IMPROVING OUTCOMES FOR SPECIAL NEEDS CHILDREN AND THEIR FAMILIES

by

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Abstract

Families with special needs children and youth face barriers to accessing services and need assistance to obtain supports to live the most optimal life possible. Social workers can assist families to navigate an unfamiliar world of services to improve the outcomes for children, youth, and their families. To fulfill the requirements of this practicum I explored the needs of special needs children and their families and the best way to provide services to this population through making connections to the literature, practicum placement, and social work practice. This report includes: A description of the practicum agency, learning goals, and theoretical orientation; a review of the literature, my practicum activities, and learning experiences; and a discussion of implications for practice. I conclude that special needs children and their families require formal and informal services and supports to live the most optimal life possible.

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Dedication

Ryan and Dylan: The reason I began this journey and developed into the person I have become. You are my teachers and my inspiration. You are and will always be my heart. I love you my sons.

Chapter One: Description of Agency, Learning Goals, and Theoretical Orientation

In this chapter, I describe the Children and Youth with Special Needs (CYSN) unit, my practicum objectives (including learning goals), the learning environment, target population, and service provision. I follow this by providing my theoretical orientation and I discuss this orientation in relation to the practicum placement. The purpose of this chapter is to provide an overview of the placement, the questions that guided my learning in the placement, and the theory used in my report and practice.

Practicum Learning Environment

I completed my practicum with the CYSN unit in Kelowna, British Columbia. This division is under the umbrella of the Ministry of Children and Family Development (MCFD). MCFD provides services for children and youth and support for their families (Province of British Columbia, 2011). Other divisions of MCFD include child and youth mental health, youth justice, early childhood development, adoptions, foster care, alternatives to foster care, and child protection (Province of British Columbia, 2011).

The office is staffed with workers holding bachelor's degrees. Two have degrees in social work (in addition to other degrees) and one has a Bachelor of Arts. A social worker with an MSW provided supervision throughout the practicum.

My practicum supervisor, Susan VanGasbeck (MSW), is the Concurrent Planning Worker for the Foster and Alternate Care Planning Team. In her position, she finds foster homes that could lead to adoption placements if the child does not return home. Susan worked with persons with disabilities in her prior employment including five years as a CYSN social worker. Her background and understanding of persons with a disability and special needs services enriched our discussions and was an asset to my learning throughout my practicum.

Target Population and Service Provision

The CYSN unit receives referrals, assesses families, and determines eligibility for support services. Children and youth require a diagnosis of a developmental disability, a diagnosis of autism spectrum disorder, or eligibility for the At Home Program to access CYSN services. Services are available to children and youth under 19 and their families. Although eligibility may be established, services are dependent on the entry route of the client, the funding available, and the needs of the family.

CYSN social workers make referrals for the At Home Program, respite, and autism funding. The At Home Program covers the cost of medical supplies and equipment (in addition to other related needs). Respite funding is used to provide parents with a break from their special needs child or youth. Autism funding is used to assist children and youth to develop social-emotional, communication, life skills, and pre-academic/academic skills.

Social workers also refer families to globally funded and community programs. Globally funded programs are contracted by MCFD to provide an array of services to meet the needs of families. These can include supported child development, nursing support, behavioral intervention, and behavioral consultation among others. Common referrals to community programs include recreational activities for children and youth with special needs. These are provided by various agencies in Kelowna.

Practicum Objectives

I chose to complete my practicum at CYSN out of personal and professional interest. My personal interest is that I have family members with a disability. My professional interest came from wanting to better understand the services available through MCFD via

CYSN, and the agencies and organizations involved with persons with disabilities in the larger Kelowna community. I also wanted to improve and develop my clinical and community development skills in working with this population.

The practicum involved 560 hours at the CYSN unit. The practicum was guided by several questions: What services are available to children, youth, and their families within the practicum placement and community? What are the needs of families with children and youth with special needs and how can social workers help parents best meet these needs? What skills and approaches are best suited to working with this population? What are the unique needs, issues and situations of Aboriginal children with disabilities and their families? How will the practicum affect my professional development?

Theoretical Orientation

A theory is necessary for good practice. Practitioners need theories that are "scientifically constructed" rather than "personally constructed" (Mullaly, 2007, p. 205). Not having a specific theory leaves practice open to dominant social beliefs which support "blam[ing] the victim" (Fook, 1993, p.10). As such, my theoretical orientation is structural social work theory.

I have chosen this orientation as it fits with my personal and professional views and beliefs. As a woman of Syilx (Okanagan Aboriginal) and Scottish descent it resonates with me as I am aware that my location affects my world view. I strive to be aware of oppression as a professional so that I do not perpetuate it in my practice. I also apply a critical lens and try to remain cognizant of the social structures that affect peoples' lives when working with my clients in order to improve my practice and, hopefully, the lives of others.

Structural social work has a basis in critical theory. Critical theory is "critical of existing social and political institutions and practices" (Leonard, 1990 as cited in Mullaly, 2007, p. 215) and has both political and practical intent (Mullally, 2007). Leonard (1990 as cited in Mullaly, 2007) argues that it is the intent of critical theory that separates it from others:

> ...the criticisms it levels are not intended simply to show how present society is unjust, only to leave everything as it is. A critical theory of society is understood by its advocates as playing a crucial role in changing society. In this, the link between social theory and political practice is perhaps the defining characteristic of critical theory… (p. 215).

Critical theory informs feminism and anti-oppressive social work among others. Some of the characteristics of structural social work are common to other forms of social work, but the overall goals of understanding the role of structures in social issues and seeking social change, are hallmarks of critical and related progressive theories. Structural social work links larger social structures to personal and societal problems (Mullaly, 2007). Social problems are, therefore, seen to be caused by oppressive social structures rather than the inadequacies of individuals or groups (Mullaly, 2007). Individual problems and social issues are constantly linked to social structures in order to: 1) make people aware of their oppression and the oppression of others, 2) avoid blaming oppressed people for their oppression, 3) make people aware of their oppression so they can work to be liberated from it and, 4) make people aware of oppressive social structures so they can work to change them (Mullaly, 2007).

Fook (1993) argues that the profession cannot improve without a fundamental shift in understanding of the causes of clients' problems. Similarly, Mullaly (2007) argues that lasting change has to be made through changing social structures not changing people. He states: “even if it were possible to change everyone presently harmed by our social structures, the source...would still be there to harm, oppress, and alienate more people along the lines of class gender, race and so on” (p. 245). Structural social work seeks to challenge oppression, has goals for change, and recognizes the social control function of social work. It also provides a critical analysis of disability, age, gender, class, race, and sexual orientation in relation to social work practice (Fook, 1993).

Social work serves both the purposes of social change and social control (Carniol, 2000). By virtue of being a professional, one is put in a position of power over others regardless of their personal intent (Shebib, 2003). The focus of structural social work is recognizing and challenging oppression as well as helping ameliorate the effects of oppression on individuals and families (Mullaly, 2007). Bishop (2002) believes that recognizing our position in society and being aware of the oppressive parts of ourselves is imperative to anti-oppressive practice. “I do not believe anyone raised in Western society can ever claim to have finished ridding themselves completely of their oppressive attitudes. It is an ongoing task, like keeping the dishes clean.” (Bishop, 2002, p. 114) Being aware of our roles as oppressed and oppressor help us to recognize it and avoid oppressing others (Bishop, 2002). This is particularly important in progressive social work as the goal is to work “alongside” (Ife, 1997, p. 181) disadvantaged groups to assist them to have their collective voice heard (Ife, 1997). To do otherwise would be using disadvantaged groups for one’s own objectives, which would be oppressing them further (Ife, 1997).

Theoretical Link to Practicum Placement

The CYSN office I completed my practicum in does not subscribe to a particular theory, however, the CYSN Framework for Action (Province of British Columbia, 2011) accounts for several of the values important to structural social work. The framework is set up to work on individual, community, regional, and provincial levels and includes education, health, and social services. Its purpose is to improve service and coordinate a continuum of accessible services for children and youth with special needs and their families. As a goal of structural social work is to work at micro, mezzo, and macro levels, and ultimately, to work with people to assist them to improve their lives, structural social work fits well for the practicum placement.

Chapter Two: Review of the Literature on Support for Special Needs Children and Their Families

Chapter two reviews the literature, the themes and implications of the literature, and provides a connection to practice. The requirements of special needs children and their families are diverse but themes in the literature also indicate commonalities among this population. These include: information and intervention at the time of diagnosis, services to meet parents' needs, the financial position of the family, and the gender of the caregiver. The need for formal and informal supports was present in all of the themes. Other considerations for working with this population are cultural considerations and parent experiences. The themes will be explored and discussed in the context of structural social work theory throughout this chapter.

Themes from the Literature

Information and Intervention at the Time of Diagnosis

Going through the process of obtaining and coming to terms with a diagnosis can be a difficult one for families (Taanila, Syrjala, Kokkonen, & Jarvelin, 2002). A child's disability may be apparent at birth or parents may have a feeling something is wrong but may not receive a diagnosis for years (Taanila et al., 2002). Some families can adjust to a diagnosis quite quickly while others may never fully adjust (Taanila et al., 2002).

Studies found that the way parents were told about their child's disability, and the information given at the time and within the first few days after the diagnosis, affected how parents felt about their child's disability and the ability of the child and family to cope and function (Taanila et al., 2002). Parents given an initial diagnosis in a supportive, realistic but optimistic way were able to internalize the diagnosis better and adopted a realistic but optimistic attitude about their child's disability (Taanila et al., 2002).

Not receiving a diagnosis in a supportive way and not receiving adequate information, advice, and services leaves parents feeling hopeless and helpless and contributes to stress and isolation (Taanila et al., 2002). Taanila et al. further found that parents' outlook affected how they felt about their child's diagnosis, their ability to relate with the child, and their ideas about their child's future and the future outcome for the family. Parents who were supported through the process and given tools to manage and adapt to their situations had positive outcomes and developed positive coping strategies; parents that were not supported had a negative outlook and developed negative coping strategies (Taanila et al., 2002).

Taanila et al. (2002) advocate for the professional to connect with parents as a human being first and a professional second. As such, it is recommended that doctors take training to learn how to properly disclose information and that doctors and hospital staff (nurses and hospital social workers) have training in counseling skills. Taanila et al. suggest that social workers and other professionals help families by ensuring that they have access to supports immediately after disclosure. This may include a series of meetings with all professionals and service providers involved to enable parents to discuss questions and concerns with the key people involved so they can receive all of the information in one place. These sessions would include not only discussion of the child's disability but how other family members are doing and how the family is coping in general. This would continue until all felt that the parents had the information they needed and could continue on their own. While this approach would seem costly, it is argued that this initial investment in the family would prevent problems and expenses later and would increase the wellbeing of the family (Taanila et al., 2002).

Taanila et al. (2002) acknowledge that professionals could initially shape parents' feelings about their child's diagnosis but the authors also took into consideration the overall outlook of parents. It was found that parents in the high coping group actively sought information, were optimistic about the future of their family, and felt that there were enough services to meet their child's needs throughout their life. The families had better communication between all members, a better relationship reported between the spouses (the mother felt supported and there was an equal division of childcare and household chores), and extensive formal and informal supports (Taanila et al., 2002).

In contrast, members of the low coping group did not seek information and did not feel that there were sufficient services to meet their child's needs throughout their life (Taanila et al., 2002). They reported a lack of communication between family members and a strained relationship between the parents (the mother did not feel supported and did not have help with childcare and household chores) (Taanila et al., 2002). Parents in the low coping group had very few formal supports and few or no informal supports (Taanila et al., 2002).

It was found that both high and low coping families experienced stress and difficulties but that families in the high coping group were able to deal with and solve issues more effectively (Taanila et al., 2002). It was also found that families with children that were diagnosed earlier did better than families with children diagnosed later (Taanila et al., 2002).

The socioeconomic status of the families was not stated in the study (Taanila et al., 2002). While the importance of early and frequent intervention by professionals can assist families to adjust and adapt to a diagnosis, the socioeconomic status of the families could provide information about the other barriers they may face. Support amongst family members may not be directly related to class but the need for both parents to work, income, if they had other children, or other children with disabilities, would all be factors in the amount of time the family had to manage the demands of their child's disability and their overall lives. (The barriers of class and gender in relation to disability will be explored further in the next sections.) The differences between the supports available in Canada and Finland would also need to be taken into account as the study (Taanila et al., 2002) was conducted in Finland.

Additionally, there is ample research about the importance of early diagnosis and intervention. It is possible that early detection and intervention could relieve the frustration of not having a diagnosis, as was described by Taanila et al. (2002). It is also possible, however, that early detection and intervention could increase the child's progress, which may, in turn, lead parents to feel more optimistic about their child's development and future.

Taanila et al. (2002) make recommendations that are structural in nature. Sensitivity in the initial interaction and meetings involving professionals to give them answers to their specific situation puts parents in control and empowers them to advocate for their child and seek services that will meet their families' needs. Taking all family members' needs into account is respectful. Giving families access to formal and informal supports could increase their skills and improve relationships between family members increasing their ability to cope and function in general and improving their lives in the long run.

From a structural view, the outlook of parents could be reflective of the realities of their lives and situations. Parents in an environment where there are few formal services, or lack of funding to access them, or a lack of informal networks to meet their families' needs could have a bleak outlook of their family's future. Collaboration between parents and professionals would then be needed to advocate for and implement such services and resources.

The work of Taanila et al. (2002) is important because it highlights the need for best practices among social workers (and other social service and medical providers) and provides strategies to improve the lives of families. The suggestions made by the authors are preventative in nature as they assist the parents not only to get through the initial diagnosis but to feel supported so they can get themselves and their family member the supports they need. This focus on the family allows them to get back to living their lives more quickly and improves their quality of life.

Services to Meet Parents' Needs

Freedman and Boyer (2000) found themes similar to Taanila et al. (2002). Freedman and Boyer found that parents wanted services to meet their needs. Among other things, parents discussed the role of social workers, collaboration of services, a focus on the family, the need for preventative services and tailored services, and the need for extra funding (Freedman & Boyer, 2000).

Freedman and Boyer (2000) found that having social workers and other professionals familiar with resources and services was important to families. Families who did not have service providers with this knowledge experienced frustration and felt as though they were alone. One parent in the study stated: "I was always very educated and thought of myself as an intelligent person, but I'm in this world that I don't know what to do or where to go" (Freedman & Boyer, 2000, p. 63). Further, parents viewed collaboration between professionals and agencies as important. Families experienced frustration when trying to access programs and services for their children: "I just wish there was some way for agencies…to cross boundaries so what the child needs would be the highest priority…. There really does need to be more of a view of the big picture" (Freedman & Boyer, 2000, p. 66).

The authors also found that parents wanted services to be focused on the whole family and on prevention, instead of crisis driven. Preventative services were those that helped families by providing services that kept caregivers healthy (Freedman & Boyer, 2000). For example, having programs and services to assist them to continue to work and meet the demands of their household and care needs significantly decreased pressure on caregivers. Their increased happiness, in turn, resulted in their continued commitment to care for their children in the home (Freedman & Boyer, 2000).

Parents expressed the need for services to be tailored to their specific needs and circumstances (Freedman & Boyer, 2000). Elderly parents caring for their adult children may need extra resources, parents of children with medical needs will require extra funding or care, and families with language or cultural barriers could require assistance to access supports. The ability to tailor services to meet the needs of the entire family increased parents' sense of choice and control increasing satisfaction with services and their role as caregiver (Freedman & Boyer, 2000).

Extra funding for expenses was requested by parents (Freedman & Boyer, 2000). As found in other studies (Parish & Cloud, 2006), there were extra expenses associated with having a special needs child that were not covered by regular funding. Though they appreciated having flexible funding that they could use for services, they wanted more money to cover these extra expenses (Freedman & Boyer, 2000).

Parents also recommended that families have access to counselling, that they receive education and training in order to make informed decisions, and that professionals (teachers, social workers, medical personnel) receive education and training about special needs children and their families (Freedman & Boyer, 2000). The authors recommended social advocacy to change legislation to increase benefits for families with children with special needs (Freedman & Boyer, 2000).

The study by Freedman and Boyer (2000) has implications for practice and theory. Parents within the study wanted social workers to have knowledge of available services and supports and to collaborate with others to provide services for their children. Those without these supports felt frustrated and isolated (Freedman & Boyer, 2000). The role of social workers and agencies, then, is important as social worker knowledge could help parents to feel empowered or leave them feeling isolated and lack of collaboration between agencies could create barriers to service. While there may be recommendations beyond individual and collective social workers' resources (the need for specific services and more funding) the need for competence in practice is implied and the need for advocacy to increase benefits is recommended. The study (Freedman &Boyer, 2000) is also conducive to structural social work as it focuses on the whole family, recommends professionals educate and empower families and keep up to date on services and programs, and supports the need for changes at individual, community, and policy levels.

Financial Considerations of Special Needs Children and their Families

In a study of families with young children with special needs Parish and Cloud (2006) found that families with special needs children were more likely to live in poverty and that financial wellbeing affects the overall wellbeing of families. Families with special needs children were unable to access appropriate and affordable childcare, made less money than parents of non-disabled children, and had less money by midlife (Parish & Cloud, 2006).

Parents found that childcare could be expensive, it might not meet their needs, or that some daycares would not take their children due to their special needs. Lack of childcare primarily affected the ability of mothers' to work. Employment of fathers was not affected by lack of childcare or having special needs children (their employment patterns were similar to those of fathers with non-disabled children) (Parish & Cloud, 2006).

Parish and Cloud (2006) found that mothers with special needs children had employment patterns similar to those of mothers with very young children - sporadic hours and fewer hours worked. However, this lasted for a longer period of time for mothers of special needs children. The inability of mothers to participate in the workforce, or having jobs with decreased hours over extended periods of time, affected the overall income of families (Parish & Cloud, 2006).

The extra out of pocket expenses of caring for their children (specialized therapies, medications, and equipment) also affect families' finances (Parish & Cloud, 2006). It is noted by the authors that this is significant to all parents with children with special needs. The cost of having them stay in the home or homecare setting through adulthood, combined with a reduced income, results in families having significantly less money overall at midlife than families with non-disabled children (Parish & Cloud, 2006). On top of the financial responsibilities parents become advocates, case managers, and decision-makers for their children – which can be overwhelming for them (Parish & Cloud, 2006).

Parish and Cloud (2006) argue that the ability for families to participate in the workforce is the key to keeping families out of poverty. The authors suggest that social workers give guidance and support to families and advocate individually and collectively for policies that will assist parents to meet the demands of working and caring for their disabled children. This would enable parents to increase their ability to care for the short and long-term needs of all of their family members (Parish & Cloud, 2006).

Investing in services to allow parents to work could result in fewer services needed later on. Families unable to work may need to rely on social assistance, may experience burnout (which could lead to the need for permanent care for their child or adult child), and would have very little money at retirement. Suggestions by Parish and Cloud (2006) respect the needs of the family and would put less strain on social supports over the long term.

Mothers as Caregivers of Special Needs Children

Parish and Cloud (2006) note a lack of literature on maternal employment and the severity of a child's disability. A study of mothers on social assistance found that mothers with severely disabled children had reduced employment while families with moderately disabled children did not (Lukemeyer et al., 2000, as cited in Parish & Cloud, 2006). Another found that employment patterns were similar between mothers with children with moderate cognitive disabilities and mothers with children without cognitive disabilities (Walker, Oritz-Valdes, & Newbrough, 1989, as cited in Parish & Cloud, 2006).

The disabilities of the children in the comparison of families with severely and moderately disabled children (Lukemeyer et al., 2000, as cited in Parish & Cloud, 2006) were not disclosed. This would be important as children with severe medical, behavioral, or cognitive disabilities would have different needs and issues than children with moderate disabilities. Their ability to participate in daycare, school, or afterschool programs, the cost of the programs, and the level of care they required, would affect parental employment.

Current income assistance policies do not support mothers (B.C. CEDAW Group, 2010). Mothers unable to work (due to their need to seek and manage services for their special needs children or their lack of suitable and affordable childcare) would need to report their inability to work in order to continue to receive assistance. Changing policies to allow mothers to stay home so they could seek and manage services for their children or providing the resources to pay for suitable childcare so they could work would allow mothers to better meet the needs of their special needs children.

Likewise, the study comparing the employment patterns of mothers of children with and without moderate cognitive disabilities (Walker, Oritz-Valdes, & Newbrough, 1989, as cited in Parish & Cloud, 2006) does not state how the disability affected the children's functioning. It also does not identify whether the mothers had access to other sources of income. The ability for the children to function in social settings would make it easier for the parent to obtain childcare and family income could determine the mothers' ability to participate in the workforce.

Though Parish and Cloud (2006) clearly advocate for the need for support services to assist families, their study may set back mothers with children with disabilities. The finding that mothers with moderately disabled children were not affected by their children's disability implies that mothers should be able to meet the demands of their careers and special needs children. Those unable to meet these demands (because of poverty, lack of services or the like) may internalize them as personal failures rather than seeking supports.

Ryan and Runswick-Cole (2008) found that mothers were the primary caregivers of their special needs children and that their care giving roles affected their ability to participate in the workforce. Ryan and Runswick-Cole found that mothers reported their work to be unsatisfying. Parish and Cloud (2006) found that work contributed to their psychological wellbeing as it provided them with a break from their childcare duties and gave them social interaction. It is possible, however, that both studies are correct and their work could be unsatisfying while also being necessary for providing an income and social interaction.

Ryan and Runswick-Cole (2008) also found that mothers, rather than fathers, were primarily responsible to take children to appointments, interact with service providers, seek services, and manage information on behalf of their children. Due to this, however, they received scrutiny and judgment from professionals and the general public (Ryan & Runswick-Cole, 2008). They also experienced discriminatory practices and attitudes, directly or indirectly, when interacting with others with their children (Ryan & Runswick-Cole, 2008). Abelist society views special needs children negatively and casts this view on their parents as well by association (McKeever & Miller 2004, as cited in Ryan & Runswick-Cole, 2008). These attitudes come across within interactions with professionals and parents can adapt a subservient position in order to appease professionals (Ryan & Runswick-Cole, 2008). These experiences can lead parents to internalize these oppressions as their own (Ryan & Runswick-Cole, 2008).

Boyd (2002) found that mothers with autistic children who were isolated were more prone to depression and anxiety than mothers with support systems. The study involved formal supports (including education and training sessions) and a parent support group. According to Boyd, parents enjoyed the education training sessions and would recommend them to other parents. The parent group was more significant than information or retention of information in the support groups. Parents enjoyed the parent group, felt supported, and reported that it gave them a chance to discuss the realities of their lives with their autistic children without judgment (Boyd, 2002).

Boyd (2002) recommended training for parents to address behavioral intervention strategies at home and in the community and training to alleviate parental stress. Providing access to formal and informal supports was recommended, as was offering a continuum of services to meet families changing needs (Boyd, 2002).

Devaluation of mothers' knowledge in favor of professional knowledge or public opinion also adds to isolation (Levine, 2009). This was exacerbated with single mothers (Levine, 2009). Levine argues that contrary to the majority of research focusing on two-parent families, special needs children are predominantly raised by single mothers. Levine found that single mothers with disabled children experienced judgment and devaluation of knowledge by service providers. Attitudes presented by service providers were patriarchal in that mothers who listened to them were given services and those who did not were refused services (Dean, 1995, as cited in Levine, 2009).

Ryan and Runswick-Cole (2008) found that mothers developed specialized skills as a result of having special needs children. Many did not have knowledge of disabilities or disability issues until having special needs children (Ryan & Runswick-Cole, 2008). The women gained advocacy, mediation, and negotiation skills, as well as educating others and becoming advocates in their communities. The majority of women in both studies experienced resilience, empowerment, and transformation through advocating for their children (Levine, 2009; Ryan & Runswick-Cole, 2008). It was recommended that social workers assist single mothers to develop skills to advocate on behalf of their children (Levine, 2009) but stressed that mothers' resilience cannot make up for the need for adequate and accessible programs and services for this population (Levine, 2009; Ryan & Runswick-Cole, 2008). Levine (2009) also recommends that professionals readjust their framework when working with single mothers as two-parent family models negate their experiences by focusing on family deficits (their lack of a partner) rather than on family resilience.

Barriers to Services Experienced by Aboriginal People

Social work values cultural views and personal experience (Mullaly, 2007). Barriers can occur at systemic, service, and individual levels and power imbalances between workers and clients can directly affect access to services and communication with service providers (Peiris et al., 2008). Individuals may experience psychosocial stress and mistrust of government agencies due to historic factors (such as discriminatory policies and experiences with child apprehension and placement in non-Aboriginal foster homes). Peiris et al. recommend that workers and agencies remain aware of power imbalances between themselves and clients, offer services relevant to their needs, and provide information about available services. Not stereotyping Aboriginal people was also recommended. This examination may also be applied to other vulnerable groups such as parents of special needs children to ensure accessibility of services (Peiris et al., 2008).

Parent Experiences of Having a Child with a Disability

By the time that parents of special needs children access services they go through a range of experiences and emotions. The book *A Different Kind of Perfect* (Dowling, Nicoll, & Thomas, 2004) examines parental experiences of having a child with a disability. There is no one way or right way to react to a child being diagnosed with a disability but common initial and ongoing emotions may include guilt, anger, and denial (Dowling et al., 2004). This may be exacerbated by discrimination from the general public (Dowling et al., 2004).

In response to judgment and scrutiny one mother summed up what it means to have a child with autism:

> It means often feeling isolated and being misunderstood, even by those who love

> you best. It means experiencing the very best and the very worst that other people can be. It means discovering coldness in the hearts of friends and immense kindness in the smiles of relative strangers. It means discovering that there are many worse things than being different, but none worse than being ignorant. Autism means receiving praise when all you really want is help, pity when all you really need is rest. Having an autistic child means realizing that even the most learned of doctors can be a fool and the most qualified of teachers can be ignorant….It means understanding that perfection is a myth and homogeneity is to be fought against….that humanity's real triumph is diversity not uniformity. (Dowling et al., 2004, p.9)

Parents also battle sugarcoated media images of the realities of their lives. Portrayal of parents as martyrs or saints and children as incorruptible can add to isolation (Dowling et al., 2004, p.9). Some equate being the parent of a special needs child as being enlisted in an army that they did not sign up for: "I hate that saying 'special children for special parents'. I don't want to be that special or heroic!" (Dowling et al., 2004, p.9)

Parents can also experience resiliency. Parents may have no previous knowledge of disabilities before having a child with special needs: "I used to feel sorry for people with children with special needs. Now I am one of those people and I certainly don't feel sorry for myself, or need anyone's pity" (Dowling et al., 2004, p.9). They may also choose to focus on their child's successes when they do occur and focus on their families' strength because of what they have been through (Dowling et al., 2004).

Themes and Implications of the Literature Review on Social Work Practice

There are implications in the themes found in the literature for social work practice.

All families, regardless of composition, faced barriers in accessing services for themselves and their children. A common theme between the studies was the need for individualized services for the family and the family member with the disability. Barriers for single parent families and the need for specialized services and supports for this population was an important finding in the literature and has implications for gender in relation to structural, anti-oppressive practice.

Other common themes included the need for: positive initial interactions with service providers; parents to receive training, education, and advocacy skills; financial considerations of families with special needs children; and, competent service providers. All of the literature speaks to the need for parents to adopt advocacy roles. However, the literature shows that mothers take on the majority of the responsibility for their special needs children.

While mothers traditionally take on caretaking roles within families, this role can be extended and far-reaching for mothers of special needs children. It can also take precedence over all other goals, or redefine goals and future roles. The literature shows that it is mothers, rather than fathers, that seek services on behalf of their children (Ryan & Runswick-Cole, 2008) and that leave work or participate in piecemeal work in order to care for their children (Parish & Cloud, 2006). Family cohesion and better outcomes were thought to be achieved through the mother leaving her job to take care of her child and family (Taanila et al., 2002). This would only work, however, if they had a spouse or partner that made a substantial enough income to support the family or there were government supports in place to allow mothers to stay home with their children.

The literature suggests, however, that many mothers of special needs children are single parents (Levine, 2009) involved in piecemeal work (Parish & Cloud, 2006) and that current social assistance policies do not support mothers to stay home with their children (B.C. CEDAW Group, 2010). As such, this would lead to the conclusion that single mothers and their disabled children would most likely live in poverty over an extended period of time. Disability and poverty leave people vulnerable to neglect, discrimination, and potentially even abuse (Titchkosky & Michalko, 2009). The need for mothers to participate in such work and their resulting poverty (or life situations) should, therefore, not be seen as resulting from personal choice or a flaw of character but as a larger social issue related to gender.

Women's work in general is undervalued and work with disabled people is further devalued (Titchkosky & Michalko, 2009). Within cultural and social norms are expectations that women should take on care giving roles, and that mothers should care for their children. As the needs of special needs children can be life-long the commitment to caring for a child can be life-long. It is further assumed that mothers should take on this role gladly and be able to manage without assistance, support (financial or otherwise), or recognition. Trying to follow these social norms could lead to stress, feelings of inadequacy, and burnout of caregivers. The normalization of this gendered role negates the needs of mothers and their children to receive adequate and sustainable services. Ensuring mothers have access to supports (financial and otherwise) could ensure the wellbeing of parents, which, in turn, would make it easier for mothers to care for their children in the home and potentially decrease the amount and extent of services (crisis intervention and/or admittance to long-term care due to parent burnout) needed later on.

The need for awareness of power imbalances inherent in systems and between workers and clients was also identified (Peiris et al., 2008). Workers are in positions of power over clients in interactions due to their role (Shebib, 2003). Awareness assists workers to not further perpetuate the oppression of vulnerable populations. Analysis and conscious implementation of progressive social work practice can be used to strive to equalize these roles.

Connecting the Literature to Structural Social Work

Parents of special needs children face many types of structural barriers and social workers must work to remove these barriers. The literature indicates that parents with children with disabilities can experience everything from lack of information and services (Freedman & Boyer, 2000) to discrimination (Case, 2000). I would argue that while social workers are capable of discrimination (as seen in Levine, 2009) it is more likely that social workers would participate in discrimination through lack of knowledge. Though overt discrimination by any worker is harmful to parents of special needs children, covert discrimination through lack of knowledge is also harmful.

As service providers, social workers could be one of the first professionals that parents access for support and resources. As first, and subsequent information, about a child's disability can affect family relationships and parental outlook for their child's disability, social workers would need to have at least a baseline knowledge of disabilities. They would also have to be able to refer to relevant resources and services. Throughout the literature, the way in which their child's diagnosis was discussed, the outlook the professional had about their child's diagnosis, and the sensitivity the professional expressed (not only their empathy but also their counseling skills) were important to parents (Taanila et al., 2002). I would also speculate that this initial interaction would shape how parents felt about their relationships with service providers and their ability to access services. As such social workers would want this interaction to be as positive and empowering as possible. This would not only ensure the ethical obligations of doing no harm to clients but would go further to foster a relationship with the parents as an ally.

Larger issues such as lack of funding also affect children with special needs and their families. Structural social work theory and practice can also be used to address these barriers. This will be discussed further in Chapter 3.

The literature has shown that parents of special needs children are resilient and resourceful and need help and guidance to achieve the most optimal life for their children. As a CYSN practicum student I strove to be aware of my practice and the skills and approaches that worked best with this population. Further, carrying a caseload and meeting with community service providers gave me insight into how the themes in the literature were, and were not, relevant to parents on my caseload and service providers.

Chapter Three: Practicum Activities and Learning Experiences

My practicum was guided by my learning goals and questions. My learning goals were to develop clinical and community development skills and knowledge specific to working with children with special needs and their families. These goals were then broken into specific activities. This chapter describes the activities completed in the practicum placement and what I learned as a result of these experiences. Connections to the literature, to my own social work practice, and to structural social work theory will be made throughout the chapter.

The practicum was guided by the following learning questions: What services are available to children, youth, and their families within the practicum placement and community? What are the needs of families with children and youth with special needs and how can social workers help parents best meet these needs? What are the unique needs, issues, and situations of Aboriginal children with disabilities and their families? What skills and approaches are best suited to working with this population? How will the practicum affect my professional development?

Clinical Social Work Skills and Knowledge

To gain clinical social work skills and knowledge I observed workers in their casework and carried a caseload. I also sought to understand the programs and services within CYSN, and CYSN in relation to MCFD, other departments of MCFD, and community agencies.

Developing Clinical Skills and Carrying a Caseload

One of the initial ways I developed clinical skills was by observing CYSN social workers as they interacted with clients and other professionals. I found that each of the workers had their own strengths and styles in counseling, assessment, facilitation, interviewing, and other skills. The process of observing others allowed me to learn new ways of approaching various clinical and other situations, which I then utilized in combination with my own skills through the practicum and in my clinical and community development work.

The main way I developed clinical skills was to actively work with clients and carry my own caseload. The literature suggests that professionals could shape parents' view of their child's disability and the ability of the family to cope and function (Taanila et al., 2002) and that parents wanted social workers familiar with services and resources (Freedman & Boyer, 2000). To address this I used counseling skills in general when speaking to parents and when discussing their child's disability, and provided them with information about programs and services specific to the needs and circumstances of their family.

Though I had assessment skills before, I developed assessment skills specific to the provision of CYSN programs and services. CYSN social workers use their skills and knowledge to assess the needs of families but are also required to fill out a scoring tool to assess parents' stressors, coping, and resources. A higher score is required to receive services faster or to increase services, thus making it deficit based and crisis driven in nature. I used interview, facilitation, assessment, and counseling skills in meetings with clients and adapted strategies used by workers to gather enough information to access services for families without being too intrusive.

To that end, parents accessing CYSN services need educated and qualified staff who have the skills to work with this population effectively. Workers could be viewed as being invasive if the information was gathered or given the wrong way and oppressive if these skills were lacking or absent. Additionally, counseling skills used by professionals during the provision of services would not substitute the need for parents to receive counseling.

My daily activities supervisor and I determined my caseload and I took six families. All were single mothers caring for a child with a disability. Each of the mothers faced multiple barriers such as poverty, health concerns, mental health, addictions issues, and/or their own disability and all required extra supports. In addition to completion of forms and agreements used for yearly contract renewals, I participated in home visits, did assessments, applied for funding, and facilitated and co-facilitated meetings with clients on my caseload. Following are two examples of my activities with these families.

In the first example, I co-facilitated a meeting during a home visit where we determined that the family needed continuation of respite, homemaker support, and daycare supplement. I put these in place. Further, at the request of the client, I met with a service provider to see if her organization and CYSN could collaborate in providing services to support the family.

The second example is of a mother on my caseload who required a change in her respite so my supervisor and I assisted her to find suitable respite care, went to the home with her to meet the respite providers, and followed up with her about how the placement was working. We also provided her with advocacy as she was at risk of losing her childcare because the daycare did not receive the supplement. The matter was resolved and the mother continued to access childcare.

Connections to the literature and practice

The first theme in the literature is financial considerations for families with children with disabilities as the literature supports that these families made less money and were more likely to live in poverty (First Call: BC Child and Youth Advocacy Coalition, 2012). CYSN workers reported that the families on their caseloads had low to moderate incomes. Services are income tested so it can be speculated that higher income families would not qualify for services. It can be further speculated that children with special needs come from families of all socioeconomic statuses. Waitlists for services, and the economic status of the clients on my caseload, would indicate that those accessing CYSN would not have the resources to purchase their own services, however.

The second theme in the literature, and one relevant to the mothers on my caseload and clients in the office,was mothers as having their caregiving roles affect their ability to participate in the workforce (Parish & Cloud, 2006). Similar to the literature, mothers that did not go to work relied on other sources of income and mothers that worked received fewer hours and low pay, resulting in less income for their families. Lack of access to appropriate and affordable childcare (Parish & Cloud, 2006) was relevant to the clients on my caseload and in the practicum office as parents were able to access daycare supplements to work but the amount of hours were limited and they were required to pay a portion of the funding. Putting these limits on funding would reduce the amount of hours that parents were able to work and their take home pay, affecting the overall income of their families. Further, though daycare supplements were available to everyone, waitlists made them inaccessible to many clients.

The themes in the literature and practicum placement have implications as both indicate that parents need to work to escape and remain out of poverty; this is impossible without support services in place such as reliable childcare. More funding for programs and services to assist mothers to continue to work should be implemented to improve outcomes for special needs children and their families. This would be particularly important for single mothers as they are the primary caregivers and income earners for their families.

Other themes were mothers as the primary caregivers of their special needs children and as being the ones to engage professionals and access services (Ryan & Runswick-Cole, 2008). It was predominantly mothers who took care of children, accessed services in the office, sought services from other agencies in the community, and took children to appointments. Further, mothers could experience devaluation of their knowledge by professionals (Levine, 2009) and discrimination and feelings of oppression (Ryan & Runswick-Cole, 2008) due to these roles. To counteract these within my own practice I assisted mothers to develop advocacy skills (as recommended by Levine, 2009) on a few occasions and remained aware of power imbalances with clients so not to oppress them (as recommended by Peiris et al., 2008). Developing advocacy skills does not make up for the need for adequate programs and services to meet the needs of this population (Ryan & Runswick-Cole, 2008) so I will advocate for these in my future practice as a social worker.

The theme of single mothers raising their special needs children did not match the caseload of the workers in the office (25% to 30%) but did match my caseload and the themes in the literature. The single parents on my caseload presented as facing significant challenges in their lives and in caring for their special needs children. As paperwork is deficit based and service provision is need (crisis) driven, their willingness to share such information could reflect their desperation to receive services due to their socioeconomic status (rather than being an indication of personal deficits). It could be speculated that they would choose not to disclose this information if they had other means of meeting their families' needs.

Deficit based and crisis driven services create an environment where workers compete to present their clients as the most in need/crisis. From a structural view, this could be seen as a way to divide workers and/or take focus off of the need for funding for people on wait lists for services. Application of a critical lens and understanding oppressive social structures provides a broader view of clients' lives and the social structures that oppress them.

I found carrying a caseload helpful to my practice as it confirmed many of the themes in the literature and gave me first-hand experience working with different families. Grounding my ideas and experiences in research allowed me to make connections between the overarching and repeating themes of gender and poverty in relation to parents of children with special needs. These experiences reaffirmed the need to base my practice in research and theory to gain a larger view of issues while appreciating the differences between families and their individual experiences of having a family member with a disability.

Understanding the Organization, Services, and Programs of the CYSN Office

In my first days with CYSN I focused on learning about the overall programs and services offered by the organization. I learned about eligibility requirements, assessment, and funding available to CYSN clients, among other things. This learning was important so that I had proficiency in explaining and presenting these services to clients, and so that I had an understanding of what was available. Learning about services and programs was difficult at times as new workers are not provided with a training manual or a list of internal and external resources.

I was given three sessions of formal training on the data management system but otherwise relied on different documents and staff to learn the programs and services. I applied for respite, autism, globally funded, and At Home Program funding throughout my practicum. I learned about transition services by listening to workers discuss them with parents and by attending an information session put on by CYSN workers and a meeting between a CYSN worker and Community Living British Columbia (CLBC) worker to discuss youth transitioning into CLBC services.

Participation in these activities gave me an understanding of the range of services provided to clients and funding access procedures. Performing the steps from initial contact and determining eligibility to completion of the tasks and transitioning out of services gave me an overview of some of the aspects of the job of CYSN workers. I also participated in development of best practices through watching workers in their interactions with clients and families. Best practices were also discussed and analyzed as a regular part of supervision.

Connections to literature and practice

The first theme in the literature is the need for preventative services that kept caregivers healthy, helped them meet the demands of their work and home lives, and reduced the need for crisis intervention (Freeman & Boyer, 2000). This theme was relevant to my practicum experience. During the practicum I applied for funding for respite to provide parents with a break from their special needs children. However, there are currently waitlists for this service. More funding so more people could access respite, and further funding to allow mothers to work, would prevent caregiver burnout and increase the overall wellbeing of families. I learned that implementation of the services as suggested would enhance the ability of the mothers on my caseload to provide for themselves and their families and meet the challenges of their everyday lives.

The second theme is money to cover some of the extra costs associated with having a child with special needs (Freedman & Boyer, 2000) such as funding for medical equipment and the like for children with significant medical needs and interventions for children with autism. During the practicum I also applied for At Home Program Funding that can be used to purchase medical equipment, supplies, and care, and Autism Funding, which can be used to purchase interventions for children with autism. Freedman and Boyer suggest that money for such interventions reduces the out of pocket expense for families but as CYSN workers reported their caseloads to be low to moderate income families it could be speculated that these families may not be able to afford these needed services otherwise. Similar to the study conducted by Freedman and Boyer, these interventions increased parental confidence and satisfaction and improved the quality of life for families by giving parents help and strategies to care for their children. These services support families and I will reflect on these experiences in my future practice when arguing the need for such preventative services.

The third theme in the literature is the need for a continuum of services to meet the changing needs of families (as discussed by Boyd, 2002). A theme that kept arising through both my clinical and community development work was a lack of information about, and services for, youth transitioning into adult services. These gaps will be discussed further in the community development portion of the report. I learned that training and a training manual have not been implemented in this CYSN office. Staff in the office informed me that the demands of the work environment have prevented implementation of a formal process but they would have found this training helpful as new CYSN workers. A basic training manual and a manual of internal and external resources would assist new employees to integrate into the environment faster and could improve the efficiency of the office in general.

Understanding the Relationship of the CYSN Office to Community Agencies

CYSN has relationships with many agencies in the community. I participated in a variety of meetings with CYSN staff and community agencies including meetings with, and presentations for, families. The following examples are not the only ways that CYSN has relationships with community agencies but are a sample of some of the meetings I was involved in reflective of my experiences.

I was involved with the At Home Program review committee meetings that are used to determine clients eligible for the At Home program. The committee members included my daily activities supervisor, an occupational therapist from the Central Okanagan Child Development Association, and a public health nurse. The cases inspired a lot of discussion and were presented and argued in different ways due to the diversity of the disciplines and specializations of the committee members. The discussions by the team members, and my ability to add my own views, added to my understanding of the complexity of the cases and an appreciation for the sometimes difficult process of determing client eligibility.

I was involved with an Integrated Case Management meeting (ICM) and an Individual Education Plan meeting (IEP) for clients on my caseload. The ICM involved a multidisciplinary team from various community agencies and the IEP primarily involved professionals that worked for the school district. The goal of both meetings was to coordinate services for the clients (the children) and to find ways to support the parents.

The ICM was the first time that I met the parent and the first time the other professionals met as a team. There were a lot of service providers involved with the child and family and each discussed the interventions they recommended or implemented in the home and/or daycare setting but there was a lack of coordination of services and service providers. The mother was glad for the interventions but frustrated that she would not be given strategies to address her main concerns until the next meeting, by which time she believed her family would be further in crisis. In the other case, the professionals introduced themselves and explained their role in her daughter's education but it was the mothers first IEP so she was overloaded by information and seemed intimidated by the language and acronyms used by the team. After the meeting I attempted to explain these to her but later realized that my own use of language and terminology may have gotten in the way. Through these experiences I reflected that the processes, practices, and language, common to social workers and other professionals may be foreign to parents and require revision to better meet the needs of families.

I was also involved in an information session for parents with youth transitioning into adult services put on by CYSN workers in collaboration with school district staff. I learned that families had concerns similar to those in the literature. Families experienced barriers to service (Freedman & Boyer, 2000) and appreciated that CYSN workers knew the resources and assisted them to gain access to services. They wanted all service providers to know services and to collaborate with other workers and agencies to coordinate services (Freedman & Boyer, 2000). Parents also discussed the development of specialized skills (advocacy) (Ryan & Runswick-Cole, 2008), the resiliency of their families because of what they had been through, and the strengths of their children (Dowling et al., 2004). They also requested a parent group (Boyd, 2002) so they could continue to receive support from one another. Also relevant to my learning was that the parents who attended were predominately represented as two parent families and the fathers in the group actively participated in the discussion.

Connections to the literature and practice

The first connection to the literature is the need for collaboration between service providers and agencies (as recommended by Freedman & Boyer, 2000) and was present in the three examples of the relationship between the CYSN office and community agencies. The At Home Review Committee was effective because it utilized the specializations of the members (including the special needs lens brought by my supervisor) and took the responsibility off of one person to make decisions regarding eligibility. The parent information session was also a good example of collaboration as CYSN workers and school district staff recognized and fulfilled the need for parents to receive information about transition services. In the case of the ICM, collaboration between the service providers would have been more effective at the onset of services in order to address the parents' immediate needs and to prevent issues from potentially developing into a crisis for the family (as recommended by Taanila et al., 2002). Similarly, the efforts of the team in the case of the IEP were not as effective as they could have been because the parent did not understand the roles, language, and acronyms used by the team members. In all cases, I was able to see how and why collaboration between these teams worked, or could have worked better. In the ICM and IEP the competence of the teams and the interventions they suggested were overshadowed by the processes used by professionals. The cannon of social work, social workers, and other professionals to formulate plans from their own discipline, work with families individually, and to collaborate or coordinate services after the first meeting, or after crisis ensues make these practices exclusionary and oppressive to clients. Recommendations by Taanila et al. (2002) to meet at the onset of services to collectively formulate a plan and provide immediate access to services would be easily implemented and better meet the needs of families.

After attending meetings I realized that I was able to keep up with the language, acronyms, and jargon used by the team members because of my personal and professional background. I reflected on my own practice and realized I had adopted the habit of using CYSN acronyms. These can be useful shorthand but also lead to a "we know what we mean" approach in meetings as well as excluding those who do not speak the language.

The literature supports that the information given to parents about their child's disability affects their perception of the ability of the child and family to cope and function (Taanila et al., 2002). Jargon and acronyms can be used by professionals to impress, overpower, or distance themselves from clients (Mullaly, 2007). Though this would not likely be the intent of workers, it could serve to create a barrier between workers and clients and parents could leave feeling frustrated and unsupported. Without critical analysis workers may be unaware of the negative effect they were having on parents. I will strive to be aware of this in my own practice.

The first relevant theme in the literature regarding the information session put on between CYSN workers and school staff was mothers as engaging services and service providers on behalf of their special needs children (Ryan & Runswick-Cole, 2008). Contrary to the literature fathers actively participated in the information session. The worker assigned to the caseload reported that it was common for mothers and fathers on his caseload to advocate for their children. The fathers' participation in the session may, therefore, have been an extension of their existing roles as advocates and because they felt supported by the workers and other parents. This scenario reinforced the need for me to act as an ally with clients so that they might feel comfortable sharing their experiences and advocating for their children.

The second theme in the literature relevant to the information session was the need for a parent group. Parent groups provide support (Boyd, 2002) but are also useful to gain strategies to face difficulties such as cutbacks to funding and barriers to services (Dowling et al., 2004). However, those that could benefit the most from this support and information may be unable to receive it. The underrepresentation of single mothers at the information session may have been because they make up a smaller percentage of workers caseloads (25% to 30%). The themes in the literature matched clients' lives as some of the single mothers I spoke with told me that they had difficulty participating in these types of activities due to their need to work and/or lack of childcare (Parish & Cloud, 2006). Providing information to these parents around their work schedules and/or providing access to childcare so they could attend information sessions or parent groups may allow this population to better access these services and supports.

Other themes in the literature to come out of the information session were the need for a continuum of services to meet families' changing needs including access to formal (education and training) and informal (parent group) supports (Boyd, 2002). During my practicum I found out that cutbacks to funding resulted in services being cancelled or having longer waitlists, and that high caseloads interfered with workers offering supports. Funding for a continuum of programs and services and reducing workers caseloads to allow them to participate in providing supports would address these needs and improve outcomes for families.

From a structural view parents who do not have advocacy skills to navigate the system and social workers unable to assist may simply preserve the status quo. Further, without analysis and recognition of social structures workers bogged down by the demands of their job could blame parents for their situations. Collaboration between workers and between workers and clients is needed for development of relationships and changing oppressive structures.

These experiences were important to my learning as they allowed me to reflect on my own practice and social work in general to see how each could be changed or adapted to better serve clients. As a person with family members with a disability and a worker I was able to appreciate the perspectives of both of these groups during meetings. Due to my personal and professional background, I was familiar with these types of meetings so many times they served to reaffirm or contribute to my existing knowledge and practice.

My biggest realization was that my knowledge and experience sometimes interfered when I shared my perspective as a person with family members with a disability into conversations on a few occasions; this was met with mixed results. In one case the rapport I developed with a client ceased momentarily and in two others I was able to connect with clients immediately when they clarified my role. I reflected that I have reacted positively to workers with family members with a disability as I believed they might better understand my experience. On the other hand, I have also experienced feeling oppressed by workers with and without family members with a disability if they identified with me without acknowledging my experience or the needs of my family. This reaffirmed for me that there are similarities and differences in having a family member with a disability but that it is individual for every family and that I need to remain aware of this in order to provide respectful anti-oppressive practice.

CYSN in the Context of MCFD and the Relationship to Other Departments

Guardianship workers shared the CYSN office during my practicum. Guardianship workers are legal guardians for children in care, and as such, deal with any legal, medical or safety issues or concerns. Having them in the office gave me the opportunity to learn more about their roles and to witness interagency collaboration as CYSN and guardianship workers can share mutual clients. While participating in discussions and meetings with the workers I learned about the dichotomies of service provision (CYSN services are voluntary and guardianship services are involuntary) and how these roles could require advocacy and diplomacy skills within their own department and other departments of MCFD.

Connections to the literature and practice

The first theme in the literature was the need for collaboration between professionals and agencies (Freedman & Boyer, 2000). The literature shows that workers should collaborate to meet the needs of families (Freedman & Boyer, 2000) but the practicum experience suggested that the demands of workers jobs may prevent them from collaborating with others. I witnessed, and workers told me, that sharing the office assisted them to better understand each other's jobs and to foster relationships between themselves and their departments, which promoted collaboration. Sharing the office gave the workers more opportunity to collaborate. Workers also need the ability to meet the demands of their jobs, such as reduced caseloads and support to participate in preventative services with clients.

The second theme in the literature is the need for professionals to understand the needs of special needs children and their families (Freedman & Boyer, 2000). Parents in the study by Freedman and Boyer (2000) wanted professionals to understand more about their child's disabilities as well as their lives as individuals and family members. Applicable to this was the theme throughout my practicum for the need for a special needs lens. Having the guardianship team share the CYSN office gave me many opportunities to participate in these discussions and developed my existing knowledge in this area. Some CYSN and guardianship workers had shared clients in foster care. I observed that CYSN knowledge of special needs and collaboration between the workers resulted in better outcomes for these clients. The knowledge I gained from these experiences will assist me when working with special needs children and their families in the future.

Mentorship and debriefing were common in the CYSN office and improved the working environment and practice as they served to keep workers connected to the purpose of the work and pass on social work knowledge and values. This was important to my learning as I was able to receive support and guidance from several workers throughout my practicum. I was also able to provide this support to others, which helped me to develop professional relationships and friendships with colleagues and also added to my experience.

Summary of the Development of My Clinical Social Work Skills and Knowledge

The diversity of the workers and their skills provided me with the opportunity to increase my own skills. Observation and implementation of these new techniques in conjunction with my own existing knowledge assisted me to develop my skills in general as well as in the context of CYSN and the population it serves. I found these skills useful throughout my practicum and will continue to utilize them in my practice. All of these experiences gave me a better sense of the job of CYSN social workers as well as the relationship of the office to other departments. Learning about CYSN programs and services gave me a better understanding of how the office worked together with services from other agencies and departments (and sometimes did not). Participation in these activities gave me a bigger picture view of MCFD and how it works with community agencies. Speaking to various workers from MCFD and community agencies gave me an understanding of some of the benefits and challenges of their work.

Throughout this section were the reoccurring themes of the gender and poverty as single mothers of special needs children face many barriers and require programs and services to assist them to get and keep themselves and their children out of poverty (Levine, 2009; Parish & Cloud, 2006). There were also repeating themes of the need for collaboration of service providers and services and for agencies to support workers to participate in preventative services to improve outcomes for families (Freedman & Boyer, 2000; Taanila et al., 2002). An underlying theme was for social workers to change or adapt their practices to better meet the needs of families (Taanila et al., 2002).

Community Development Social Work Skills and Knowledge

One of my learning goals was to expand my knowledge of, and skills pertinent to, the community development field. Through my placement I increased my knowledge of how communities work in general, and of the special needs community in Kelowna specifically. I developed a better understanding of the strengths, needs, and gaps of larger community services for special needs children, youth, and their families. I also sought to understand the strengths, needs, and gaps specific to Aboriginal CYSN clients and their families. Through my activities I also improved my community development skills such as networking, facilitating meetings, and identifying ways in which the community could better meet the needs of special needs families and children.

Meeting with Community Service Providers

As part of my practicum I participated with the CYSN Community Table and met with individual service providers. Both served different purposes in my learning. People from various agencies attended CYSN Community Table meetings so I was able to learn about a lot of agencies, their programs, and services, and how they worked together (or not) in a very short period of time. It gave me a chance to learn the specific roles of service providers and the terminology they used from their discipline or profession as well as how they interacted with each other. One of the most significant things I learned from the community table meetings was that service providers lacked knowledge of what other service providers did and the services and supports available in the community. Thus these meetings were important and useful in service providers learning more about what other services were available for their clients and I was able to facilitate the sharing of information with service providers to improve service access by clients.

I met with individual service providers in the community to learn more about the services at their agencies. The majority of agencies I met with were contracted services through MCFD or Community Living British Columbia (CLBC). Others were services that CYSN social workers referred families to frequently. I started with service providers I met through the community table, and then expanded to meet others in related service fields. I was at a disadvantage as someone new to the community and a practicum student. As someone unknown I was a low priority for busy service providers trying to meet the needs of their clients, programs, and agencies. It was much easier when I was helped by other social workers in the placement office, as they were respected among service providers and knew large networks of people. On a few occasions I gained accessibility to hard-to-reach people or organizations through my association with these workers. They informed me of the services, took me to agencies, and introduced me to other service providers at meetings, training events, and networking events. Through these experiences I learned about the culture of the community and became aware of a broader array of community services. My meetings with individual service providers were held at their agencies. This was beneficial as I was able to see where the agencies were located and the work environments. I was also able to view workers spontaneously interacting with clients on a few occasions. This provided me with a more concrete and realistic view of these community agencies and services, as well as more knowledge of the service providers. I also found that people were willing to tell me more in one to one meetings.

Through these meetings I also developed networking skills and built professional working relationships with others in the field. When meeting people I took the opportunity to give them a brief summary of who I was and set up a time to meet with them. I became familiar to many workers in the community through my involvement on the CYSN Community Table, meetings, and training events and further developed my networks from these connections. In these meetings, and my practicum placement, the sharing of knowledge, theory, and humor, among other things, assisted me to form professional working relationships and friendships with other workers.

I was also provided with a current and historic view of organizations, services, and service provision in Kelowna. I learned that historically there was a continuum of funding and services that made it easier for workers to collaborate and coordinate services and that division of these into child and adult services caused division of services and service providers. This correlates with the information that many community service providers I met with lacked knowledge of what other service providers did and the services and supports available in the community.

The Strengths, Needs, and Gaps of Services in Kelowna

Throughout my practicum I was observant of the strengths, needs, and gaps of services in Kelowna relevant to CYSN clients and their families. There were several reoccuring themes.

Strengths

I learned that, similar to Taanila et al. (2002), some workers developed the practice of meeting at the beginning of service provision with families and that this allowed them to provide more effective intervention. Workers told me that parents liked this method, as they were able to gain information from all service providers at once and advocate for services to meet their needs. Workers liked this method as having all service providers at meetings ensured connection and access to relevant and available services and supports for families, reduced duplication of services, and increased communication between teams. Further, implementation of plans that met the immediate and ongoing needs of families diverted crisis and the need for crisis intervention services. These discussions were important for my learning because they confirmed that this method was effective for use with clients and their families in Kelowna.

I also learned that historically workers collaborated with community members to create the foundational services for special needs people in Kelowna. Through my practicum experience I found community service providers to be dedicated people that cared about their clients. This was apparent in the practicum office in conversations I had with workers, meetings I was involved in with workers and clients, and observation of their interactions with clients and one another. I also observed one worker collaborate with others from the community to provide an information night for families and with a community agency to create an employment program for clients. For all of these reasons I came to view service providers as one of the strengths of the community services in Kelowna.

Preventative services were viewed to be a strength by Aboriginal and non-Aboriginal wokers because they increased parents' ability to care for themselves and their families. Cultural services were believed to be a strength by all Aboriginal workers as they improved the lives of individuals through connections with culture and community. Though I knew it before, these experiences confirmed the need for preventative services in general and access to cultural services for Aboriginal people.

Needs and Gaps

Through meetings I learned that there were needs and gaps specific to Aboriginal people, that the most common gap for Aboriginal and non-Aboriginal service providers was funding, and the most significant was transitions.

Cultural safety was mentioned by all workers. Cultural safety can be practiced by individual workers through being aware of culture and cultural values but goes beyond this to examine the power inherent in the positions of professionals (Ramsden, 1992). Under this model, the only ones that can determine whether services are culturally safe, or not, are Aboriginal people (Ramsden, 1992). Workers informed me that cultural safety had improved within non-Aboriginal organizations but that cultural services, such as incorporating language and practices into programs, were important as they fostered identity, pride, and connection to family and community, among other things.

All workers noted a lack of food amongst their clients. Poverty was believed to be the biggest factor in lack of food amongst Aboriginal clients accessing Aboriginal services in Kelowna. Workers provided information to families about where they could access food but reported the demand to be overwhelming.

Lack of funding was noted by both Aboriginal and non-Aboriginal service providers and resulted in programs being cutback or cancelled. Aboriginal workers were concerned about their clients' access to services due to constant underfunding of their programs and services and believed they would be able to assist and reach more people with more funding. At present, Aboriginal children and youth with disabilities receive the same services and funding for services as non-Aboriginal clients through CYSN and workers wanted this to continue. Workers were also concerned about devolution of services for Aboriginal children transitioning into adult services as alternate sources of funding (the person's band for example) are sought before funding is provided through CLBC. This results in longer wait times for funding, the possibility of not receiving funding, and has implications for denying identity in order to receive services. These experiences helped me to form connections between the larger structures of oppression faced by Aboriginal people, including poverty, to the lives of Aboriginal clients.

In regard to transitions, I learned that CLBC provided funding and services for children and adults with disabilities (Community Living British Columbia, 2010) and that this resulted in a continuum of services for clients because there was no disruption of funding and services when youth became adults. Division into CYSN for children and CLBC for adults caused gaps as youth are now required to prove eligibility for adult services. This is significant because there are currently many youth transitioning into adult services in Kelowna and families struggling to adapt to these changes to secure funding and services for their children. I also learned that CLBC currently provides Individualized Funding (IF) and that clients accessed this through creating a plan with a friend, family member, or approved agency to outline supports and services needed to live and participate in the community (Community Living British Columbia, 2010).

Connections to the literature and practice

In relation to the themes in the literature and my practicum experience I found one theme related to meetings with community services providers, two regarding strengths, three regarding needs and gaps, and three specific to Aboriginal families with special needs children. Through meeting with service providers I learned that one of the important themes in the literature was for social workers to know about available services and to meet the needs of their clients' (Freedman & Boyer, 2000; Taanila et al., 2002). This has implications for relationships with parents as service provider knowledge (or lack thereof) can affect whether they are viewed as allies or obstacles. I saw this during the information session when parents viewed the worker assigned to their caseload as an ally because he was knowledgeable about services and proficient in accessing them for his families.

The CYSN Community Table is addressing this by providing information about agencies, services, and supports available in the community through promotion of the same. In the bigger picture service providers could lack knowledge due to division of services. Division of services results in service providers narrowing their focus to their own agency and services and those that offer similar programs and services. Lack of knowledge of services and the implications this has for clients and their families could, therefore, not be an intention of social workers but the result of the way the services have been set up. I realize that it will be important in my future practice to maintain an ongoing awareness of broader community services in order to be able to share this information with clients.

The service providers I spoke with contributed to knowledge of the services for CYSN clients and their families in Kelowna. I was also able to foster and develop professional relationships and friendships through this process. These professional networks will assist me as a community member and in my future practice.

I found three connections to the literature and my practicum related to strengths of services in Kelowna. The first connections were recommendations made by Taanila et al. (2002) for professionals to meet at the beginning of service provision and suggestions for working with families. Similar to Taanila et al. workers in Kelowna confirmed that meeting at the beginning of service provision and on an ongoing basis was more efficient and better met the needs of families. Workers also reported a reduction in the need for crisis intervention services confirming the success of this method as a form of prevention. Reduction in duplication of services was also believed to be a benefit among workers, though this was only implied in the study by Taanila et al. In speaking to service providers I did not specifically address whether collaborative meetings were also used to assess the overall coping and functioning of families and to put supports in place to ensure coping, an important component of the study by Taanila et al. Future research could be done into the applicability of the study by Taanila et al. to families in Kelowna.

I found that this method was conducive to structural social work because plans were built around the needs of families (Taanila et al., 2002). I believed, and workers confirmed, that barriers to this method would be that it may be unfamliar to workers or they may not be supported to use it by their agencies. My involvement with the CYSN Community Table leads me to believe that this method may be useful to the Community Table as its goal is to promote collaboration between service providers and agencies. Discussions with service providers confirmed that this method worked with families in Kelowna and I intend to use it in my future practice.

I also implemented suggestions by Taanila et al. (2002) for working with families throughout my practicum. I collaborated with others to provide services for clients but this would have been more effective if the teams met at the beginning of service provision. I spoke to parents about their children's disability in a realistic but optimistic way, and though parents were already accepting of their child's disability (a benefit of this technique), they appreciated my optimism and focus on the strengths of their children and families. I also presented resources to clients that increased their access to formal and informal supports, knowledge, and social networks; the later two being the most important coping strategies for families (Taanila et al., 2002). Family and spousal wellbeing are also connected to access to formal and informal supports (Taanila et al., 2002). The worker involved in the information session for parents reported his caseload to be predominantly two parent families with both spouses advocating for funding and services for their children. Family and spousal unity would not be determined by, but may have been assisted by, the workers proficiency in explaining, obtaining, or creating formal and informal services and supports for his families. This also has implications for CYSN services in general as they are preventative in nature and social workers seek and provide resources to promote wellbeing of families and keep them together.

The second relevant theme in the literature regarding the strengths of community services in Kelowna was collaboration between professionals and agencies (Freedman & Boyer, 2000) and access to services and supports for families (Taanila et al., 2002). Social workers are also required to find ways to improve the lives and situations of clients (Mullaly, 2007). I learned that historically programs and services were created between workers and community members to fulfill needs that were not being met for clients. Likewise, workers told me that they collaborated to provide information sessions because it was a way to connect with families. Seeing these values in practice was helpful to my learning as it reminded me of the importance of the need for social workers to take the initiative to create and provide these formal and informal services and supports for clients.

I adopted and participated in strengths modeled by workers in the practicum office of reframing difficult situations and making connections with practice and using humor to alleviate tension and form friendships with colleagues. Use of these with different workers added to my existing knowledge of the benefits and challenges of work with this population and developed my existing skills and knowledge of the uses of analysis and humor to deal with the difficulties and stresses of practice.

I found three themes in relation to needs and gaps in the literature and practicum experience. The first theme in the literature relevant to the needs and gaps of community services in Kelowna was for services and funding to be tailiored to the unique needs and circumstances of families (Freedman & Boyer, 2000). Similar to parents in the study (Freedman & Boyer, 2000), parents in the practicum placement wanted funding for respite, training sessions, extra funding for therapies, and, where applicable, funding for home nursing care, medications, and adaptive equipment (Freedman & Boyer, 2000). During my practicum I completed paperwork to obtain respite to provide parents with a break from their special needs children and autism funding which can be used to purchase training sessions and therapies specific to autism interventions. I also participated on the At Home Committee and completed paperwork for families in the practicum placement for the At Home Program; which provides funding for nursing care, medications, and medical equipment to eligible clients. There are wait lists for respite and Autism funding and strict criteria for the At Home Program, however, so these funds are not accesible, or not readily accesible, to families accessing CYSN services. Like parents in the study (Freedman & Boyer, 2000) parents that had access to these support services reported that they increased their ability to better meet the demands of their work and home lives and increased the quality of life of their families.

I learned that accessing Individualized Funding through CLBC required approval of plans developed by clients in conjunction with a friend or family member (Community Living British Columbia, 2010). This would imply the need for knowledge of funding and services as well as advocacy skills. Some of the family members of clients that I met in the practicum office would not be able to meet the demands and requirements of funding or have the skills to advocate for the extent of services needed. Others had these skills but, similar to parents in the study by Freedman and Boyer (2000), were intimidated and overhwhelmed by the time and effort required to maintain funding and coordinate services (Freedman & Boyer, 2000). I learned that clients could hire an agency to coordinate services and manage their funding (Community Living British Columbia, 2010) but that clients could only purchase services from that agency, thus limiting their options for supports and services.

The second theme in the literature relevant to gaps concerned single mothers. Similar to the literature (Levine, 2009; Parish & Cloud, 2006; Ryan & Runswick-Cole, 2008), mothers on my caseload could work piecemeal work, were the primary caregivers of their special needs children, and had health, mental health, or addiction issues. As such, it may be unlikely that they would have time to research funding and service options or to develop the skills necessary to advocate to the degree needed for this situation. The discrimination experienced by mothers, and the internalized oppression as a result of this discrimination (Ryan & Runswick-Cole, 2008), would also affect their ability to advocate their cases.

The third connection to the literature regarding gaps was the need for a continuum of services (Boyd, 2002). Access to a continuum of services became harder with the division of CYSN and CLBC. Division of child and adult funding and services has made it necessary for youth to prove eligibility for adult services, for families to learn a new set of funding and services, and has caused disconnection between workers on both sides transitioning their clients. This has also decreased the amount of people asking for support and/or the amount they would receive if these were provided on a continuum.

From a structural view, keeping services and service providers separate and requiring them to adhere to different funding and services leaves parents and workers to piece together supports for families. Putting the onus on individuals and their ability to access services based on their ability to advocate for themselves gives the appearance of fairness and supports being offered while preserving the status quo. Internalized oppression would also make mothers grateful for amounts received even if they were signficantly less than they required. Further, families would receive more funding, services, and supports if they demanded them as a united group or if they were offered on a continuum. For these reasons social workers and parents need to advocate for changes to legislation to increase benefits for families, to increase funding for programs and services, and for a continuum of services to improve outcomes for special needs children and their families.

During my practicum I observed and participated in discussions wherein parents, workers, and management recognized these gaps and the need for change, such as the strategies mentioned, to improve services and supports for clients and their families. I knew the gaps from the perspective of a family member of persons with a disability but these experiences allowed me to see the frustrations and barriers faced by workers in providing services and supports. These experiences developed my understanding of these issues and this knowledge will benefit me in my personal life when accessing services and in my professional practice in the future.

I found three themes from the literature than were relevant to my practicum experiences with Aboriginal families with special needs children. The first theme in the literature regarding services in Kelowna for Aboriginal families with special needs children was the need for anti-racist practice. Racism prevents access to the same services or funding for services as other groups, causing devolution of services, and creates unsafe cultural environments (Mullaly, 2007). Racism also demeans culture and cultural practice and keeps disadvantaged groups in poverty (York, 1990). Concerns by Aboriginal workers that their clients should receive the same funding and services as non-Aboriginal clients, and should have access to culturally safe environments and cutural services, were, therefore, not unfounded. I also made links to poverty in relation to the overwhelming need for food reported by workers amongst this population. Connections between the literature and the concerns of Aboriginal workers confirmed for me the need to continue to be aware of these issues and to promote and practice anti-racist, anti-oppressive social work, such as structural social work.

The second connection to the literature related to services for Aboriginal people was the strengths of preventative services. Preventative services kept caregivers heallthy and assisted them to meet the demands of their lives (Freedman & Boyer, 2000). Connection to culture promotes cultural pride and increases wellbeing of individuals, communities, and nations (Graveline, 1998) and, as such, service providers viewed them to be imperative for their clients. These experiences reaffirmed the need for these services and increased my knowledge of how I could implement them within my own practice in the future.

The third theme in the literature and the gap forAboriginal people was funding (York, 1990). Lack of funding would affect Aboriginal families with children with special needs the same ways including gaps in transition services and the barriers associated with accessing funding and services. Constant underfunding of programs and services for Aboriginal people would also be associated with the larger structures of racism (York, 1990). All Aboriginal workers I met with noted lack of funding for their programs and services and believed this prevented them from running programs to their full potential and reaching the number of clients that required service. Through these experiences I made connections to racism as an additional barrier to accessing funding for Aboriginal agencies and service providers. I was aware of these barriers due to my own professional experience but they reaffirmed that they were relevant to community services for Aboriginal people in Kelowna.

Recognition of the need for anti-racist, anti-oppressive practice, such as structural social work, is needed when working with oppressed groups (Mullaly, 2007). Without analysis problems could be seen as resulting from personal deficits rather than from oppressive social structures (Mullaly, 2007); for example, blaming individuals for not applying themselves or agencies for not writing better proposals rather than making connections with the larger structures of racism. Recommendation and application of solutions based on analysis of problems as being caused by personal deficits would be oppressing people further. Recognition of these issues as structural would result in action at micro, mezzo, and macro levels to address issues associated with lack of funding, poverty, and the like, associated with racism.

Historic factors and power imbalances between workers and clients can also create barriers to service (Peiris et al., 2008). Recognition and analysis of power imbalances (Peiris et al., 2008), in addition to the lens of race and knowledge of the history and circumstances of Aboriginal people (Mulally, 2007), could assist workers and agencies to provide respectul culturally appropriate services. Anti-oppressive practice and the skills of analysis, application of special lenses, and an understanding of the barriers and situations of Aboriginal people, and persons with disabilities, are required for practice with this population.

Summary of the Development of Community Development Skills and Knowledge

A few of the ways I developed community development skills were participating with the CYSN community Table and with meeting individual service providers. The CYSN community table allowed me to meet a lot of service providers in a short period of time and find out what they did, as well as how their services worked together, and sometimes did not. I learned that service providers lacked information about services in the community and the community table provided them with the opportunity to learn more about these for their clients. Through meetings with individual service providers I developed networking skills, learned about available services and the culture of the community, and gained a current and historic view of services. I also gained knowledge of the strengths, needs, and gaps of community services in Kelowna, as well as these applied to Aboriginal clients and their families. I found out that the strengths were the workers and preventative services and the needs and gaps were funding and transition services. I learned that the strengths of community services were the same for Aboriginal clients and their families. Their needs and gaps were continued access to funding and services, cultural safety, and food insecurity and I made connection between consistent underfunding of programs, lack of cultural safety, and food insecurity to the larger social structures of racism. Application of structural social work was recommended as it is anti-oppressive, and utilizes special lenses, such as race, to better understand and meet the needs of clients. All of these experiences also allowed me to form professional relationships and friendships and these will assist me in my future work in the community.

Conclusion

I participated in clinical and community development work as part of my practicum to gain an understanding of how social workers assisted parents to navigate services to improve outcomes for families. As part of my clinical activities, I observed workers in their casework and applied the skills and knowledge I learned to my existing skills and knowledge. I carried a caseload and interacted with and observed clients in the placement office, which allowed me to make connections between clients' lives and the themes in the literature. I also developed a better understanding of programs and services offered by CYSN, its relationship to MCFD, other departments of MCFD, and community agencies.

As part of my community development activities I participated with the CYSN Community Table and met with individual service providers. These experiences developed my networking skills, knowledge of available community services, and how they worked together (or sometimes did not), as well as providing me with a current and historic view of services. I also gained knowledge of the strengths, needs, and gaps of community services for this population, including those specific to Aboriginal clients and their families. There were similarities and differences in these and I recommended implementation of structural social work theory and practice to better understand, and meet the needs of, non-Aboriginal and Aboriginal clients and their families. The themes of gender and poverty, specifically single mothers as raising their special needs children and the barriers they faced, were prominent in the literature and throughout the practicum. Recommendations were for workers and agencies to collaborate to meet the needs of families and advocacy to change legislation to increase benefits, funding for programs and services, and a continuum of services for special needs clients and their families.

I learned everything I set out to through the clinical and community development activities. I learned much more than I thought I would through the generosity of the time given to me by the workers in the practicum office and community. I have benefitted from this experience and the professional relationships and friendships I have built, and the knowledge and skills I have developed will serve me well and inform my practice in the future.

Chapter Four: Discussion and Implications for Practice

In this chapter I discuss what I have learned and the implications this has for my practice. I describe my learning and skill development through connections to the practicum questions, literature, and structural social work theory and practice. Connections to the role of social workers as assisting parents to navigate services to improve outcomes for special needs children and their families will be the focus throughout.

What Services are Available to Children, Youth, and Their Families within the Practicum Placement and Community?

During my practicum I learned that part of the job of CYSN social workers was accessing funding for families. Autism funding was used to purchase interventions for children with autism, respite was used to provide parents with a break from their special needs children, and At Home Program funding was used to cover the costs of medical supplies and equipment. MCFD also contracted services to meet the needs of families, including behavioral intervention, behavioral consultation, nursing, and homemaker services and these were referred to as globally funded programs. I completed all steps to access funding for clients on my caseload and all steps from initial contact to transitioning out of services.

I further learned about the At Home Program and eligibility for the same through involvement with the At Home Review Committee. These meetings also provided me with a different view of cases as members were from different disciplines and agencies. The backgrounds of the members, including the special needs lens brought by my daily activities supervisor, enriched the discussions and increased my knowledge of the barriers and supports available for this population.

I also met many service providers and learned about available community services in a short period of time through my involvement with the CYSN Community Table. I then met with workers individually, starting with those I met on the committee, to find out what their agencies offered. When I experienced difficulty social workers in the placement office assisted me by introducing me to people at meetings and networking events, and I sometimes gained access to service providers through my association with these workers. Through these experiences I found out about the services specific to special needs children and their families and the broader array of community services available for this population in Kelowna.

Various workers provided me with a current and historic view of community services. I also learned about the relationship of CYSN to other departments of MCFD and community agencies and how these worked together, and sometimes did not. I received mentorship and guidance throughout my practicum from workers in the placement office and my MSW mentor and I explored connections between the themes in the literature and practice regularly. I would not have gained this knowledge without the generosity of the workers in Kelowna and I intend to pass this knowledge on to others and use it in my future practice as an MSW.

What are the Needs of Families with Children and Youth with Special Needs and How Can Social Workers Help Parents Best Meet These Needs?

There were several reoccurring themes in the literature and practicum placement regarding the needs of families with children and youth with disabilities. The first reoccurring theme was gender and poverty, specifically as related to single mothers raising their special needs children and barriers to employment. Workers within the practicum reported twenty-five to thirty percent of their caseloads to be single mothers but my caseload and the themes in the literature indicated that special needs children were predominantly raised by single mothers (Levine, 2009). Similar to the literature, clients on my caseload and many in the practicum office experienced lack of access to appropriate and affordable childcare, their caregiving roles affected their ability to work, and both of these factors led to their participation in piecemeal work (Parish & Cloud, 2006; Ryan & Runswick-Cole, 2008). This was significant to gender as working was believed to be the key to getting and keeping families out of poverty (Parish & Cloud, 2006). Lack of childcare and participation in piecemeal work over long periods of time would result in mothers and their children living in poverty. Poverty and disability leave people vulnerable, open to neglect, and potentially abuse (Titchkosky & Michalko, 2009). The lives and circumstances of single mothers should not, therefore, be viewed as resulting from personal choice or personal deficits but from the larger social structures of gender and poverty. During my practicum I applied for respite to provide mothers with a break from their children and daycare supplement funding which could be used while they worked. One difficulty clients experienced was that respite could not be used for childcare while they worked. Another difficulty was that daycare supplements only provided a certain amount of hours per week and mothers were expected to contribute to funding, thus restricting the amount they were able to work each week and their take home pay. Increasing funding for services for respite and advocacy by workers and clients for universal childcare and increasing wages for women could assist mothers to get and remain out of poverty.

I learned that clients were put on waitlists for some CYSN services and, as such, services were prioritized to families based on need/crisis. Crisis driven services create environments where workers compete to present their clients as being in the most need/crisis, which may serve to divide workers and put focus on family deficits rather than on the need for more funding for services for this population. The literature and practicum supported that access to these types of preventative services allowed parents to work and meet the demands of their home lives which, in turn, improved the financial and overall wellbeing of families (Freedman & Boyer, 2000; Parish & Cloud, 2006). Preventative services were considered to be strengths of families in Kelowna and more funding should be implemented to make them accessible to all CYSN families.

The second reoccurring theme in the literature, and a strength of services in Kelowna, was collaboration. The first example of collaboration was service providers meeting at the beginning of service provision and on an ongoing basis to improve outcomes for families (Taanila et al., 2002). Similar to the literature, workers found that they were able to provide more effective service because plans were built around the needs of families (Taanila et al., 2002). They also reported increased communication between teams and reduced need for crisis intervention (Taanila et al., 2002). These experiences taught me that this method worked with families in Kelowna and I intend to implement it in my future practice with the connections I made during my practicum.

The second example in the literature related to collaboration was for workers to provide formal and informal services and supports (Boyd, 2002). I learned that workers were the strength of services as they collaborated with each other and the community to establish services, and continue to create formal services to meet the needs of clients. I participated with an information session between CYSN workers and school district staff for families that provided parents with the opportunity to learn about formal services and to request a parent group that would increase their informal networks (as supported by Freedman & Boyer, 2000). I also saw benefits of when CYSN and guardianship staff shared the CYSN office as their proximity to each other led to increased understanding of each other's jobs and increased camaraderie and collaboration between workers. Workers must be supported to participate in collaboration, including reducing caseloads and being adequately compensated for their extra activities, to ensure the best quality of services for clients. These experiences reminded me of the need for social workers to provide and create formal and informal services to meet the needs of families and I will continue to do so in my future practice.

The third recurring theme in the literature and practicum placement was providing services and funding tailored to meet the needs and circumstances of families (Freedman & Boyer, 2000). Similar to the literature (Freedman & Boyer, 2000), clients on my caseload and parents in the practicum placement wanted funding for services and supports that helped them meet the demands of their work and home lives and improved the quality of life of all family members. These included respite, money for training and therapies, and where applicable, home nursing care, and money to cover the cost of medical expenses and medical equipment (Freedman & Boyer, 2000). During my practicum I applied for respite to give parents a break from their special needs children, autism funding, which can be used to purchase training and interventions, and At Home Program Funding, which can be used to cover nursing care and medical expenses and equipment. Families are generally put on wait lists for respite and autism funding and there are strict criteria for the At Home Program so funding and services are not available, or not readily available, to all CYSN families. More funding so more families can access these needed, preventative, programs and services is recommended.

The main need and gap for services in Kelowna was funding for youth transitioning into adult services. Through the practicum I learned that funding and services for adults and children were previously provided under CLBC and that this led to a continuum of services as clients were automatically transitioned from one set of funding and services to another. Division into CYSN for children and CLBC for adults now requires youth to prove eligibility for adult funding and services, for caregivers to research and understand a different set of funding and services, and has caused division and difficulties for workers trying to transition their clients. More importantly, requiring all youth to prove eligibility for adult funding and services has decreased the amount of people asking for or receiving funding and the amounts they would receive than if these were still offered on a continuum. This was significant and a reoccurring theme throughout my practicum as there were many families with youth transitioning into adult services in Kelowna.

I learned that Individualized Funding (IF) was provided through CLBC and that clients accessed this funding through creating a plan with an agency, friend, or family member outlining supports and services the client would need to live and participate in the community (Community Living British Columbia, 2010). I also learned that clients could hire an agency to manage their funding and services (Community Living British Columbia, 2010) but that this limited their choice of services to those provided by the agency. This criterion implies the need for family members to have the ability to research and understand funding and services and to possess strong advocacy skills. Some of the caregivers I met in the practicum office would not have these skills. Others would have these skills but, similar to parents in the study by Freedman and Boyer (2000) felt overwhelmed by the responsibility of managing funding and coordinating services. Similar to the literature (Levine, 2009) mothers on my caseload raised their special needs children and faced multiple barriers such as having their own disabilities, health, mental health and/or addiction issues. They also faced scrutiny and judgment from professionals when with their children and, like mothers in the literature (Ryan & Runswick-Cole, 2008), this led them to develop a subservient position toward professionals and internalize these discriminations as their own oppression. As such, it would be unlikely that the single mothers on my caseload, and this population in general, would have developed the skills necessary to advocate to the extent needed in this situation. From a structural view, basing the ability to receive funding on caregivers' ability to advocate for it gives the appearance of fair and equal access to funding and services while preserving the status quo. Further, as an oppressed group, single mothers, would likely advocate for another oppressed group, their disabled children. This also has implications for oppression and discrimination based on gender and disability.

Social workers and clients need to advocate for more funding for services, changes to legislation to increase benefits for families (Freedman & Boyer, 2000), and for a continuum of services to meet the changing needs of families (Boyd, 2002). Increasing benefits and providing a continuum of services would increase the quality of life for families and ensure continued access to needed funding and services for persons with disabilities throughout their lives.

What are the Unique Needs, Issues, and Situations of Aboriginal Children with Disabilities and Their Families?

I also met with Aboriginal service providers to learn about barriers for Aboriginal children with disabilities and their families, and Aboriginal people in general, in Kelowna. I learned that cultural services were the strength of community services, were considered to be very important, and continuation of these was recommended. This matches the theme in the literature that culture served to strengthen families, communities, and nations and improved the wellbeing of Aboriginal people (Graveline, 1998).

One of the most significant things I learned was that all workers noted a lack of food amongst their clients. I also learned that cultural safety had improved in organizations in Kelowna but that this did not replace the need for cultural services such as community events and incorporating language and culture into programs to foster pride in heritage and connection to family and community. Aboriginal workers also wanted their clients to receive the same funding and services as non-Aboriginal clients. Aboriginal children currently receive the same funding and services under CYSN as non-Aboriginal children. Through CLBC, however, funds are withheld until all other potential sources of funding are exhausted (bands for example) and may result in funds not being provided for families. This process causes difficulty and stress for families and has implications for denying identity to receive services.

Anti-oppressive, anti-racist theory and practice, such as structural social work, is needed when working with oppressed groups. The literature indicates that racism and discrimination against Aboriginal people causes lack of access to funding and services, demeans culture and cultural practices, and keeps oppressed groups in poverty (Mullaly, 2007; York, 1990). Viewing social problems as being caused by the deficits of individuals or agencies (for example, if individuals only applied themselves, or if agencies only wrote better proposals) serves to further their oppression (Mullaly, 2007). Structural social work theory views problems as caused by social structures and practice is to make changes at micro, mezzo, and macro levels to address the cause of the problems (Mullay, 2007), in this case, poverty, lack of funding, and lack of cultural safety due to racism. Special lenses, such as gender and disability, are also implemented to further understand, assist, and prevent the oppression of clients (Mullaly, 2007).

Awareness of mistrust of government and the psychosocial stress of Aboriginal people related to historic factors (such as discriminatory policies and child apprehension and placement in non-Aboriginal foster homes) is also needed (Peiris et al., 2008). These factors may affect how Aboriginal people interact with workers and agencies (Peiris et al., 2008). Peiris et al. recommend that workers and agencies constantly evaluate and remain aware of power imbalances between themselves and clients at individual, service, and systemic levels. Peiris et al. also recommend providing services that meet the needs of clients, providing information about services, and not stereotype Aboriginal people.

I was supported by the Kelowna CYSN team leader and my MSW mentor to gather information about how MCFD could better meet the needs of, and provide more culturally appropriate service for, Aboriginal clients and their families. During my practicum I observed genuine interest from the CYSN Community Table and some workers in the placement and community to learn more about how they could implement this in their work and agencies. I also saw interest and willingness from the Aboriginal community to share this as well as knowledge of Aboriginal practices and culture. Part of my intent in the practicum and this report was to further this goal by contributing what I learned and my own view as a social worker, family member of persons with disabilities, and person of Scottish and Syilx (Okanagan Aboriginal) descent. Interest would be the first step in dialogue and openness to this information would be the second in implementation of these important goals and continuation of this work. What I learned from these experiences will serve me personally and professionally in my future practice as an MSW.

What Approaches and Skills are Best Suited to Working with This Population

The first approach that I found useful in my work with this population was awareness of the similarities and differences in the experience of having a family member with a disability (Dowling et al., 2004). During meetings with three caregivers I contributed my own experience of this and found that I developed rapport instantly with the two who clarified my role and lost rapport momentarily with one that did not. I reflected that I have felt oppressed by workers without family members with disabilities who identified with my experience as well as by workers with this background who negated the individual needs and circumstances of my family. These experiences reinforced the need for this awareness and for me to cater to the individual needs and circumstances of families as part of delivering effective service and anti-oppressive practice.

The second approach was the underlying theme in the practicum and literature of the need for social workers to adapt their practice to better meet the needs of clients (Freedman & Boyer, 2000; Tannila, et al., 2002). I realized that I had adapted the practice of using CYSN acronyms and jargon and that these were shorthand used by professionals that could lead to a "we know what we mean" approach in meetings as well as excluding those that do not speak the language. They can also be used by workers to distance or overpower clients (Mullaly, 2007). Further, I realized that the practices of professionals (for example, the need for parents to decipher the roles and language of professionals and for professionals to meet as a team after families were in crisis) could be in themselves exclusionary and oppressive to clients. I intend to use plain language and implement strategies by Taanila et al. (2002) of meeting at the beginning of service provision with other workers to address these needs and will continue to remain aware of the need to evaluate and adapt my practice throughout my career.

A skill that I found useful for working with this population was application of structural social work theory and practice. The use of structural social work theory, based in critical theory and using special lenses (Mullaly, 2007), helped me to gain more knowledge of the barriers of this population. Basing my knowledge in theory and themes from the literature review also assisted me to make connections to clients' lives and to evaluate my own practice. These skills and knowledge were essential to my learning and I will continue to develop them in my practice.

I also observed and participated in assessment, interview, facilitation, and counseling skills as part of my practicum. The workers in the office had different strengths in these and other areas and observation of these techniques developed my knowledge of the use of these in clinical practice with this population. I combined these techniques with my own existing skills and knowledge and used them throughout the practicum. These skills were useful when using an assessment tool required for parents to access or get more services as questions assessed family stressors and resources and priority was given to those with a higher score; thus making it deficit based and crisis driven in nature. As such, I adapted practices to gather enough information to access services for families without being too intrusive. Though I had these skills before, using them with this population furthered my skills and increased my knowledge of special needs children and their families in general. These experiences also reaffirmed the need for workers to have these and others skills (such as analysis and special lenses), a basic understanding of disabilities, and knowledge of the barriers of clients and families. Without these skills and knowledge workers may be ineffective, or worse, oppressive to clients and their families.

Effective service provision and anti-oppressive practice must also be supported by agencies and institutions. Crisis driven services pit workers against each other to present their clients as being the most in need/crisis. It also focuses on family deficits so those desperate for services, such as the single mothers on my caseload, readily shared this information. This has implications as it serves to reinforce stereotypes of this population, thereby reinforcing blaming the victim and adding to the larger overarching problem of gender and poverty. This is important as others would have similar problems but could choose not to divulge them if they had access to other resources. If caregivers were Aboriginal they may also fear the ramifications of giving this information due to psychosocial stress from historic factors (Peiris et al., 2008). All of these are barriers and take focus from the need for more funding for services for all clients. Workers and clients need to advocate for more funding for services so these services can be accessed by all CYSN clients.

How did the practicum affect my professional development?

One of the ways I developed my clinical skills and knowledge was through observation of workers in the placement office. Observation of the range of their clinical skills allowed me to gain knowledge of practical application of these with this population of clients. I also integrated their interview, assessment, facilitation, and counseling skills (among others) with my own existing skills and utilized them throughout my practicum. I have found these useful and will continue to develop them in my future practice.

I also carried a caseload to develop my clinical social work skills and knowledge. I carried a caseload of six clients determined between my mentor and I; all were single parents with special needs children and all faced significant barriers such as poverty, mental health concerns, or their own disabilities. My clients were not reflective of the population of clients in Kelowna as workers told me that only twenty five to thirty percent of their clients were single parents but was reflective of the literature as the literature indicates that it is often single mothers raising their special needs children and facing significant barriers (Parish & Cloud, 2006; Ryan & Runswick-Cole, 2008). These experiences allowed me to see how these barriers affected mothers and their families in Kelowna and gave me the ability to utilize my skills and the resources of the CYSN office to mitigate these barriers.

I also gained knowledge of CYSN, the relationship of CYSN to other departments of MCFD and in the context of MCFD, and in relation to community agencies and was able to learn how these services worked together, and sometimes did not. The dynamics of the voluntary services of CYSN and involuntary services in other departments of MCFD and the need for a special needs lens were present throughout my practicum. Instances of consultation of CYSN knowledge of special needs and collaboration between CYSN workers and guardianship staff to better meet the needs of children in care was a good example of interagency collaboration. I learned that preventative services, such as those provided by CYSN, contributed to the overall wellbeing of families, reduced the need for crisis intervention, and reduced the cost of services over the long term (Taanila et al., 2002). These services, and workers with the specialized knowledge to serve this population, therefore, need to continue to be supported to improve outcomes for special needs children and their families.

I developed my community development and networking skills by participating with the CYSN community table and meeting with community service providers. Through these experiences I learned about the services offered in the community specifically for special needs children and their families as well as the broader range of services available for this population. These experiences reinforced the need for collaboration amongst workers and agencies and my need to remain aware of services to assist my clients. Although I knew it before, my interactions with workers in the placement office and community reinforced that I needed to provide and create services to meet the needs of clients. The networks I developed assisted me throughout my practicum and I will continue to benefit from them in my future work as an MSW in Kelowna.

Conclusion

I set out to find out how social workers improved outcomes for special needs children and their families. I participated in clinical and community development activities to understand this and to develop knowledge and skills for working with this population. One of the most significant things I learned during my practicum was that there was a need for action by professionals, families, self advocates, and communities to advocate for changes to legislation to increase benefits for families (Freedman & Boyer, 2000), for more funding for programs and services, and a continuum of programs and services for persons with disabilities. These would improve the quality of life of all family members and ensure funding and services for persons with disabilities throughout their lives. Like other parents, parents of children with disabilities want the best for their children. The purpose of these service and support networks then would be for children and adults with disabilities to have the support of their families, in their communities, and to live their most optimal life possible.

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