnosed in Ontario, Canada by conducting 43 chart reviews. The ACT-DD program encompasses a team approach with involvement from a psychiatrist, nurses, social workers, a vocational specialist, a team leader, a family physician, and two behavioral
technicians. The program's mission is “to provide client-centered biopsychosocial interventions in supporting individuals with developmental disabilities and serious persistent mental illness through the provision of comprehensive community-based services” (King, Jordan, Mazurek, Earle, Earle, & Runham, 2009, p. 2). King and colleagues (2009) utilized qualitative research methods in conducting secondary data analysis of chart reviews for all individuals served by the ACT-DD program during the summers of 2004, 2005, and 2006.

Secondary data analysis of the chart reviews also involved examining the information relevant to Axes 1-4 diagnoses of the APA manual (2000) for each person included in the study (King et al., 2009, p.3). Axis 1 diagnoses (APA, 2000) ranged from mood disorders (40%), schizophrenia (33%), anxiety disorders (21%), substance-related disorders (12%), sleep disorders (9%), mental disorders due to a general medical condition (5%), disorders of childhood and adolescence (2%), and impulse control disorders (2%) (King et al., 2009, p.3). Axis 2 diagnoses (APA, 2000) were used to determine the level of intellectual disability each individual had noted within their chart that was reviewed. Data indicated individuals functioned as follows: borderline (2%), mild (72%), moderate (19%), severe (2%), and unknown (5%) (King et al., 2009, p.3).

Axis 3 diagnoses (APA, 2000) were documented to determine conditions that could potentially complicate or interfere with treatment. Axis 3 conditions included endocrine disorders (53%), disease of the musculoskeletal system (33%), seizure disorders (19%), diseases of blood (19%), diseases of the nervous system (16%), diseases of the circulatory system (16%), diseases of the genitourinary system (9%), diseases of the respiratory system (9%), and diseases of the digestive system (7%) (King et al., 2009, p.4).
Finally, Axis 4 (APA, 2000) was evaluated to determine the level of interdisciplinary support needed by the DD/SMI individual. Main themes collected from the data included other psychosocial and environmental problems (84%), occupational problems (51%), housing problems (35%), problems related to social environment (23%), problems with primary support group (9%), and problems related to interaction with legal system/crime (9%) (King et al., 2009, p. 4).

Analyses of the secondary data from the chart reviews were conducted on 1) course of treatment modalities of support offered by ACT-DD (Pharmacotherapy (100%), behavioral (56%), vocational (46%), leisure (42%), group psychotherapy (40%), individual psychotherapy (23%), nursing care (14%), primary care physician (9%), and substance abuse rehabilitation (2%)), 2) syndromes associated with psychiatric diagnoses (Prader Willi syndrome, fetal alcohol syndrome, fragile X syndrome, and chromosome #9 deletion), 3) reasons for termination with team (pre and post ACT-DD) (move out of catchment area (8%), deaths (8%), re-hospitalization (8%), other (5%), client chooses not to work with team (5%), completion with referral (3%), and team chooses not to work with client (2%)), and 4) number of hospitalizations pre and post ACT-DD support (number of days & number of episodes) (King et al., 2009, p. 3-6). The number of psychiatric hospitalizations before program were 217 (60,550 days in psychiatric facility), whereas post program involvement were 72 (3,001 days in psychiatric facility) (King et al., 2009, p. 5).

King et al. (2009) did not specifically give recommendations for future research but did offer several recommendations as to changes in the fidelity of the ACT-DD model for greater success in use with the DD/SMI population. Recommendations included five main areas. The first recommendation was to have flexibility in the admission criteria, as this would address the
misdiagnosis and the under diagnosis of SMI in the DD/ID population. The second recommendation was in regards to flexibility in maintenance and follow-up supports due to the knowledge of the reality of limited funding sources of various DD agencies. The third recommendation was the need to encourage and develop sub-specialties amongst team members and allow for educational and program development in those areas to better support the DD/SMI population in the community. The fourth recommendation was to provide education about the specific needs of individuals with DD/SMI while in the hospital setting to the support team working with the individuals. Finally, the last recommendation was to be aware of the incidence of abuse and PTSD amongst the DD/SMI population and provide available resources and specialty supports to help manage this need (King et al., 2009, p. 6).

King and colleagues (2009) recognized the benefits of ACT in improving outcomes for individuals with DD/SMI and advocated its use in the future with continued deinstitutionalization efforts. The team’s approach of using client-centered and flexible services to meet the needs of individuals with DD/SMI in the community further assists with informing community service needs (King et al., 2009).

The second program compared the effectiveness of ACT (ACT-ID) and standard community treatment (SCT-ID) with 20 ID/SMI participants in London, United Kingdom by Martin and colleagues (2005). This exploratory experimental study was conducted by a specialist mental health service agency for individuals with ID with long-term care needs. Martin and colleagues (2005) hypothesized “service users placed on ACT-ID would show decreases in level of needs and carer burden as measured by the Camberwell Assessment of Need in Adults with Developmental and Intellectual Disabilities (CANDID)” (Martin et al., 2005, p. 518). Increased quality of life and functioning were secondary hypotheses for
individuals in the ACT-ID intervention. Intervention methods were not specific but indicated the ACT intervention methods were taken from Test (1992) and the SCT methods were taken from Meisler et al. (2000) (Martin et al., 2005). ACT focus was to increase levels of functioning and assist with managing symptoms. The treatment program lasted for 1 year (Martin et al., 2005).

Participants were selected through new referrals to the clinical services of the mental health agency following giving consent. Inclusion criteria for the study included an age range of 16-65 years, an ICD-10 criteria for mild/moderate ID, and presence of a psychiatric disorder (i.e. schizophrenia spectrum psychoses, or mood/affective disorders) (Martin et al., 2005, p. 517). The team psychiatrist assessed each individual for level of ID and presence of psychiatric disorder. Following psychiatrist assessment, a research assistant assessed participants for “met and unmet needs (CANDID scale; Xenitidis et al., 2003), functional disability (Global Assessment of Functioning (GAF); Enicott et al., 2003), quality of life (QoL-Q; Shalock & Keith, 1993), behavioral problems (Aberrant Behaviour Checklist (ABC); Aman & Singh, 1986), severity and improvement in symptoms (Clinical Global Impressions (CGI); Guy, 1976), and carer burden (Uplift/Burden Scale; Pruchno, 1990)” (Martin et al., 2005, p. 518). Both the psychiatrist and research assistance were blind to the other’s assessment. Participants were then categorized into affective disorder or psychotic disorder based on results from the Psychiatric Assessment Schedule for Adults with Developmental Disability (PAS-ADD) (Martin et al., 2005). Stratified sampling was utilized to randomly assign participants to a strata (affective vs. psychotic disorder, male vs. female) within one of the two treatment groups. Following assignment to a treatment group, the interventions commenced for a period of 6 months. After the 6 month time period, the research assistant assessed each participant for “current mental
Data analysis by Martin and colleagues (2005) utilized comparisons of pre (baseline) and post (6 months) assessment data with ANCOVA methods. Analysis of data indicated no significant results between pre and post data for ACT-ID and SCT-ID at both $p = 0.01$ and $p = 0.05$ levels of significance (Martin et al., 2005). The non-significant findings were more favorable for SCT-ID than ACT-ID (Martin et al., 2005). The SCT-ID intervention group showed increases in met needs, quality of life, and functioning; and decreases in unmet needs, behavioral problems and carer burden. The ACT-ID intervention group showed increases in functioning and behavioral problems; and decreases in met and unmet needs, and quality of life (Martin, et al., 2005, p. 519). Analysis of covariance between ACT-ID and SCT-ID showed no significant differences between the two groups.

Limitations of the Martin and colleagues (2005) study included a small sample size ($n = 20$), limiting individuals who were able to give informed consent (i.e. mild ID with verbal communication skills), potential lack of fidelity to the ACT model, and lack of full team to conduct model (i.e. no social worker) (Martin et al., 2005). Contradictory study results to previous ACT data from the U.S. were attributed to a difference in service supports in the U.K. The ID services provided in the U.K. (SCT-ID) were more intensive than expected, and the two treatments were too similar for differences to be detected (Martin et al., 2005). Study results from Martin and colleagues (2005) further support the customization of services and supports for the DD/SMI population within the community to best meet their needs.

The third research study examined the use of ACT and standard community care with 30 participants with ID/SMI in London, U.K. (Oliver et al., 2005). The randomized controlled trial
of ACT for ID/SMI is a follow-up study conducted by Burns and colleagues (1999), better known as the UK 700 study (Oliver et al., 2005). Study outcomes for the UK 700 were not preferential of intensive case management services for SMI individuals in the UK, but the borderline ID group showed significantly better results to the intervention. Therefore, Oliver and colleagues (2005) developed the Trial of Assertive Community Treatment in Learning Disabled (TAC-TILD) to determine the effectiveness of ACT and standard community treatment with ID/SMI individuals. Oliver and colleagues (2005) hypothesized:

1. Global improvement of clinical and social functioning of those with learning disability, dual diagnosis and/or challenging behavior, would be superior in those treated by an assertive community team compared with those in a standard team;
2. Improvement in quality of life in this population would be superior in those treated by an assertive community team compared with the standard team; and
3. The burden of care on carers in this population would be no different in those treated by an assertive community team compared with the standard team. (Oliver et al., 2005, p. 508).

The study utilized a “simple parallel design” with randomized assignment of participants to two groups; 1) assertive outreach (ACT), and 2) standard care (SCT) (Oliver et al., 2005, p. 508). Baseline data was collected at the beginning of the study, with repeated assessments conducted 12 weeks later. Sample inclusion criteria included individuals with mild or moderate level of ID who had either “1) serious mental health problems or 2) challenging behaviors, or both 1 and 2, 3) were living in community homes with professional carers or in family homes with relatives, 4) were aged between 18 and 65 years, and 5) gave consent and assent for the trial” (Oliver et al., 2005, p. 508). Exclusion criteria included an IQ greater than 75, a severe learning disability, and individuals for whom the risk of randomization would have been unethical (Oliver et al., 2005).

For the purposes of this study, the Oliver and colleagues (2005) defined the ACT group intervention to be “those who received more than one visit per week from one or more professionals” and the standard group intervention to be defined as those who “received no more
than one visit per week from any one professional in a week” (Oliver et al., 2005, p. 508). Six ID service centers in North London participated in the study. After referral, there was a 2-week assessment, and participants were placed into one of three groups: 1) needing ACT—would be unethical to randomize, 2) could be randomized, and 3) failed to satisfy inclusion and exclusion criteria (Oliver et al., 2005, p. 509). Group 2 patients were then randomly assigned to the ACT or SCT interventions. Baseline data was collected for each participant in each of the following areas: multi-axial diagnosis (level of ID & SMI) using DSM (APA, 2000) and ICD-10, global assessment of functioning (GAF), burden on carers using the Uplift/Burden scale, Quality of Life (QOL) using the WHOQOL-Bref (Oliver et al., 2005, p. 509). A total of 30 participants engaged in the research study over a period of 25 months. All 30 participants were assessed at baseline and at 3 months of inclusion in intervention (Oliver et al., 2005).

Data analysis consisted of using mean scores for total GAF, WHOQOL-Bref, and carer uplift burden. Mean scores for these categories showed no differences in outcomes (Oliver et al., 2005). Researchers also utilized a two-way analysis of variance in “which differences in outcome were measured by time/treatment model interaction,” results showed no significant differences in clinical symptomatology (p = 0.80), social functioning between ACT and SCT groups (p = 0.79), and carer burden (p = 0.84), uplift of primary carers (p = 0.84), or improvement in quality of life (p = 0.18) (Oliver, et al., 2005, p. 510). The WHOQOL-Bref for physical subscale (p = 0.05) and psychological subscale (p = 0.06) areas showed moderate significance in favor of SCT (Oliver et al., 2005).

Several limitations to the study including lack of fidelity to the ACT model, the small sample size (n = 30), and use of the Global Assessment of Functioning (GAF) as an outcome. Similar to the previous article, Oliver and colleagues (2005) noted the lack of significant findings
being related to the difference of intensity in SCT in London versus the U.S. in producing differences between SCT and ACT data. Recommendations for future research included combining qualitative and quantitative methodology in evaluation of ACT and use of larger sample sizes (Oliver et al., 2005, p. 513-514).

**Dialectical behavior therapy (DBT).** Sakdalan, Shaw and Collier (2010) conducted research on a pilot program to determine if the use of DBT group skills training would be an effective approach for six individuals with ID/SMI in a forensic and mental health inpatient setting. According to previous research, individuals in forensic and inpatient settings have comorbid personality disorders and substance use disorders (Sakdalan, Shaw, & Collier, 2010).

The Adapted DBT Coping Skills Training used in this pilot was adapted from material from Marsha Linehan’s DBT Skills Training Manual (Linehan, 1993), and the coping skills program for individuals with ID developed by Verhoeven (2007) (Sakdalan, Shaw, & Collier, 2010). The pilot program ran for 13 weeks and consisted of weekly group sessions that lasted approximately 90 minutes. The training modules were sequenced as following: “1) orientation and group rules, 2) mindfulness, 3) distress tolerance, 4) emotional regulation, 5) interpersonal effectiveness, and 6) closing” (Sakdalan, Shaw, & Collier, 2010, p. 569). The overall focus of the intervention was to target quality of life and therapy interfering behaviors (Sakdalan, Shaw, & Collier, 2010).

Participant outcomes were evaluated using pre and posttest measures on 5 measures. These included the Short-term Assessment of Risk and Treatability (START) scale (Webster et al., 2004), the Vineland Adaptive Behaviour Scales – Second Addition (VABS-II) (Sparrow et al, 2005), the Health of the Nation Outcome Scales for people with learning disabilities (HONOS-LD) (Wing et al, 1996), incident reports, and the DBT assessment and feedback form.
Overall, 6 participants were actively involved in the pilot program (Sakdalan, Shaw, & Collier, 2010).

Data analysis involved use of a paired samples t test comparing pre and posttest data. The START risk and strengths domains \( (t = -4.00, p < 0.01) \) and the HONOS-LD \( (t = 2.60, p < 0.05) \) were found to be significant, while the VABS-II coping skills was insignificant (Sakdalan, Shaw, & Collier, 2010, p. 571). The DBT assessment, a subjective measure, was determined to have indicated a moderate to high range of achievement for the participants in learning the skills (Sakdalan, Shaw, & Collier, 2010).

While the study had noteworthy findings, Sakdalan and colleagues (2010) are cautious due to the limitations of the study which included a small sample size, lack of a control group, and also use of the adapted DBT skills training vs. full access to the complete DBT program. Future study recommendations included a larger sample size, the inclusion of a control group, and longitudinal research focus to determine the impacts of DBT Skills Training on the risk of recidivism for offenders (Sakdalan, Shaw, & Collier, 2010). The further research and potential development of DBT as a treatment option for the DD/SMI population could further support their needs of customized, responsive, and empowering community services.

A second study that utilized DBT as an intervention was Brown, Brown, and Dibiasio (2013). While the study’s primary purpose was to examine the challenging behaviors of individuals with DD/ID, the majority of their sample had an SMI dual diagnosis. Brown and colleagues conducted a four year longitudinal study with 40 participants from the Justice Resource Institute-Integrated Clinical Services (ICS) organization in Rhode Island. Researchers utilized a modified DBT treatment and adapted skills training to meet the comprehension needs
of the sample which had an average full scale IQ of 60; indicating their sample average was in the mild intellectually disabled range of intelligence (Brown, Brown, & Dibiasio, 2013).

The program intervention consisted of three to four hours weekly of therapeutic intervention of DBT (1 hour), skills training (1 hour), and group skills training (1 hour). Most individuals also were supported by a formal behavioral support plan. Brown and colleagues utilized random regression modeling for statistical analyses. Study outcomes indicated statistically significant reductions in challenging behaviors across all four years, with the greatest decrease within the first 12 months of participation in the program (Brown, Brown, & Dibiasio, 2013).

**Cognitive behavioral therapy (CBT).** Ghafoori, Ratanasiripong, and Holladay (2010) conducted research on a pilot study to determine the effectiveness of cognitive behavioral therapy for mood management in eight participants with ID. Ghafoori and colleagues (2010) “hypothesized that individuals who received the treatment would have a decrease in distressing mood symptoms at post-treatment and follow-up” (p. 3).

The pilot study was conducted at a community-based outpatient clinic attached to a large urban university. The clinic also functions as a training facility for Marriage and Family Therapy graduate students, and therefore provides mental health services at a reduced rate. Referrals to the clinic are made from a variety of sources including community agencies, university campus organizations, and local schools (Ghafoori et al., 2010).

Eligibility criteria for inclusion in the group therapy pilot program included:
Over 18 years old; identification of ID by teacher and school district; identification and referral by teacher as having depressed, anxious, or angry mood that is problematic in their work, school, or social relationships when briefly interviewed by the researcher. (Ghafoori, Ratanasiripong, & Holladay, 2010, p. 4)
A criterion for exclusion from the study was related to participants exhibiting suicidal and/or homicidal ideation at the time of screening. A total of 8 participants consented to participate in the pilot program. Data collection methods utilized the Symptom Checklist-90-Revised (SCL-90-R; Derogatis, 1994) prior to implementation of the intervention, immediately after the intervention was completed, and again at a 4-month follow-up to the end of the intervention (Ghafoori et al., 2010). Questionnaires were read to each participant at all three points of data collection. The CBT intervention was run for a duration of nine weeks (one session weekly), with each session lasting 90 minutes. Sessions were facilitated by a licensed clinical psychologist and a Marriage and Family Therapy graduate student. The focus of the CBT intervention was on depression, anger, and anxiety management (Ghafoori et al., 2010).

Paired samples t tests were used for data analysis purposes to “compare the within-group mean pre and post test scores as well as pre and follow-up test scores for each of the nine primary symptom dimensions” on the SCL-90-R (Ghafoori et al., 2010, p. 7-8). Primary symptom dimensions significant at the p = 0.05 level were somatization (t = 3.25), obsessive-compulsive (t = 3.11), depression (t = 3.14), anxiety (t = 2.47), and psychoticism (t = 2.43) (Ghafoori et al., 2010, p. 8). The only symptom dimension significant at the p = 0.01 level was interpersonal sensitivity (t = 4.36) (Ghafoori et al., 2010, p. 8). Overall, study results indicated significantly decreased levels of depression and anxiety following the CBT treatment (Ghafoori et al., 2010).

Ghafoori and colleagues (2010) recommended future studies to determine the effectiveness of CBT with the ID/SMI population that utilize a randomized controlled trial with a larger sample size (p. 12). Findings from Ghafoori and colleagues (2010) further assist with
expanding the research base for the DD/SMI population in promoting effective treatment strategies to empower individuals to live successfully in the community.

**Emerging Trends in Practice**

Upon review of the research, some notable areas of practice and support for the DD/ID, SMI, and DD/SMI populations were identified. These areas included family and caregiver supports, peer to peer supports or peer mentoring, self-directed or participant directed services, and gentle teaching.

**Family and caregiver supports.** For individuals with a DD/ID diagnosis, families were the largest providers of support in 2000 according to Freedman and Capobianco-Boyer (2000). While no nationwide estimate exists as to the number of individuals with DD who live at home, it is approximated that 60-85% of individuals with a DD/ID live with their families with some remaining in the family home their entire lives (Freedman & Capobianco-Boyer, 2000; Heller, Miller, & Hsieh, 1999; Heller, Arnold, van Heumen, McBride, & Factor, 2012). Family supports are defined as:

> Services, resources, and other types of assistance that enable the individual with developmental disabilities of any age to live with their families and to be welcomed, contributing members of their communities. The major goals of family support are to deter unnecessary out-of-home placement, return people living in institutions back to families, and enhance the caregiving capacity of families. (Freedman & Capobianco-Boyer, 2000, p. 59)

Family and caregiver supports for individuals with DD/SMI diagnoses are multi-faceted. According to McGinty, Worthington, and Dennison (2008), individual and family advocacy involves taking into consideration the following; 1) establishing relationships with care providers, 2) ensuring coordination of care, 3) addressing family concerns, 4) including a psychiatrist perspective, and 5) having knowledge of important systems of care (p. 194-202).
Peer to peer or peer mentor supports. The second emerging area of practice is the peer to peer or peer mentor movement. Peer mentors are individuals with a DD/ID or SMI diagnosis that are trained to support individuals with similar diagnoses and needs by advocating with and on behalf of individuals, supporting others to live independent lives, build bridges between individuals and the community, help build support circles, and are guided by the principles of self-determination (Michigan Department of Community Health, 2013). More formally a peer mentor is defined by the Michigan Developmental Disabilities Council (2013) as:

A person with a developmental disability who has learned problem solving strategies, how to be a self-advocate, how to live a self-determined life, and knows how to access services and resources in the community. Peer mentors offer the benefit of their experiences, passing along encouragement and support to help others construct their own advocacy to bring about the changes they want for their lives. (Michigan Department of Community Health, 2013)

Peer mentoring was part of the DD Act of 2000 and 2008. The Developmental Disabilities Councils in each state are responsible for the training and development of peer mentors. The ideology behind this movement is for individuals with disabilities to help empower and promote self-determination for other individuals with disabilities (Michigan Department of Community Health, 2013).

Self-directed or participant directed services. The third area of emerging practice trends is that of self-directed or participant directed services. Self-directed services have reportedly increased in the last decade with the assistance of the Real Choice Systems of Change, which was legislation enacted in 2000 as part of the New Freedom Initiative (Heller, Arnold, van Heumen, McBride, & Factor, 2012). The Centers for Medicaid and Medicare Services (CMMS) define self-directed services as “allowing participants to have the responsibility for managing all aspects of service delivery in a person-centered planning process” (Heller et al., 2012, p. 464). Self-direction also promotes giving the individual receiving services
the personal choice and fundamental control over the delivery of services such as waiver or state plan services. Some common characteristics of self-directed services include “person centered planning, service plans, individualized budgets, information about assistance in support of self-direction, and quality assurance and improvement (Heller et al., 2012, p. 464). Currently, research indicates 17,500 individuals are using self-directed services within 15 states nationwide (Heller et al., 2012).

Gross and colleagues (2012) assert that there are multiple studies comparing self-directed with agency directed services. The studies noted by Gross et al. (2012) found that self-directed services showed; “increased levels of community participation for the individual, increased satisfaction with services, increased financial well-being due to increased caregiver employment and/or fewer expenditures, increased emotional and/or physical well-being, and decreased unmet needs” (p.89).

**Gentle teaching.** Gentle teaching has emerged as a way of working and approaching all people, but has been advocated for use with individuals with DD/ID and DD/SMI for quite some time. According to the Gentle Teaching International organization (2016):

Gentle teaching is many things. Gentleness toward others, in spite of what anyone does or does not do, is the critical factor. It is a paradox. Fists are met with hugs. Cursing is met with words of affection and nurturing. Spiteful eyes are met with warmth. Gentleness recognizes that all change is mutual and interwoven. It starts with caregivers and, hopefully, touches those who are most marginalized. Its central focus is to express unconditional love. It is the framework around a psychology of human interdependence. The main idea of gentleness is not to get rid of someone else’s behaviors, but to deepen our own inner feelings of gentleness in the face of violence or disregard.

Gentle teaching is also considered a teaching method for caregivers who support individuals with DD/SMI. Caregivers use the approaches taught within gentle teaching to support individuals with disabilities to feel safe, loved, loving, and engaged in their environments (Gentle Teaching International, 2016). These feelings develop over repeated interactions between caregivers and
people with DD/SMI through the gentle teaching tools of presence, hands, words, and eyes (Gentle Teaching International, 2016).

Presence refers to the caregiver being present and attentive with the person they are supporting. This could be through cooking a meal together, playing a game or activity, or simply talking about the person’s day. The tool of hands is in regards to being conscious and thoughtful with hands and gestures when supporting a person with DD/SMI. The goal is to keep hands soft and supportive versus tense (ie. fist shapes) or intimidating with motions. The tool of words refers to the language we use in interacting with a person with DD/SMI. The goal is to keep language positive and supportive, and to help the person to understand that caregivers are with them even when they are struggling. The final tool of eyes is in relation to the caregiver’s eye contact and gaze when supporting a person with DD/SMI. The goal is for the caregiver to be conscious of their eye contact when interacting with a person with DD/SMI to meet him or her where they are at and support them in a positive way (Gentle Teaching International, 2016).

**Gaps in Literature Reviewed for DD/SMI**

This literature review process found gaps in the research and therefore, the knowledge base of this area. To begin, research studies for individuals with DD/SMI focused on individuals with borderline, mild, and moderate levels of ID (Brown, Brown, & Dibiasio, 2013; Hackerman et al., 2006; Ghafoori, Ratansiripong, & Holladay, 2010; Shedlack & Chapman, 2004). **There is a large gap in the literature in regards to practice methods and treatment interventions for individuals with severe and profound levels of ID with SMI.** The exclusion of severe and profound ID individuals can be seen by the inclusion and exclusion criteria by Shedlack and Chapman (2004) of “verbal communication skills, and use of toilet without assistance” (p. 10) and by Martin et al. (2005) in requiring participants to have ID within a mild to moderate range.
The lack of research for individuals with severe and profound ID could be due to speech impairments which make communicating responses difficult, a lack of comprehension of treatment approaches, and mobility issues which can require hands-on assistance from care providers (Barnhill, 2008). The lack of attention to individuals with severe and profound ID continues to further marginalize the most vulnerable within the DD/SMI population.

A second observation about the literature review was the research available tends to focus on program evaluations and evaluations of potential interventions for use with the DD/SMI population (Hackerman et al., 2006; Ghafoori, Ratansiripong, & Holladay, 2010; King et al, 2009; Martin et al., 2005; Oliver et al, 2005; Sakdalan, Shaw & Collier, 2010; Shedlack & Chapman, 2004). This is an encouraging finding, especially since the majority of the research for DD/SMI individuals was dated from 2004 to 2011, indicating a growing recognition of the needs of this population in regards to developing a knowledge base with treatment and practice interventions. However, the existing gaps seem to leave practicing clinicians that are working to support DD/SMI individuals in the community with little information to proceed with developing supportive community services to meet the population’s needs.

A third observation about the literature review was the use of both quantitative and qualitative research methods with the DD/SMI population. The studies tended to focus on quantitative research methods (Brown, Brown, & Dibiasio, 2013; Hackerman et al., 2006; King et al, 2009; Shedlack & Chapman, 2004) utilizing surveys or questionnaires as the primary sources of data collection, or more qualitative methods of secondary reviews of participant files and case studies (Ghafoori, Ratansiripong, & Holladay, 2010; Martin et al., 2005; Oliver et al, 2005; Sakdalan, Shaw & Collier, 2010). A review of the literature by Benson (2004) in regards to psychological interventions for the DD/SMI population also notes the repeated occurrence of
case studies as a prominent method for research. The studies presented previously focused heavily on descriptive research (Benson, 2004). As the DD/SMI population has a very limited knowledge base at this time, researchers may want to consider more exploratory research methods to begin to develop a solid base to build from (Benson, 2004). The exploratory methods could benefit the DD/SMI population in identifying further elements of services that would be supportive of customized, responsive, and empowering strategies in the community setting.

A fourth observation about the literature review was the lack of data collection directly with the participants and their families (Hackerman et al., 2006; Shedlack & Chapman, 2004). By using the methods of file reviews, the researchers missed out on feedback from the participants about how they “felt” their interaction with the program or intervention worked for them, or feedback from caregivers within their families about observations of the individual during or after the interventions were applied. The data relied heavily on files documented and produced by professionals working in mental health settings (Hackerman et al., 2006; Shedlack & Chapman, 2004). That is not to say the data produced during those times with participants was not accurate, but to illustrate the lack of interaction with the DD/SMI population in providing valuable feedback about their own perspective and outcomes.

A fifth observation about the literature review was the location of where the research was conducted was most often within mental health agencies in communities (Brown, Brown, & Dibiasio, 2013; Hackerman et al., 2006; Ghafoori, Ratansiripong, & Holladay, 2010; King et al, 2009; Martin et al., 2005; Oliver et al, 2005; Sakdalan, Shaw & Collier, 2010; Shedlack & Chapman, 2004). Sometimes the organizations were identified as Community Mental Health Centers, or as mental health organizations depending on the country in which the research was conducted. At present, it appears community services have identified some of the needs of the
DD/SMI population and are working to increase this knowledge base with research on effective programs and treatment interventions. As such, certain limitations are unavoidable in community agency settings. Common limitations noted included small sample sizes (Martin et al., 2005; Oliver et al., 2005), lack of fidelity to the intervention model (King et al., 2009; Martin et al., 2005; Oliver et al., 2005), and ethical concerns about randomization of participants to treatment conditions (Sakdalan, Shaw & Collier, 2010).

A final observation about the literature review was the countries of origin of the research on DD/SMI. Of the studies presented for DD/SMI, four were conducted in the United States (Brown, Brown, & Dibiase, 2013; Ghafoori, Ratanasiripong, and Holladay, 2010; Hackerman et al., 2006; & Shedlack & Chapman, 2004), and the remaining four were conducted in the United Kingdom (Martin et al., 2005; Oliver et al., 2005), New Zealand (Sakdalan, Shaw, & Collier, 2010) and Canada (King et al., 2009). There is also a similar pattern of research studies for the DD/ID population, with one study conducted in the U.S. (Gaus, 2011), and the remaining three conducted in Canada (Burge, 2009), Sweden (Nyden, 2007), and Ireland (McGrath, Jones, & Hastings, 2010). Several countries have been contributing to the development of research for the DD/ID population, and have begun to with the DD/SMI population as well. The countries most often noted include the United Kingdom (Martin et al., 2005; Oliver et al., 2005), New Zealand (Sakdalan, Shaw & Collier, 2010), Sweden (Nyden, Myren, & Gillberg, 2007), and Canada (Burge, 2009; King et al., 2009).

**Mental Health Professional’s Perspectives on Community Services**

The current research will focus on the community service needs of individuals with DD/SMI from the perspective of mental health professionals (MHP). The perspective of the mental health professionals who support individuals with DD/SMI are valuable in evaluating the
efficacy of current community services and supports available to individuals with DD/SMI (Hemmings & Al-Sheikh, 2013). By investigating further the knowledge, experience, and observations of the mental health professionals who have supported the DD/SMI population, the nuances and details of the people’s experiences can be illuminated to help further research that may one day re-define the available services for this population (Hemmings & Al-Sheikh, 2013). With the addition of first hand testimonials from professionals who support individuals with DD/SMI diagnoses, a further research base can be developed to evaluate and build upon the needs of this population (Hemmings & Al-Sheikh, 2013).

For the purposes of this research, mental health professionals (MHP) are individuals who have a bachelor’s and/or master’s degree in the helping professions (i.e. social work, psychology, counseling, rehab counseling, sociology, family studies, etc.) and are currently working in the mental health field supporting individuals with DD/SMI in accessing services and supports in their communities.

Hemming’s and Al-Sheikh (2013) looked at the expert opinions of 14 professionals in regards to the community service provision for individuals with ID/SMI. They examined the professionals opinions in four areas related to community service provision, which included: “1) review and monitoring of service users, 2) access to social, leisure and occupational activities, 3) support, advice, and training around mental health for a person’s family or carers, and 4) “out of hours” and crisis responses” (Hemmings & Al-Sheikh, 2013, p. 169). Mental health professionals were from a variety of backgrounds including psychiatry, nursing, psychology, social work and occupational therapy. Participants engaged in semi-structured in-depth interviews to elicit their opinions on the four provision areas of community services. The study resulted in ten emerging themes identified by the professionals of what individuals with ID/SMI
need from community services. These ten themes included “configuration/structure of services, clarity of purpose/care pathways, joint working, training, flexibility, resources, evidence-base, holistic/multidisciplinary, needs led/personalized, and accessible information” (Hemmings & Al-Sheikh, 2013, p. 174).

The study conducted by Hemming’s and Al-Sheikh (2013) is the most closely related to the current research project. The framework of the current research and differences between the two studies will be outlined further in Chapter 3 within the Methods section.

Summary

While the literature available in regards to the DD/SMI population is limited at present, strides are being made within the United States and many other countries to address this area and build knowledge for professionals to work from. The studies presented that outlined practice interventions have offered several recommendations for future research to assist in building knowledge as well as creating valid and reliable methods of supporting individuals with DD/SMI in the community. Emerging practice trends in relation to family and caregiver supports, peer mentoring, and self-directed supports are also areas for future evaluation to determine if they are effective supports for individuals with DD/SMI in the community.

The present research will be examining the perspective of mental health professionals (MHP) in regards to the community service needs of individuals with DD/SMI. A similar study conducted by Hemming’s and Al-Sheikh (2013) was presented. The research will be supported by systems theory in relation to how individuals with DD/SMI navigate and access services and supports within their communities.
CHAPTER 3: METHODS

Research Question

The purpose of this study was to add knowledge to the research base to expand the available resources for the DD/SMI population. One of the primary areas to be addressed was to determine what the current community service needs were for individuals with DD/SMI. While some of the research presented previously focused on possible interventions and approaches (Hackerman et al., 2006; Ghafoori, Ratansiripong, & Holladay, 2010; King et al., 2009; Martin et al., 2005; Oliver et al., 2005; Sakdalan, Shaw & Collier, 2010; Shedlack & Chapman, 2004), these were single studies with no further data published on the topic to date.

The focus of this study was to examine the mental health professionals’ perspectives of the community service needs of individuals with DD/SMI. The previous research presented by Hemmings and Al-Sheikh (2013) was a similar study in which the researchers elicited qualitative research information about the service needs of individuals with DD/SMI in the community. There are a few differences between the Hemmings and Al-Sheikh (2013) study and the present research that should be noted.

First, Hemmings and Al-Sheikh (2013) research was conducted in London, United Kingdom. This study was conducted in Michigan to begin to develop a knowledge base for the DD/SMI population in the United States. Second, the Hemming’s and Al-Sheikh (2013) study sample consisted of 14 participants from various educational backgrounds who were considered “multidisciplinary professionals” by the researchers (p. 169). The current study had 24 participants, and had added criteria for participation to elicit the most “rich” information from those involved by requiring a minimum of five years of professional experience in supporting individuals with DD/ID or DD/SMI in the community for participation. Third, Hemmings and
Al-Sheikh (2013) utilized interviewing as their primary method of data collection. The current study utilized two forms of data collection, with interviewing and focus groups. Finally, the Hemmings and Al-Sheikh (2013) research incorporated participants from across the United Kingdom, while the present research incorporated participants from two geographic locations in Michigan.

This study further expands the knowledge base for the DD/SMI population by eliciting the expert opinions of mental health professionals who have supported and worked closely with DD/SMI individuals in the community and were aware of their unique support needs. The primary research question for this study was: **What are the community service needs of individuals with DD/SMI from the perspective of the mental health professional?**

The focus of this research study was to examine the knowledge available from mental health professionals to address the gaps in the existing literature. Mental health professionals and study results from the literature review had several recommendations for future studies that included such areas as: accessibility of services, flexibility of services, crisis and emergency response, collaboration with service systems, training for mental health professionals, an evidence-base to provide empirically evaluated data for use in the field, personalized services to meet the individual’s needs, and multidisciplinary team approaches (Hackerman et al., 2006; Hemmings & Al-Sheikh, 2013; King et al., 2009).

**Qualitative Approach**

**Grounded theory.** Taking into consideration the narrow and limited nature of the knowledge pertaining to the DD/SMI population, grounded theory was utilized for this research. According to Bryant and Charmaz (2007), the grounded theory “comprises a systematic, inductive, and comparative approach for conducting inquiry for the purpose of constructing
theory” (p. 1). Grounded theory is designed to encourage the frequent and persistent interaction between the researcher and the emerging data to streamline data collection and analysis. Empirical checks are built into the grounded theory approach to the analysis of data to assist the researcher in examining all possible theoretical explanations for their findings (Bryant & Charmaz, 2007). “The iterative process of moving back and forth between empirical data and emerging analysis makes the collected data progressively more focused and the analysis successively more theoretical” (Bryant & Charmaz, 2007, p. 1).

One of the advantages of utilizing grounded theory in the study was in regards to its inductive method. Induction is defined as “a type of reasoning that begins with the study of a range of individual cases and extrapolates from them to form a conceptual category” (Bryant & Charmaz, 2007, p. 15). For the development of knowledge in regards to the DD/SMI population, this assisted with identifying specific information about the population and potentially developing more broad conceptualizations. According to Creswell (2007), grounded theory provides a process for “developing categories of information (open coding), interconnecting the categories (axial coding), building a “story” that connects the categories (selective coding), and ending with a discursive set of theoretical propositions” (p. 160). As such, systems theory was used as a supportive framework to grounded theory to sensitize participants to the theory constructs.

To incorporate grounded theory into the study methods, the PI utilized a member “check-in” process by utilizing the data collected at the interviews with individual participants to identify primary themes and then subsequently create the focus group protocol. That information was then shared anonymously at subsequent focus groups to compare and contrast the experiences of the participants across interviews and focus groups. This enabled the PI to utilize
grounded theory process to determine if similar patterns were appearing across the data sample (Liamputtong, 2011).

Qualitative methods were utilized for this study. The study included two types of data collection methods; interviews and focus groups. First the primary investigator engaged in interviews with experienced mental health professionals who supported DD/ID or DD/SMI individuals within community services. Second, focus groups were utilized to collect data from mental health professionals who were currently working to support DD/SMI individuals to live in the community.

Interviews were utilized first in the research process to elicit one on one, first-hand information from mental health professionals supporting DD/SMI individuals in the community at present. The purpose of the interviews was to obtain information on the observations, knowledge, and experiences of the mental health professionals to determine the current needs of the DD/SMI population within community settings. Interviewing was a supportive research method for this study as it assisted with collecting broad and narrow data from participants on the topic of the needs of individuals with DD/SMI in the community.

According to Creswell (2007), the use of interviews as a qualitative method plays a central role in the collection of data for studies that incorporate grounded theory. Creswell (2007) also indicates that while multiple methods of data collection are helpful in developing grounded theory, other forms of data collection such as focus groups and observations “play a secondary role to interviewing in grounded theory studies” (p. 131).

The method of interviewing has been used only once within the current research available (Hemmings & Al-Sheikh, 2013) for the DD/SMI population, and would be a helpful tool to build the knowledge base and information available for this population. The interviews were also used
as an initial data collection method. After the interviews were completed, they were analyzed for primary themes. The primary themes identified from the interviews were then used within the focus groups as a form of member checking for reliability and triangulation of the data. The data collected within the interviews was used in two focus group sessions to “member check” if the information presented was accurate across the DD/SMI population (Corbin & Strauss, 2008).

Focus groups were chosen as a secondary data collection method for this study for a variety of reasons. First, the available research literature pertaining to individuals with DD/SMI was quite limited. Therefore, the use of qualitative methods was being used to help build new exploratory knowledge upon the current literature and continue to develop a “rich” knowledge base for this population (Corbin & Strauss, 2008; Liampittong, 2011). Second, the research literature that was available was from a variety of resources, including U.S. (Ghafoori, Ratansiripong, & Holladay, 2010; Hackerman et al., 2006; Shedlack & Chapman, 2004) and international locations (Hemmings & Al-Sheikh, 2013; King et al., 2009; Martin et al., 2005; Oliver et al., 2005; Sakdalan, Shaw & Collier, 2010). As community services and supports vary from state to state, as well as from country to country, it is important to develop a context of community services within the U.S. as a base of comparison.

Third, focus groups were utilized to help elicit the experiences, knowledge, and observations of MHP’s that were currently working with DD/SMI individuals in community settings as they are considered “key informants” for this population (Liampittong, 2011). This information is important to building an accurate picture of the current state of community services, the needs that are being met, and also the needs and gaps that are going unmet for individuals with DD/SMI. This is an important first step to recognize and evaluate before
community services can be adapted to be more customized and responsive for the DD/SMI population.

Fourth, focus groups were used for this research to enable the participants the opportunity to build upon the observations obtained within the interviews and also of their co-workers and peers experiences and provide in-depth and broad data about the status of community services for individuals with DD/SMI (Corbin & Strauss, 2008; Krueger & Casey, 2009; Liamputtong, 2011). According to Krueger and Casey (2009), the “focus group presents a more natural environment than that of an individual interview because participants are influencing and influenced by others – just as they are in life” (p. 7). The focus group process also enabled the researcher to observe how the participants constructed meaning through the group interaction and assigned understanding of relevant information to the DD/SMI population (Liamputtong, 2011). Previous research pertaining to individuals with DD/SMI has incorporated either quantitative methods of data collection (i.e. scales and measures) (Ghafoori, Ratansiripong, & Holladay, 2010; Martin et al., 2005; Oliver et al., 2005; Sakdalan, Shaw & Collier, 2010) or qualitative methods of file reviews (Hackerman et al., 2006; King et al., 2009; Shedlack & Chapman, 2004). This research study was unique in using both interviews and focus groups as an approach to data collection for the population of DD/SMI individuals.

Finally, focus groups have been proven to be helpful in regards to needs assessments, as they offer people the opportunity to reflect and listen to the opinions of others within an interactive environment (Krueger & Casey, 2009; Liamputtong, 2011). As the primary research question was focused on the needs assessment of the DD/SMI population in regards to community services, the use of focus groups to collect data was optimal.
Sampling

Participants. The sample of participants was made up of mental health professionals who obtained a bachelor’s and/or master’s degree in the helping professions field (ie. social work, psychology, family studies, rehabilitation counseling, counseling, sociology, education, etc). Participants also had to have at least five years of experience or more in the field of supporting individuals with DD/ID and DD/SMI within community services.

The primary investigator (PI) set out to conduct 5-10 interviews with mental health professionals at two geographic locations (ie. Ingham & Oakland counties). The total number of interview participants was 15. Total number of participants was to be based on a high level of saturation of data drawn from the interviews. According to Corbin and Strauss (2008) saturation has been achieved when no new information is emerging from the existing data. Saturation also refers to the point when the existing data presents categories and/or concepts that have been clearly defined and explained (Corbin & Strauss, 2008).

The PI also conducted two focus groups with approximately 4-6 participants in each group following the interview process (Krueger & Casey, 2009; Liamputtong, 2011). While the total number of participants within the focus groups was nine, the goal of the data collection was overall to reach a point of saturation (Corbin & Strauss, 2008; Krueger & Casey, 2009; Liamputtong, 2011).

A purposive sampling method was utilized for this research at the two community locations. The two community service locations included in this study were Ingham and Oakland counties. The community service location in Oakland county was Community Living Services or CLS. Community Living Services (CLS) of Oakland County Michigan was identified for this study for several reasons. First, CLS is one of the largest non-profit providers
of community services to individuals with DD/ID and DD/SMI in the state of Michigan.

Second, this agency has been serving individuals with DD/ID and DD/SMI in the community since 1983, and has experienced the effects of deinstitutionalization and understanding of the community needs of individuals with DD/ID and DD/SMI (Community Living Services, 2014).

Third, CLS has also been a leader in the movement towards community inclusion and self-determination for individuals with DD/ID and DD/SMI diagnoses to live successfully in the community (Community Living Services, 2014). The agency was a recipient of the Robert Wood Johnson grant to aide in their movement towards community inclusion and self-determination for DD/SMI individuals in the mid-1990’s (Community Living Services, 2014). Currently, Community Living Services (2014) serves over 4,000 individuals with DD/ID and DD/SMI, with the majority of individuals living in their own homes (owned, leased, or rented) in the community. They also support 1,700 individuals that are utilizing self-determination arrangements and are directing their own services and supports (Community Living Services, 2014).

Finally, CLS (2014) also offers a variety of services to the individuals they support, including advocacy, behavioral health, benefits coordination, children/family services, clinical supports, community living supports, crisis intervention, fiscal intermediary services, supports brokers, independent facilitation, medication treatment review, peer mentoring, respite, rights and advocacy, supports coordination, self-determination, residential supports, substance abuse, skill building, and supported employment/micro enterprise development.

Community Living Services (2014) currently employs 30 case managers/supports coordinators, and contracts with another 100 case managers /supports coordinators to help support the growing number of DD/SMI individuals in their county. The sample of participants

83
was drawn from both the directly employed and contracted case managers/supports coordinators from this agency who wished to volunteer to participate. The director of the agency assisted with notifying staff of the opportunity and connecting them with the PI. Participation was voluntary.

A pre-screening tool was utilized prior to the interviews and focus groups to determine which mental health professionals within Community Living Services (CLS) and Ingham county MHP’s would meet the inclusion criteria for participation in the study. Sample participants were pre-screened to determine if they met the criteria of being a MHP, having a minimum of five years of experience in the field, as well as providing demographic and background information to support the outcome of the research. The demographic and background information included age, gender, ethnicity, education, tenure in field, position in agency, and primary disability served within the agency. These areas will help to provide some further context to the data collected, and aid in data analysis. The PI reviewed the pre-screen information to determine if the individual met the criteria. If the individual met the basic criteria, they were contacted by the PI to arrange a date and time for inclusion in the individual interviews or focus group sessions. A copy of the pre-screen is available as appendix A.

**Limitations of sample.** Some of the limitations to note in regards to the sample of participants included; 1) the sample was from two locations/regions for feedback on the community services for individuals with DD/SMI, (ie. Oakland & Ingham counties in MI), 2) the philosophy of the agency in regards to a focus on self-determination and community inclusion could impact the reliability of the data to be generalized across community service systems or other regions/locations, specifically for CLS. A third limitation worth noting was the inclusion of mental health professionals as the sample versus individuals from the DD/SMI population.
The inclusion of mental health professionals to gather information and build a knowledge base was purposeful at this time in comparison to individuals with DD/SMI. This study will focus on the development of knowledge to contribute to community services for the DD/SMI population, with the long term research goal to include further studies to incorporate the DD/SMI population to have a more active voice in the evaluation of what it takes to develop community services to meet their needs.

**Research Protocol**

Data collection occurred from August through November 2015. This data collection window was based upon the approval of the dissertation committee and successful approval of the research by the MSU Institutional Review Board.

**Interviews.** The interview protocol (see appendix B) when administered took approximately 30-45 minutes to complete per interview. The sample included a total of 15 individual interviews.

The process on the date of data collection for the interviews included 1) going over the informed consent (see appendix D), 2) a brief review of the purpose of the research, 3) the interview protocol (see appendix B), 3) closing of the interview with a review of how the data would be used and accumulated and a thank you for participation.

The interview protocol also included a variety of probes and prompts that were used to a varying degree based on the depth and breadth of response provided by the participant. Probes and prompts were used to elicit greater descriptive information and examples on the topics presented by the participant and to clarify understanding of the information presented. Therefore, the interview protocol primary questions were consistently asked, but the related
probes and prompts were only included when needed. The flow of the interview protocol questions was also variable based on the topics presented by the participant.

**Focus groups.** The focus group protocol (see appendix C) took approximately 90 minutes to 2 hours to complete per focus group (Liamputtong, 2011). Sample included two focus groups in Oakland county, with one group having four participants and the other having five participants.

The process on the date of data collection was the pre-screen (if not already completed), the informed consent for the project (see appendix E), the focus group protocol, and debriefing/closure of the focus group. The focus group protocol (appendix C) included the following: 1) a review of the informed consent and contact information of the researcher, 2) an introduction and purpose of the study, 3) review of expectations of the focus group including rules, confidentiality, audio-recording, and storage of data after the completion of the group, 4) clarification of key terminology being used during the focus group (ie. community services and DD/SMI), 5) proceed with the eight questions and prompts/probes, 6) check in process where the researcher reviewed notes from the focus group in regards to the major concepts and ideas shared to determine if they were an accurate representation from the groups discussion as a form of “member checking” after each individual question was discussed, and 7) closure of the focus group with any additional feedback from members and thank you for participation.

The focus group protocol also included some additional probes and prompts to some questions to help elicit information from the participants. For the focus group, probes were mostly used in the area of eliciting information in regards to the psychiatric needs of individuals with DD/SMI. Other probes or prompts were used by the PI, to gain clarity, understanding, or examples from participants to illustrate their point of view on the topics discussed. Therefore,
the primary questions outlined within the focus group protocol were asked consistently, but the probes and prompts presented were only used to gain greater depth and breadth on the topic if not already presented by participants. The flow of the focus group questions was also variable depending on the topics presented by the groups.

**Participant incentives.** Each participant was provided with a $10 gift card to a local retailer as reimbursement and incentive for the time they spent in the interview or focus group. The incentive was provided to all participants whether or not they completed the entire interview or focus group, or elected to discontinue participation at any time. All participants elected to complete the full interview or focus group protocol session.

**Data collection methods.** To aide in the collection of accurate data, audiotape recordings were utilized for each of the interviews and focus group sessions. To ensure the data was captured, two audio-tape devices were used. Each interview and focus group was later transcribed for the purposes of data analysis. Transcription of the audiotapes was done by an experienced transcriber. Upon receiving the transcribed data, the PI reviewed the transcripts for accuracy to the recorded interviews and focus groups. Other resources such as field notes and the audit trail were developed and maintained by the PI.

**Trustworthiness of data.** The researcher engaged in triangulation of data to help increase the trustworthiness of the study results. First, the PI utilized individual interviews to collect initial “rich” data about the topic. After the interviews were completed, the results were accumulated to create the focus group protocol. The interview data was then used as a form of “member checking” of the interview results within the focus groups to determine if the results were reflective of both groups’ perspectives (Creswell, 2007). Second, the PI documented field notes following each interview and focus group to further capture a summary of observations in
regards to non-verbal reactions, impressions of focus in particular group, group dynamics, non-verbal behaviors, and any other relevant data that was exhibited (Corbin & Strauss, 2008; Creswell, 2007). This element of the methods helped to increase the trustworthiness and credibility of the data by documenting an audit trail immediately after each interview and focus group’s conclusion while data was still fresh in the PI’s mind. Third, the focus group session notes were also accumulated from each participant regarding the activity about needs of individuals with DD/SMI, as well as from a note taker who attended the sessions to assist and facilitate with capturing information presented by participants (Corbin & Strauss, 2008). Fourth, interview transcription and focus group transcription captured the bulk of the narrative data from each group, and were triangulated with the other data sources within thematic development and coding. Finally, the focus group transcriptions were reviewed by the secondary facilitator who assisted with capturing session notes, as another source to increase reliability and consistency of the study’s findings (Corbin & Strauss, 2008; Creswell, 2007). The secondary facilitator reviewed the focus groups transcription files individually, and provided the PI with written documentation of presenting themes.

**Confidentiality.** The confidentiality of the sample participants was performed in several ways. First, the pre-screen was completed by each of the participants to “screen” for individuals that met the study inclusion criteria. While this form included the participant’s name, it was later changed to a number to protect the individual’s confidentiality in the interview and focus group process. Second, the interview and focus group session participants only identified themselves by first name, and in the transcription process their names were altered in print to an identification number to further support confidentiality. Finally, the audiotape recordings and transcribed data will remain in a private and locked space for the duration of the IRB
requirement of seven years, and only be accessible to the researcher and their doctoral committee chair and IRB for any future audit purposes.

**Reflexivity statement.** The researcher was a Caucasian, middle-class, female, who is 34 years old from the mid-Michigan area. The researcher is also employed at a Community Mental Health Center in mid-Michigan, and has worked as both a case manager/supports coordinator and supervisor. The experiences of this researcher have led to many observations and questions about the community service needs of individuals with DD/SMI to live successfully in the community. As such, the present research study was developed from those observations and subsequent review of the research literature for an evidence base to utilize or expand upon. Due to the researcher’s employment history, there were certain biases that may exist in pre-conceived notions about the outcome of the research. These were addressed through both the previous review of literature, use of an audit trail, and finally a second party objective individual to review primary data for repetitive themes. It should also be noted, that the researcher was not employed or associated with Community Living Services (CLS) of Oakland county, or the participants from the Ingham county area where the study samples were drawn.

**Analysis**

The researcher utilized qualitative analysis methods for this research study. To begin, the researcher utilized descriptive coding methods to explore the data and get an overall impression of which further form of analysis would be appropriate (Saldaña, 2013). After the initial review of the data the direction of implementing coding strategies that supported grounded theory development were utilized. The coding strategies outlined by Corbin and Strauss (2008) of open, axial, and selective coding were used for data analysis.
**Corbin & Strauss (2008) coding.** The three primary steps of coding, according to Corbin and Strauss (2008) include open coding, axial coding, and selective coding. The initial step in data analysis was open coding. Open coding consisted of reviewing the data collected from the interviews and focus groups and breaking it apart into concepts or blocks of data that related to the research question (Corbin & Strauss, 2008). The second step in data analysis was axial coding where the researcher reviewed the concepts and blocks of data from open coding and determined which concepts were related to one another (Corbin & Strauss, 2008). Finally, selective coding was utilized as the final step to determine the primary or core themes identified within the interviews and focus groups. Once those were determined from the axial coding, then the researcher reviewed the transcribed data collected again to identify any information that related to the primary or core themes (Corbin & Strauss, 2008).

According to Corbin and Strauss (2008), coding of data should begin soon after data is collected, as the initial data tends to serve as a form of foundation for future data collection and analysis. For Corbin and Strauss (2008):

> Once the researcher has read and digested the entire document it is time to “go to work on the data,” so to speak. I use natural breaks in the manuscript as cutting off points, and usually these breaks denote a change in topic, but not always. Then I examine each section in depth. Using this detailed approach is more tedious than just doing a general reading of a manuscript, then pulling out some themes. However, it is the belief of this author that a “close encounter” with data in the beginning stages of analysis makes the analysis easier in later stages because there exists a strong foundation and less need to go back to find the missing links. Detailed work like this in the beginning is what leads to rich and dense description and as well as to well-developed theory. (p.163)

By using the strategies outlined by Corbin and Strauss (2008) above, the researcher was able to implement data analysis processes that assisted in identifying primary or core themes, as well as sub themes or lower level themes that assisted in describing the similarities and differences of those higher level themes. According to Corbin and Strauss (2008), “lower level concepts fill in,
explain, and tell us something about [the topic] and give us some of the properties and dimensions” to provide further conceptualization (p. 165).

The PI engaged in hand coding of the transcribed interviews and focus groups for both open and axial coding steps. The final step of selective coding was implemented by utilizing an excel spreadsheet on the computer. A coding spreadsheet was created to track the selective coding process and progression of the subsequent themes. Through the use of the spreadsheet and supplemental data (ie. interview and focus group transcripts, audit trail, field notes, and secondary reviewer of the focus group), the researcher was able to identify primary/core themes and sub-themes.

**Sensitivity.** During the analysis process, the researcher engaged in measures to increase sensitivity to the data and the coding process. Sensitivity refers to “having insight, being tuned in to, and being able to pick up on relevant issues, events, and happenings in the data” (Corbin & Strauss, 2008, p. 32). The primary goal of sensitivity for the researcher was to accurately code the data to present the most genuine information and themes that represent the DD/SMI population (Corbin & Strauss, 2008). The researcher is currently a practicing clinician in the community service system and has insider knowledge and experience about the system that can be an advantage to assist with the data coding process. Corbin and Strauss (2008) also present three important elements to sensitivity in regards to data analysis:

The first is to always compare knowledge and experience against data, never losing sight of the data themselves. The second is to always work with concepts in terms of their properties and dimensions, because it keeps the researcher focused on the similarities and differences in events and prevents being overwhelmed by descriptive data. A third point is that it is not the researcher’s perception of an event that matters. Rather, it is what participants are saying or doing that is important. (p. 33)

According to Corbin and Strauss (2008), sensitivity can also be increased by professional experience. As stated in the reflexivity statement, this researcher has been working with the
DD/ID and DD/SMI population for the last 12 years, which will aide in the understanding and familiarity of the language used by the participants during data collection and analysis.

**Code book.** A codebook was also utilized during the data analysis process. The codebook was created in an excel spreadsheet to help keep track of the number of codes that emerged from the data, as well as tracking how they adapted or changed through subsequent coding approaches (Corbin & Strauss, 2008; Saldaña, 2013).

**Theory development.** As outlined previously, the grounded theory approach was utilized for this research study to assist in the process of possible theory development. The use of the inductive method within this research study has assisted in examining the individual interviews and focus groups and extrapolating from them higher level conceptual categories (Bryant & Charmaz, 2007). The higher level primary or core themes and descriptive sub themes were developed through the analysis process of open, axial and selective coding methods developed by Corbin and Strauss (2008).

According to Corbin and Strauss (2008) the activity of developing a theory can be very complex. For Corbin and Strauss (2008) a:

> theory denotes a set of well-developed categories (themes, concepts) that are systematically interrelated through statements of relationships to form a theoretical framework that explains some phenomenon” (Hage, 1972, p. 34). The cohesiveness of the theory occurs through the use of an overarching explanatory concept, one that stands above the rest. And that, taken together with the other concepts, explains the what, how, when, where, and why of something. (p. 55)

The goal of the present research was to review the data collected and determine if the results met the above criteria and could possibly be articulated into a theory to assist in the greater understanding of the community service needs of individuals with DD/SMI. At present, the current study is being supported by systems theory as a framework for the theoretical approach
until further data can be collected or articulated to present another theoretical option to accurately reflect the experiences of individuals with DD/SMI.
CHAPTER 4: RESULTS

Research Question

What are the community services needs of individuals with DD/SMI from the perspective of the mental health professional (MHP)?

Participants

A total of 24 participants volunteered to participate in the research study from two geographic locations, with nine from the Ingham county area, and 15 from the Oakland county area.

Demographics

The sample demographics are provided within table 3. These included the areas of gender, age, ethnicity, years of professional experience, level of education achieved at the time of the interview or focus group, the primary disability being supported by the participant in their work, and the MHP’s current role in supporting people with DD/ID or DD/SMI in the community.

Table 3: Background Information of Sample (Interviews & Focus Groups Combined)

<table>
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</table>
The majority of participants were middle-aged Caucasian females with graduate degrees in social work and psychology. They were experienced practitioners with roles of direct practice or administration. All reported serving people with DD/ID and nearly half also serving individuals with DD/SMI.

The participant’s reported educational backgrounds were from a range of helping profession fields. Participants identified bachelor’s degree areas of sociology, psychology, social work, education, communication arts and therapeutic recreation; with social work (9) and psychology (8) being the most obtained areas. Participants identified master’s degree areas of social work, sociology, psychology, education, counseling, and rehabilitation counseling; social work (9), counseling (2) and rehabilitation counseling (2) were the most identified areas. One participant reported having a doctoral degree in psychology.

**Findings**

In response to the research question, six primary themes were identified from the participant’s responses to the interview and focus group protocol questions. The six primary
themes identified were in the areas of 1) staffing supports and other supportive services, 2) having access to services or service provision, 3) suggestions for a new structure for services, 4) having support from a person who knows the DD/SMI person well, 5) identified barriers to accessing services, and 6) understanding people with DD/SMI. All primary themes were drawn from data presented by participants at both locations. Participant responses to interview and focus group protocols assisted study in reaching saturation of information.

Table 4: Main Finding Themes for Study

<table>
<thead>
<tr>
<th>Main Themes</th>
<th>Subthemes</th>
</tr>
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</table>
| 1. Staffing supports and other supportive services. | 1.1 Staffing supports  
1.2 Concerns about hiring and maintaining consistent staffing  
1.3 Other supportive services |
| 2. Having access to services or service provision. | 2.1 Not having services; don’t know what is available  
2.2 Outpatient model of service delivery  
2.3 Attention to DD services recently due to political influences |
| 3. Suggesting new structure for services.       | 3.1 Streamline services to one location  
3.2 Inclusive of all community members, not just DD/SMI  
3.3 Specialty supports for DD/SMI included |
| 4. Having a support person who knows them well. | 4.1 Case manager/Support coordinator  
4.2 Family or other natural supports  
4.3 Functions of the support person |
| 5. Identified barriers to accessing services.   | 5.1 Funding and insurance issues  
5.2 Issues with accessing services  
5.3 Lack of transportation  
5.4 Person with DD/SMI engaging and maintaining services |
| 6. Understanding of DD/SMI                      | 6.1 Perspective of professionals  
6.2 Perspective of community |

Primary Themes

**Theme 1: Staffing supports and other supportive services.** Across both interviews and focus groups in both locations, the most frequently noted supportive service need was for individuals with DD/SMI to have staffing supports. The most frequently noted other supportive
services by participants were psychiatric services, employment/vocational assistance, and opportunities for social activities.

**Staffing supports.** Staffing supports are funded through the Community Mental Health system in the form of the service Community Living Supports (CLS). From participant responses, staffing supports took on two caveats. These were either around staffing as a supportive service and people with DD/SMI understanding their role or around the concerns with hiring and maintaining consistent staffing to support people with DD/SMI.

**Staffing as a supportive service.** Participant responses regarding staffing supports for people with DD/SMI appeared to discuss the elements of supervision, assisting with ADL’s, and helping the person to be a part of their community.

Community living supports [CLS] because the person did require 24 hour supervision because of the fact that they weren’t able to live independently. They had hoarding issues, they had hygiene where they needed lots of reminders for changing clothes, bathing, things like that. (Oakland County Interviewee 6, p. 5)

The people that we serve in this situation needed a lot of individual support [CLS] with all kinds of things from transportation to just being out in the community experiencing going out to eat going to the fair or going shopping – real basic kinds of things. (Ingham County Interviewee 3, p. 3)

Oakland County Interviewee observed for a person with DD/SMI having “*a clear understanding of support staff, care-giving staff in their home, and knowing that they’re not your personal servants or they’re help. They’re there to help teach, guide, and train you how to...master skills for yourself*” (Oakland County Interviewee 4, p. 3).

**Concern of maintaining consistent staffing.** The second area reported by participants was that of the concerns of finding, hiring, and maintaining consistent staffing supports for individuals with DD/SMI. This was much more strongly noted by the participants from Oakland County as supported by the quotes below.
We’re close to a crisis with our direct care staff and support staff…I just left a home and she [support staff] was like ready to fall asleep at 35 hours right now in a row, which is just unacceptable. It’s a staffing crisis…Your starting salary as a direct care worker basically is minimum wage now with no benefits. So we need adequately trained staff, and they need a living wage, and we need to be well focused on the well-being of these caregivers. Without that we are functioning in a very crisis mode. So that, to me, is key, because then they can mentor and they can focus on the well-being of the people [DD/SMI] that they support. (Oakland County Focus Group 2, p. 8)

Staff is a huge issue. We’re having a hard time finding staff…It’s getting pretty tough. I mean, most people are getting their needs met. Unfortunately, there’s a percentage that aren’t…I always say that like 50% of my job is always…searching for staff…Finding, training, following up, showing up…But it’s hard. Our employment competition is retail, and you know, unskilled labor…or low skilled labor jobs that someone doesn’t have to worry about getting yelled at or spit on or…cleaning a diaper or something for between eight and ten bucks an hour. (Oakland County Focus Group 1, p. 30-33)

“Staffing supports [are a big need], I think sometimes people will not look at the DD side of it and just look at the MI side. And there’s not a lot of staffing supports for that” (Oakland County Interviewee 5, p. 7).

*Other supportive services.* Participants across locations offered many perspectives on the supportive services that a person with DD/SMI could benefit from. As mentioned previously, the most frequently noted supportive services other than CLS for a person with DD/SMI were psychiatric services, employment/vocational supports, and opportunities for social activities.

*Psychiatric services.* Participant responses about the need for psychiatric services included a focus on diagnostics, having consultation about symptoms and medications, and coordination with medical care.

Diagnostics for me are really quite paramount, and I think there critical even though it’s not an easy situation or always readily available to diagnose and then get…treatment, because the symptomology of folks with developmental disabilities doesn’t always match exactly the DSM-V. So it just takes patience and lots of work by the clinical team. But I think diagnostics are the critical feature…Access to psychiatric consultation, medication adjustment…I think can really help, along with the supports of the clinical team to help the person with DD be able to articulate, see, and understand their disorder as well as the other people around them. (Ingham County Interviewee 4, p. 3)
Having very good psychiatric monitoring, medication if it’s necessary, having access to the proper meds, or meds that are going to be therapeutic and someone reviewing the meds. The coordination of care...between the medical physicians and the psychiatrist, so that the psychiatrist knows what the medical doctors are prescribing and vice versa. (Oakland County Interviewee 6, p. 5-6)

**Employment.** Participant responses regarding employment tended to be about how persons with DD/MI often live in poverty, and how having access to employment would give them the opportunity to earn more money and potentially increase their quality of life.

“There’s vocational needs...That’s huge...The most of them [people with DD/SMI] are poor...Our folks live very minimally” (Ingham County Interviewee 3, p. 4).

“I think we’re in the early stage to getting people in community employment. Employers are kind of waking up a little bit to the needs and to the benefits for hiring individuals with disabilities” (Ingham County Interviewee 9, p. 1-2).

“Access to employable opportunities” (Oakland County Focus Group 1, p. 6).

“Employment opportunities for people...assistance with income generation.” (Oakland County Focus Group 2, p. 7-10)

“Or working toward their independence of having some support exposure to employment if they’re in that area” (Ingham County Interviewee 7, p. 3).

**Social opportunities.** Participants also noted the need for access and involvement in social activities as a need for individuals with DD/SMI. Participant responses included opportunities for individuals with DD/SMI to have access to social activities and chances to build relationships and expand support circles.

And social need, opportunities to participate in things. Being in an environment where they feel like people like them. For instance, with autism, social situations are difficult for them. So recognizing that and making...sure there’s systems in place that those people can say no if they want to. (Ingham County Interviewee 6, p. 3)
Places that they can interact and engage, …in a setting that they feel comfortable and yet safe and reassured… Or community integration of like activity centers, or areas where they can be exposed to the community with some supports to help them function. So they complement society, not stand out” (Ingham County Interviewee 7, p. 3).

“Relationship development, a focus on expanding people’s circular support beyond just paid supports. And then support in the establishment of solid community connections and active contributions, participation in the community” (Oakland County Focus Group 2, p. 10).

**Theme 2: Having access to services or service provision.** Many caveats of service provision were identified within the interviews and focus groups by participants. The main subthemes identified from participant responses were 1) people not receiving services or not knowing what was available, 2) the outpatient model of service delivery, and 3) the increased attention to DD services recently due to political influences.

*Not receiving services; don’t know what is available.* The first area of service provision noted by participants was in regards to people with DD/SMI not receiving services or not being aware of what services were available. Participants reported a lack of knowledge of the system and what services were available, and a lack of comprehension of services, supports and medical needs were common observations of their work in supporting individuals with DD/SMI.

As surprising as it is, I think knowledge of the system is…or what’s available, is the first [issue]. In the years that I worked with adults, many of the families of adult children that are graduating from the school system weren’t aware of the mental health system. For one reason or another, there were a number of people that just didn’t know that the adult system existed. So I think knowledge would be first. (Ingham County Interviewee 4, p. 6)

I think that’s a big [issue], is just knowing how to get started with things. And then knowing how to maintain contact, because a lot of our folks like that are living on their own, that have these diagnoses, their phones are getting shut off, they forget appointments, they don’t show up to things. So it’s really difficult to keep them engaged. (Oakland County Interviewee 5, p. 10)

Probably even knowing where to go or what it is that the person has to have. Or what service is needed. So where do you start? Understanding again, the paperwork, knowing
that it has to be returned. It’s a very short turnaround on the paperwork. Being able to talk with people personally. That’s another thing. Because if it’s a DHS related entity, you may not speak to anyone. There may be phone calls and you have to call on a certain day, and when you call on a certain day, then that person is not available, and then once you finally talk to somebody, that person is no longer the social worker anymore. The case was transferred to somebody else. So that’s one of the barriers, definitely. (Oakland County Interviewee 6, p. 9-10)

**Outpatient model of service delivery.** A second area noted was participant’s reports of the outpatient model of service delivery and how it can impact the person with DD/SMI accessing, receiving, and maintaining services and supports.

Some of the services are expensive. Some of the services are only open Monday through Friday, 8 to 5…9 to 5. Some of the services are not accessible by transportation. Again, some of the services are only available if you are highly troubled, and these people [DD/SMI] are highly troubled. (Ingham County Interviewee 2, p.15)

I think the whole barrier of anyone trying to access mental health treatment and the stigma associated with it…I think barriers of insurance, of limited resources, accessing those services, and like the wait time, awaiting to get services. Our insurance versus Medicaid and everyone should have some type of insurance, but then there’s not usually…I think barriers of “We’re not accepting new patients” kind of thing. Or it’s a four month wait. Not many people can wait four months when having a crisis. (Ingham County Interviewee 7, p. 8)

What I would like to see is a knowledgeable advocate, where each person had an advocate that was aware of all the services and already could do the brokering for the person. So I think…it’s too fragmented. The person – and I get it – but the person has to adjust their whole life around all of these services, and that’s not consistent with what would be required in a job. So how can they manage the extra burden of a job when you have to wait so long to get an appointment or to get the service you need. (Ingham County Interviewee 8, p. 5-6)

Medical services, that’s another area. It would be great to see some medical services that were provided either like in an office building like this [ie. community service agency], or in the home, because I have a lot of folks who are unable to attend those appointments, which is a real concern too. (Oakland County Interviewee 5, p. 9)

**Attention to DD due to political influences.** Participants from both locations noted that services for the DD population have received increased attention due to political advocacy, for
example by Lieutenant Governor Calley with the Behavioral Health Treatment (ie. Autism Benefit) waiver in Michigan.

What I notice currently is that many people in positions of great power in the state are advocating for additional services and inclusion of their family members who are either developmentally disabled or mentally ill, and consequently creating larger programs, bigger public awareness, and way more interest in the private sector in providing services and treatment for those people. (Ingham County Interviewee 2, p. 2)

“There’s been a huge amount of attention to Autism probably due to the political influences and...changes in the laws due to that political influence” (Ingham County Interviewee 5, p. 2).

Theme 3: Suggesting new structure of services. When participants were asked to envision a new service system that met the needs of individuals with DD/SMI, they most frequently identified the component of streamlining services into one central location. Participants also wanted this location to be an inclusive system that was open to everyone in the community and not just limited to individuals with DD/SMI, but that also had accommodations available to guide a person with DD/SMI when needed.

Some place...kind of like a drop-in center, but something more community based and organized where...they could work and people would be acceptable and understanding, where they were not treated any differently. Where they could do that independently, but supports would be there if they needed to access them. (Ingham County Interviewee 7, p. 6)

I’ve thought of like transforming sheltered workshops into places where, more community-based places, where people are coming in. It’s not just people with developmental disabilities that are using those places, but the community’s using those places...People with disabilities and people without disabilities can be together and just kind of socialize and do whatever. (Ingham County Interviewee 9, p. 8-9)

I think some kind of service or agency that have all those components in place, like I mentioned before, the ability to have some kind of therapy or psychiatry support, case management support. Also, like some kind of agency to work with just community living supports, or the staff to help with the different independent living skills that they need. (Oakland County Interviewee 1, p. 10)
I think it would include a program...like a clubhouse where people can go. They can get services there, or they can hang out and do social things as well...I love animals and I’m really into animals as just a therapy. I’d get that involved and maybe some gardening—anything that’s nurturing...beneficial and therapeutic for anybody. Those are things that I would find to be really cool, and I think other people that had mental health issues, DD and MI, could benefit from those types of things...But I just feel like a program like that would be really beneficial to individuals myself. Could other people come there and participate? Sure, why not? I think that would be helpful to. But just something that’s not exclusively, but really tailored to a person with DD and MI. (Oakland County Interviewee 2, p. 14-15)

I would probably like grass root almost like type organization where everyone would come together. It would be a coordination of care, where everyone that would be needed would be there, so your psychiatric, your DHS, your transportation, your medical...social work. Individuals that you actually provide services to would be the ones that could guide you into what the needs are. They need to be the ones that tell you what they need. (Oakland County Interviewee 6, p. 8)

**Theme 4: Having a support person who knows them well.** Participant’s responses indicated that having access to a support person who knows them well and can assist them with navigating many facets of their life is beneficial to a person with DD/SMI. Participant’s responses have been broken down into the role of the case manager or supports coordinator, the family or other natural supports, and the functions of the support person most identified. Participants varied in responses from the support person being a natural support or a paid support such as a case manager or supports coordinator, therefore both will be presented here.

**Role of case manager/supports coordinator.** Many of the participants indicated that a case manager or supports coordinator typically filled the supportive role for individuals with DD/SMI. For case management/supports coordination (CM/SC), participants most often referred to their role of the contact with the person they support with DD/SMI, coordinating services and supports across the team and with community members, and helping the person to access supports when needed.

I’m talking about 24-hour access to [CM/SC] who they can come and bounce some ideas off of, and maybe get grounded again to the point where they get that listening ear kind of
thing. Somebody to help them through and walk through some potential options that are going to be helpful for them and maybe keep them in the environment that they’re in. (Ingham County Interviewee 5, p. 8)

*I think the supports coordinator is definitely key, because that’s the person that will help* ...*bridge the gap in between the person we provide services to and that community connection*”

(Oakland County Interviewee 3, p. 4).

*“The supports coordinator is the person that kind of oversees all that [services], makes sure its running smoothly”* (Oakland County Interviewee 5, p. 6).

I think a combination of those things, having someone support them. Community living supports, where you have that staff to help with different things, the self-care, the independent living skills, whether its bathing, hygiene, paying bills, those things. The psychiatric portion, whether it be psychiatric or whether it just be some therapy. So those components as well as the case manager to help coordinate everything and make sure everyone is staying on task with everything. (Oakland County Interviewee 1, p. 7)

**Family or other natural supports.** Other participants observed that family or other natural supports in the community helped to fill the supportive role for individuals with DD/SMI. Responses from participants indicated they have observed people with DD/SMI that they support to seek out natural supports in the form of family, community, friends, churches, and schools for assistance when needed. Seeking out family or extended family was the most frequent response given by participants when asked about what type of natural supports a person with DD/SMI would access. When prompted about why individuals with DD/SMI seek out natural supports, participants indicated for socialization, for additional support, or due to relational issues in regards to burned bridges with family or difficulty making and keeping friends.

I see a lot of folks I work with depending heavily upon their families…I talked about that one guy at the health club. I mean he goes out with friends at work, he related to his friends at work. They talk. He comes in when he’s not working just to kind of socialize…I see a lot of folks who use community supports…I think they’re seeking companionship. I have a few people who kind of seek out support. A client who was going to go buy a car, and he needed somebody to help him with that. And he had a
friend that went with him to help him finance a car. He could buy his own car, but he couldn’t do the paperwork. (Ingham County Interviewee 9, p. 7-9)

We’re very fortunate in that most of the people we provide supports and services to are primarily with their family…So aside from family, of course, then there’s community members that can also provide natural supports and in that capacity. We have many people that are connected to churches, volunteer organizations. We’re really big on helping individuals and finding those opportunities in the community. [DD/SMI people access natural supports] to give back, to truly participate, and have this reciprocal relationship that, yes, I have skills, I have value, let me lend my skills and what can you lend to me as a provider. (Oakland County Interviewee 3, p. 8)

“A couple of my people have really supportive families, and that’s wonderful. Some of my other folks have burnt those bridges, and so that’s no longer available.” (Oakland County Interviewee 5, p. 8).

Lots of families, which is much more available than it ever used to be. Families when I started had often, based on the advice of the clinicians at the time, put their son or daughter in an institution and kind of left them. And so that changed quite a bit over the years of my employment. And families are more available and often try to do the best they can with natural supports, and they need guidance as well and education about the disorders their son or daughter have. (Ingham County Interviewee 4, p. 4)

**Functions of support person.** Some of the functions that were identified by participants for the support person to assist with included guiding through services, assisting with paperwork and maintaining entitlements, navigating a crisis and helping the person to access mental health care as needed. Of the functions identified, the most frequently identified areas were assistance with navigate a crisis, developing a crisis plan, and access to mental health care as needed.

I think there needs to be a contact person for either the family or the person to be able to call when they’re feeling like things are spinning out of control. I think they need to make sure that if they do have a psychiatric diagnosis, that there’s someone following up, making sure that…person’s taking their medication, that they’re safe…That whenever the crisis happens that there’s oftentimes you see there’ll be a short fix, but making sure that the long-term issues are addressed. (Ingham County Interviewee 6, p. 8)

I think an established relationship with somebody not only could get them where they need to go, but would be able to even help them identify that they’re having a crisis to
before it’s really bad. And that could mean just anything. But having...those relationships established I think can de-escalate a situation, or at least be able to help them identify that they’re in a crisis. Because we know some people have mental health issues that they can’t self-identify.  (Ingham County Interviewee 8, p. 7)

I think at our agency we...provide a pretty high level of support. Everybody has my cell phone number and we have a crisis line and things like that. Folks have a hard time knowing when they need to reach out for that [support]. So that can sure be a challenge. But my folks specifically, they have a staff person with them at all times, and when they enter into a crisis, that staff person has the ability to reach me, or somebody else here at CLS [agency] to provide immediate support. So, I think that’s important because if you are one on one, a staff sitting with an individual who’s becoming aggressive and violent, it’s very tempting to call the police. But we always...try to encourage them to call us and utilize our resources first.  (Oakland County Interviewee 5, p. 11)

They [person with DD/SMI] also need to be able to have someone to support them if they were having an episode of mental illness, whether it was bipolar or depression...to be able to recognize that and not see it purely as a behavior that needed to be consequated or punished, but supported through that piece. So usually things went well if they had a supportive person that could recognize when things were getting to a level that the person wasn’t being able to manage it, that they knew who to call.  (Ingham County Interviewee 6, p. 2)

**Theme 5: Identified barriers to accessing services.** Participants identified four areas as common barriers for people with DD/SMI. These four areas included 1) funding and insurance issues, 2) issues with accessing services and supports, 3) lack of transportation, and 4) the person with DD/SMI engaging and maintaining services and supports.

**Funding and insurance issues.** The first area of funding and insurance issues was the most frequently identified barrier by the majority of participants across the interviews and focus groups. Funding and insurance issues often centered on the lack of funding for adequate supports, and the issues of being able to access services if an individual did not have Medicaid or another form of accepted insurance.

I see a lot of changes in funding, and I hope it does not stop a lot of the services...what would happen to this population if they don’t have the amount of services and supports that they currently have. So hopefully they don’t take away from those services and supports any more than they already are.  (Oakland County Interviewee 1, p. 1)
Money is always [an issue]. The current services and supports that are provided are for only basically low income…the lowest of income folks that are Medicaid eligible. What about all those other people that are working poor that aren’t eligible for some of those benefits? They still…those folks are still out there. I’m not sure that they’re any better supported and there’s huge gaps there now especially that there’s no general fund dollars left. (Ingham County Interviewee 3, p. 8)

Funding. Along with funding, you get all the whole things that come with the funding – the whole paperwork, and making sure that x and y, equals z. But sometimes when you have all the paperwork…trying to find that balance with helping the person and making sure that the paperwork is done so you can continue to fund these [services]. (Oakland County Interviewee 1, p. 10)

We’re a very under-funded system. So we have got to provide services and supports in a very structured, very limited way, because it is very tight. We have discharged quite a few people over the past couple years because they’ve lost their Medicaid funding, because they didn’t have Medicaid. So helping people keep their benefits…can be very difficult sometimes. So then you’ve got people that you can’t provide supports and service to anymore, because you can’t continue to keep them open with you. And Oakland County’s taking a huge cut over the past year. And not that the other counties haven’t, but I think even at the top, like at the state level, mental health has always been under-funded, it’s the first place to cut, it’s the least understood. But yet, when you watch television and there are shootings and different things, it’s the first thing – that person has mental illness. (Oakland County Focus Group 1, p. 44-45)

**Issues with accessing services.** In regards to issues with accessing services, difficulty with service provision was the most frequently given gap in services with participant responses that illustrated the lack of flexibility, the paperwork requirements, and the lack of comprehension of how to access services.

I think currently would be access to the system. I think that’s being limited for a variety of reasons currently, because of insurance issues and payment issues. And those are absolutely critical. So a bigger safety net for folks to be able to access service. Second would be the services being available once they were able to get the service, so that the providers aren’t over-stressed with too many…never enough staff, never enough resources, and always demand is higher than the service providers can do. (Ingham County Interviewee 4, p. 5)
“It’s difficult accessing CMH services. It’s difficult qualifying, it’s difficult even knowing how to do it, so the process is difficult. Just understanding coverage and benefits that they have is almost too much for some people” (Ingham County Interviewee 8, p. 5).

It’s a bunch of paperwork that has to be completed over here to get this, and then you go over here and there’s a bunch of paperwork that has to be completed over here. And most of the things that have to be completed are not always that comprehensive either. They’re probably very long, lengthy applications and it really isn’t geared toward sometimes a person, because I don’t think the person even understands half of what needs to be completed. However, it must be completed and it’s always time-based. (Oakland County Interviewee 6, p. 9)

I think people fall in between the cracks a lot of times. For instance, we’ve seen people come through intake who don’t quite meet the definition of developmental disability, but function like they do. And so because the system isn’t set up to be able to make those people eligible for services, they often end up on the streets, or with no supports, when really you say, “Can they do these things?” – for instance, the self-care if they can read, they can write, but will they do it, no. Because of whatever. Maybe it’s Aspergers or maybe its depression. But those people sort of, fall through the cracks. And a lot of that is probably based on the mental illness to some extent. (Ingham County Interviewee 6, p. 6-7)

**Lack of transportation.** Participants across interviews and focus groups have observed the lack of accessible and broad reaching transportation to be a barrier for individuals with DD/SMI to accessing social interactions, employment and also supportive services.

Not having transportation to get to places, and then a lot of times, where are the places that they’re using? Not in your community, that you need to access for whatever the services are that you need. So like DHS and Social Security, if you needed to turn in paperwork and you live in this areas, more than likely that office may be 10 to 20 miles away from where you live. And if you don’t have transportation to get there, then that’s a barrier too. (Oakland County Interviewee 6, p. 10)

“Lack of transportation. That is key. It’s a huge barrier. (Oakland County Focus Group 2, p. 39).

“Definitely transportation” (Ingham County Interviewee 5, p. 10).

“Transportation can be an issue” (Ingham County Interviewee 8, p. 5).
We don’t have good public transit in this area. I mean, there are areas that have it, and I actually believe that if you can’t drive, you should probably try to live near public transit, so that you have that opportunity. But it’s not the most reliable…To me it’s a problem that is beyond the disability community. It’s a problem in general, but hits our community harder because there are more people who can’t drive or whatever…If you go to either other countries or big cities; you can truly get anywhere you want through public transportation. My sister lives in England in a small town, and I can fly into London, hop on a train, I have to go into downtown London, change trains, take a train to another city, hop on a bus, and I can get within like ten minutes’ walk of her house. She lives in a tiny little town. You can’t do that here. But if you lived in Washington D.C., San Francisco, New York, Toronto, Chicago, or Atlanta, I mean, we could name quite a few places…But there’s lots of areas that have better transit than we do. Unfortunately, the fact that we’re in Detroit where the auto industry systematically destroyed public transportation is a big problem. (Oakland County Focus Group 1, p. 27-29)

**Person with DD/SMI maintaining services.** Another barrier observed by participants was that of the person with DD/SMI and the impact of their disabilities on their ability to engage in and maintain services and supports.

The specific organizational skills or lack thereof, of the client. Inability or lack of desire to keep appointments. You know, especially the kids that I’ve seen transition from childhood to adults far as age and expectations of the system. They’re also at a point, just like any other kid where “I can do this on my own.” And so their understanding of the need to rely on people is really diminished…and that’s another barrier, I think. (Ingham County Interviewee 5, p. 10)

Or the individual themselves [won’t follow through with treatment]. I saw it all the time. Before I worked at Easter Seals, I worked at Kingswood Psychiatric Hospital, and I worked on the child and adolescent units for years. We also worked with adults. That’s part of the illness, you don’t…recognize you’re doing well, because you’re on your medications, you’re going to therapy, and then it’s like “whew!, I’m feeling good! I don’t need any of this, I’m doing good!” I mean …the person themselves can really, be a barrier to their own treatment and well-being. (Oakland County Interviewee 2, p. 17-18)

I think for people who have co-occurring issues, some of it is their willingness to engage…There are people who have staff and they turn their staff away at the door every time their staff show up to help them. There are people who refuse to go to their psychiatric appointments. There’s people who refuse to get out of bed…Compliance with treatment. With medications…They take their medication, they’re feeling good, and then “oh, I don’t need this anymore. I’m feeling good”…A lot of people I work with don’t have the ability to kind of see the big picture. (Oakland County Focus Group 1, p. 52-56)
Theme 6: Understanding of DD/SMI. Participants reported many observations about the lack of understanding about individuals with DD/SMI. The most identified responses can be conceptualized into two categories of perspectives of the professionals and perspectives of the community.

Perspectives of professionals. In regards to the category of perspectives of the professionals around the understanding of the DD/SMI population, or the lack thereof, participants identified several areas. These areas included 1) professionals understanding that a person with DD can also have a diagnosis of MI, 2) accessing therapists who are aware of the needs of people with DD/SMI, 3) psychiatric and ER services struggling to support a DD/SMI person, 4) the question of where a person with DD/SMI should be supported within community services, and 5) the need for education about individuals with DD/SMI.

People with DD can have an MI diagnosis. The lack of understanding of the DD/SMI population impacts several community supports a person could come in contact with. One identified by participants was the recognition that persons with DD can have an MI diagnosis.

I don’t think there’s a huge emphasis to focus on that population [DD/SMI]. I think that the focus of treatment is typically directed towards folks with developmental disabilities and their mental illness that they may have is kind of an afterthought. It’s not that it doesn’t get treated, but the focus seems to be on how you would typically treat somebody with a developmental disability, and the mental illness part gets kind of added on, as opposed to a dual focus or a primary focus on the mental illness with the developmental disability as the second. (Ingham County Interviewee 4, p. 1)

“I remember when we first were getting psychiatric services with persons with developmental disabilities and mental illness. When I started, people with developmental disabilities didn’t have mental illness, and I had more than one psychiatrist tell us that” (Ingham County Interviewee 1, p. 7).

The staff they kind of didn’t know what to do…But it was just, “okay, you can’t really treat this individual the same as you are the other kids.” They don’t really comprehend,
they’re not understanding. Some did to a certain extent…I think some of the support staff didn’t understand that they could be dually diagnosed with the MI and the DD. (Oakland County Interviewee 2, p. 19-20)

Therapists who understand and can work with people with DD/SMI. Participants have observed therapists struggle with supporting a person with DD/SMI due to their deficits in intellectual functioning and difficulty in meeting the person where they are at.

“I think it’s a really difficult population to treat, first of all…really difficult to treat because of their cognitive disabilities” (Oakland County Interviewee 2, p. 2).

Therapists that understand this population, the DD population…How do you get people to talk to them on their level, but not like a child? You know? How do you take somebody who might be 30 but cognitively they might be like 10, but talk to them like they’re 30 that a 10 year old would understand. That is difficult. (Oakland County Focus Group 1, p. 59)

We’ll have therapists who say, “I can’t work with this individual, I can’t deal with it, because they don’t have the cognitive abilities to learn or, I’m trying to teach them there different skills to cope with and they don’t have the cognitive ability to follow through.” And so they’re saying the therapy’s not going to work for this individual, even though they do have a dual diagnosis, but because of the cognitive impairment, they’re saying that therapy’s not going to work. (Oakland County Focus Group 2, p.44)

We’ve had situations where people have psychiatric issues and diabetes, and the psychiatrist says, “well, I’m not going to treat you until you get your diabetes under control. Because I can’t. You’ve got to get that under control. And then that doctor says, “I can’t treat you because you’re completely noncompliant. You need to go get that under control.” And they both want to drop them as their patient. (Oakland County Focus Group 1, p. 14)

These are older adults who have been taken care of their entire life by a parent. …Parents pass away and they are devastated. They have no idea how to, you know, process those feelings and its very heartbreaking to me...I have looked everywhere for a grief and loss group for… people with DD. Because I don’t think they would be very well services just in any grief and loss group, I think it would have to be more specialized and tailored. (Oakland County Interviewee 2, p. 4)
Psychiatric services and emergency room supports. Psychiatric services and emergency room struggles were also an area reported by participants as they don’t recognize the MI or just contribute those elements to behaviors as part of the DD diagnosis.

It’s difficult to find psychiatrists or somebody who understands the dual needs of a person with a developmental disability as well as a mental illness, and then when they do, I don’t think they treat the entire person. Some of it may be brushed off of needing treatment because they have a DD and it just kind of falls under that, without identifying the needs associated with a mental illness. Even trying to get in-patient treatment, if they’re needing more intensive supports…because they’re not there. Then they’re spending time in the emergency room or in the hospital, and they’re not. ..equipped to deal with those dual needs of an individual [with DD/SMI]. (Ingham County Interviewee 7, p. 1)

A lot of times with people, who were in psychiatric crises, they would come like through the ES [emergency services]. And because they were DD, they would often just call the residential unit. It was very difficult to get them to, you know, number one, evaluate for the MI component. Just being DD alone, what they wanted to just send them back to where they came from, and...which was the group homes or the families and look to the DD case manager or home manager to be able to figure out the behaviors. And unless someone was really violent or in danger, danger to themselves or others, then they were hospitalized. So basically, I think it was just, you know, a lot of it was just crises management was difficult to, you know, get the services that the MI population just would be able to get. (Ingham County Interviewee 6, p. 1)

For folks who had the dual diagnosis, a lot of times it was very difficult for us to get people admitted to the [psychiatric] hospital. Although they may have presented with a lot of violence…or harm to themselves or others. I have called at one point like every hospital that was on our list and no one could take the person, and the person was at the screening center forever…And a lot of hospitals don’t really want to provide services to individuals that have a developmental disability, because they feel like there’s not a whole lot that they can do…They [psychiatric hospitals] felt more equipped to be able to address the mental illness. But the developmental disability, it was just very difficult, especially if it was someone who maybe had a diagnosis of autism, and they also had maybe some signs of schizophrenia or some kind of psychosis, and they just felt like they really couldn’t provide the services. Or if they did provide the services, those folks [person with DD/SMI] may be in like restraints. (Oakland County Interviewee 6, p. 11-13)

Emergency rooms or hospitals, they’re not equipped to deal with dual needs of an individual, which poses a burden to families which makes them become kind of hopeless and helpless that there’s nothing to do, so they just take the child home. And they’re living in torment all the time and don’t know where to go, because there’s limited resources. (Ingham County Interviewee 7, p. 1)
Questioning where a person with DD/SMI should be supported within community services. Another area reported by participants was questioning where people with DD/SMI would be best served within community agencies. Is it within services for people with mental illness, or within services for people with developmental disabilities?

We’ll have people that come through the screening at Common Ground, and it’s clear they have a lot more MI needs…they’ll have like a mild cognitive impairment. And I feel, and I think my colleagues too feel that they would be much better serviced…by an MI provider. If they need to work with a therapist, we will definitely try and pair them with a supports coordinator who has experience working with the mentally ill. (Oakland County Interviewee 2, p. 3)

I think that it’s hard for agencies sometimes to know how to serve them. So, for example, my five folks that I have, their primary diagnosis is the mental illness. So most of them have schizophrenia…also that developmental disability, agencies are very concerned that they don’t have the resources to serve them. So sometimes you’ll see like back and forth… a DD provider might say, Wow, those persons should be served by an MI provider. There’s a little back and forth with that. (Oakland County Interviewee 5, p. 2)

Need for professional education. The final area noted by participants was the observation and recommendation of training for professionals that support individuals with DD/SMI to help understand their needs and be able to support them more successfully in the community.

I think they need better educated clinicians, better educated ancillary providers. And by that I’m talking about teachers, nurses, doctors, lawyers, shop-keepers, kind of the general community. I think we all need to be educated about the specific…the uniqueness that goes with either of those conditions [DD/SMI]. (Ingham County Interviewee 2, p. 4)

Particular illnesses require some specific approaches. And when you have somebody with both, it requires a whole ‘nother level of expertise, I think, and sensitivity. So like I think…that having folks have more awareness that it isn’t just a DD or just an MI but there’s a combination of factors and features that require addressing. (Ingham County Interviewee 4, p. 2)

The individuals are really misunderstood. I think people in this field need to have a better understanding of the challenges and the issues that they face having the cognitive impairment. I think it really makes things difficult to try to treat them. And the community at large…they don’t understand that somebody that has a developmental disability could also be mentally ill. So just a greater understanding and other forms of
treatment that are specifically tailored to meet their needs. (Oakland County Interviewee 2, p. 13)

So training, education, and if we’re all serving the same…type of caseload, then we are working together. And I think bridges would build that aren’t there. And that’s the problem. There’s still a lot of lack of education about persons with developmental disabilities, and who they are and what they are. And that causes a lot of disservice. (Ingham County Interviewee 1, p. 7)

An Ingham county participant even indicated that education about people with DD/SMI should start when children are in school to help educate and normalize the interactions.

I think education on the part of the community as a whole. Sensitivity training…I think that our kids in school don’t get that, and so as adults, often they’re uncomfortable around people that struggle. And I think if…the community were better educated, I think they’d be in a better position to provide the kinds of supports that people need and actually require to be able to participate successfully. (Ingham County Interviewee 3, p. 2)

**Perspectives of community.** In regards to the perspectives of community members, the lack of understanding about individuals with DD/SMI manifested into the stigma and segregation that has been observed by participants.

*Stigma and segregation.** Participants observed different forms of stigma and segregation in their work supporting individuals with DD/SMI. Some of their experiences are shared below, along with the participants recommendations about how these issues can be addressed.

Lack of understanding, lack of training, lack of empathy. Or tolerance. People don’t understand and if they’re not open to understanding and they’re not educated, and if people are close-minded. I think there’s still that discrimination part of – “they belong over there,” they believe [people with DD/SMI] belong on that island and “we’re over here, we don’t want to deal with that kind of stuff,” that obstacle. Why can’t you take them somewhere else? Why do you have to be here? Or that sympathy vs. empathy, “Well, that poor family.” (Ingham County Interviewee 7, p. 7-8)

What we’ve identified isn’t really about the system, oddly enough. It’s more about society and…that stigma…It’s a challenge. It’s an apartment complex, and somebody wants to rent there, and getting through to them that this person is a normal person and should be able to live here…I think getting rid of all the stuff that a system creates that segregates people, because then it leads to all this stuff that’s the stigma in the
community isolation. So if we got rid of sheltered workshops and we got rid of day programs, and we did something different in the schools. (Oakland County Focus Group 1, p. 41-44)

“I personally think it’s a move away from any segregated setting. I think segregated settings tend to bring people away from community versus making them part of the community” (Oakland County Focus Group 2, p. 17).

“So ideally for a service agency, it would be one that there would be no stigma. People would just be seen as people” (Oakland County Interviewee 3, p. 9).

I think that’s why things like segregating people with disabilities becomes a bigger problem than just the fact that all those people are segregated. But you’re exactly right. Then the community at large doesn’t see people with disabilities…so now people are hidden. So you don’t see people doing something successful because you never encounter “those” people [with DD/SMI], because they’re all hidden away in these special schools and special little programs, or huge programs, where they’re just not a part of peoples everyday interactions…And schools seem to be decades behind us. They seem to still push all of the antiquated kind of stuff. I mean, we’ve got resurgence here in Michigan of people who want to build farms and things that are what became institutions in the past. And there’s people who want to do that again. (Oakland County Focus Group 1, p. 23)

Summary

Participant responses from interviews and focus groups led to the articulation of six primary themes. These included the 1) staffing supports and other supportive services, 2) having access to services or service provision, 3) suggestions for a new service structure, 4) having a support person who knows them well, 5) identified barriers to accessing services, and 6) a lack of understanding about people with DD/SMI. Primary themes were consistent across both data collection sites in Ingham and Oakland counties. Participant responses were reflective of a frequency which is consistent with achieving saturation of topic material. The primary themes and finding of this study will be discussed further in chapter five.
CHAPTER 5: DISCUSSION

Chapter Framework

The discussion chapter will expand the findings in more detail, especially as applied to the research question, “What are the community service needs of individuals with DD/SMI from the perspective of the mental health professional (MHP)?” This includes a more detailed and exploratory review of the study findings and what can be learned from the observations and knowledge of the participants. The content is ordered by a discussion of the theory development, themes and subthemes, missing content, and a comparison of the findings from the present research and Hemmings and Al-Sheikh (2013) study.

Theory Development

The present research study was utilizing the theoretical orientation of systems theory to assist in sensitizing the constructs of the community service needs of individuals with DD/SMI from the perspective of the mental health professional. Although the topic questions of the interviews and focus groups were broad enough to answer without a systems frame, it appears this sample tended to offer service recommendations within a systems frame. Therefore the systems theoretical orientation seemed a best fit in supporting the research. The PI also utilized grounded theory method to potentially assist in building and developing a theory that was more individualized and specific to the community service needs of individuals with DD/SMI.

After completing the research and analysis, it appears that a systems-grounded theory combination was developed with the grounded theory components superimposed on the systems frame. This blended theory framework assists in illustrating the “how to” of service delivery (ie. accessible, streamlined, flexible, individualized, and providing choices), along with identifying new resources within the system (ie. support person). These elements are illustrated within
Figure 4 (p. 153) in regards to the community service format of service delivery and also the types of community services that were recommended to support individuals with DD/SMI. The new elements identified in the present research are bolded and italicized within Figure 4 to highlight their importance and impact within the community service structure for individuals with DD/SMI within the blended systems-grounded theory. The elements included in the blended system-grounded theory for the DD/SMI population assist with addressing barriers to services, increasing access to services, and building new models for future services.

In examining the interactions of the primary themes more closely, they appear inter-related when looking at the community service needs of a person with DD/SMI within Figure 4. For a person with DD/SMI having community services of a support person, social activities, transportation, psychiatric services, assistance with employment, assistance with ADL’s, and community living supports were the most identified needs. From a community service format perspective, people with DD/SMI benefit the most when community services are streamlined, accessible, flexible, individualized, and provided with choices.

From the perspective of the DD/SMI person, having flexible services to support them is very important. For example, a person with DD/SMI may be employed. To support the person with DD/SMI in their work environment, they would need an individualized plan of service, an accessible environment to meet their needs, and potentially a flexible schedule for when psychiatric symptoms and conditions occur which could create barriers to attending work regularly.

While the present study’s findings have provided some initial data to build upon, the researcher believes further studies will need to be completed to build a comprehensive theoretical orientation to illustrate the needs of the DD/SMI population. Future research should
include the community services needs of the DD/SMI population from the perspectives of people with DD/SMI, families and other natural supports of people with DD/SMI, and also SMI mental health professionals. Having expanded samples could assist with developing an enhanced systems-grounded theory model to support the DD/SMI population.

A blended systems-grounded theory enhanced model for individuals with DD/SMI in regards to the community service needs should likely include several considerations that have been presented by participants within this research. The first is in regards to having a service system that is accessible and flexible to meeting the needs of people with DD/SMI. A second consideration is the understanding of the DD/SMI population and how their unique symptomatology can impact their ability to engage and maintain services and supports. A third consideration is the recognition that services and supports should be individualized as a person with DD/SMI is first and foremost a person with their own unique needs and wishes in life. A fourth consideration is to identify the barriers to individuals with DD/SMI accessing services and supports, and address those impacts within the system. A final consideration is to acknowledge the need for expanded education and training for professionals in supporting individuals with DD/SMI.
Figure 4: Blended Systems-Grounded Theory Model for Community Services for DD/SMI Population
Primary Themes

The purpose of the study was to determine what the community service needs of individuals with DD/SMI were from the perspective of the mental health professional. Six primary themes were identified from study findings in the areas of 1) staffing supports and other supportive services, 2) having access to services or service provision, 3) suggestions for a new structure for services, 4) having support from a person who knows the DD/SMI person well, 5) identified barriers to accessing services, and 6) understanding people with DD/SMI. These six themes will be expanded further and given greater context in regards to the participant observations and impacts for the DD/SMI population. Themes one through six will be compared and contrasted with the existing literature.

Theme 1: Staffing supports and other supportive services. Participants illustrated the need for staffing supports, concerns about hiring and maintaining consistent staffing, and having access to other supportive services as a community service need for individuals with DD/SMI. Other staffing supports identified for the DD/SMI population were psychiatric services, employment assistance, and opportunities for social activities.

When looking more closely at the data regarding staffing supports, participants appeared to be identifying the staffing support needs of individuals with DD/SMI from three perspectives. The first was in regards to supervision and monitoring. Participants mostly indicated a person with DD/SMI was unable to live alone and had needs that justified having a supportive person available for small periods of time (ie. 1-3 hours a day) or up to 24 hours. The staffing support needs identified varied and appeared to be based on the person’s individual needs. Staffing supports are a vital component of the needs of the DD/SMI population as they provide regular and ongoing monitoring and support of the individuals needs in regards to daily living,
psychiatric symptoms, and engagement with the community. Without staffing supports, many individuals with DD/SMI would not be able to maintain living in the community.

The second observation was in regards to assisting with activities of daily living such as personal hygiene. Personal hygiene was an area that was brought up by many participants in relation to the person with DD/SMI and their ability to be successful in the community. Participants referenced the need for good hygiene to engage in social activities and to build relationships with others. Good hygiene was also an area brought up for individuals who are employed or wish to become employed within the community. Having poor personal hygiene was noted as an indicator to many participants that the person with DD/SMI could be struggling psychiatrically and need further assistance. In this instance, staffing supports is available to provide feedback to the psychiatrist or treatment team supporting the individual with DD/SMI to assist in making informed decisions about medications and treatment approaches.

The final area identified was working on skill acquisition towards the goal of greater independence for the person with DD/SMI. Acquisition of skills can be in a variety of areas that includes cleaning, cooking, learning to ride public transportation, and navigating the community. The majority of participants reported wanting individuals with DD/SMI to have choice in their life and independence where they were able. Participant responses seemed reflective of the self-determination philosophies and gentle teaching approaches that are common in practice for both data collection locations. Self-determination, as stated previously, is an approach that provides for the individual to direct their supports (Heller et al., 2012). It is also referred to as participant directed supports. Gentle teaching is a form of Rogerian therapeutic approach that reinforces an unconditional positive regard for all people. Gentle teaching also advocates for interdependence for the individual with DD/SMI to receive the support they need to be successful in combination
with providing as many opportunities for individual choice in creating a quality life (Gentle Teaching International, 2016).

In regards to other supportive services, participants frequently identified three other areas which included psychiatric services, employment assistance, and opportunities for social activities as community service needs for individuals with DD/SMI. Psychiatric services were a commonly reported need for individuals with DD/SMI in the community.

What is interesting to consider is the inter-relationship between the supportive services identified by participants. The four most frequently identified services were community living supports (CLS), psychiatric services, employment, and opportunities for social interaction. According to participants, having just one of these services may or may not meet the individual needs of the person with DD/SMI. Participants frequently indicated that a person with DD/SMI needed some combination of these services to be successful. For example, a person with DD/SMI could receive employment assistance and potentially be hired and have a job. The question then becomes if they would be able to maintain that employment over time without any other services besides employment assistance or job coaching. Participants reported that individuals with DD/SMI struggle with taking care of themselves in regards to personal hygiene and can often lose employment due to this issue. Also, if the person with DD/SMI were to struggle psychiatrically and need to take time off work to stabilize or even have an in-patient psychiatric hospitalization, the employer may not be willing to hold his or her position for an extended period of time.

Examples offered helped clarify participant recommendations for services as a combination of support for individuals with DD/SMI to aide them in many areas of their life to be successful living in the community. For example, a person with DD/SMI may have CLS staff
that assist with hygiene and monitoring for psychiatric symptoms. If symptoms arise, they can assist with accessing more preventive psychiatric services and hopefully prevent any impact on the person’s ability to continue working or engaging in social activities with others. Therefore, participant reports appear to indicate that individuals with DD/SMI would benefit from a combination of individualized supportive services to live successfully in the community.

The staffing support findings are strongly supported by previous research from Rizzolo and colleagues (2013) who indicate residential habilitation and companion/homemaker/chore/personal assistance/supported living as two of the three most utilized services for individuals with DD/ID within the HCBS waiver programs. The need for individualization and customization of services is also supported by Shedlack and Chapman (2004) as well as from Martin and colleagues (2005). The need for a combination of supportive services is also supported by findings from Hemmings and Al-Sheikh (2013).

Theme 2: Having access to services or service provision. The main subthemes identified by participants were 1) people not receiving services or not knowing what services were available, 2) the outpatient model of service delivery, and 3) the increased attention to DD services recently due to political influences.

Participant observations about having access to services and supports were illuminating about the challenges that individuals with DD/SMI and their natural supports can encounter when attempting to access and/or maintain services and supports. One of the areas identified was that of individuals with DD/SMI not knowing what services are available and therefore not be receiving supports. Participants generally did not elaborate about the lack of information, other than to indicate that this was an issue for individuals with DD/SMI who needed supports.
Another response was in regards to individuals with DD/SMI and the challenges they encounter when interacting with the mental health and medical systems for service delivery. The *outpatient model* operates as a Monday through Friday, 8am to 5pm structure. Participants in both locations frequently indicated that this was an issue for individuals with DD/SMI who often had occurrences of situations that needed to be addressed outside of that timeframe. The responses by many participants indicated that individuals with DD/SMI needed access to services and supports that were flexible and available on evenings and weekends. Participants provided examples of individuals with DD/SMI having a form of crisis, and how they as the mental health professional attempted to fill that flexible role by being available to the person to process the situation or available to staff who support the DD/SMI person to process through issues and provide suggestions. This function was identified across interviews and focus groups to support individuals with DD/SMI in the community.

Another way in which the outpatient model is not supportive of individuals with DD/SMI is in regards to the person and their *disability specific challenges*. This can be illustrated by the individual with ID and severe depression who is unable to leave her home due to her current mental health issues to access psychiatry or supportive therapy services. In the outpatient model, the person with DD/SMI would not be able to access support. If the system were to adapt to the needs of the DD/SMI population, then a therapist or even psychiatrist could be available in many different forms to assist. Therapy could potentially be offered in a variety of formats including as a home based service or over the phone or other telecommunication venues. Also, the therapist or psychiatrist could have sessions via Skype or Facetime with the individual with DD/SMI to visually engage and consult on therapeutic or psychiatric needs and provide medication consultation as needed.
Therefore, participants indicated that the outpatient model of services with its more structured days and hours of supports is not currently meeting the needs of the DD/SMI population and would need to change in the future to meet their ongoing support needs in the community successfully. Current results emphasized the need for flexibility in the service system, which was also presented in previous research by Hemmings and Al-Sheikh (2013). Other than Hemmings and Al-Sheikh (2013), the previous research appears to have focused little attention on the model of service delivery for individuals with DD/SMI and how it impacts service outcomes. Previous information presented on systems of care have offered some service models that can assist in this area including having a Mobile Urgent Treatment Team or tele-emergency services available to consult and assist with after-hours support needs and crisis situations (Erickson, 2012; Mueller et al., 2014).

Participants noted the growing awareness of developmental disabilities, especially autism, with the political influences that have prompted and influenced the behavioral health treatment (BHT) benefit (ie. Autism Wavier) in Michigan. Participants noted the influence of Lieutenant Governor Calley in raising awareness within the community about the needs of individuals with DD, as well as advocating for the BHT benefit. The BHT is an early intervention program that utilizes applied behavioral analysis (ABA) as a direct one on one therapeutic approach to develop and build communication and socialization skills. Applied behavioral analysis has been established as evidence based practice for individuals with autism. The BHT is a Medicaid funded program for individuals with autism or related conditions from ages 18 months thru 20 years. The BHT benefit appears to be assisting in raising awareness about the needs of individuals with DD in the community, as well as offering evidence based therapeutic approaches to support individuals with autism.
Theme 3: Suggesting new structure of services. Participant recommendations about a new structure for services and supports were most often in relation to streamlining services into one central location. This meant that any public, governmental, or social service would all be housed in one location for all individuals in a community to access, not just individuals with DD or MI. Participants indicated such services as Community Mental Health, Social Security, Department of Health and Human Services, and even medical and psychiatric services would optimally be included and accessible at this location to better meet the needs of the individuals with DD/SMI in the community. This research finding is strongly supported by Ervin, Williams, and Merrick (2015) whose research advocates for integration of mental, behavioral, and primary healthcare systems for individuals with DD/SMI. The previous research on systems of care strongly supports a community service system that involves the collaboration and coordination of services and supports for individuals and families (Erickson, 2012; Miller et al., 2012; Mueller et al., 2014).

An interesting observation from participant recommendations was the focus of the new service system being accessible and inclusive to all members of the community, while still having supportive features for individuals with DD/SMI. Participants frequently pointed out that the new structure should be inclusive and not segregated to only individuals with DD/ID, MI or DD/SMI; and should therefore also support any individual in the community that may need to access support. With that said, participants still wanted the new service structure to take into account the needs of the DD/SMI population and provide supports for them to be able to access the needed services. One participant described it as one stop shopping for an individual with DD/SMI, so that he or she could access all of their support in one place versus needing to travel around a large urban area to multiple locations. Another participant illustrated this quite
eloquently when talking about the paperwork needs of the entitlement programs with social security and DHHS, where the individual with DD/SMI they supported needed to travel 10-15 miles away from their home by bus to turn in paperwork to maintain their DHHS services of Medicaid and food assistance, and then would need to travel to another area to meet with Social Security.

Another frequently identified recommendation for the service structure was to provide opportunities for employment and social interaction for individuals with DD/SMI. A similar observation in this area was for the environment to be free of segregation and stigma and open to the community, but also meet the needs of the DD/SMI population. It was important to many participants that this location was accepting and understanding of individuals with disabilities. This is a very relevant concern for participants as individuals with DD/SMI can struggle with making and maintaining friendships or social relationships, so having a place to go where they are accepted and understood would be important to helping individuals with DD/SMI work on these issues and stretch their skills within the community. While previous research (Bush et al., 2009; Cook et al., 2006) indicates positive outcomes for individuals with disabilities who gain employment, no previous research evaluates the need for social interaction amongst the DD/SMI population within the community.

**Theme 4: Having a support person who knows them well.** Having access to a support person to assist with many areas of life was a frequent response from individuals in regards to the community service needs of individuals with DD/SMI. Participant responses in this area varied between a support person being a paid support (ie. case manager or supports coordinator) or a natural support such as a family member or friend. This could have been in regards to the related observation that some individuals with DD/SMI may not have family or may have lost
their families or other natural supports over time due to their struggles with maintaining relationships.

Participants often identified primary functions of the *case manager or supports coordinator* as to link, coordinate, and monitor services and assist with advocating for additional supports as needed by the person with DD/SMI. Participants also indicated that they as mental health professionals (MHP) have worked to develop positive relationships with the people they support over time. The importance of the positive relationship between the MHP and the person with DD/SMI was often illustrated by participants in relation to the person with DD/SMI feeling comfortable reaching out to the MHP for support when in crisis. Discussions from focus group one in Oakland county talked about this area at length and how one participant gives her contact number to the people with DD/SMI she supports to assist in case of an emergency. The participant reported that sometimes the phone calls are just a few minutes and others may be half an hour based on the person with DD/SMI’s needs. While having access to a support person’s phone after hours can be a concern about maintaining professional boundaries with individuals with DD/SMI, the discussion in the focus group was much more directed towards meeting the needs of the individual with DD/SMI and working to adapt to those needs to support the person to be successful. This again reiterates the importance of services being flexible and accessible to meet the needs of the person with DD/SMI in the community.

In regards to a support person who is a *family member or other natural support*, participants indicated that family was the most frequent response. This research finding is strongly supported by Freedman and Capobianco-Boyer (2000) which indicates that families continue to be a large provider of support for individuals with DD in the United States.
Other natural supports identified included friends, churches, schools, and the community. Participants identified several community organizations and activities that people with DD/SMI access or could access on a regular basis when needs arise. Groups such as the YMCA, community parks and recreation programs, Boys and Girls Clubs, 4H, Boy Scouts, and local fairs and festivals were identified. Participants also mentioned some local advocacy groups such as Autism Masks, Citizen Advisory Committee, and the Capital Area Center for Independent Living (CACIL), as possible supports to access in the community for the DD/SMI population.

Some of the functions that were identified by participants for the support person to assist with included guiding through services, assisting with paperwork and maintaining entitlements, navigating a crisis and helping the person to access mental health care as needed. Of the functions identified, the most frequently reported areas were assistance with navigating a crisis, developing a crisis plan, and access to mental health care for a person with DD/SMI in the community.

Participant responses indicated that support with maintaining paperwork and entitlements was one of the primary functions of the support person. As individuals with DD/SMI have the co-occurring DD that often times includes a certain level of intellectual disability, the ability to comprehend and follow through with filling out and turning in paperwork to a variety of agencies can present an ongoing support need. As participants illustrated in quotes from the results chapter, the bureaucratic system of community services can present many challenges for individuals with DD/SMI in accessing and maintaining services and supports. If an individual with DD/SMI is unable to maintain their services, they would struggle to live in the community. For example, a person with DD/SMI may receive food assistance from DHHS and SSI. Funding
supports from SSI are on average about $731 per month. Food assistance from DHHS can vary based on income, but can reach as high as $200 per month. For many individuals the SSI and food assistance funding are their total financial resources for a month to meet their housing, utilities, food, and miscellaneous needs. If an individual were not able to navigate paperwork for redetermination of these entitlements (ie. food assistance and SSI), then they could have no financial resources to support their living in the community and therefore become homeless or need to depend on family or others for support.

Another function that was frequently identified by participants was in relation to the support person assisting with navigating a crisis, developing a crisis plan, and accessing mental health care as needed. Often these areas were inter-related in the participant responses. Some of the examples presented indicated that a person with DD/SMI could become psychiatrically unstable and need assistance with accessing mental health care. Participants often reported, especially in Oakland county, that individuals have a crisis plan in place so that if and when a crisis occurs the team has a plan of how to approach and support the person with DD/SMI per his or her wishes. These responses appear to indicate that for individuals with DD/SMI having individualized plans of service, especially in regards to the crisis plan, are important to supporting them within the community setting.

Current results heavily emphasize the need for access to a support person to assist people with DD/SMI in accessing and navigating their communities. This finding is new to the DD/SMI literature, as no previous research indicated having access to a support person as a study finding or within recommendations for future research.

**Theme 5: Identified barriers to accessing services.** Participants identified four areas as common barriers for people with DD/SMI within the community. These four areas included 1)
funding and insurance issues, 2) issues with accessing services and supports, 3) lack of transportation, and 4) the person with DD/SMI engaging and maintaining services and supports.

The first area identified, funding and insurance issues, was the most frequently noted barrier by participants across interviews and focus groups. These two issues are tied together because the majority of community services are funded through Medicaid or Medicare, not by private insurance. A number of examples were provided by participants about how the dynamics of funding and insurance issues can impact people with DD/SMI. One of the dynamics was that of individuals with disabilities being cut from services that did not have Medicaid insurance to therefore fund their supports. The State of Michigan government has made cuts to the general fund across the state for mental health services, thereby reducing or eliminating the option for community services to support individuals without Medicaid or Medicare for insurance, according to participant reports. This dynamic therefore could limit the access that individuals have to community services if they do not have active Medicaid insurance for funding.

A second dynamic noted was the lack of accessibility and support for individuals with DD/SMI who are considered working poor. This group of individuals earns an annual income above the poverty level, but do not earn enough income to pay out of pocket for services and supports that could potentially be needed, such as staffing supports to maintain personal hygiene and housing. This potentially is a gap in services where individuals with DD/SMI who receive SSI and are employed could fall off of Medicaid services and then no longer be able to have supports. The new Healthy Michigan Plan (HMP) mentioned in the literature review may assist in decreasing this gap, as it helps to provide funding and supports for services to individuals that have typically been characterized as “working poor” (Michigan Department of Health & Human Services, 2016).
Finally, the last dynamic noted was in regards to how mental health services were observed by participants, especially in focus group one in Oakland county, to be very underfunded and typically one of the first areas to be cut. This observation and discussion was then related to the lack of funding to support a greater number of individuals who may struggle and be highly publicized, such as individuals who engage in school shootings or at movie theaters. Participants commented on how the individual who perpetrated violence is usually identified as having a mental illness or another type of disability, but state and local governments continue to cut funding to support people with DD and SMI needs within services that could assist individuals who are struggling.

A second barrier noted by participants was issues with accessing services and supports. Participants illustrated the difficulty with service provision for individuals with DD/SMI including the lack of flexibility of services, the paperwork requirements, and the lack of comprehension of how to access services.

Participants seemed to indicate that one of the biggest issues was the difficulty in accessing services in regards to knowing what was available but then also qualifying for services and supports. The area of qualifying was presented as quite time consuming and difficult in regards to meeting eligibility criteria. Several participants noted how eligibility criteria can vary between community services and entitlement programs (ie. SSI or SSDI).

Another challenge presented was in regards to the paperwork requirements to maintain services and supports. Participants reported issues with individuals with DD/SMI being unable to comprehend and complete paperwork for the variety of supports in a timely manner to stay connected with receiving services.
The final area noted by participants was the lack of *comprehension of how to access services* for individuals with DD/SMI. Each community service agency has its own access process and information to navigate before receiving services. For agencies like DHHS, individuals with DD/SMI may wish to access adult home help services or food assistance to support them in the community. Participants explained that each of these benefits has a separate application process and follow-up requirements. For example, for adult home help the person with DD/SMI needs to complete an application, have a doctor sign off on their disability, and have an in-person interview with a DHHS representative to establish services. After that, there is a mandatory six month re-determination with required paperwork that must be returned within a certain period of time. According to participants, that is just one illustration of community service processes that can take anywhere from four to six weeks to get established. It may be easy to see why any person would struggle with maintaining services and supports with processes that are lengthy and complicated, let alone for a person with DD/SMI who may struggle with comprehension and follow through.

A third barrier noted across interviews and focus groups was the *lack of broad reaching and accessible transportation* to meet the community service needs of individuals with DD/SMI. Participants referred to the lack of transportation as impacting individuals with DD/SMI in regards to socialization opportunities, employment, and accessing supportive services. While both Ingham and Oakland counties have public transportation systems, participants noted how it was not meeting the needs of people with DD/SMI due to having limited schedules and routes. Some participants even noted how MHPs may advocate for individuals with DD/SMI who rely on public transportation to live closer to bus routes so they are able to get around the community. The discussion in focus group one also included a comparison of the public transit systems in
other major cities, such as San Francisco, New York, Chicago, and Atlanta. Participant discussion indicated that the other major cities noted had much better public transit systems that were more broad reaching and accessible for all community members, and did not appear segregated or have a sense of stigma attached. Participants, mostly in Oakland county, reported that some individuals they support with DD/SMI would refuse to ride the public transit system because of their belief or the stereotype in the area that it was for individuals with disabilities, and the people they supported with DD/SMI reported they did not want to be seen in that way.

The final barrier noted was in regards to the person with DD/SMI maintaining services. This barrier was presented by participants as the person with DD/SMI being impacted by their own disability related symptomatology to engage in and maintain services and supports. Participants offered several examples. The first was in regards to the lack of organizational skills or lack of desire, on the part of the person with DD/SMI, to follow through with appointments to maintain services. The second was the lack of insight of the individual with DD/SMI to maintain treatment, such as medications, when they improve and are feeling well. Several participants commented on how individuals with DD/SMI can often be their own worst enemy in lacking insight about why they are improving and choosing to discontinue medications. The third example was in regards to an individual with ID and severe depression who was unable to get out of bed to attend therapy and psychiatry appointments, and would turn staff away at the door when they came to assist and support the person with DD/SMI. These examples appear to be common observations across the participants in the interviews and focus groups as being concerns for individuals with DD/SMI in regards to how they struggle with approaching and maintaining services with their dual diagnosis. This also further illustrates the needs of
individuals with DD/SMI and how a service structure that is flexible and accessible can help to meet their needs.

The current research emphasizes the need to address the barriers impacting the DD/SMI population to support them to be successful in the community. This appears to be a fairly new finding within the present research as only one previous study (Hackerman et al., 2006) mentioned service utilization of the DD/SMI population within its recommendations. It appears that addressing the barriers that impact service delivery to the DD/SMI population have gone largely unaddressed in the literature to date.

**Theme 6: Understanding of DD/SMI.** Participants indicated that a lack of understanding about the DD/SMI population has been observed between professionals and the community. Professionals were identified as therapists, psychiatrists, and agency representatives such as the Social Security Administration and the Department of Health and Human Services (DHHS). The community was more broadly defined to include members of the communities in which people with DD/SMI live and receive services.

The lack of understanding from the professionals perspective was broken into several areas that included participant observations of 1) professionals understanding that a person with DD can also have an MI diagnosis, 2) accessing therapists who are aware of the needs of people with DD/SMI, 3) psychiatric and ER services struggling to support a person with DD/SMI, 4) the question of where a person with DD/SMI should be supported within community services, and 5) the need for education about individuals with DD/SMI.

The first observation was that of professionals understanding that a person with a developmental disability can also be diagnosed with a mental illness. As stated previously in the literature review, when referring to a dual diagnosis this has typically been in reference to a
mental illness and substance use disorder occurring simultaneously (Drake et al., 2001). The greater issue in this area, as illustrated by participants, appears to be the belief that individuals with DD do not have psychiatric issues but behavioral problems that are considered characteristic of the DD diagnosis. Participants provided examples of psychiatrists, CLS support staff, and even other mental health professionals who struggle with understanding a person with DD can have an MI diagnosis and how that can impact their services and supports negatively. If a professional is functioning under the assumption that a person with DD cannot have an MI dual diagnosis, then the person with DD/SMI could have needs going unmet in the community which could create barriers to their success.

This finding emphasizes the need for professionals to have an understanding of DD/SMI diagnostics and the ability to diagnose accurately for successful treatment in the community. Research from King and colleagues (2009) and Ervin, Williams, and Merrick (2015) further support this finding and reinforce the need to recognize that individuals with DD can also have an MI diagnosis.

The second observation was in regards to the lack of access to therapists who can work with people with DD/SMI. A common frustration presented by participants was not having access to therapists who would accept clients with DD/SMI. Another frustration reported by participants was then having the therapist understand the person with DD/SMI and how to work with him or her successfully. One of the biggest challenges presented by participants was the lack of understanding of therapists in how to adapt their therapeutic approaches to work with an individual with an intellectual disability. Participants reported that therapists had refused to even support a person with DD/SMI previously because they did not either work with individuals with
DD, or did not believe the person with DD would be able to comprehend and engage in therapy due to their cognitive limitations.

A few participants also presented how a *gap in therapy services* exists for individuals with DD/SMI in certain areas such as grief, loss, and trauma. For individuals with DD/SMI who have lived with family or relatives for the majority of their life, the loss of a parent or their primary support is a devastating event. The DD/SMI population is a very marginalized and vulnerable population that typically experiences trauma at a higher rate than that of the general population (Slayter, 2007). As such, participants thought that this was an area that was typically neglected in therapeutic services. Participants said they wanted to see therapy groups available that were tailored to support the DD/SMI population to meet their needs in the community.

The third area of observation included professionals’ understanding about individuals with DD/SMI in regards to *psychiatric services and emergency room supports*. An interesting dynamic to note is the connection between the need for psychiatric services and supports identified by participants and the observations of how psychiatric supports struggle to meet the needs of individuals with DD/SMI once they are admitted. One of the most frequent observations in this area was the comment of psychiatric and medical hospitals not being equipped to support a person with DD/SMI within their facilities due to a lack of knowledge on behalf of the healthcare professionals. This was both in regards to understanding the person with DD could be diagnosed with a mental illness, and also in regards to their therapeutic approaches. One participant even provided an example where a person with DD/SMI she supported was put into restraints because the psychiatric facility reportedly did not know what else to do to support the person. Other observations included the lack of psychiatric facilities that would be willing to accept a person with DD/SMI, and also how the lack of psychiatric services then falls on the
family to support a person who is potentially unstable and unsafe. This study finding emphasizes the need for increased training and understanding of the DD/SMI population, and is strongly supported by Chan, Hudson, and Vulic (2004).

A fourth observation was how mental health professionals even question where a person with DD/SMI could be best supported within community services. Within the community service system, individuals with DD/SMI can be challenging to serve as most systems relegate services to either developmental disabilities or mental illness services (Davis, Barnhill, & Saeed, 2008; Ervin, Williams, and Merrick, 2015). Community services for individuals with DD/SMI could be offered at a variety of agencies including Community Mental Health Centers (CMHCs) or agencies contracted with CMH’s to provide services and supports within the community.

Participants seemed to be questioning which area of practice (ie. DD or MI) was most equipped to support a person with DD/SMI. When an individual with DD/SMI needed a case manager, participants would often indicate the person was paired up with a case manager who had experience supporting people with MI in an attempt to meet his or her needs. The discussion within focus group two was very interesting as the group members indicated a person with DD/SMI should not be defined by their diagnoses and to foremost be seen as a person. The group indicated the focus should be on person centered planning (PCP) and working with the person with DD/SMI to decide what services and supports were needed to assist him or her in being successful in the community. Participants also indicated that the person with DD/SMI likely needs a combination of services and supports from both DD and MI services to be successful in the community as supported by their observations regarding services for CLS, employment assistance, opportunities for socialization, and psychiatric services and therapy.
A final area noted in regards to the perspective of professionals was the realization that 
more education is needed about individuals with DD/SMI. Participants reported needing more 
training and education for all mental health and healthcare professionals in regards to assessment 
and diagnosis, challenges that may occur, and even therapeutic approaches to support people 
with DD/SMI successfully. With greater education and training for mental health and healthcare 
professionals there may be expanded service providers that could adequately meet the needs of 
the DD/SMI population and reduce the number of unmet needs currently going unaddressed. 
This study finding is strongly supported by previous research from King and colleagues (2009) 
as well as Hemmings and Al-Sheikh (2013) who also recommended further training and 
education for professionals who support individuals with DD/SMI.

The second subtheme identified was the perspective of the community in regards to the 
lack of understanding of the DD/SMI population by community members. The lack of 
understanding about individuals with DD/SMI within the community appears to have manifested 
into the stigma and segregation that has been observed by a majority of participants and shared 
within the interviews and focus groups. Participants appear to indicate the current service 
system is set up to reinforce segregation and therefore stigma amongst the community as 
individuals with disabilities are separated from the community. Participants noted that 
separation of individuals with disabilities prevents community members from interacting with 
individuals with DD/SMI and gaining an understanding about who they are and forming 
relationships. The separation also further maintains the mentality of the community in justifying 
that individuals with disabilities should be “over there” as stated by one participant, and not a 
part of the community due to generalized stereotypes.
Some participants advocated for the discontinuation of sheltered workshops or other segregated day programs for people with disabilities, while others still saw them as a safe place for people with DD/SMI where they could have opportunities for work and social engagement that they may not get in the community without the same level of supportive services. An expressed concern in the first focus group was the continuation and expansion of segregated settings and how that could potentially lead back to the development of institutional settings over time.

While both data collection locations had participants on both sides of this argument, the Oakland county area was more often in the direction of discontinuing any activity or facility that was segregating in any way. This was a very purposeful response from Oakland county participants, as their agency Community Living Services, has made the choice not to contract with any segregated settings for the individuals with DD they support. Community Living Services of Oakland county focuses on using the approaches of self-determination and gentle teaching to support individuals in making choices and assisting them to become integrated into their communities and building natural supports. Participants from the second focus group in Oakland county said the best way to address the stigma is to help a person with DD/SMI to form relationships with others in his or her community. An example provided was to assist a person with DD/SMI to take a swim class and facilitate building relationships with the other swim class members. Over time the goal would be to fade the support person from attending, and just let the person with DD/SMI be a person interacting with friends at his or her swim class. Participants projected that the forming of relationships between people with DD/SMI and community members could assist in confronting the stigma attached to individuals with disabilities. By community members gaining first hand experiences with individuals with DD/SMI through
friendships and socialization, they can begin to see the person as a person and not just as the label they are given within society.

Within theme six, the areas of having therapists who are trained in working with the DD/SMI population and also the lack of medical and psychiatric facilities that are equipped to support individuals with DD/SMI is new information that has not been presented in previous research within the literature review.

**What seems to be missing from the data?**

While participants offered a wide range of observations and knowledge about their experiences in supporting individuals with DD/SMI, some areas of information appear to be missing in comparison to information provided in the background and literature review chapters.

A primary area missing from the data is the experiences and interactions of families who support individuals with DD/SMI. While families were noted as an informal support that could often take on the role of supporting the person to access services and supports in the community, not much else was presented about families. This is somewhat contradictory to Freedman and Capobianco-Boyer (2000), who indicate families were a primary support for individuals with DD/ID living in the community after deinstitutionalization and into the present.

Participants noted the need for more therapists and psychiatrists to assist in supporting individuals with DD/SMI. What participants did not mention at length was the need for more therapeutic approaches that are evidence based in meeting the psychiatric needs of a person with DD/SMI as previously noted by Davis and colleagues (2008) within chapter one. Participants tended to focus more greatly on the therapist and their understanding of how to support the person with DD/SMI and not the available research based therapeutic approaches that could assist in this process.
Participants did not provide information about interactions of the DD/SMI population in regards to the criminal justice system. Only a few of the 24 participants mentioned this as an experience that they have had in supporting individuals with DD/SMI. The greatest discussion close to this area was during focus group one in Oakland county where group members recommended that police, lawyers, and judges receive more education about individuals with DD/SMI and their symptomatology. The lack of information in regards to the DD/SMI population and interactions with the criminal justice system is somewhat surprising considering the current research base which identifies it as a more common occurrence in the lives of individuals with DD/SMI and MI diagnoses (Chan, Hudson, & Vulic, 2004; Cohen, 2007; Slayter, 2007; Swartz & Lurigio, 2007).

Participants also did not mention the occurrence of homelessness amongst the DD/SMI population. The occurrence of homelessness appears to be well established within the research literature for individuals with MI diagnoses and to a lesser degree for individuals with DD/SMI (Cunningham et al., 2006; Grob, 1994; Slayter, 2007; Umb-Carlsson & Jansson, 2009). This may be due in part to the characteristics of DD services in regards to providing supports of CLS to maintain community housing as well as a support person to provide assistance with payments for rent and utilities which assist in maintaining housing situations. This may differ for a person who is DD/SMI and receiving services from a department or agency that is more geared towards providing MI services and does not offer the same combination of supportive services to assist in maintaining housing.

Comparison of Findings from Hemmings & Al-Sheikh (2013) & Current Research

The current research and Hemmings and Al-Sheikh (2013) both had a similar focus of examining the community service needs of individuals with DD/SMI from the perspective of
mental health professionals. While the two research studies had similarities and differences (noted previously in the methods section), some similar results occurred within both studies. The Hemmings and Al-Sheikh (2013) study identified ten themes from their analysis. The ten emergent themes included the areas of 1) configuration/structure of services, 2) clarity of purpose/care pathways, 3) joint working, 4) training, 5) flexibility of service delivery, 6) resources, 7) evidence-based, 8) holistic/multidisciplinary, 9) needs-led/personalized, and 10) accessible information (Hemmings & Al-Sheikh, 2013).

The first similarity is between the configuration/structure of services and the primary theme from the current research of suggesting a new structure for services. Both themes address the need for services to meet the needs of the DD/SMI population perhaps in a mainstreamed or streamlined way, but still have accommodations to support people with special needs. The second similarity is in regards to adequate training and experience for professionals supporting individuals with DD/SMI. Both studies advocate for additional training and experience for professionals from various settings like mental health, medical facilities, and psychiatric facilities. The third similarity is from the need for service to show flexibility from Hemmings and Al-Sheikh (2013) and the primary theme of having access to services or service provision from the current study with the sub-theme of the outpatient model of service delivery. Both of these areas illustrate how the typical nine to five services are not adequate to meet the needs of the DD/SMI population, and how services need to be available after hours to address support needs. A final similarity is in regards to the need for adequate resources for Hemmings and Al-Sheikh (2013) in comparison to the identified barriers to accessing services subtheme of funding and insurance issues within the current research. Both areas identify funding as an issue for
people in accessing services or developing further services that could assist in meeting the needs of the DD/SMI population.

While six other themes remain within the Hemmings and Al-Sheikh (2013) study, the interpretation and definition of those themes are dissimilar to the current research findings interpretation.

**Summary**

The results of the current research have been illustrated within a blended systems-grounded theory frame. From this framework, the primary themes of the study have been expanded and illustrated the community services needs of individuals with DD/SMI in greater depth. While responses from participants were vast in acknowledging many areas relevant to the DD/SMI population, some data from the literature review was missing within the findings. This included such areas as the involvement of families, the need for research based therapeutic approaches, interactions with the criminal justice system, and homelessness. A comparison of findings from the current research and Hemmings and Al-Sheikh (2013) indicates some similarities in findings amongst four areas of the structure of services, need for training of professionals, the need for flexibility within service delivery, and the need for adequate resources. The remainder of the current study’s findings is unique in definition and approach from the previous research by Hemmings and Al-Sheikh (2013).
CHAPTER 6: CONCLUSION

The conclusions will include a more expanded view and application of the study results to the implications for practice, policy, and research. The chapter content will also include the limitations and strengths of the study, the unique knowledge development, the recommendations for future research, and a summary.

Implications

The study findings have several implications to consider in the areas of practice, policy, and research. As the research question pertains to the community service needs of individuals with DD/SMI, these implications can assist in building knowledge to inform practice, policy, and research decisions in the future.

Practice. Study findings indicate several practice implications for the community service needs of individuals with DD/SMI from the perspective of mental health professionals. These implications include six primary areas of 1) having access to a support person, 2) streamlining services to fewer locations, 3) individualizing and customizing services and supports, 4) having a flexible service delivery model, 5) being aware of barriers to services to problem solve and address, and 6) further training to support professionals who interact with the DD/SMI population.

*Having access to a support person* for individuals with DD/SMI was a frequent response from participants across interviews and focus groups in both locations. Participant opinions varied about this being a paid support, such as a case manager or supports coordinator, or a family member or other natural support. Whether the support person is from a formal or informal support, the importance of this finding for practice is the inclusion of a support person for an individual with DD/SMI to assist with several functions. It is recommended an accessible
support person take on several functions including assisting with paperwork to maintain entitlements, coordinating services and supports, monitoring for prevention of psychiatric needs, and assisting with a crisis when it occurs. For an individual with DD/SMI, having access to a support person appeared to be a vital element to being successful in the community. Based on these findings, it is recommended that individuals with DD/SMI have access to a support person to assist them with navigating the community service system and monitoring for psychiatric services as needed.

The second practice implication was to examine the service structure in existence and attempt to \textit{streamline services} when possible. Study findings indicated that individuals with DD/SMI can struggle with maintaining services and supports, and the added expectation of navigating several service structures and locations further compounds their ability to meet this expectation. Some of the participants recommended such services as Community Mental Health Centers, Department of Health and Human Services, and Social Security Administration being located in the same building as a helpful suggestion to meet the needs of the DD/SMI population. This could also assist in bridging the gap between service providers to collaborate and communicate more effectively about the needs of the person with DD/SMI. This finding aligned with Hackerman and colleagues (2006) and Hemmings and Al-Sheikh (2013) who also support the idea of examining the service delivery systems for individuals with DD/SMI and making them more accessible. Previous systems of care research (Erickson, 2012; & Miller et al., 2012) also strongly advocates for collaboration and coordination amongst service providers to better support individuals in the community. The current and previous research emphasizes the need for a change to the community service system structure to better meet the needs of the DD/SMI
population. Therefore, it is recommended for community services to be streamlined into fewer locations to provide better access to individuals with DD/SMI.

The third implication for practice was in regards to the *individualization and customization of services* and supports for individuals with DD/SMI to meet their specific needs in the community. Davis and colleagues (2008) support this recommendation and indicate treatment planning should be individualized and focus on long-term management of both the DD and SMI conditions. The study findings herein indicated that services such as CLS, psychiatric services, employment assistance, and opportunities for social activities were commonly accessed by individuals with DD/SMI. While these identified services provide support for the individual with DD/SMI, it appears that a combination of individualized services and supports were the ideal mix to support the person with DD/SMI to be successful in the community. The individualization process is supported by the use of person centered planning (PCP) at both data collection locations at this time.

An example of individualization and customization would include a person with DD/SMI utilizing CLS supports to develop his skills with art and then building that skill into a profitable business where he can sell his pieces around his community. Another example would be the customization of a job to meet the interests and needs of an individual with DD/SMI. An example provided during the second focus group in Oakland County was the development of a shredding job for an individual with DD/SMI who liked to listen to music and shred paper. This type of individualization and customization helps to meet two functions. First, it provides individuals with DD/SMI the opportunity to be in their community, build social relationships, and earn money doing job tasks that they may enjoy. Second, it provides the community with a real life individual with DD/SMI to challenge the stereotypes that have been presented during the
study through regular daily interactions. The study findings of individualization and
customization of services are further supported by findings from Hemmings and Al-Sheikh
(2013) and recommendations from Martin and colleagues (2005) and Shedlack and Chapman
(2004). Based on these study findings, it is recommended that service providers who support the
DD/SMI population should utilize person centered planning as well as consider a combination of
services and supports.

The fourth implication for practice is to have a *flexible service delivery model* to help
meet the needs of individuals with DD/SMI in the community. Study findings indicated the
outpatient service delivery model has not been effective in meeting the needs of the DD/SMI
population at this time. Participants indicated the structured hours and days of service are too
limited and restricting to assist individuals with DD/SMI to gain access to services in the
community. Hemmings and Al-Sheikh (2013) found similar results within their study which also
recommended greater flexibility in service delivery to meet the needs of the DD/SMI population
in the community.

A frequent example presented was the issue of individuals with DD/SMI not attending
psychiatry or therapy appointments regularly due to their own disability issues. For a person
with DD/SMI having regular contact with a therapist or psychiatrist is vital to maintaining their
living in the community. Without regular monitoring of psychiatric conditions and medication
consultation, individuals with DD/SMI are at increased risk for psychiatric hospitalization and
potentially interactions with the criminal justice system from actions which could be interpreted
as causing harm to themselves or others. Specifically, as psychiatric and therapeutic services
were identified as needed supports, they should adapt their service delivery to better meet the
needs of the DD/SMI population in the community setting. Therapy could potentially be offered
in a variety of formats including as a home based service or over the phone or other telecommunication venues. Also, the therapist or psychiatrist could have sessions via Skype or Facetime with the individual with DD/SMI to visually engage and consult on therapeutic or psychiatric needs and provide medication consultation as needed. Tele-emergency services were presented as a central element of rural systems of care in the literature review by Mueller and colleagues (2014). A system of care for the DD/SMI population could encompass a tele-emergency and tele-communications aspect to consult and provide therapeutic and psychiatric support as needed for individuals with DD/SMI. It is recommended that mental health service providers explore alternative systems of care to provide therapeutic and psychiatric services to the DD/SMI population to better meet their needs and support them to be successful in the community.

The fifth implication for practice was in regards to being aware of common barriers to services and supports for the DD/SMI population and problem solving to address them. Some of the barriers presented in this study included issues with funding, transportation, access to services, and the person with DD/SMI maintaining services and supports. Each of these barriers should be explained and addressed as much as possible when working to support a person with DD/SMI to assist him or her to be successful in the community. While the barriers of funding and transportation are larger macro issues that need to be addressed by county and state officials, the MHP can advocate for these changes on behalf of the DD/SMI population. The barrier of access to services is one that service providers that support the DD/SMI population should consider and evaluate. It is recommended that service providers may want to consider strategies to support the DD/SMI population with making services accessible and taking into account the persons disability specific needs with maintaining services and supports.
The final implication for practice is for increased *training* for all professionals who support individuals with DD/SMI. This training is needed for several reasons. First, is to educate professionals that individuals with DD can also have an MI diagnosis. This was a frequent observation from study participants and needs to be addressed with the community service system to meet the needs of the DD/SMI population. Second, is to provide better access and understanding of the DD/SMI population with mental health therapists and psychiatrists. Many participants indicated that few therapists and psychiatrists knew how to support the DD/SMI population and this was a need area. Finally, further training for professionals would assist with diffusing information about the needs of the DD/SMI population and also aide in making changes to the community service system to meet their needs in the community better.

Study findings from Chan, Hudson, and Vulic (2004), King and colleagues (2009), and Hemmings and Al-Sheikh (2013) also support increased training and education for professionals who support individuals with DD/SMI. Based on the current and previous research findings, it is recommended for mental health and healthcare professionals to receive increased training regarding the psychiatric and community service needs of individuals with DD/SMI.

**Policy.** In examining the community service needs of individuals with DD/SMI from the MHP perspective, four main implications for policy were identified. These four areas included 1) a need for increased funding and resources, 2) increased advocacy to address workforce issues, 3) adaptation of the structure of services, and 4) a review of the eligibility criteria for accessing services.

The first implication for policy is the need for *increased funding* to support the DD/SMI population to be successful in the community. Participants across interviews and focus groups repeatedly noted funding as a barrier to services and supports for individuals with DD/SMI.
Participants at both locations noted the community service systems that typically support the DD/SMI population had sustained heavy cuts in the last fiscal year, and were anticipating further cuts in the future. It was noted that many participants expressed fears about the needs of the DD/SMI population going unmet because of these cuts, as well as the realization that without sufficient funding possible preventive services would not be available to support individuals with DD/SMI who are unstable. This was related to acts of violence that have been televised where the individual who perpetrated the act is usually identified as a person with some level of disability or mental illness. Without adequate funding to support community services, the service providers said they would not be able to meet the needs of individuals with DD/SMI.

As the primary source of funding for community services is through Medicaid, this limits the accessibility of services and supports for individuals with DD/SMI who do not have or are not eligible for Medicaid insurance. For some individuals with DD/SMI the issue may be maintaining their Medicaid insurance to stay connected to services. Participants in both locations indicated that previous to the budget cuts, they were able to support people with DD/SMI who did not have Medicaid within their services. As the budget cuts have been so heavy, neither location is able to support individuals with DD/SMI who do not have Medicaid. Participants even talked about having to cut many people from services who did not have Medicaid insurance. The addition of the Healthy Michigan Plan, may assist with bridging the insurance gap over time, but at present the limited funding options for community services for individuals with DD/SMI is a barrier to them gaining needed services and supports.

Therefore, it is recommended that mental health professionals advocate to the directors of their organizations and to the State government about the impact of funding issues on the DD/SMI population. It is further recommended for community service providers to explore
possible cost effective interventions or programs that could meet the needs of the DD/SMI population. One such example is the intervention of adapted dialectical behavior therapy (DBT) which Brown, Brown, and Dibiaso (2013) utilized in Rhode Island to support individuals with DD/SMI. Brown and colleagues (2013) findings indicated that individuals who participated in their adapted DBT study saved approximately $491,340 per client per year in 2006, in comparison to individuals with DD/SMI who are supported within psychiatric hospitalizations or institutional settings. Therefore, by community service providers examining different therapeutic approaches provided within the research (ie. DBT, assertive community treatment, and cognitive behavioral therapy, etc.) or various systems of care models, they may be able to implement supportive approaches to meet the needs of the DD/SMI population and in relation find more cost effective ways to work within a limited budget and perhaps be able to support individuals without insurance limitations.

A second policy implication to consider is the inherent workforce issues presented by the participants in reference to hiring and maintaining consistent staffing to support individuals with DD/SMI. Without access to staffing supports, individuals with DD/SMI would struggle to maintain their living situations, adequate personal hygiene, and monitoring of psychiatric conditions. The lack of staffing supports could potentially lead to outcomes of individuals with DD/SMI becoming homeless, having interactions with the police or criminal justice systems, or increased psychiatric symptoms or psychiatric hospitalizations. Staffing supports provide a number of key elements that provide monitoring and feedback to the individual and also their team of supports when needed. For example, a person with DD/SMI may have periods of psychiatric instability where the staffing supports are observing the symptoms and provide feedback to their psychiatrist to better inform approaches of treatment in the future. Some of the
workforce issues presented included staffing supports working long hours (ie. up to 35 hours in one example from Oakland County), and also the low rate of pay. Participants indicated the pay rate for staff was typically around minimum wage. With a rate of pay that low, the competition for hiring staff becomes retail and fast food organizations, where the staff person does not have to worry about verbal or physical aggression or performing personal care tasks. To assist in this area, there needs to be increased advocacy for a minimum wage that is reflective of a livable wage to support staff that in turn supports individuals with DD/SMI.

A third policy implication is to adapt the structure of services and supports to meet the needs of the DD/SMI population. Participants indicated that a streamlined service structure would best meet the needs of the DD/SMI population at this time. To meet this need, policy initiatives could be considered to re-structure organizations that support the DD/SMI population into fewer central locations. Potentially having one streamlined service location would be ideal, but also looking at reducing the number to fewer to navigate over time would be helpful. As participants mentioned, having primary services such as Community Mental Health Centers, Department of Health and Human Services, and Social Security Administration in the same building would be ideal to meet the needs of the DD/SMI population. This recommendation is similar to ones from Ervin, Williams, and Merrick (2015) which advocate for treatment integration for mental, behavioral, and primary healthcare systems. According to Ervin, Williams, and Merrick (2015), two noteworthy models of treatment integration in the United States are the Developmental Disabilities Health Center (DDHC) in Colorado and the New Jersey DD Health Home model (p. 102).

The final implication for policy is to review the eligibility criteria for accessing services and supports for individuals with DD/SMI. This issue at present appears to be two-fold in
regards to 1) the accessibility of services, and 2) the program where services are offered for individuals with DD/SMI. The first issue is in regards to individuals with DD/SMI being found eligible for services under the criteria for individuals with developmental disabilities or mental illness. At present, this criterion is set by the Michigan Mental Health Code and implemented by Community Mental Health Centers across the state. As a person with DD/SMI has both a DD and an MI diagnosis, they run the risk of being found ineligible for both programs due to their dual diagnosis, and the occurrence of each program indicating the other program should serve him or her. This was a dynamic presented within the interviews and focus groups as well. It is recommended that the eligibility criteria for community services for individuals with DD/SMI be reviewed and potentially revised to better reflect the clinical presentations and needs of this population in accessing services.

The second issue pertains to where services and supports should be offered for an individual with DD/SMI. Should it be within DD or MI programs? Ervin, Williams, and Merrick (2015) also reported this observation where individuals with DD/SMI are caught between two systems. Study findings would suggest that as this is a dual diagnosis issue, the person with DD/SMI could benefit from services and supports from both programs. Therefore, to meet the needs of the DD/SMI population, it is not necessarily where services are offered (ie. DD or MI programs), but that a combination of services and supports is available to ameliorate the symptomatology of the population, and provide opportunities for a quality life. Based on the current and previous research findings, it is recommended that CMH centers and mental health providers offer a combination of services from both DD and MI structures to meet the needs of the DD/SMI population.
**Research.** The study’s findings indicate three main implications for research in regards to the community service needs of individuals with DD/SMI from the perspective of the MHP. These include 1) research with additional stakeholder groups, 2) research in more geographic locations, and 3) the inclusion of a more stratified sample within data collection.

The first implication for research is the *need for more research with additional stakeholder groups.* The present research utilized a sample of mental health professionals as a first step in developing the base of information with individuals with DD/SMI. To develop a broader conceptualization of the community service needs of the DD/SMI population, research with stakeholder groups should be expanded to include individuals with DD/SMI. It is very important to obtain the perspective of individuals with DD/SMI as they are the primary stakeholder group who receive and are impacted by services and supports. The people with DD/SMI could provide feedback about their community service experiences, as well as recommendations for services and supports that would best meet their specific needs. Other stakeholder groups would include the families and other natural supports of the DD/SMI population, and also possibly mental health professionals from MI programs who support individuals with DD/SMI. Gaining the perspectives of these three stakeholder groups would assist in developing a more comprehensive view of the DD/SMI population and their needs within the community setting which can later contribute to the development of a service structure to meet the needs of the DD/SMI population.

Previous research studies regarding the DD/SMI population have largely relied on quantitative methods of surveys or questionnaires (Hackerman et al., 2006; King et al., 2009; Shedlack & Chapman, 2004) or qualitative methods of secondary reviews of participant files or case studies (Ghafoori, Ratansiripong, & Holladay, 2010; Martin et al., 2005; Oliver et al., 2005;
Sakdalan, Shaw, & Collier, 2010) to build knowledge. To continue increasing the knowledge base for the DD/SMI population, it is recommended that qualitative methods be utilized for future research to provide stakeholder groups with an opportunity to present and elaborate on their experiences through possible methods of interviewing, focus groups, narration, or ethnography. These forms of data collection would continue to build a “rich” knowledge base about the needs of individuals with DD/SMI within the community setting.

The second research implication is in regards to the inclusion of more data collection locations with the research sample. The present study utilized two data collection locations in Lansing and Oakland counties. To be able to generalize data across the DD/SMI population, future research should involve data collection from a variety of geographic locations across the state of Michigan. In relation to policy implications in regards to funding supports with Medicaid, it may be advantageous to also think nationally about geographic locations to support the knowledge base for individuals with DD/SMI across the country. As Medicaid is a federally and state funded joint program, being able to provide data from other states across the country to support the community service needs of the DD/SMI population could assist in gaining future funding and supports. It is recommended that urban, suburban, and rural locations be studied in multiple states in the future and be compared and contrasted in regards to the community service needs and available community services structures for the DD/SMI population. This can help in providing information about existing community service structures, as well as information to inform policy decisions in how to create a community service system that can better meet the needs of the DD/SMI population.

The final implication for research is to include a more stratified sample amongst participants. The present study utilized a purposive sampling method to gain the richest data
possible from mental health professionals. To be able to increase the validity of future research, a more stratified sample of participants could assist with providing more generalizable data about the community services needs of the DD/SMI population. Taking into consideration the previous recommendation of stakeholder groups, the possible strata to consider for inclusion could be people with DD/SMI, the families and other natural supports of people with DD/SMI, and mental health professionals that support individuals with DD/SMI. A sample of participants could be randomly drawn from each of these stakeholder groups (ie. strata) to assist with increasing the validity of future research. Therefore it is recommended that future research samples with the DD/SMI population use stratified or randomized sampling methods when appropriate.

**Limitations & Strengths**

While steps were taken to create and implement a rigorous qualitative study in the current research, limitations are inevitable and need to be recognized. The primary study limitations included sample size, sampling method, participant perspective, and the data collection sites.

The first limitation of this study was the *sample size*. The present study included 24 participants total. This number could be considered small by some researchers, but appears to be somewhat reasonable in comparison to the sample sizes of the previous research noted in the literature review. In examining the sample sizes of the previous research presented for interventions for individuals with DD/SMI the sample sizes ranged drastically from one research study to another. Quantitative studies ranged from sample sizes of six to 130 with Ghafoori, Ratanasiripong and Holladay (2010) having eight participants, Hackerman and colleagues (2006) having 130 participants, Brown and colleagues (2013) having 40 participants, Martin and colleagues (2005) having 20 participants, Oliver and colleagues (2005) having 30 participants,

In comparing and contrasting the present and past research, their a few considerations to note. First, among the previous literature and research, the current sample size is actually pretty moderate in size in looking at the whole of data. While three previous studies had larger sample sizes, the present study had a larger sample than the four other previous studies. The second item to consider is the method of data collection for the previous qualitative research. King and colleagues (2009) utilized the method of chart reviews to collect data, while Shedlack and Chapman (2004) utilized case studies. The present research utilized interviews and focus groups to build knowledge for the DD/SMI population. A final item to note in relation to sample size is that within qualitative research the number of participants is variable as the goal is not to have a certain sample size, but to reach a point of saturation within the data being presented by participants. Creswell (2007) recommends a sample size of 20 to 30 participants within grounded theory research “in order to develop a well-saturated theory” (p. 127-128). The PI believes the research reached a strong level of data saturation after interviewing 15 participants and having two focus groups with another nine participants, for a total of 24.

The second limitation recognized by the researcher is that of the sampling method. A purposive sampling method was utilized for the present research. This was an intentional choice on the part of the researcher to gain the richest data possible from mental health professionals who have had experience in supporting individuals with DD/SMI in the community. To address this limitation the purposive sample was further supported by requiring that participants had a bachelor’s and/or masters in a helping profession and had been working with individuals with
DD for a minimum of five years. As presented previously, the study sample overall had an average of 24 years of experience supporting individuals with DD/ID or DD/SMI in the community.

While the goal of future research would be to utilize a stratified sampling method to increase validity, the present research included several validation strategies to assist with building validity and trustworthiness of the data (Creswell, 2007). Creswell (2007) recommends using at least two validation strategies in qualitative research (p. 209). The present study has utilized four validation strategies within its methods to further reinforce the validity of the research findings. The validation strategies utilized were the triangulation of data sources, an audit trail, interview data to inform the focus group protocols for member checking, and finally incorporating a second objective party to review the focus group data and provide feedback about primary themes. Creswell (2007) further indicates that reliability “can be enhanced if the researcher obtains detailed field notes by employing a good-quality tape recorder and by transcribing the tape,” as well as having multiple coders review and code the data (p. 209). The present research utilized the data collection methods of audio recording each interview and focus group, keeping an audit trail of detailed notes following each interview and focus group session, as well as having a secondary coder to assist with the focus group data. By utilizing multiple methods to build trustworthiness within the study, the researcher believes the data presented by participants can be used towards building a valid and reliable knowledge base for professionals to support the DD/SMI population.

The third limitation noted is in regards to the participant perspective. The present study included the participation of mental health professionals to build knowledge in regards to the community service needs of individuals with DD/SMI. Gathering data from mental health
professionals was a purposeful choice after evaluating the existing research and finding that very limited information has been developed to support individuals with DD/SMI to date. To understand the community service needs of individuals with DD/SMI holistically in the future, research should include expanded stakeholder groups. The primary stakeholder group to research in the future is individuals with DD/SMI themselves. The second group to consider is the families and other natural supports for people with DD/SMI. The final stakeholder group to consider may be mental health professionals from the MI perspective. The incorporation of these other stakeholder groups could help to develop a more comprehensive perspective of what the needs of the DD/SMI population are and help to inform practice and policy in the future.

The final limitation identified is in regards to the limited number of data collection locations. The current study incorporated data collection in two counties in the state of Michigan (ie. Ingham and Oakland). Both counties could be considered geographically urban in comparison to other counties around the state of Michigan. While some differences existed between the two data collection locations, responses were similar and therefore aggregated to represent the whole. While the locations were limited the overall study sample had similar responses across locations, even though site one was older on average and had slightly more years of experience in comparison to site two.

While the number of locations of data collection was small, the choice of counties was purposeful in collecting the richest data to begin to build knowledge and research for individuals with DD/SMI. As stated previously, the agency Community Living Services (CLS) has been supporting individuals with DD/SMI for many years and has a focused mission on helping people they support to live in and be connected to their communities. The inclusion of study participants from this agency was very helpful in identifying the needs of the DD/SMI
population in the community as that is work they have been doing for quite some time. Also, participants from the Ingham county area represented several different areas of practice experience (ie. case managers, therapists, school social work, etc.) which could therefore provide many different perspectives of the needs of individuals with DD/SMI from their work observations. Having a mixture of professionals from the two different counties with a variety of work experience will assist in building knowledge towards the area of DD/SMI in a real life way. Meaning that gaining information from professionals who support and experience the needs of the DD/SMI population on a regular basis can help to inform practice, policy, and future research needs for this group.

Unique Knowledge Development from the Study

In comparison to the previous research presented from chapters one and two, the study findings have a few unique characteristics that are new to the knowledge base for individuals with DD/SMI. The first unique finding is in regards to a person with DD/SMI having access to a support person, whether it is a professional or a family member or other natural support to assist them. The second unique finding was in regards to service delivery and the barriers that exist to accessing services for the DD/SMI population. The third unique finding is in regards to having access to therapy, medical, and psychiatric staff and facilities that are equipped to support a person with DD/SMI. The fourth unique finding is in regards to a person with DD/SMI having access to opportunities for social interaction and engagement within his or her community.

Recommendations

After reviewing the study findings, implications, and limitations, the researcher has identified several recommendations for future research.
The first recommendation is to continue to build the research base for the DD/SMI population by incorporating samples with expanded stakeholder groups. The researcher intends to expand stakeholder input by incorporating research with individuals with DD/SMI, families and other natural supports, and also mental health professionals from the MI perspective. Incorporating expanded stakeholder groups could also assist in building knowledge towards developing a theory to better inform practitioners about how to approach the community service needs of individuals with DD/SMI in the future.

The second recommendation is to expand data sources and increase the number of participants with a goal of utilizing a stratified sampling method to achieve a stronger research design. Building a knowledge base on rigorous research with reliable and valid methods could assist with informing future practice and policy initiatives for the DD/SMI population. This accumulated data could be used in the future to develop DD/SMI service programs within communities. Future research would then include evaluations of the DD/SMI service programs to determine if they were continuing to meet the needs of the DD/SMI population and use the data provided to inform change within the service system as needed.

The third recommendation is to examine more closely the staffing support needs of the DD/SMI population and some of the benefits and challenges that were presented in regards to this area. As stated previously, Community Living Supports (CLS) was the most identified community service need for individuals with DD/SMI. For individuals with DD/SMI they can utilize this service in a few different ways by hiring a provider agency or hiring their own staff through a self-directed or self-determined arrangement. Across interviews and focus groups, especially focus group two, some of the challenges of hiring, training, and maintaining staffing supports were presented. These dynamics appear to have several impacts on the DD/SMI

162
population and would be helpful to examine more closely in building knowledge for this group in the future.

The fourth recommendation is to examine the area of mental health therapy and psychiatric services for individuals with DD/SMI. These were services and supports that participants presented were very important to the success of individuals with DD/SMI in the community. At present, it appears from participant observations that several challenges in relation to therapy and psychiatric services are impacting supports for individuals with DD/SMI. The first was the recognition that a person with DD can have an MI diagnosis. The second was having access to therapists who could support individuals with DD/SMI. The third was having access to psychiatric services, such as psychiatric hospitals, when needed. Many different dynamics in this area were presented by participants during interviews and focus groups. To help understand this area more adequately in relation to the needs of the DD/SMI population, future research with therapists and psychiatric service providers would also be helpful.

The fifth recommendation is to examine the structure and service delivery of services and supports to individuals with DD/SMI. The study findings have indicated that individuals with DD/SMI can struggle with 1) knowing what services are available, 2) how to access services and supports, 3) how to maintain services, and 4) how to navigate multiple complicated service systems. Taking these findings into consideration, the researcher would recommend that community services for individuals with DD/SMI be streamlined as much as possible to assist people with DD/SMI to be successful in the community. At present, the Community Mental Health center in Ingham county has begun to address this initiative by incorporating several services into one building location. These services include psychiatry and medication services,
medical health clinic, access to Department of Health and Human Services representative, and also case management/supports coordination.

The final recommendation is to increase and expand education and training for all professionals who interact with and support individuals with DD/SMI in the community. Study findings indicate that a variety of professionals can struggle with supporting the DD/SMI population with their variable and often intense needs. As such, additional training and education in how to support the DD/SMI population could assist with providing therapeutic strategies and supports to meet the needs of individuals with DD/SMI within the community.

Summary

The purpose of the present study was to examine the community service needs of individuals with DD/SMI in the community from the perspective of mental health professionals. A secondary purpose to this study was to continue to build knowledge to support the DD/SMI population within practice, policy and the research literature. The primary findings of the study have indicated that the community service needs of individuals with DD/SMI include having access to staffing supports and other supportive services, a need for flexibility in service provision, a need for a streamlined structure of services, having access to a support person who knows the DD/SMI person well, acknowledgement of the barriers facing individuals with DD/SMI, and helping professionals and the community to have a better understanding of the needs and supports for individuals with DD/SMI in the community. These study findings have helped to inform implications for practice, policy, and future research to help support the DD/SMI population in the community.
APPENDICES
APPENDIX A: Pre-Screening Questions

Name:__________________________________________________________________

1. What degree(s) do you currently possess (ie. bachelors and/or masters)?
   Bachelors:
   Masters:

2. How long have you worked with individuals with Developmental Disabilities/Intellectual Disabilities and/or Developmental Disabilities/Severe Mental Illness diagnoses?

3. What is the primary disability that you support at your agency? (Please circle one below)
   a. Developmental Disabilities/Intellectual Disabilities
   b. Severe Mental Illness
   c. Developmental Disabilities/Severe Mental Illness

4. Background Data:
   a. Age:
   b. Gender:
   c. Ethnicity:
APPENDIX B: Interview Protocol

Community Service Needs of Individuals with DD/MI Dual-Diagnosis

Introduction and Purpose: This is a research project called “The Community Service Needs of Individuals with DD/MI from the Perspective of the Mental Health Professional.” The purpose of my research is to build knowledge in the area of DD/MI. As Mental Health Professionals (MHP’s) your observations, knowledge, and experience from working in the field with individuals who have DD/MI needs is very important to me and will contribute to my research.

What to Expect: Today’s meeting is a research interview. This means I will ask you some questions and ask you to think and respond to them as you see fit. Your participation is entirely voluntary and you may choose to answer, or not answer, any or all questions.

Question 1: Can you tell me about the work that you do?

Question 2: What do you see going on in your community?

- Probe: What do you see going on in the community for individuals with DD/MI?

Question 3: What do you believe would make the lives of individuals with DD/MI better?

Question 4: What did it look like when a case with a DD/MI individual went well?

- Probe: What treatment approaches were used?
- Probe: What services were utilized?
- Probe: Can you give an example of that?

Question 5: Can you tell me what you see as the needs of people with DD/MI?

- Probe: Can you give an example of that?
- Probe: What else? Other ideas?

Question 6: What kind of natural supports do you see individuals with DD/MI utilizing?

- Probe: When do you observe DD/MI individuals seeking natural supports?
- Probe: Can you give an example from your work?

Question 7: If you had a magic wand, what would it look like to build a community service system for individuals with DD/MI?

- Probe: Can you give an example of that?
- Probe: What else? Other ideas?
- Probe: What gaps are there in current services to achieving your vision/dream?
Question 8: Can you tell me what you have observed to be the barriers to accessing DD/MI services for the people you support with DD/MI?

- Probe: What was it a barrier to?
- Probe: What made it important?
- Probe: Can you give an example of that?
- Probe: What else? Other ideas?

Transition: You have offered me a great deal of your observations, knowledge, and experience on many different areas that impact individuals with DD/MI. In closing, can you take a minute to consider any other information that I may not have asked about that could be important to my research. (Give 30 - 60 seconds for participants to consider)

Question 9: What else is important for me to know in researching the community service needs of individuals with DD/MI?

- Probe: Can you give an example of that?
- Probe: What else? Other ideas?

Closing: Thank you for sharing your ideas and suggestions today. Please remember to take your consent paper with you.
APPENDIX C: Focus Group Protocol

Community Service Needs of Individuals with DD/MI Dual-Diagnosis

Introduction and Purpose: This is a research project called “The Community Service Needs of Individuals with DD/MI from the Perspective of the Mental Health Professional.” The purpose of my research is to build knowledge in the area of DD/MI. As Mental Health Professionals (MHP’s) your observations, knowledge, and experience from working in the field with individuals who have DD/MI needs is very important to me and will contribute to my research.

What to Expect: Today’s meeting is focus group. This means I will ask you some questions and ask you to think and respond to them as you see fit. Your participation is entirely voluntary and you may choose to answer, or not answer, any or all questions.

Question 1: Can you tell me about the work that you each do?

Question 2: Can you take a few moments and think about what you see as the primary community service needs for people with DD/MI and write them down?

- Activity – participants will be given 2-3 minutes to write their thoughts down on a piece of paper. This will give them a frame of reference and also will turn it in at end of focus group for triangulation of information.

Question 3: Can you tell me about the community service needs you identified?

- Activity – researcher will write the items on a marker board for reference and discussion.

Question 4: If you had a magic wand and could create a community service system for individuals with DD/MI, what would it look like?

Question 5: What gaps do you see in the current service system to achieving your vision?

Question 6: What do you see as the barriers for people with DD/MI to accessing services and supports?

Question 7: Can you share your thoughts with me regarding the psychiatric needs of people with DD/MI?

- Probe: Importance of differential diagnosis?
- Probe: Emergency/crisis planning?
- Probe: Psychiatry services?
- Probe: Medication monitoring and review?
**Question 8:** In closing, can you think of any other information that may be important to my research that I may not have asked you about?

**Closing:** Thank you for sharing your ideas and suggestions today. Please remember to take your consent paper with you.
APPENDIX D: Informed Consent Process - Interviews

**Researcher:** Trisha M. Thrush, doctoral student at Michigan State University with the Social Work Department.

**Research Title:** The community service needs of individuals with dual diagnoses of developmental disabilities (DD) and mental illness (MI) from the perspective of the mental health professional.

**Explanation of Research:** Currently the population of DD/MI individuals is under-represented in the research literature. The majority of dual diagnosis research has been in regards to individuals with a mental illness (MI) and substance abuse (SA). The current literature available in regards to the DD/MI population is quite narrow in focus. The research literature available does illustrate the DD/MI population as being largely disproportionate in the prison system, over utilizing psychiatric facilities, and being the most expensive to serve in the community service system. These factors point to a lack of effective services available in the community system to adequately meet the population’s needs.

**Purpose of the Research:** The purpose of this research study is to conduct a needs assessment to determine the community service needs of individuals with DD/MI from the perspective of the mental health professional. Professionals interact with the DD/MI individuals on a daily/weekly/monthly basis and have observations, experience, and knowledge about the individual’s needs and the community service systems they interact with on a regular basis. You as a professional will be a valuable asset in offering this information towards my research.

**Duration of Participation:** The research participant will participate in a semi-structured interview, lasting approximately 45-60 minutes in length.

**Procedures:** The session will be audiotaped. The session will begin with the researcher reviewing the informed consent with the participant and gaining signatures of consent. The signed copy will be kept with the researcher, and a copy of the form will be given to each participant. Next, each participant will be assigned a Personal Identification Number (PIN) to assist with confidentiality during the interview and transcription process. The researcher will offer a formal introduction of herself, and outline the participation process of the interview. The researcher will then begin the interview by providing a review of what has been covered, the purpose of the study, and begin asking the questions outlined in the interview research protocol. At the end of the interview, the researcher will engage in member checking to determine if observation notes accumulated during the interview are accurate and reflective of the participant’s statements, and ask for any further feedback. Following the member checking process, the researcher will reiterate the contact information in the informed consent form in case of any further questions, comments, or concerns by the participant.

**Foreseeable Risks or Discomforts to the Participant:** This study will ask you to offer your observations, knowledge, and experience on the topic of individuals with DD/MI. While the interview questions ask for the participant’s opinion/perspective, certain questions could create an uncomfortable response from individual participants based on their previous experience and
observations in supporting individuals with DD/MI in the community. There is also the risk of breach of confidentiality in any research study. As the researcher I am taking several precautions to safeguard your confidentiality as a research participant by assigning a numerical code instead of using names, eliminating identifying information from the transcribed data, and storing all raw and electronic data in a locked space with limited access.

Benefits to the Participant: Your participation in this study will assist the researcher in accumulating needs assessment data on the DD/MI population. The researchers’ long-term research goals are to continue research with this population to develop services and programs that are customized, responsive, and empowering for the DD/MI population; as well as contributing to the knowledge base of this area to support mental health professionals in their work.

Confidentiality of Records: During the informed consent of the research process, each participant will be assigned a Personal Identification Number (PIN) to assist with confidentiality. The researcher will be audiotaping the interview so all your comments and ideas will be captured. However, if anyone says anything that might identify her or him during the interview; the researcher will delete that content from the transcriptions of the audiotapes. Thus your ideas will be gathered - but no one will know what YOU said specifically. The audiotapes will be stored in a locked file cabinet of the researcher, located at 4427 Helmsway Drive, Lansing, MI 48911, phone contact 517-490-1508, or email rubinght@msu.edu. After five years (or sooner), they will be destroyed. The transcriptions of the audiotapes will also be kept locked up and will be restricted to access by Dr. Riebschleger, myself, and the MSU IRB. In summarizing the community service needs, I will put together interview content from across 10-20 interviews and 2-3 focus groups; the data will be combined as a whole. This makes it even harder for someone to identify what was said by a specific person.

Who to contact for answers to questions about research and research subjects’ rights: For any questions related to the research study, contact the researcher Trisha Thrush (517-490-1508; rubinght@msu.edu). For questions related to research subject’s rights, contact the Michigan State University Institutional Review Board (IRB) located at 408 W. Circle Drive, Room 207 Olds Hall (517-355-2180; irb@msu.edu).

Compensation for Participation: Each participant will be given a $10 gift card as compensation for their participation in the research study. The gift card will be provided at the end of the interview process. If the participant chooses to discontinue participation in the study at any time, they will still be provided with a gift card at the time of discontinuation.

Voluntary Participation: Your participation in this research study is voluntary. You may discontinue participation at any time if you feel it is necessary without any penalty or loss of benefits. Refusal to participate will involve no penalty or loss of benefits to which the participant is otherwise entitled.

Number of Participants Involved in the Study: This research is a qualitative research study. The researcher will be targeting a total of 25-35 subjects for participation between interviews and focus groups.
If you agree to participate in this research study, please sign below.

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<th>Name (Printed)</th>
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| Name (Signature) |
APPENDIX E: Informed Consent Process – Focus Groups

Researcher: Trisha M. Thrush, Doctoral student at Michigan State University with the Social Work Department.

Research Title: The community service needs of individuals with dual diagnoses of developmental disabilities (DD) and mental illness (MI) from the perspective of the mental health professional.

Explanation of Research: Currently the population of DD/MI individuals is under-represented in the research literature. The majority of dual diagnosis research has been in regards to individuals with a mental illness (MI) and substance abuse (SA). The current literature available in regards to the DD/MI population is quite narrow in focus. The research literature available does illustrate the DD/MI population as being largely disproportionate in the prison system, over utilizing psychiatric facilities, and being the most expensive to serve in the community service system. These factors point to a lack of effective services available in the community system to adequately meet the population’s needs.

Purpose of the Research: The purpose of this research study is to conduct a needs assessment to determine the community service needs of individuals with DD/MI from the perspective of the mental health professional. Professionals interact with the DD/MI individuals on a daily/weekly/monthly basis and have observations, experience, and knowledge about the individuals needs and the community service systems they interact with on a regular basis. You as a professional will be a valuable asset in offering this information towards my research.

Duration of Participation: The research participant will participate in a focus group, lasting approximately 90-120 minutes in length.

Procedures: The session will be audiotaped. The session will begin with the researcher reviewing the informed consent with the participants and gaining signatures of consent. The signed copy will be kept with the researcher, and a copy of the form will be given to each participant. Next, each participant will be assigned a Personal Identification Number (PIN) to assist with confidentiality during the focus group and transcription process. The researcher will offer a formal introduction of herself, and outline the participation process of the focus group. The participation process will include the following; 1) one individual speaking at a time, 2) everyone is encouraged to share their thoughts/comments on each question, 3) participants may have different view-points, but to remain respectful of each group member. The researcher will then begin the focus group by providing a review of what has been covered, the purpose of the study, and begin asking the questions outlined in the research protocol. At the end of the focus group, the researcher will engage in member checking to determine if observation notes accumulated during the focus group are accurate and reflective of the groups discussion, and ask for any further feedback. Following the member checking process, the researcher will reiterate the contact information in the informed consent form in case of any further questions, comments, or concerns by the participants. The researcher will also reiterate the importance of confidentiality in the focus group process with the participants and request that the information presented by kept and or maintained as confidential.
**Foreseeable Risks or Discomforts to the Participant:** This study will ask you to offer your observations, knowledge, and experience on the topic of individuals with DD/MI. Some participants may express different viewpoints during the focus group that are similar or contradictory to yours. Contradictory views can impact participants differently, and could create feelings of stress or anxiety during the group process. Also, as this is a focus group, there is the risk of breach of confidentiality as participants may talk about the discussion from the study outside of the research setting. Depending on the topics and perspectives shared, the information presented by individual participants could be shared outside of the research study.

**Benefits to the Participant:** Your participation in this study will assist the researcher in accumulating needs assessment data on the DD/MI population. The researchers’ long-term research goals are to continue research with this population to develop services and programs that are customized, responsive, and empowering for the DD/MI population; as well as contributing to the knowledge base of this area to support mental health professionals in their work.

**Confidentiality of Records:** During the informed consent of the research process, each participant will be assigned a Personal Identification Number (PIN) to assist with confidentiality. The researcher will be audiotaping the focus group so all your comments and ideas will be captured. However, if anyone in the group says anything that might identify her or him during the focus group; the researcher will delete that content from the transcriptions of the audiotapes. Thus your ideas will be gathered - but no one will know what YOU said specifically. The audiotapes will be stored in a locked file cabinet of the researcher, located at 4427 Helmsway Drive, Lansing, MI 48911, phone contact 517-490-1508, or email rubinght@msu.edu. After five years (or sooner), they will be destroyed. The transcriptions of the audiotapes will also be kept locked up and will be restricted to access by Dr. Riebschleger, myself, and the MSU IRB. In summarizing the community service needs, I will put together content from across 10-20 interviews and 2-3 focus groups; the data will be combined as a whole. This makes it even harder for someone to identify what was said by a specific person.

**Who to contact for answers to questions about research and research subjects’ rights:** For any questions related to the research study, contact the researcher Trisha Thrush (517-490-1508; rubinght@msu.edu). For questions related to research subject’s rights, contact the Michigan State University Institutional Review Board (IRB) located at 408 W. Circle Drive, Room 207 Olds Hall (517-355-2180; irb@msu.edu).

**Compensation for Participation:** Each participant will be given a $10 gift card as compensation for their participation in the research study. The gift card will be provided at the end of the focus group process. If the participant chooses to discontinue participation in the study at any time, they will still be provided with a gift card at the time of discontinuation.

**Voluntary Participation:** Your participation in this research study is voluntary. You may discontinue participation at any time if you feel it is necessary without any penalty or loss of benefits. Refusal to participate will involve no penalty or loss of benefits to which the participant is otherwise entitled.
**Number of Participants Involved in the Study:** This research is a qualitative research study. The researcher will be targeting a total of 25-35 subjects for participation between interviews and focus groups.

*If you agree to participate in this research study, please sign below.*

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<th>Name (Printed)</th>
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<th>Name (Signature)</th>
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## APPENDIX F

Table 5: Literature Search Results for Practice Modalities for DD/ID, SMI and DD/SMI Populations

<table>
<thead>
<tr>
<th>Date of Search</th>
<th>Source</th>
<th>Key Terms Searched</th>
<th>Program/Intervention</th>
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<tbody>
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<tr>
<td>6)</td>
<td>Relationship Base Care</td>
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<td>7)</td>
<td>Acceptance and Commitment Therapy</td>
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<td>8)</td>
<td>Adolescent Coping with Depression</td>
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<td>9)</td>
<td>Cognitive Behavioral Social Skills Training</td>
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<td>10)</td>
<td>Critical Time Intervention</td>
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<td>11)</td>
<td>Double Trouble in Recovery</td>
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<tr>
<td>12)</td>
<td>ICCD Clubhouse Model</td>
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<td></td>
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<tr>
<td>13)</td>
<td>Modified Therapeutic Community for Persons with Co-Occurring Disorders</td>
<td></td>
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<tr>
<td>14)</td>
<td>Multisystemic Therapy with Psychiatric Supports</td>
<td></td>
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<tr>
<td>15)</td>
<td>Partners in Care, Pathways Housing First Program</td>
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<tr>
<td>16)</td>
<td>Psychoeducational Multifamily Groups</td>
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<td>17)</td>
<td>Teen Screen</td>
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<td>18)</td>
<td>Interpersonal Psychotherapy for Adolescents</td>
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<td>19)</td>
<td>Wellness Recovery Action Plan</td>
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<td>20)</td>
<td>Dialectical Behavior Therapy</td>
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<td>21)</td>
<td>Compeer Model</td>
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<td>22)</td>
<td>Double Trouble in Recovery</td>
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<td>23)</td>
<td>HOMEBUILDERS</td>
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<td>24)</td>
<td>Life Goals Collaborative Care (LGCC)</td>
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<td>(*30 interventions listed – 29 in regards to SMI/SA approaches)</td>
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<tr>
<td></td>
<td>- co-occurring disorders</td>
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<td></td>
<td>- dual diagnosis - developmental disability - intellectual disability - cognitive impairment - mental retardation</td>
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<td></td>
<td>evidence based practice</td>
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<tr>
<td>*Website does not have categories for DD or ID. Has categories for “autism and related disorders,” “traumatic brain injury” and “dual diagnosis: SA and SMI”</td>
<td>1) Supported Employment 2) Family to Family (support group) 3) Peer to Peer (support group) 4) Assertive Community Treatment 5) Cognitive Behavioral therapy *Support for integrated treatment of dually diagnosed disorders (i.e. SMI/SA)</td>
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<td>Date</td>
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<td></td>
<td>- Developmental disabilities - Co-occurring - Co-occurring intellectual disability - Interventions for intellectual disabilities</td>
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<td></td>
<td>- Dual diagnosis programs - Depression and intellectual disability - ADHD</td>
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| 1) Early Start Denver Model (ESDM) for children |
| 2) Treatment for Adolescents with Depression Study (TADS) – CBT |
| 3) Treatment for Adolescents Suicide Attempters Study (TASA) – CBT Suicide Prevention |

| 4) TEAMcare – Case managed care for depressed patients with medical conditions |
| 5) Family Focused Therapy – children (12-17) with Bipolar Disorder |
| 6) System Training for Emotional Predictability and Problem Solving (STEPBS) – Borderline Personality Disorder |
| 7) Systematic Treatment Enhancement for Bipolar Disorder (STEP-BD) |

*Note: Most recent search shows “Autism Spectrum Disorder” has been added as a category of “Health Topics” on home page.*
Table 5 (cont’d)

<table>
<thead>
<tr>
<th>Date</th>
<th>Organization</th>
<th>-dual diagnosis</th>
<th>1) Medication Therapy *150 results (149 regarding SMI/SA, and some SMI/chronic medical conditions.</th>
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<tbody>
<tr>
<td></td>
<td></td>
<td>-intellectual disability</td>
<td>3) Social Skills Training</td>
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<td></td>
<td>-co-occurring</td>
<td>4) Healthy Lifestyles Curriculum</td>
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<td>5) Family Psychoeducational Therapy</td>
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<td>6) Parent Training</td>
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<td></td>
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<td></td>
<td>7) Cognitive Behavioral Therapy (intervention in multiple studies)</td>
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<td></td>
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<td>8) Behavioral Theory – Milieu Communication Teaching</td>
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<td>9) Parent Management Training</td>
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<td>10) Responsive Caregiving</td>
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<td></td>
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<td>11) Cognitive enhancement Therapy</td>
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<td></td>
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<td></td>
<td>12) Behavioral – Early Social Interaction Project</td>
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<td></td>
<td>13) Multi-media Social Skills Training</td>
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<td>14) Intensive Behavioral Therapy</td>
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<td></td>
<td>15) Problem Solving Therapy</td>
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<td>16) Healthy Lifestyles Curriculum</td>
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<td>17) DBT Skills Group</td>
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<td>18) Parent Supported Behavioral Interventions</td>
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Table 5 (cont’d)

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<tr>
<th><strong>Interventions for SMI/SA population</strong></th>
<th>-developmental disabilities/developmental delays</th>
<th><strong>Note:</strong> Most recent search shows the following categories with subsequent number of research studies for DD/ID diagnoses:</th>
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<tbody>
<tr>
<td>19) Social Skills Training</td>
<td> </td>
<td>- Asperger’s Syndrome (64)</td>
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<tr>
<td>20) Cognitive Enhancement Therapy</td>
<td> </td>
<td>- Autistic Disorder (579)</td>
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<tr>
<td>21) CBT</td>
<td> </td>
<td>- Intellectual disability (410)</td>
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<tr>
<td>22) Resistance Training Program</td>
<td> </td>
<td>- Learning Disorders (34)</td>
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<td> </td>
<td> </td>
<td>- Mild Cognitive Impairment (412)</td>
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<tr>
<td><strong>Additional research on programs identified for ID/SMI in literature.</strong></td>
<td> </td>
<td><strong>Assertive Community Treatment</strong></td>
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<td> </td>
<td><strong>ACT</strong></td>
<td>2) Cosden, Ellens, Schnell, Yamini-Diouf (2005)</td>
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<td>-ACT: MI/DD</td>
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<td>-ACT: ID</td>
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<td>-ACT: MI</td>
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<td>-DBT: DD</td>
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<tr>
<td>-Modified Therapeutic Community (MTC)</td>
<td>-MTC: MI/ID</td>
<td>4) Oliver, Piachaud, Tyrer, Regan, Dack, Alexander, Bakala, Cooray, Done, &amp; Rao (2005)</td>
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<tr>
<td>-MTC: MI/DD</td>
<td>-MTC: MI</td>
<td>5) Tschopp, Berven, &amp; Chan (2011)</td>
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<td>-MTC: DD</td>
<td>-</td>
<td>7) Gold, Meisler, Santos, Carnemolla, Williams, &amp; Keleher (2006)</td>
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<tr>
<td>-Johns Hopkins Special Needs Clinic</td>
<td>8) Kortrijk, Mulder, Roosenschoon, &amp; Wiersma (2010)</td>
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<tr>
<td>-Psychoeducational Groups (PG)</td>
<td>-PG: ID/MI</td>
<td>12) Salyers, Rollins, Clendenning, McGuire, &amp; Kim (2011)</td>
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<td>-PG: DD/MI</td>
<td>-PG: ID</td>
<td></td>
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<tr>
<td>-PG: MI</td>
<td>-PG: DD</td>
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<tr>
<td>1) Urbano-Blackford &amp; Love (2011)</td>
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<tr>
<td>2) Sakdalan, Shaw, &amp; Collier (2010)</td>
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<td>3) Lew, Matta, Tripp-Tebo, &amp; Watts (2006)</td>
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<td>4) Brown, Brown, &amp; Dibiasio (2013)</td>
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<td>5) Baillie &amp; Slater (2014)</td>
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<td>Modified Therapeutic Community</td>
<td>Johns Hopkins Special Needs Clinic</td>
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REFERENCES
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illness benefit from evidence-based supported employment. *Psychiatric Services*, 58(11), 1412-1420. doi: http://dx.doi.org.proxy1.cl.msu.edu/10.1176/appi.ps.58.11.1412


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