A qualitative study on advocacy for employment in mental health

by

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Abstract

Advocacy is an expectation in health delivery services including occupational therapy (OT) services. Advocacy in health care has been related to assisting vulnerable individuals in protecting them from social exclusion and accessing opportunities. Employment is one of the most valued roles among individuals diagnosed with depression (IDDs), yet unemployment rates are high. The disparity between unemployment rates and desire for IDDs to be employed makes it imperative to investigate advocacy in ameliorating the barriers to employment. Furthermore, advocacy practices need to be clearly defined as lack of clarity in advocacy roles and processes contribute to challenges with implementing advocacy.

This qualitative study explores the perceptions of the advocate role and the advocacy process among IDDs and OTs regarding employment related goals. IDDs were interviewed individually and OTs participated in a focus group to explore their perceptions of the advocate role and how the advocacy process is carried out. The recovery model and Canadian Model of Occupational Performance Model & Engagement (CMOP-E) were used as practice models to inform the topic choice.

Study results indicate significant differences in expectations of the advocate role and how the advocacy process is carried out. However, there were some similarities in perception, such as the relationship established the foundation of the advocacy process, the advocate role addresses both health and employment issues, and advocacy processes yields outcomes. IDDs and OTs agreed that the advocacy process faciltated change by considering the dynamic interaction between the person, the occupations the IDDs wished to engage in, and the individual's environments, which is consistent with core elements of the CMOP-E.

OTs' perception of the advocate role was consistent with the core elements of the recovery model of enhancing individual autonomy, facilitating client empowerment, and increasing client responsibility. On the other hand, IDDs felt that the advocacy process was having the advocate speak to others on their behalf, which is not consistent with the core elements of the recovery model. A number of complex issues contributed to why IDDs relied significantly on their advocates, such as 1) mental health stigma 2) previous negative experiences, 3) poor self-esteem and 4) fears related to disclosure of their depression.

This study contributes to the existing body of literature as this study describes the advocacy process and advocate role as perceived by IDDs and OTs. The study is unique in design that it is one of the only studies that explores the concept of advocacy from two different perspectives (health providers and health users).

Future research is indicated to establish a consistent definition of advocacy and establish a framework for carrying out the advocacy process. A consistent definition and advocacy framework would provide OTs a frame of reference in implementing the advocacy process. Furthermore, advocacy processes at all levels should be integrated into OT scope of practices to further enhance the practice of advocacy.

Key words: advocacy, employment, depression, advocate roles, advocacy process

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Dedication

"You must be the change you wish to see in the world"
-Mahatma Ghandi

"Be kind, for everyone you meet is fighting a battle you know nothing about"
-Wendy Mass

To my immediate core family:
-You inspire me to learn, grow, and enjoy the present everyday. May you continue to grow, learn, and continue to explore the world with a fresh perspective each and every day.

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Abbreviations

IDDs: Individuals diagnosed with depression

IMI: Individuals with mental illness

OTs:Occupational therapists

CMOP-E: Canadian Model of Occupational Performance and Engagement

COTM:College of Occupational Therapists of Manitoba

1.0 Introduction

Advocacy: The impact of advocacy on mental health

Advocacy is an expected professional responsibility of many health care clinicians, such as occupational therapists, nurses, job coaches, and peer support specialists, as advocacy has shown to be effective in overcoming mental health stigma and improving quality of life for individuals with depression (Blitz & Mechanic, 2006; Dhillon, Wilkins, Law, Stewart, & Tremblay (2010); Funk, Minoletti, Drew, Taylor, & Saraceno, 2005; Stylianos & Kehyayan, 2012). Occupational therapy literature describes advocacy as a traditional role within the occupational therapy profession. From an occupational therapy perspective, McColl (2003) defines advocacy as "initiatives taken by a therapist on behalf of a client, to pursue change in the environment that will ultimately enhance occupation" (p. 5). However, McColl's definition of advocacy has been criticized for not addressing collaboration between the therapist and client (Dhillon et al., 2010). Advocacy in health care has been primarily related to individuals/ clients who are vulnerable (Jugessur & Iles, 2009). While advocacy has been identified as a critical service in health care delivery to address an important cause or pursuit of a meaningful goal, there are no consistent definitions of advocacy and there is limited literature dedicated to understanding the advocacy process within occupational therapy, specifically in mental health (Dhillon et al., 2010; Sachs & Linn, 1997; Smith, 2005; Stergiou-Kita, Moll, Walsh, & Gewurtz, 2010; Swedlove & Brown, 1997).

The impact of employment on health

Employment is one of the determinants of health which is linked to health and well-being, and is identified as one of the most valued roles and occupations for individuals (Gutman, Kerner, Zombek, Dulek, & Ramsey, 2009). Engaging in meaningful occupations, such as employment,

promotes recovery and wellness in health care as well as facilitates social inclusion for individuals diagnosed with depression (Boyce, Secker, Johnson, Floyd, Grove, Schneider, & Slade, 2008). The health benefits of employment for all individuals, with or without mental illness, include: structure and routine (Dunn, Wewiorski, & Rogers, 2008; Koletsi, Niersman, van Busschbach, Catty, Becker, & Burns 2009;), financial stability to meet basic needs such as food and shelter (Dunn et al. 2008; Koletsi et al., 2009; Moll, Huff, & Detwiler, 2003), a social network and sense of belonging to a community (Koletsi et al., 2009), improved self-esteem (Bell, Lysaker, & Millstein, 1996; Blankertz & Robinson, 1996; Koletsi et al., 2009), and development and refinement of skills (Koletsi et al., 2009).

Being employed has also been linked with independent living, improved quality of life, and participation in meaningful activities and roles (Gutman et al., 2009). Kirsh, Stergiou-Kita, Gewurtz, Dawson, Krupa, Lysaght, & Shaw (2009) describe employment as a "fundamental right of citizenship", indicating that employment opportunities must be equally accessible to all individuals regardless of age, gender, and/ or race (Kirsh et al., 2009, p. 391).

Employment and depression

Despite the positive impact of employment on health, 70 to 90 percent of individuals who have been diagnosed with a mental illness, including depression, are unemployed in Canada (*Mood Disorders Canada, 2013*). Depression has been identified as the "fastest growing category of disability costs for Canadian employers" (*Mood Disorders Canada, 2013*) and according to statistics published by the Canadian disability insurance industry, 75 percent of the short term disability claims and 79 percent of the long term disability claims are attributed primarily to depression (*Mood Disorders Canada, 2013*). The World Health Organization indicates that depression is ranked as the leading worldwide cause of disability and individuals with depression can struggle significantly with functional performance in the workplace *(*Shields, 2006; *World*

Health Organization, 2013). Furthermore, individuals diagnosed with depression (IDDs) have demonstrated decreased work productivity in the workforce (Shields, 2006). Based on statistics provided by the Canadian Mental Health Association, three million Canadians will experience a period of depression at least once in their life time, occurring within the "working ages" between twenty-four to forty-four. *(Community Mental Health Association, 2013).* Depression, along with anxiety and substance use disorders, is one of the most prevalent mental illnesses in Canada that can negatively impact functional performance in the workplace (Koletsi et al., 2009).

Individuals with mental illness, including individuals diagnosed with depression, desire employment and identify paid work as an important component of their recovery despite low employment rates (Bond, Becker, Drake, Rapp, Meisler, & Lehman, 2001; Lord, Scharr, & Hutchison, 1987; Moll et al., 2003; Tse, 2002).

Advocacy and employment for individuals diagnosed with depression (IDDs)

The disparity between the number of IDDs participating in competitive employment and the high number of IDD wanting to be employed makes it imperative to investigate the role of advocacy in ameliorating the barriers to employment (Bond et al., 2001; Lord, Scharr, & Hutchison, 1987; Moll et al., 2003; Tse, 2002; Munro & Edward, 2008). Furthermore, advocacy within the occupational therapy (OT) role need to be clearly defined (Stergiou-Kita et al., 2010) as lack of clarity in the advocate role and advocacy process contributes to the difficulties OTs have in advocating effectively and consistently in their clinical practices (Dhillon et al., 2010; Jugessur & Iles, 2009).

Purpose of research study

The overall purpose of the study is to explore the perceptions of the advocate role and to describe the advocacy process from IDDs' and OTs' perspectives.

Search strategy

The search criteria for the literature review included English language articles, using the search terms: "adult mental health," "employment," "psychiatry and mental illness," and "advocacy." Key words that were included in the abstract, title, and/ or subject headings included "vocational rehabilitation" OR "return to work" OR "employment" AND "depression" OR "mood disorder" OR "serious mental illness" OR "psychiatric illness" OR "mental illness" AND "advocacy" OR "justify" OR "recommend OR "rectify"." Additional articles were used based on the reference lists of relevant articles. Please refer to Tables 1 and 2 for the combination of key terms and phrases used in the literature review process. The asterisks indicate a search for all the words that begin with that prefix in relevant articles and the 'W/5' symbol indicates a combination of one word in close proximity to another specific word. For example, ("advoca* W/5 work") reads as 'advocacy' OR 'advocating' OR 'advocate' within 5 words of the word 'work.' Each of the key words were used in combination with one another where the word "AND" is indicated between each phrase or term. The only exclusion criteria for this paper were publications not published in English. No limits were put in terms of the publication dates, as the researcher did not want to exclude any studies or review articles on this specific topic. Pubmed, Cinahl, PsychInfo, Googlescholar, Scopus, and OTDbase were the databases used to obtain relevant articles for this paper. A total of 69 references were included in this literature review paper, as listed in the reference section.

Table 1.a) Word combinations used in literature search

Vocational rehabilitation	**AND**	Depression	**AND**	Advocacy
OR		**OR**		**OR**
Return to work	**AND**	Mood disorder	**AND**	Justify
OR		**OR**		**OR**
Employment	**AND**	Serious mental illness	**AND**	Recommend
		OR		**OR**
		Pychiatric illness		Rectify
		OR		
		Mental illness		

Table 1.b) Abbreviations used in literature search

Mental illness	**AND**	Psychiatric w/5 disabilit	**AND**	Vocation* w/ rehabilit*	**AND**	Advocacy
OR						**OR**
Advoca* w/		**AND**				Advocate
OR						**OR**
Vocational rehabilitation		**AND**				Advocated
OR						
Advoca* w/5 work						
OR						
Advoca* w/5 job						

2.0 Literature review

Definitions of advocacy

Advocacy has been defined differently in various health fields. The definition of advocacy originated in a legal context whereby advocacy is influencing and persuading others to make decisions on the basis of individuals exercising their rights, being treated equally, and being protected from abuse or exclusion (Jugessur & Iles, 2009; Stylianos & Kehyayan, 2012). The concept of advocacy in health care has been primarily related to individuals/ clients who are vulnerable (Jugessur & Iles, 2009). Advocacy has also been defined as an obligation/ moral commitment to facilitate individual autonomy (Gadow, 1989).

Sheafor & Horejsi (2003) indicate that successful processes of advocacy are based on: 1) a set of actions to carry out a plan/ goal 2) establishing an alliance with others based on self-interest and trust 3) genuine understanding of the individual's circumstances 4) strategies of overcoming opposing views and 5) the implementation of various advocacy skill sets and strategies. Advocacy is a role that can lead to organizational and social change, therefore advocacy within the employment sector is very important (Chima, 2005). Individuals with mental illness (IMI) are often discriminated from employment opportunities, therefore the role of advocacy is to address employment related issues for IMI (Chima, 2005).

Chima (2005), who discusses the advocacy perspective for individuals with a disability, further describes the advocate role of the rehabilitation counselors as addressing both interpersonal and psychosocial issues by minimizing the impact of mental illness on employment, assisting individuals to develop appropriate skills, and modifying environmental conditions to enhance vocational opportunities.

From the perspectives of community health workers (CHW), advocacy is a core function within community level advocacy, whereby the advocate role is to address structural issues and health inequities such as poverty, employment, housing, and discrimination (Ingram, Sabo, Rothers, Wennerstrom, & Guernsey de Zapien, 2008). Based on Ingram et al.'s study, which explored the advocacy efforts among CHW, the advocacy process was more likely to be carried out depending on the individual's work setting, the individual's level of autonomy in the work setting, and the individual's perception of having a leadership role. Furthermore, receiving leadership training indicated a higher potential of engaging in community level advocacy (Ingram et al., 2008).

Negarandeh, Oskouie, Ahmadi, Nikravesh, & Hallberg (2006), who explored barriers and facilitators of advocacy among Iranian nurses within an inpatient setting, found that facilitators such

as the client-nurse relationship, knowledge and skillset of the nurse, awareness of the client's needs, and collaborative relationship with the physician promoted the implementation of the advocacy process within inpatient health delivery services.

Advocacy and occupational therapy: Occupational therapists as advocates for others

One of the primary occupational therapy roles is to advocate for and enable individuals to participate in meaningful occupations of their choice, including employment, within their own environments (Restall, Ripat, & Stern, 2003; Townsend, Langille, & Ripley, 2003). Occupational therapists are agents of change who challenge current practices and policies and bring forward innovative ideas to promote occupational engagement (Townsend et al., 2007). Occupational therapists demonstrate the advocacy process on behalf of their clients when they (OTs) move beyond identifying the barriers that prevent occupational engagement (such as limited funds, decreased social supports, or poor confidence) to implementing strategies to achieve client engagement in activity. Advocacy for occupational justice and societal inclusiveness in mental health can lead to social integration, normalization, and access to employment opportunities and resources that should be accessible to everyone (Funk et al., 2005). Providing education to the general public and employers is also a form of advocacy, which is a critical role in de-mystifying myths about IMIs' abilities in the workplace (Stergiou- Kita et al., 2010; Townsend & Wilcock, 2004). Occupational therapists can educate employers by emphasizing the employee's strengths, establishing a vocational plan, and justifying workplace accommodations (Tse, 2002; Shaw et al., 2008; Stergiou-Kita et al., 2010; Tahan, 2005).

Dhillon et al. (2010) conducted a phenomenology study with OTs to gain a comprehensive understanding of advocacy by occupational therapy clinicians. Six themes were identified as to why occupational therapists advocate and how OTs learned to advocate: 1) personal fulfillment, 2) having power and influence, 3) focusing on outcomes leading to the client engaging in meaningful

occupations,4) facilitating client-centred practice, 5) addressing human rights and basic needs, and 6) improving quality of life (Dhillon et al, 2010). The occupational therapists in this study perceived advocacy as part of their scope of practice and learned advocacy skills through job experience, observing colleagues, and eliciting workplace feedback from colleagues. The therapists also believed that learning advocacy skills was an ongoing process. Dhillon et al.'s (2010) study was one of the only in-depth studies published that specifically aimed at exploring the definition of advocacy by occupational therapy clinicians. However, one of the critiques of this study is that the advocacy role primarily focused on advocacy at the micro-level between client and occupational therapist.

Advocacy at the micro-, meso-, and macro- levels.

Advocacy has also been identified as a process that occurs within different system levels, such as the micro-, meso-, and macro- levels. Advocacy within the micro- level impacts change within one individual's life or environment, meso- level advocacy impacts service delivery within a program, facility or within populations, and macro- level advocacy impacts change within large populations such as communities, ethnicities, or people living within the specific geographical locations (Moll et al., 2003; Negarandeh et al., 2006; Shaw, Hong, Pransky, & Loisel, 2008; Stergiou-Kita et al., 2010; Tahan, 2005; Tannous 2000;Townsend et al., 2007).

From an occupational therapy perspective, Tannous (2000) categorizes two types of advocacy: individual advocacy (micro-level) and systemic advocacy (meso- and macro- levels). Tannous (2000) further divides individual advocacy to two subtypes referred to as citizen advocacy and self-advocacy to describe two advocate roles within the micro- level. The advocate role within citizen advocacy includes tasks such as connecting an individual to various community networks, collaborating with funding agencies, providing companionship, and monitoring progress within programs or services the individual is receiving. Self-advocacy and facilitating self-advocacy, on

the other hand, is an empowering strategy for individuals to independently learn to assert and advocate for themselves (Jugessur & Iles, 2009; Tannous, 2000).

A study by Tahan (2005), who explored the concept of micro-, meso-, and macro- level advocacy within the context of the case management role, emphasized the importance of advocacy within all systems levels. Tahan (2005) classified advocacy occurring within a four-tier system referred to as: 1) client advocacy (micro level), impacting an individual life; 2) organizational advocacy (meso level), which aimed to improve the operation and health care delivery of an organization; 3) community advocacy (macro level), which aimed to create new services in communities to serve many people within a community; and 4) Global advocacy (macro level), which aimed to affect change at the political level (health laws and policies) and influence change for the general public. Tahan (2005) indicated that advocacy was a vital role in case management and also believed case managers consistently advocated for clients across the health care continuum within all advocacy levels (i.e. within and outside of hospital settings). Tahan (2005) described the process within case management as: 1)completing an evaluation of health services; 2) transitioning and integrating clients from one setting into another environment; 3) having ongoing communication with third party payers providing funds for care; 4) obtaining approval for services/ equipment related to client care; and 6) coordinating overall health service delivery for their client.

Restall & Ripat (2008) found that occupational therapists were more knowledgeable in implementing advocacy strategies at the micro- level but identified the need for OTs to implement meso- and macro-level advocacy strategies. Meso- and macro- level strategies, such as responding to initiatives, partnering with professional organizations, or presenting information to others, were identified as important because a significant goal of advocacy within these systems

levels is to ameliorate social injustice within a group of people or population (Restall et al., 2008; Stergiou-Kita et al, 2010).

Macro-level changes may be initiated when a population of individuals facing similar issues form advocacy groups to demonstrate a need for change, which is an effective method in empowering and supporting each other (Funk et al., 2005). Funk et al. (2005) indicated that advocating for changes to mental health policies was unlikely to be modified or implemented without the involvement of individuals diagnosed with mental illness or mental health service agencies. Furthermore, macro-level advocacy was more likely to be successful if the groups of people working together were knowledgeable about marketing ideas, developing collaborative relationships with government, and navigating within current political practices (Restall & Ripat, 2008). Therefore, change within the meso- and macro-level systems required a complex integration of specific skill sets carried out by motivated groups of individuals.

Enabling self-advocacy.

Individuals who self-advocate demonstrate more autonomy with decision-making,negotiating with others/ employers, and engaging in conflict resolution processes (Koch 2000). Therefore, teaching individuals/ clients to develop self-advocacy skills would be a role for an advocate/ occupational therapist. Individuals/ clients were more likely to become self-advocates when they learned their employment rights and how employment is impacted by mental illness (Townsend, Langille, & Ripley, 2003). Learning skills in assertion, effective communication, conflict management, and negotiation were important in order for an individual to become a self-advocate (Tse, 2002; Koch, 2000). Funk et al. (2005) also describe the importance of individuals self-advocating in activities at the meso- and macro- levels, (particularly in promoting action and change at the policy level for workplace issues), so that their voices could be heard regarding the workplace policies that impact their employment.

Examples of ways in which IDDs can self- advocate at the meso- and macro- levels include: interacting with the public to challenge myths about mental illness, sharing personal experiences in managing their illness with others, sharing successful employment accomplishments related to maintaining or having employment, and developing a social network with other individuals who struggle with both mental health issues and employment (Corrigan & Wassel, 2008; Funk et al., 2005).

Several studies (Chan, Shaw, McMahon, Koch, & Strauser, 1997; Roessler, Rumrill, Brown, & Palmer, 1999) developed a step-by-step conflict resolution approach that facilitated self-advocacy and workplace relationship-enhancing techniques. The steps to this approach included: 1) specifying the issue(s) causing conflict, 2) paraphrasing the issues identified by the employer to ensure the information was interpreted correctly, 3) Incorporating user-friendly language to identify possible collaborative solutions to the issues, 4) generating as many solutions as possible and being open to different solutions, 5) documenting the list of solutions discussed, and 6) selecting one or two of the options to trial or implement. This conflict resolution framework was developed to assist health professionals in empowering their clients to negotiate, approach situations diplomatically, problem-solve through difficult situations, enhance the worker-workplace relationship, and promote employer collaboration.

Advocacy is a complex process

Advocacy is a complex process because there are many components that make up the concept of the advocacy process. Based on the literature review, implementing hope, providing education, addressing mental health stigma and occupational justice issues, and implementing workplace accommodations were the various components that make up the advocacy process and advocate role (Corrigan, 2002; Fabian, Waterworth, & Ripke, 1993; Munro & Edward, 2008; Nolan,

2007; Shaw et al., 2008; Stergiou- Kita et al., 2010; Tahan, 2005; Townsend & Wilcock, 2004; Tse, 2002;).

Implementing hope for IDDs is a significant part of treatment and recovery in mental health. Hope is facilitated by developing an interpersonal relationship with the individual, encouraging the client, helping the client accept their illness, and helping the client recognize their strengths/skill sets (Tse, 2002; Corrigan, 2002). An individual being hopeful about their futures was a prerequisite before IDDs could engage in new occupations, such as employment, especially if that individual lacked confidence and skill sets (Tse, 2002).

It is ideal for IMI to feel revitalized and motivated to pursue goals and lead meaningful lives after receiving mental health services; however according to Nolan (2007), many recipients of mental health care often feel disappointed and disabled despite receiving health services.

Kay (2001), who cited a National Health Interview Survey-Disability Supplement in her study, identified stigma as a major contributor to IMIs feeling hopeless; participants believed they were discriminated from employment opportunities. While instilling hope does not directly lead to obtaining employment, individuals accepting their illness and having realistic expectations regarding work capabilities are more likely to begin a successful journey towards obtaining employment (Tse, 2002).

Mental health stigma

Stigma is a significant contributor to unemployment among individuals with depression (Boyce et al., 2011; Cook, 2006; Munro & Edward, 2008). According to Cook (2006), longitudinal studies have indicated that stigma exists in the workplace and employers have negative views about hiring individuals with a mental illness. Addressing mental health stigma, occupational justice, and promoting societal inclusiveness are significant roles for advocates in mental health (Corrigan, 2002; Townsend & Wilcock, 2004). Townsend & Wilcock (2004) defined occupational

justice as the “convergent relationship between occupation and justice”; occupational justice occurs when individuals have equal access to meaningful occupations, such as paid employment, within their community (Townsend & Wilcock, 2004, p. 76). Social inclusiveness, occupational justice, and mental health advocacy cannot be explored without addressing stigma.

Stigma is a significant barrier to employment for individuals with depression and a major contributor to social exclusion (Funk et al., 2005). Social exclusion and injustice occur when individuals with a disability are excluded from activities typically available to all individuals, including participation in competitive employment (Corrigan, 2002; Gutman et al., 2009; Kelly, 2006; Townsend & Wilcock, 2004). Gutman et al. (2009) noted that social exclusion for IMI was manifested in limited supported education for IMI compared to people with other disabilities and suggested that stigma accounted for this disparity in access to supported education. The inequality in resources for the mental health population compared to other disability populations was an indicator that advocacy for increased vocational supports and programming for IMI is needed. This is especially true since higher education and vocational training is a prerequisite to employment for most individuals with or without a mental illness (Morbray, Collins, & Bybee, 1999; Unger, 1994).

Implementing workplace accommodations

Implementing workplace accommodations is another advocacy strategy to successfully re-integrate IDDs and individuals with other mental illness into previous employment (Fabian, Waterworth, & Ripke, 1993; Munro & Edward, 2008). This involved negotiating work structures, such as making flexible changes to work schedules (Blitz & Mechanic, 2006; Tse, 2002); implementing breaks; accommodating time off for medical appointments (Blitz & Mechanic, 2006; Tse, 2002); tailoring job duties to the employee’s skill set (Becker, Whitley, Bailey, & Drake, 2007; Blitz & Mechanic, 2006; Purnima & Ochocka, 2004); job re-structuring; modifying work procedures and expectations (Raderstorf & Kurtz, 2006; Tse, 2002) and extended time off from work (Tse,

2002). Eliminating structural barriers to employment, such as transportation issues, housing, and finances, was another form of workplace accommodation (Blitz & Mechanic, 2006; Tse, 2002). Blitz and Mechanic (2006) indicated that the role of the advocate should address these structural barriers by assisting individuals in securing housing and addressing individuals' financial issues and psychosocial issues. Job flexibility, relationships with employment counselors, and opportunities to develop skill development relevant to work were other factors that also enhanced opportunities to maintain employment for IDDs (Munro & Edwards, 2008).

Implementing workplace accommodations has demonstrated successful re-integration to work for individuals with depression (Becker et al., 2007; Blitz & Mechanic, 2006; King et al., 2006; Kirsh et al., 2009) implementing workplace accommodations is a key advocate role in assisting individuals who have a job to return to that job. The advocacy process regarding implementing workplace accommodations include: minimizing the period of time between looking for employment and securing employment (Kirsh et al., 2009), ensuring ongoing and long-term follow up for both mental health and vocational services is in place (King et al., 2006), promoting part time and flexible work hours (Becker et al., 2007; Blitz & Mechanic, 2006), exploring opportunities for work adaptation and on-the-job training (Purnima & Ochocka,2004; Van Oostrom, van Mechelen, Terluin, de Vet, and Anema, 2009), and facilitating relationships between a vocational worker and the work manager (Becker et al., 2007; Koletsi et al., 2009: Van Oostrom et al., 2009), and implementing health promotion and mental illness awareness activities in the workplace (Alverson, Carpenter, & Drake,2006; Purnima & Ochocka, 2004).

Advocates have multiple skill sets

Advocates need a significant amount of knowledge and skills to be effective advocates in the workplace(Stergiou-Kita et al., 2010; Funk et al., 2005; Juggesur & Iles, 2008). Advocates must be knowledgeable about 1) the clinical aspects of depression and its impact on workplace

performance, 2) workplace legislation and policies in relation to mental illness/ depression and 3) the client's story (Stergiou-Kita et al., 2010; Funk et al., 2005; Juggesur & Iles, 2008). Hellwig, Yam & DiGiulio (2003) indicate that the abilities to develop trust with the other individual, effective communication skills, credibility, tenacity, and persistence within challenging situations are required advocacy skills for health professionals to be effective advocates.

Outcomes of advocacy

Self-advocacy and personal empowerment.

Empowerment is the promotion of personal power, increased self-efficacy, and sense of control of one's life (Corrigan, 2002; Stylianos & Kehyayan, 2012). Therefore, individuals who are able to self-advocate are most likely to feel good about themselves, feel they are active participants in situations, and may be more willing to take risks in their life, such as seeking employment. While advocacy and empowerment are related, empowerment is not synonymous with advocacy and they are not interchangeable concepts. Advocacy is about facilitating positive change; empowerment is the internal drive to assist with facilitating the change.

Corrigan (2002) states that people who feel empowered often experience better mental health outcomes. For example, individuals who feel empowered in a dynamic relationship with their advocates show more benefits in psychiatric treatment follow up and better symptom management (Corrigan, 2002). One could conclude that if an IDD is managing his or her psychiatric symptoms and feels empowered, that individual would be at a higher readiness level to be exploring employment or a return to work compared to someone who continues to experience significant psychiatric symptoms and limited empowerment.

Employment for individuals with depression (IDDs).

Employed individuals with depression demonstrate decreased workplace productivity as compared to individuals without depression, which is often impacted by difficulties with social

participation, comprehension, communication, and daily functioning (Dewa, Thompson, & Jacobs, 2011).

Lerner et al., 2004, who assessed work outcomes among employees with depression based on baseline and six month follow up data, found that individuals with depression expressed more co-morbid health problems, physical health problems, and poorer mental health and presented with more absenteeism and job loss in comparison to the control group. However, study results indicated that as depressive symptoms subsided, employment outcomes also improved (Lerner et al., 2004).

Blitz and Mechanic (2006) suggested that opportunities for successful job placements increased as the individual's level of academic and vocational skills education increased. Therefore advocates helping individuals seeking employment must have a good working knowledge of the available vocational and educational programs so that they (advocates) were able to educate the individual on alternative long-term options if immediate employment or return to work was not realistic (Tse, 2002).

Barriers to employment

While the focus of this study was on the topic of advocacy, it is important to note the barriers to employment because the advocacy process is about overcoming the barriers that hindered an individual's goal.

As previously mentioned, mental health stigma is a significant contributor to unemployment for IDDs. Existing vocational programs and structures for individuals with mental health issues have also been a barrier for employment for IDD. Cook (2006) criticized the lack of integration of vocational programs with mental health care, which resulted in poor coordination and gaps in health service delivery. Other critiques of existing vocational programs include a mismatch between job placements and clients' vocational goals as well as the decreased longevity with work

placements (Cook, 2006). Supported employment, a service delivery approach that aims to help individuals achieve competitive employment through an individualized treatment approach, has proved more effective than prevocational training (Cook, 2006; Becker et al., 2007; Blitz & Mechanic, 2006). Several studies (Becker et al., 2007; Cook, 2006) indicated that a higher percentage of individuals in the supported employment program achieved better employment outcomes, such as securing employment and increased workplace longevity, than those who received vocational services through other programs.

Barriers to advocacy

Advocacy is an important role and expectation within health service delivery and occupational therapists identify being an advocate within their scope of practice area. However, many factors limit a health professional's abilities in carrying out the advocacy process. The barriers within the micro- level are primarily related to the IDD's limited skill sets in the cognitive and social domains whereas the meso-and macro- level barriers are more related to systemic issues that the advocates face. It is important to be aware of these barriers as these are the reasons that contribute to the difficulties in implementing the advocacy process.

Barriers to micro-level advocacy include: the severity of an IDD's psychiatric symptoms that affect their functional abilities in the workplace (Baron & Salzer, 2002; Kelly, 2005; King et al., 2006; Kirsh et al., 2009), poor interpersonal skills (Baron & Salzer, 2002; Kelly, 2005; King et al., 2006) affecting working relationships with the stakeholders, presence of cognitive deficits (Baron & Salzer, 2002; King et al., 2006), dependence on income assistance programs for cash and medical coverage limiting the individual's motivation and ability to work longer hours (Baron & Salzer, 2002), and decreased job consistency with one employer (Baron & Salzer, 2002).

Meso-level system barriers to advocacy include length of hospital stay or institutional policy restrictions that prioritized medical issues over longer-term rehabilitation issues (Baron &

Salzer, 2002; Jugessur & Iles, 2009; King et al., 2006;Tannous, 2000), institutional budget constraints limiting program development related to employment (Baron & Salzer, 2002; King et al., 2006; Kirsh et al., 2009), time constraints impeding work time allocated to advocacy, specifically for employment issues (Baron & Salzer, 2002; Hellwig et al., 2003), lack of knowledge of available employment resources (Baron & Salzer, 2002; Kirsh et al., 2009), and conflict in the culture of the hospital system or work environment (Baron & Salzer, 2002; Dhillon et al., 2010; Hellwig et al., 2003; Jugessur & Iles, 2009; King et al., 2006; Tannous, 2000).

Macro-level system barriers to advocacy include lack of access and availability of vocational programs (Baron & Salzer, 2002; King et al., 2006), an individual's fears of financial struggles and access to government assistant funds (Baron & Salzer, 2002; Blitz & Mechanic, 2006), and stigma (Baron & Salzer, 2002; King et al., 2006; Kirsh et al., 2009;), which can have an impact on promoting any type of change in employment policies as they relate to mental illness.

Inpatient nurses who participated in a study to explore barriers and facilitators to advocacy, identified many meso- level system barriers which implicated their advocacy roles in their worksettings (Negarandeh et al., 2006). These specific barriers included: 1) sense of powerlessness in their workplace, 2) lack of support from managers, 3) physicians doing all the leading within the treatment, 4) time constraints and limited time allocated for communication with the clients, and 5) lack of motivation as a direct result of the frustration with their work. Other studies that explored OTs' perspectives on advocacy indicated that the advocacy role was an "add on" to their job description rather than as part of a current function of their role in their workplace (Restall & Ripat, 2008; Dhillon et al., 2010). Therefore while advocacy was identified as an important component in health care, many clinicians felt that these barriers limited their ability in advocating within their role.

Practice models related to advocacy

The recovery model and Canadian Model of Occupational Performance and Engagement (CMOP-E) will be used as lenses through which results will be interpreted. These two models were chosen based on the following reasons; 1) the recovery model is the model used in mental health (Frese, Stanley, Kress, & Vogel-Scibilia, 2001) 2) the CMOP-E embraces the cornerstone philosophies of occupational therapy practices of client-centredness and occupational performance (Townsend & Polatajko, 2007) 3) the concepts of advocacy are parallel to both concepts within the recovery model and CMOP-E).

Recovery model.

Recovery is described as an individual and personal experience in which individuals are empowered to take ownership of their health to lead satisfying and hopeful lives (Frese et al., 2001). The core concepts of the recovery model include hope, empowerment for one's own recovery journey, availability of goal-oriented services, attention to human rights, and developing purpose in life beyond the context of living with mental illness and its negative impact (Frese et al., 2001; Jacobson & Greenly, 2001). The recovery model emphasizes an individualized process with the intent of improving an individual's quality of life, life satisfaction, level of hope, promoting autonomous decision-making, independence, and facilitating positive attitudes and values (Frese et al., 2001).

In contrast to the medical model, the recovery model focuses on an individual's strengths and improving an individual's quality of life despite the presence of the illness (Frese et al., 2001). Munro & Edward (2008) describe recovery as a multidimensional journey that may consist of medical recovery, personal recovery, and social recovery. Medical recovery is the absence of illness symptomology; personal recovery alludes to intrinsic rewards such as self-reliance, independence, being hopeful, and creating meaning; and social recovery is re-engaging and re-

connecting with others through community activities (Munro & Edward, 2008). The recovery model will be used as a lens to inform the topic choice and establish research questions, specifically how both IDDs and occupational therapists perceive the advocate role and advocacy process in the context of the recovery model/ journey. The concepts of advocacy and recovery are parallel in that both concepts are goal oriented and promote positive change.

The Canadian Model of Occupational Performance and Engagement (CMOP-E).

The Canadian Model of Occupational Performance and Engagement (CMOP-E), which is an extension of the Canadian Model of Occupational Performance, focuses on occupational performance and can be utilized as a tool to facilitate professional reasoning (Townsend & Polatajko, 2007). Client-centred practice is the underpinning practice approach of the CMOP-E, whereby the client-centred practice approach embraces the core concepts of respect, partnership, availability of client choices, client autonomy and decision-making, enablement, accessibility and flexibility, and is contextually appropriate to the client's environment (Baptiste, 2003; Law, Baptiste, & Mills, 1995;). The CMOP-E views occupational performance and engagement as the dynamic interaction between the person (cognitive, affective, physical, spiritual), occupation (self-care, productivity, leisure), and environment (cultural, institutional, physical, social). The CMOP-E identifies issues or barriers hindering occupational engagement when considering various factors within the person's occupational performance or the person's environment (Townsend & Polatajko, 2007, p. 185). The CMOP-E will be used as a lens for establishing research questions regarding how the perception of the advocate role and advocacy process contributes to the overall process of enabling occupational performance when exploring employment opportunities for IDD.

Facilitating occupational engagement and occupational performance is the primary focus within the CMOP-E, which is consistent with the goals of advocacy. The commonality between the recovery model, CMOP-E, and advocacy is that all approaches focus on the individual client as

being central to the overall process of recovery, client-centred processes, and advocacy and facilitate change, whether it is improving a client's quality of life, promoting client-centred practice at the meso and macro levels, or enabling occupations.

Gap in the literature

There is a gap in the literature describing the role of an OT advocate when working with individuals with depression in obtaining and maintaining employment. While there have been studies indicating the importance of micro-, meso-, and macro- level advocacy, it is unknown how occupational therapists perceive their advocate role when advocating for employment for individuals diagnosed with depression. Furthermore, there is a lack of a consistent definition of advocacy and description of the advocacy process from the perspective of occupational therapists and individuals with depression seeking advocacy support. This study aims to address this gap by exploring the perception of the advocate role and description of the advocacy process by IDDs and occupational therapists.

Purpose and Objectives of study

Purpose.

The purpose of the study is to explore the perceptions of the advocate role and description of the advocacy process from two different perspectives.

Study objectives.

This study has two overall objectives. The first objective is to understand the role of an advocate and advocacy process from the perspective of IDD (recipients of health services) in the context of obtaining or maintaining employment. The second objective is to explore the advocacy process and the advocate role in occupational therapy clinical practice from the occupational therapist perspective (providers of health service delivery) in the context of working with IDD towards achieving their employment goals.

3.0 Methods and procedures

Design

This study uses a qualitative description approach. No studies have explored the concepts of the advocacy process and advocate role particularly in relation to exploring employment for IDDs. Qualitative research seeks to generate insights about a phenomena and "aims to describe and understand the nature of reality through participants' eyes with careful and on-going attention to context" (Milne &Oberle, 2005, p. 413). A qualitative research study approach allowed the researcher to explore individuals' stories and how they experience and describe the phenomena of the advocacy process and advocate role within their worlds and how they comprehend this phenomena (Milne & Oberle, 2005; Sandelowski, 2000; Sandelowsi, 2010).

Qualitative description research is also appropriate to address the research questions and objectives as qualitative description provides a comprehensive summary of the participants' experiences of the advocacy process. Through the participants' stories, data also emerged to describe how both IDDs and OTs view the advocate role within that advocacy process.

The investigator proceeded with the following the basic tenets of a qualitative research study, which involves choosing a particular sample group and utilizing an inductive process to ensure credibility of the thematic schemas of the collected data and rigour through the data analysis whereby the researcher continually examines the research design and research implementation congruence of the research questions fit within the context of the study (Morse, Barrett, Mayan, Olson, Spiers, 2002; Sandelowski, 2000).

Interview questions were set up to obtain a descriptive summary and understanding of the experience of advocacy from the perspective of both IDD and occupational therapy clinicians. A sample of two population groups, IDDs and OTs, were interviewed in order to gain a fully rounded

perspective of the advocate role and how they experienced the advocacy process while either receiving health services (IDDs) or delivering health services (OTs). As this is a qualitative description study, the goal of the study was to describe the data as given or as close as possible given by participants with minimal opportunities to deviate from the raw data.

Due to cost and time constraints, modifications to the study made it more realistic to obtain a general understanding of the participants' experience of advocacy rather than obtain an in-depth account of the participants' lived experiences with the process of advocacy.

Recruitment strategies

Purposive sampling strategies were used to recruit IDD and OT participants. Figure 1 depicts the summary of the recruitment process for both IDD and OT participants. Recruitment letters, advertisement posters, and word of mouth were the primary means of recruiting study participants. The advertisement posters contained a brief description of the study, a list of the participant inclusion criteria, and the primary investigator's contact information. Interested participants were encouraged to contact the researcher for further information on the study. Please refer to Appendices B and C for copies of the recruitment letters and advertising posters that were distributed to organizations and health clinics. The following steps were employed as part of the recruitment process:

1. Packages containing recruitment letters and advertising posters were mailed out and/ or emailed to a number of mental health resources/organizations and Winnipeg psychiatric clinics.
2. Recruitment letters were mailed and/ or emailed to clinicians and physicians/psychiatrists so they could distribute posters to their clients who fit the study criteria.
3. A recruitment package including the poster advertisement and recruitment letters, were sent and emailed to the College of Occupational Therapists of Manitoba (COTM) and the Manitoba

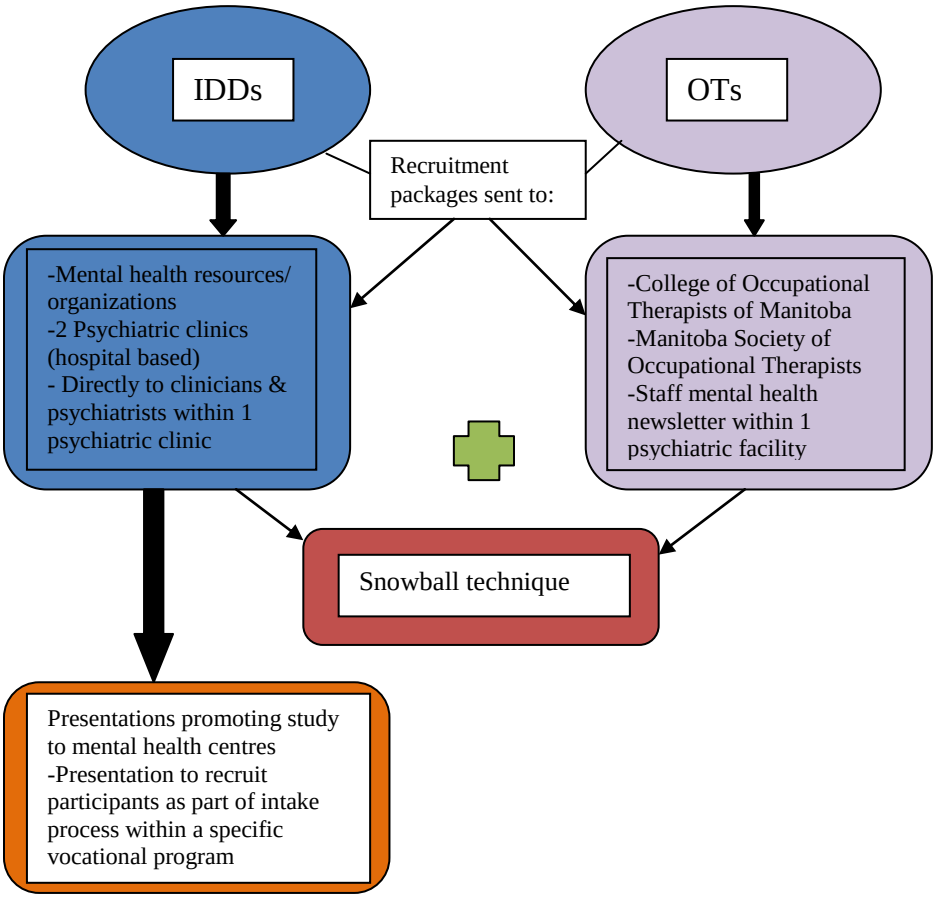
Society of Occupational Therapists (MSOT), who assisted with distributing the recruitment letters for the study to all registered occupational therapists practicing in Manitoba.

4. The investigator set up and attended community visits with the mental health organizations that responded to the investigator's request to present my research study to program directors/ managers and program participants.

5. The investigator was invited to participate with an intake process of one of the vocational organizations as a result of the program director's interest in this research. The investigator attended four intake sessions and informed potential research participants through this arrangement.

6. A copy of the poster advertisement and recruitment letters were submitted to the mental health newsletter in one of the Winnipeg psychiatric programs as a strategy to inform all health professionals of this study, to post the advertisement posters in their clinical practice areas, and distribute information to their clients.

Figure 1. Summary of the recruitment process



Recruitment of participants

Inclusion criteria.

This study focused on recruiting two separate sample groups- IDDs and OTs. All participants were required to speak and read English so that they could effectively participate in the interviews or focus groups and fully comprehend the information.

Inclusion for IDD participants.

Two phases occurred to ensure interested IDD participants fit within the study criteria. These two phases included: 1) IDDs participating in the screening interview 2) confirmation of the IDD's diagnosis by the designated health professional. All participants (both IDDs and OTs) who

contacted the primary investigator were screened (Appendix A) to ensure they fit the criteria for the study. Once OT participants met eligibility criteria passed in the screening process, they were immediately included in the study as the second recruitment phase was not required for the OTs. Consent forms were only distributed to the IDD research participants, either via mail, fax, or email, once it was determined they were eligible for the study after completing the screening interview. The IDD participants received these consent forms immediately after the screening interviews; consent forms were returned to the investigator via mail or fax before arranging to interview the participant. Two consent forms were signed by the IDD: (1) the release of information consent form to obtain information only on their diagnosis and mental competency from their physician/ health care professional (Appendix D) and (2) the research participant information and consent form outlining the description of the study (Appendix E). Upon receipt of the two consent forms, the investigator contacted the designated health professional as identified in one of the consent forms, to acquire confirmation of the individual's diagnosis of depression. All participants were a given a copy of the consent forms.

Inclusion for OTs.

OT study participants were required to have at least one year of clinical experience working with individuals who have had been diagnosed with depression and valued the role of employment for IDDs.

Exclusion criteria.

Participants were screened out of the research study if an individual was not diagnosed with depression. Two separate instances occurred where two individuals self- identified with having depression, but were excluded from the study as their designated health professional denied a diagnosis of depression within those two individuals.

No occupational therapists were excluded from the study as all OTs had experience working with IDDs and identified employment as an important occupation for their clients.

Instruments

A flexible, semi-structured interview guide was utilized for both individual interviews and focus groups as the primary means of data collection. Appendix A contains a copy of the interview guide.

The interview guides focused on questions around the participants' experiences with the advocacy process and their perception of the advocate role.

Individual, semi-structured interviews were utilized to gather the data on the IDD participants' experiences with advocacy, their perception of the advocacy process, and the role of the advocate within their experiences. Facilitating individual interviews provided the opportunity to explore an individual's experiences of advocacy for employment in a private setting. Furthermore, an individual interview is a critical source of data collection in grounded theory research and qualitative description (Creswell, 2005; Sandelowski, 2000; Sandelowski, 2010).

Additional questions were added to subsequent interviews based on emergent data collected from previous interviews or groups, which focused on obtaining further details on their experiences with the advocacy process. These follow up questions were included in interviews with IDD participants: 1) Can advocates who assist with mental health issues also be advocates for employment issues? 2) How did you know when to ask for help and accept help? 3) Was it difficult for you to come to that acceptance (of requiring help)? 4) Does a mental health advocate have the same qualities as an advocate for employment related issues? 5) Is it helpful to have more than one advocate when dealing with employment? 6) What information do you share with your advocate? 7) How do you know when changes or improvements are happening when working with an advocate?

The following questions were additional questions/ topics that were added to the OT focus groups based on emergent data collected from the IDD interviews and from information obtained throughout the focus group: 1) Do your colleagues support your role as an advocate at work? If so, how, and if not, why? 2) Does your team support your role of promoting employment? If so, how, and if not, why? 3) Where does the role of advocacy fit within the occupational therapist's role? 4) Do you use the word advocacy when working with your clients? Why or why not? How do you describe advocacy to your clients? 6) What challenges have you experienced when advocating for your clients, particularly when promoting employment?

Ethical considerations

Informed consent and confidentiality.

This study was reviewed and approved by the University of Manitoba Health Research Ethics Board. A consent form outlining the purpose and goals of the research study was sent out to each participant prior to their participation. This consent form and expectations around confidentiality of the collected data and interviews were also reviewed by the researcher and participant prior to collecting data. Each participant was aware that any information they shared was voluntary and that they were free to withdraw from the study at any time. Participants signed the consent form to indicate their consent with voluntary participation in the research study and understood the research goals and expectations.

Ethical issues in data analysis and interpretation.

Protection of the research participants' identity remained confidential with the use of pseudonyms. Any names of organizations or community resources identified by the study participants also remained confidential by omitting organization names and replaced by a blank space within the transcripts. All participants were designated with a research number. Documents were filed in a locked and secured area and all audio recordings will be destroyed once the study is

completed. Only the researcher and research advisors had access to the transcripts. Two peer reviewers participated in the data analysis process therefore had access to three participant transcripts.

Data collection

Individual interviews with IDDs.

Consultation input was provided by a peer support/ outreach worker prior to the use of the interview guides to ensure questions were comprehensive and consistent with study objectives. The following steps describe the process in which data was gathered for the IDD group.

1. IDDs were interviewed for approximately 60- 90 minutes in length, which were either conducted in a conference room at the University of Manitoba, a conference room at a particular resource centre, or in a meeting room where the primary investigator was employed. Interviews were recorded so that interviews could be transcribed verbatim.

A verbal definition of advocacy from the 2010 Compact Oxford English Dictionary was given at the very beginning of the interviews, which defined advocacy as,

..Any action that you take or another person or group takes on behalf of an important issue. These actions are done to influence positive changes in one's life based on their needs, rights, and wants. A person who advocates can be advocating for themselves (also known as a self-advocate) or can be advocating for others (*Compact Oxford English Dictionary,* 2010).

Provision of the advocacy definition was omitted in some of the subsequent interviews to facilitate more of an open-ended discussion about the IDD's perceptions of the advocacy process and advocate role. After the first two IDD interviews where the advocacy definition was provided at

the very beginning of the study, the participants kept referring back to the phrases and words used in that definition as their definition of the advocacy process and advocate roles.

2. Immediately after each interview, the investigator wrote field notes to reflect on the collected data, document other significant observations, and document subsequent questions for future interviews as a result of the information collected on the interview. Field notes were not transcribed but were used as part of the data analysis process.

3. The investigator transcribed the interviews verbatim and completed the transcriptions within one week of conducting the interviews.

4. Transcripts were mailed or emailed out to the IDD participants within one to two weeks of their interview being conducted. All IDD participants were given a week and a half to two weeks to receive the transcripts through the mail and review the transcripts before the investigator contacted them via phone to discuss the transcripts. Each participant was asked to review the transcripts, ensure accuracy of the information documented in the transcripts so that information was reflective of their perceptions, and provide additional comments/ information on the topic of advocacy if it was not discussed or explored during their interview.

5. The investigator contacted the IDD participants via telephone within two weeks of mailing out the transcripts to complete the member checking process. The member checking process provided an opportunity for the IDD participant to clarify and confirm the information documented within the transcripts and provide additional information not discussed in the interview.

Additional questions were added to subsequent interviews based on emergent information from previous interviews and focus group. Topics further explored in subsequent IDD interviews included: the importance IDDs placed on learning self-advocacy skills, how depression impacted their employment, and the importance IDDs placed on their advocate. The advocate role was also further examined in subsequent interviews by inquiring about qualities of an effective advocate,

effectiveness of having multiple versus one advocate, and whether issues of employment and health were dealt more effectively when addressed simultaneously.

Focus groups with occupational therapists.

An interview guide was utilized to facilitate the focus group discussions among the OT participants. Questions were focused on exploring the OTs' perceptions of the advocate role and how they implemented advocacy within their clinical practices. This interview guide was reviewed by another OT clinician (who at the time was also a graduate student) to ensure questions were comprehensive and ensure consistency with study objectives, and provide recommendations on phrasing of questions. Focus groups were conducted to collect the data efficiently and facilitate discussion on the topic of advocacy among occupational therapists, which is conducive to an exchange and discussion of ideas and perceptions.

Additional questions were added to subsequent focus groups based on emergent information. Topics further explored in the second focus group included collegial support of the advocate role in the workplace, perceptions of promoting engagement in employment as part of the recovery process, use of language when conversing with clients about the advocate role, and challenges encountered when promoting client engagement in employment opportunities. Please refer to Appendix A for list of subsequent questions for focus group interview guide.

The following steps occurred as part of the data collection process within the focus groups for the occupational therapy group.

1. Two separate focus groups were conducted due to the availability of two additional participant therapists. The first focus group was held in a board room at the University of Manitoba; the second focus group was conducted in one of the clinician's office. A verbal definition of advocacy from the 2010 Compact Oxford English Dictionary was given at the very beginning of

both focus groups. The same definition of advocacy provided within the IDD interviews was given at the very beginning of the focus groups, which defined advocacy as:

> …Any action that you take or another person or group takes on behalf of an important issue. These actions are done to influence positive changes in one's life based on their needs, rights, and wants. A person who advocates can be advocating for themselves (also known as a self-advocate) or can be advocating for others (*Compact Oxford English Dictionary,* 2010).

2. Immediately after each focus group, the investigator wrote field notes to reflect on the collected information, document other significant observations, and document subsequent questions for future focus groups. Field notes were not transcribed but were used as part of the data analysis process. The investigator continuously reviewed field notes and went back for subesquent reviews of the same field notes as new emergent data unfolded. The investigator maintained reflective notes, lists of queries, and/ or affirmations and utilized this information to guide future interactions and interviews with other study participants.

3. The investigator transcribed the focus groups verbatim and completed the transcriptions within two weeks of conducting the focus group.

4. Transcripts were emailed out to the OT participants within two weeks of the focus group. All OT participants were given a week to review the transcripts before the investigator contacted them to discuss the transcripts. Each participant was asked to review the transcripts, ensure accuracy of the information documented in the transcripts so that information was reflective of their perceptions, and provide additional comments/ information on the topic of advocacy if it was not discussed or explored during the focus group.

5. The investigator contacted the OT participants individually via telephone within one week of emailing out the transcripts to complete the member checking process. The member checking process provided an opportunity for the OT participant to clarify and confirm the information documented within the transcripts and provide additional information not discussed in the focus group.

Both data collection and data analysis occurred concurrently, employing the constant comparison method to determine similarities and differences between the data as data was collected.

Data analysis

Content analysis ensued whereby there was a systemic reduction of data gathered from both IDDs and OTs into coded units, which were then clustered into categories based on shared commonalities, which were then incorporated into themes to generate a description/ schema of the advocacy process and advocate role (Milne & Oberle, 2005; Sandelowski, 2010).

Table 2 provides a brief overview of the steps that occurred during the data collection and data analysis phases. The following sections provide a detailed explanation of the data collection and analysis steps.

The PI employed the constant comparison method, comparing new data and themes with previously obtained data to find common themes. As the investigator completed individual interviews with the IDDs, the investigator would review/ analyze transcriptions and the complementing field notes of the emergent data with previously obtained data to explore similarities and major differences between IDD perceptions. The investigator completed approximately 4 individual interviews with the IDDs before the focus groups were conducted, primarily due to the availability of the OTs. As the two focus groups were held, the investigator not only compared the data among the OTs in the focus group, the investigator also compared data

between the OTs and IDDs to find similarities and differences between the two sample population groups.

Data collection and analysis with IDDs and OTs.

Step 1: Consultation input: Interview guides were provided to a peer consultant (community mental health worker) to ensure interview questions were consistent with study objectives. Focus group guide questions were provided to another peer consultant (OT colleague with mental health clinicial experience) to ensure discussion questions were consistent with the goals and objectives of the study.

Step 2: Conduct the interviews/ focus groups: Interviews were conducted with IDDs; 2 focus groups were conducted with the OTs.

Step 3: Transcriptions: All interviews and focus groups were transcribed from audio recording. Trasncriptions were sent to all IDD and OT participants for their review.

Step 4: Data analysis through open coding, categorizing codes, and establishing common themes: In constant comparison, new emergent data was consistently compared to previously obtained data. In line by line analysis, each phrase was taken into consideration in determining important words or codes that would assist in formulating categories. Codes and categories were used to group meaning units (descriptive words or phrases) and the categories were grouped to form themes. Analysis of field notes and field journal was also part of the analysis process whereby investigator reviewed notations taken during and afer the interviews. A peer review process occurred to ensure consistency of themes. Copies of three transcripts were provided to an advisory member and colleague and interviews were discussed and coded. Data saturation was achieved when additional themes or categories no longer emerged from subsequent interviews.

Step 5: Member checking: Each study participant was contacted via phone to verify accuracy of information as documented in the transcription and to obtain additional information that was not previously discussed in the interviews.

Step 6: Peer reviews: Advisory committee members and a colleague were provided with transcripts for review. After review of the 3 transcripts, analysis process and findings were compared among the advisory committee members, colleague, and investigator to ensure consensus among the categories and themes. Additional transcriptions were reviewed on an ongoing basis with the research advisor.

Other tools for data collection & analysis.

A field journal was maintained throughout the study. Additional observations and thoughts following the interviews and focus groups were immediately documented by PI. This process was helpful in further exploring other emergent themes not initially identified. The PI utilized the field journal as part of the data analysis process, whereby reflections on the interviews either supported the themes or challenged the ideas/ perceptions of other study participants.

Table 2. Data collection & analysis plan

	Data collection and data analysis steps	Activities
Individual interviews	**1. Consultation input**	• Provided a copy of the interview guide to a community mental health peer worker external to the study • Obtained feedback from the consultant to ensure the guided questions fit the study objectives and were comprehensive
	2. Conduct interview	
	3. Transcriptions	• Transcribed verbatim from audio recording
	4. Analyze - Open coding - Categories - Establish themes	• Constant comparison • Line by line analysis • Analysis of field notes • Peer review
	5. Member checking **-**Provide transcripts to participants - Clarify information as indicated	• Contact participants via phone • Verify accuracy of information as documented in the transcription • Inquire whether study participants had addition information to offer
	6. Peer reviews	• Provide transcripts to advisory committee members and colleagues • Achieve consensus among themes • Ongoing provision of transcripts to advisor

Focus group	**1. Consultant input**	• Provide a copy of the interview guide to an occupational therapy colleague external to the study • Obtain feedback from the consultant to ensure the guided questions fit the study objectives and were comprehensive
	2. Conduct the focus group	
	3. Transcription	• Transcribed verbatim from audio recording
	4. Analyze data -Open coding -Categories - Establish themes	• Constant comparison • Line by line analysis • Analysis of field notes • Peer review
	5. Member checking **-** Provide transcripts to participants - Clarify information as indicated	• Contact each participants via email or phone • Provision of transcripts to advisory committee members and colleagues
	6. Peer reviews	• Achieve consensus among themes

Rigour in data collection and trustworthiness

Rigour for data collection.

1. ***Instrument Development.***

Individual interview guides and focus group interview guides were developed by the PI, followed by an evaluation by two consultants (community peer worker and OT clinician both external to the study). One of the consultants was a seasoned occupational therapist who had extensive clinical experience working in mental health; the other consultant was a peer support worker who provided psychosocial support for individuals struggling with depression within both the hospital and community settings.

2. ***Peer review.***

All data collection tools and methods were reviewed by the advisory committee members. Open coding was completed with some of the interviews whereby each peer reviewer generated open codes and then compared results obtained during this initial analysis stage. For example, the PI and peers independently generated open codes and compared findings.

3. Constant comparative.

A constant comparative method was used throughout the analysis process whereby emergent information was consistently compared to previously obtained information as it was collected (Creswell, 2005). Data was compared to previously obtained data to ensure consistency in themes. Data from the OT participants were intermingled with data from the IDD participants to compare similarities and differences in perception of the advocacy process and advocate roles.

Trustworthiness.

Techniques, such as member checking, triangulation of sources, and coding process, were used to ensure rigorous data analysis. Processes of credibility, confirmability, and reflexivity were used within this study. Processes of ensuring rigour was an iterative process whereby the "researcher moves back and forth between design and implementation to ensure congruence among question formulation, literature, recruitment, data collection strategies, and analysis" (Morse et al., 2002, p. 10).

Rigour in qualitative research is supported by evidence such as audit trails, member checks, and additional memos/ notes (Morse et al., 2002). Rigour in research indicates the reliability and validity of the research study (Davies & Dodd, 2002); therefore the following steps occurred throughout the course and progression of the study:

1. ***Member checking.***

Credibility of the data collected within the interviews and focus groups were addressed through member checking. Research participants were contacted to review transcriptions of their interviews and provide feedback to provide any other additional information not explored during the interview. Transcripts were mailed or emailed to all research participants.

2. ***Triangulation of sources.***

Used to ensure accuracy and authenticity of the result findings, triangulation entails a comparison of data from multiple sources/individuals. In this case, the interviews and focus group discussions were compared with one another to develop and establish consistent themes. The PI made these comparisons after each interview and with all prior interviews throughout the entire data collection process.

3. ***Field Journal.***

A field journal was maintained throughout the data collection and data analysis processes as a way to document investigator's reflections and to connect data previously obtained from other participants. This journal was also used to reflect upon the investigator's own biases to be aware of the influences the researcher has on the study. According to Davies & Dodd (2002), the researcher's ethics and biases intertwine with the investigator's approach with asking questions, responding to questions, and reflecting on data. The investigator's reflections and thought processes were shared with the advisor. The field journal addressed the reflexivity processes.

4. ***Coding Process.***

The study advisor and a colleague familiar with qualitative research were involved in the coding process to further ensure consistency in interpretation of results. Each of the members received three of the same transcripts at a time and had the opportunity to analyze the material and meet to review the findings. Codes, categories, and themes were finalized once there was a majority of agreement of the information, which indicated a stability of responses to multiple coders for the data sets.

Role of the investigator

The role of the investigator has an impact on the data collection and interpretation of data as the investigator's influences and behaviours impact the study participants' responses (Finlay, 2002). Therefore, the process of reflexivity (the conscious self-awareness) was an important part of the process to address the trustworthiness of the data (Finlay, 2002).

The investigator has clinical experience relating to advocacy for IDDs exploring employment opportunities. The investigator has worked primarily in the mental health field as an occupational therapist since 2004. She worked at a tertiary hospital within a psychiatric inpatient setting for seven years and two years in the community as a case manager for individuals with both physical and mental health issues. She actively sought out opportunities to advocate with and for

her clients regarding their health and to pursue goals as mental stigma has contributed to her clients' challenges with occupational engagement. The investigator pursued graduate studies within the Masters of Science degree in Medical Rehabilitation and completed courses relevant to pursuing the present study.

The investigator has an invested interest in the topic of advocacy in health care, therefore has biases towards the concept of advocacy. Some of the researcher's initial biases prior to carrying out the study included: (1) Health professionals providing a health service "should" teach their clients self-advocacy skills so that clients are less reliant on health professionals as the advocate (2) Advocacy is not a commonly used term in clinical practice (3) It is better for individuals to have one main advocate to facilitate continuity of services (4) Advocacy is about facing challenges and working towards eliminating barriers that prohibit individuals in achieving goals.

The investigator put her beliefs aside, as best as possible, while conducting the interviews and focus groups to ensure data results were not influenced by the investigator's perceptions and biases.

4.0 Results

Participants

IDD participants.

A total of seventeen individuals with various mental health diagnoses contacted the investigator and expressed a desire to participate in the study, but only six IDD participants fit the study criteria. Therefore six IDD participants were interviewed. Individuals who did not fit the study criteria included individuals diagnosed with anxiety disorders, bipolar disorder, schizophrenia, substance abuse, and rapid cycling bipolar 1 disorder. Table 3 summarizes all the IDD participants who participated in this research study, including their employment status at the time of their

interview, their level of recovery, and the major challenges expressed by the IDDs regarding their perceptions of the advocacy process and advocate role.

All IDD participants were denoted with pseudonyms to ensure anonymity and gender neutrality. IDD participants ranged in age from their mid- twenties to mid-sixties and experienced difficulties in obtaining or sustaining employment as a result of their depression. The participants were at varying stages of their recovery. At the time of the study, half of the IDD participants were actively employed while the other half were unemployed; however, the individuals who were not employed identified employment as a long-term goal they would like to achieve in the future. The unemployed participants were focused on managing their depression and developing pre-employment skills, as they felt that were not ready to engage in paid employment.

Participant one had a background in business marketing, was self-employed, and did a significant amount of work on meso- and macro-level advocacy by educating employers and the general public about the impact of mental illness on employment. He/she was further along in his/her recovery process relative to the other IDD participants. Participant one discussed at length the challenges of mental health stigma among employers and the general public. He/ she desired advocacy practices to work towards implementing change at the meso- and macro- levels such as promoting healthy workplace environments.

Participant two was in the early stages of transitioning into employment. He/she had been employed for three months at the time of the interview. Prior to his/her employment, he/she spent approximately two years focusing on health-related goals. He/ she focused his/ her discussions around the holistic aspect of the individual person and the important connections between a stabilized mental health and employment-related goals.

Participant three was successful in securing funding and vocational training, which led to employment. He/she discussed the various challenges of navigating the mental health and

employment systems throughout his/her journey in finding employment. He/ she described the challenges he/ she encountered with navigating the health/ employment systems and expressed pessimistic views about current resources in mental health and within employment services.

Participant four appeared to be struggling with his/her health. While his/her initial goal was to secure employment, he/she felt a lack of readiness to engage in work. Therefore, the focus of his/her recovery was to maintain or improve his/her mental health. He/ she focused on the challenges within her recovery process.

Participant five was an immigrant and struggled with cultural differences and societal expectations regarding employment and health in Canada. He/she was on a leave of absence from work and had no immediate plans to return to work. Participant five described the challenges he/ she encountered in relation to cultural and societal expectations in Canada.

Participant six was working on stabilizing basic needs and focusing on volunteerism. He/she anticipated employment within the next three months. He/ she discussed his/ her ambivalence around the transition from being unemployed to being employed as he/ she was transitioning from unemployment to having employment at the time of the study.

The researcher identified three different stages of recovery based on the researcher's clinical interpretation of participants' disclosures: earlier stages, mid stages, later stages. Researcher defined the recovery stages accordingly:

Earlier stages: individuals were presently focusing on improving their mental health due to difficulties with managing the symptoms of their depression. Individuals within this stage expressed lack of readiness for employment.

Mid stages: individuals were accepting of their depression and seemed to have a good awareness of their symptoms and how to manage their depression. Individuals within this stage were transitioning from being unemployed to being employed.

Later stages: individuals had a strong understanding of their depression and were actively participating in healthy occupations with minimal impact of their depression on their occupations.

Table 2. Description summary of IDD participants

	Employed	Level of recovery	Challenges the participants expressed regarding the advocacy process/ role
Participant #1	• Yes • Business marketing • Advocate and speaker about mental wellness in the workplace	Later stages	• Discussed challenges around stigma • Desire to increase advocacy within the meso- and macro- levels
Participant #2	• Yes	Mid stages	• Focused on the holistic aspect of mental health and impact on employment
Participant #3	• Yes • Secured funding and access to vocational training	Mid stages	• Encountered many challenges in accessing information and navigating the health system • Expressed pessimistic views about current resources in mental health
Participant #4	• Unemployed	Early stages	• Struggled with health and identification of goals • Difficulties in discussing challenges within his/her journey • Discontinued interview
Participant #5	• Unemployed • Heavily involved in volunteering • Volunteered in three different opportunities	Early stages	• Immigrant • Struggled with cultural and societal expectations regarding employment in Canada
Participant #6	• Unemployed but anticipated employment within the next three months • Volunteered at a pre-employment centre	Mid stages	• Discussed ambivalence around transitioning from being unemployed to being employed

OT participants.

Six occupational therapists were eligible and interviewed for this study. Two focus groups were conducted due to availability of two additional therapists. Therefore a small focus group of two therapists was conducted separately. *A*ll occupational therapists worked in mental health. While the study was extended to all OTs practicing in Manitoba who had experience working with individuals diagnosed with depression, whether depression was their clients' primary or secondary diagnosis, only OTs specifically working in mental health in Winnipeg volunteered to participate in the study.

All therapists were female and had varied years of experience, ranging from one year to over twenty years of practice. The OTs also worked in various settings, such as acute psychiatric inpatient units, day hospital programs, and outpatient clinics. Five of the six therapists worked with a large population of individuals diagnosed with depression. The other therapist worked primarily with an entirely different population group but occasionally worked with individuals diagnosed with depression. She was able to draw upon her work with the individuals diagnosed with depression to participate in the focus group discussions. Therapists one, three, five, and six worked in outpatient settings, such as outpatient clinics and day hospital programs, therapist two worked with an inpatient population in an acute care hospital unit, and therapist four carried a mixed population caseload of inpatient and outpatient clients.

Table 3. Areas of practice for OT participants

Therapists	Area of practice
1	Outpatient setting (outpatient clinics or day hospital program)
2	Inpatient setting- Acute care setting
3	Outpatient setting (outpatient clinics or day hospital program)
4	Mixture of inpatient and outpatient caseload
5	Outpatient setting (outpatient clinics or day hospital program)
6	Outpatient setting (outpatient clinics or day hospital program)

Emergent themes

The overall purpose of the study was to explore the perceptions of the advocate role and description of the advocacy process from IDDs and OTs perspectives.

Similar themes emerged from the data analysis between both IDD and OT participants, therefore results are documented to reflect similarities among the IDD and OT perceptions within the same themes. Significant differences between IDD and OT perceptions of the themes will also be captured.

There were four themes that emerged from the data analysis. Themes included: 1) Expectations of the advocate role: challenges of power dynamics within the advocate role 2) The IDD/ advocate relationship is the foundation of the advocacy process 3) Addressing both health and employment issues as part of the advocate role 4) The advocacy process is about outcomes and accomplishments.

Theme #1: Expectations of the advocate role: challenges of power dynamics within the advocate role.

The power dynamics between an IDD and their advocate established the expectations and role responsibilities within the advocacy process. The continuum between IDDs' dependence on an advocate versus being a self-advocate was discussed at length among all research participants. IDDs and OTs held significant different expectations of the advocate role, which was impacted by their belief systems around role responsibilities, expectations, and power dynamics. The IDD participants interpreted the advocate role as an individual who was an authoritative figure, such as a "boss", someone who was knowledgeable about the areas of mental health and the resources within the employment sector and mental health services, an individual who was a an expert, and an individual who acted in the best interest of others/ on behalf of others. On the other hand, the majority of OTs perceived the advocate role as a "facilitator", "supporter", and "guidance" role. OTs described the advocacy process as a joint learning experience with their clients and a partnership between the advocate/ client dynamic. Empowering the clients and engaging the IDDs within the decision-making process were identified as the main roles of an advocate according to the OT participants.

IDDs perceive the advocate role as a "voice for the voiceless".

Many of the IDDs expressed a strong expectation and reliance on their advocates in doing active work on their behalf and described the advocate role as an external source of support. One IDD participant described the advocate role as someone who "is a voice for the voiceless" (Participant 2) as the advocate communicated to others what they (the individual seeking advocacy support) could not articulate themselves. IDDs felt they were limited in their communication skills to clearly articulate what needed to be communicated, especially to stakeholders (such as employers) and participants felt that their individual voices would not change their circumstances or how others

perceived mental illness. IDD participant 3 described advocates as knowledgeable individuals who spoke on behalf of marginalized individuals:

> I just think it's like speaking for somebody when they can't really maybe don't know or can't speak for themselves maybe somebody else know is more knowledgeable on whatever they need to ….to do like if you had an issue with say social services or something then you could get somebody to be an advocate for you. (IDD Participant 3).

IDD participants also felt that advocates were able to communicate IDD's strengths to others that the IDDs could not communicate or self-identify. Participant one relied on his psychologist to speak on his/ her behalf and communicate to others what he/she was capable of. Participant 1 felt that his/ her psychologist was a good advocate because the psychologist was trustworthy, credible, and a competent individual:

> Level of trust is very important, if somebody is going to advocate on your behalf you, have to trust them because they are talking to someone that you do not know at that point in time, have no idea what the other person is all about, and so you certainly you do have to trust the person advocating for you is acting in your best interest (IDD participant 1).

IDD participants also described the role of the advocates as authoritarian figures who held the authority to make decisions and often made decisions based on the best interest of the IDDs. Participant four described advocates as "determining what's suitable or not suitable for the person" while participant five used the term 'boss' to describe an advocate:

> So you need little help like a boss, and you need to have someone who knows what depression have, what a depressed person feel like and, its' good to have somebody to advocate for you to talk in your name or help you to find a job in your name. (IDD participant 5).

Participant one also emphasized that a necessary advocate role was to actively communicate with others on the behalf of others. He/ she further distinguished the role of a supporter versus an advocate, which were clearly different from one another:

> My wife actually does not outwardly….speak on behalf advocate or promote but she encourages me to keep going and keep working on this, and she sees what I'm doing as my mission in life, you know, to speak ….up about mental illness. And she does point articles in the newspaper, things that she sees on the web but she doesn't sort of outwardly outside of our home really go out and advocate, she's just a pillar behind everything I'm doing….I wouldn't consider it advocacy because advocacy is talking to other people in my opinion. (IDD participant 1).

The IDDs perceived the advocates as an 'expert', which is why the majority of the IDDs viewed the advocates as being authoritarian figures who took the lead role in making decisions, providing relevant information, and communicating for the IDD. One participant described the need to work with professionals who specialized in the area of employment, specifically in assisting IDDs with employment related issues. He/ she compared working with an employment specialist to address workplace issues to seeing a dentist for dental work:

….The best thing would be if there are people specialized in in that area (employment)….Advocates for your employment so you always feel good when it's like, you know you go to dentist and he'll cure that so you…feel much better that for, you need, you know to whom to go so it would be really excellent if there are people who you can count on and maybe that's their expertise that you can go and say…my situation is like this, I feel I am so far now with my health I would like to start at something simple…could you please help me? (IDD participant 5).

IDD participants indicated the benefits of having an external structure imposed upon them (IDDs) by the advocate. This external structure provided specific direction and direct instructions as to how things need to be done, which was greatly appreciated by the IDD participants:

…Great to have that structure where they (advocate) can tell you..this is what you to do this, this, and this and then you…cuz you don't know what to do. And then you can go oh okay and you go and do it and bring it back to them. (IDD participant 6).

Only one therapist held the same perception that advocates directly 'led' the advocacy process with a firm approach. She felt that her clients required a health professional to advocate on their behalf because of the limitations of her clients to effectively communicate with others on their own behalf. She indicated that a big component to her advocate role was knowing the context of what her clients needed and whom to advocate to regarding her clients' needs, stating,

> A lot of the clients that require the assistance of an occupational therapist usually need that advocacy because they are having difficulty in advocating for themselves or knowing how to advocate for themselves. And knowing what to say and, you know, who to say it to…. (Therapist 1).

She strongly felt that her advocacy role was about speaking to others (i.e. Stakeholders such as agencies or employers) on her client's behalf, which is consistent with how the IDDs perceived the advocate role.

OTs perceive the advocate role as working collaboratively with the individual.

Contrary to the IDD perceptions of the advocate role, many of the OTs struggled with balancing control, power and dividing the responsibilities with their client, especially when there were disagreements with establishing realistic goals or when clients expected them (OTs) to do all the work for the client. Therapists did not want to be viewed as an "expert; rather the majority of therapists identified the need for therapists to relinquish control and demystify the perception of the advocate role as one being in control. One therapist stated,

> But I will also say that it isn't up to me to determine what I think the best perspective is. It's really for each person for themselves to determine, meaning the clients themselves. I don't ever try to ever presume that I know better than they do for themselves (Therapist 6).

While therapists agreed that they were knowledgeable about facilitating occupational performance, task analysis, and facilitating goal setting, many therapists held the perspective that the advocate role was not about being the "expert"; but rather acknowledged that as advocates, they can't know everything and that the advocacy process was a joint-learning process. Therapist 4

emphasized her perspective that the advocacy process was about learning along with the client, stating,

> Or, if you're not familiar perhaps with, you know, what you're navigating is actually learning with the individual along the way. And being honest about that. And saying, you know what, I wasn't expecting this. So, let's take this route, you know, or let's try this. So it's actually problem solving with the individual along the way. Especially if it's not familiar with you too. Or for myself. (Therapist 4).

Occupational therapists managed power dynamic issues within the advocacy process by doing 'joint-learning' with their clients, which OTs felt facilitated the equal distribution of power within the advocate/ client relationship. The joint learning process was about learning new information together. Therapists felt that the joint learning process within the advocacy process occurred through interventions such as role modeling behaviours, ,problem-solving various solutions with the client specific to a case situation, and teaching IDDs how to integrate self-advocacy skills within their situations. IDDs learned self-advocacy skills through the joint-learning process with their advocates:

> It (the joint learning process) makes us more human and helps a client see that… you have to figure it out just the same as I do so maybe I can do this and it provides a bit more empowerment for them…. and maybe they feel like they can self-advocate more knowing that, I have these steps and skills that I've learned while in hospital so now I can take them and apply them in the community as well. (Therapist 6).

Another therapist engaged her clients in the decision-making process by having the individual describe their job duties and identify employment goals. Her approach facilitated the individual to self- identify what his/ her job entailed and indicate what goals were meaningful for the IDD to achieve instead of the OT imposing on the IDD what was going to occur:

> …I often will do with individuals is have them actually write down their own job description. Like they probably have one in their workplace but to write down what do they actually do in their job. And then one of the things that we might do in preparing for say a meeting with the network person or case manager is to figure out okay, what would be things that you might start with or you might begin with when you get back to work. And then what would you gradually do a little bit more of (Therapist 3).

In addition to the joint learning process between the IDDs and OTs, therapists facilitated shared decision-making and increased client responsibilities to promote equal distribution of power and to clarify expectations within the advocate role. Negotiating, setting boundaries, and establishing expectations with clients were important in establishing the therapist's advocacy role, especially in the initial stages of the relationship. One OT participant deferred working with clients until a client was willing to be more engaged within their recovery, especially if that client expected the advocate to lead the entire advocacy process without taking responsibility within that process. Therapist 5 indicated,

> making clients as they're able to take on more responsibilities in the recovery as they recover and they're working towards a return to work goal, what parts can they take on? And negotiating that?... I'm not prepared to do more than you (client) are. It has to be that

> they're a partnership. And if you're (client) not ready, then that's okay too and I will say that I will be here when you are (Therapist 5).

The majority of therapists also believed that it was important to draw upon the client's knowledge and facilitate client goals regardless if the OT agreed with that goal. Therapist 5 never wanted to presume that she knew what was best for her clients and never assumed something was unattainable for the client. She also did not believe advocacy was about taking over the process or suggesting different occupations when occupations did not match the individual's preferences or goals. However, not all therapists held the same perception. One therapist (therapist 1) argued that occupational therapists are the skilled experts in navigating the health and employment systems; therefore she felt therapists were responsible for modifying unrealistic goals and encouraging alternative occupations such as volunteerism if client goals seemed unrealistic. She indicated,

> There's other people that I know, it's just not going to make sense for them (clients) to…you know, its, that's probably more most my population in terms of volunteering, ….it's that, they're not able to approach the place on their own, it's just better if I do it …, I'm just thinking of a certain organization that I actually sent an email to the person about kind of introducing my client, how we're gonna come down and how I'm available and how it's sold a little bit better that way. So sometimes people need a little bit more advocacy. And you know it just makes sense to do it that way. So it's, it's with knowing your client (Therapist 1).

However, she explained that this authoritarian approach was appropriate if clients lacked appropriate skills and functional abilities to be employed.

IDDs and OTs held similar perceptions of the advocate role in the instances when advocates needed to take a leadership approach in guiding the advocacy process when IDDs were unable to effectively manage their illness and/ or presented with severe depressive symptoms impacting basic daily functioning. When individual's lacked the stability in health and demonstrated limitations to make informed decisions (as self-identified by either the IDD or assessed by the occupational therapist), all IDD and OT participants felt that it was the advocate's responsibility to make judgment calls on behalf of the IDD, such as which occupations were safe for the IDD to participate at that moment in time.

Therapists identified tasks within the advocate role when they advocated for employment for their clients, such as 1) having direct contact with the employers to negotiate a return to work plan, 2) accompanying clients to work sites, 3) helping clients develop pre-employment skills such as resume writing, preparing for interviews, effective job searching strategies, 4) validating their client's experiences and instilling hope within the clients, 5) navigating the health and employment systems with the client by writing letters to employers, obtaining information for the client, networking with relevant parties (employer, human resources), and facilitating community linkages to relevant resources, 6) educating clients about workplace stigma through role playing workplace scenarios .

It is important to note that while the OTs identified tasks/ interventions affiliated with their advocacy role, not all therapists were able to implement some of these tasks within the advocacy roles due to scope of practice issues, limitations in caseload management, and cognitive impairment of the OTs' clients which would impact the advocacy process. Therapists identified that the ideal power dynamics between an IDD and the advocate would be an equal distribution of power and decision-making between therapist and client; however, the therapists indicated that this ideal power dynamic was very difficult to achieve and challenging within

certain practice settings. Please refer to Figure 4, which depicts a pictoral diagram of the various imbalances within the power dynamics in a client/ therapist relationship.

The concept of self-advocacy and being a self-advocate: To be or not to be?

There were significant differences in the perception of the importance of learning self-advocacy skills. The majority of IDDs did not identify self-advocacy as a component of the advocacy process whereas all OTs consistently emphasized the importance of teaching self-advocacy skills to their clients.

IDDs place less emphasis on self-advocacy within the advocacy process.

IDDs felt their level of recovery, fluctuations in mood, decreased self-esteem, and cognitive status limited their own abilities in advocating for themselves. The majority of IDD participants (four of the six IDD participants) did not place importance on being self-advocates. One IDD (IDD participant six) believed that the word self-advocacy was not commonly used by other IDDs, but rather a term primarily used by researchers in the health field. His/her encounters with the word "self-advocacy" were associated with seeing the term "advocacy" and "self-advocacy" advertised in research posters. In addition, he/she felt that IDDs specifically sought assistance from health professionals to have someone advocate on their behalf, not to learn self-advocacy skills. IDDs related to the concept of self-advocacy only after the researcher read the dictionary definition of advocacy to them.

Only two IDD participants expressed the importance for individuals to acquire self-advocacy skills. Participant 2 believed that one of the roles of an advocate was to support and teach IDDs to speak and act on their own behalf, indicating,

> …One part of advocacy …is that someone can do the work for you or do the talking for you and the other side of advocacy is supporting you in a way that you can…do the talking yourself or ….request what you need, …. yourself …. (IDD Participant 2).

IDD participant 2 felt that IDDs were capable of learning to be a self- advocates only if the individual's overall mental health and confidence level were stable; however recognized that being a self-advocate was challenging. The other IDD participants also agreed that self-advocacy required a prerequisite of other skills, such as a healthy level of self-esteem, effective communication strategies, openness in disclosing their depression to others, knowledge about the health system, and adequate coping skills to manage stress. With the exception of one IDD participant, many of the IDD participants were learning to develop basic skills such as managing self-esteem, effective communication strategies, developing a sense of identity, and coping with stress, which is why five of the six IDD participants felt that they were unable to self-advocate on their own behalf.

IDD participant one, who was the only IDD participant able to effectively self-advocate on his own behalf, described self-advocacy as the ability to promote and market one's skills and strengths to others. He/ she self- advocated by distributing his/ her business cards, advertising his/ her website, and speaking to others about the impact of mental illness in the workplace. Self-advocacy was a part of his/ her recovery, as he/ she stated, "…as I recovered from that (depression) I decided that I would speak about mental health because I think we need to speak about mental health a lot more than we do in our society" (IDD participant 1).

While many of the IDDs believed that it was possible to learn how to be a self-advocate, the majority of the IDD participants described a preference in distributing the power in the advocate's favour and relied on advocates to speak to others on their behalf.

OTs perceive teaching self-advocacy skills as an empowerment strategy.

All the therapists identified teaching their client self-advocacy skills and facilitating client empowerment as a primary advocate role. Therapists described client empowerment as the process of facilitating the client in having a sense of control, responsibility, and "buy in" to the idea of valuing independence and client responsibility. Therapist 2 described self-advocacy and client empowerment as a process that instills hope within the IDD and encourages them (IDD) to participate in making changes to their lives:

> I feel like it's important for the client to advocate for themselves. I think it's important for us to advocate for them as well but they need to also have some buy in and some willingness to participate and to believe that they are able to do this and make these steps. (Therapist 2).

Teaching self-advocacy skills facilitated less reliance from the IDD on the advocate. Each OT participant emphasized IDDs in taking ownership and increased responsibility within their own recovery processes, which is related to OTs expectations within the advocate role.

Theme #2: The IDD/ advocate relationship is the foundation of the advocacy process

Both IDDs and OTs identified the IDD/ advocate relationship as the foundation to the advocacy process and described similar attributing factors that established the IDD/ advocate relationship. Developing trust and navigating the health and employment systems were identified as the primary components to the advocacy process.

Trust was described as a reciprocal process by both IDDs and OTs. Trust between the IDD and advocate established the foundation to the relationship whereas the navigation within the health/ employment systems was the core concept of the advocacy process. Each IDD participant

worked with their advocates over a long duration of time, ranging from six months to nine years, which enabled the IDD to form long term relationships with their advocates. While OT participants agreed that the ability to work with their clients over a longer period of time facilitated better rapport with their clients, it was not always possible for them (OTs) to work with clients over an extended period of time due to the parameters of practice as established by their employer. Despite limitations in some of the therapists' abilities in working with clients for an extensive period of time, all therapists felt they were able to establish effective working relationships with all their clients to facilitate the advocacy process.

1. Trust within the IDD/ advocate relationship.

IDDs and OTs identified trust as the main factor which established the groundwork for the IDD/ advocate relationship. All study participants indicated that establishing trust was a unique and individualized process, one that was centred on the IDDs' needs and preferences. Trust between the IDD and advocate was gained when the advocate learned the essence of the whole persona to know and understand the IDD/ individual seeking advocacy support, which included learning about the individuals' strengths, capabilities, limitations, goals, and fears. IDD participant 1 described this 'getting to know the person' process as the "groundwork", indicating,

> Groundwork is going through the process of getting to know somebody watching how they do things, understanding how they do things, accepting, being accepting of how they do things because some people do things in certain ways that I'd say well I just don't want to be affiliated with that. So the groundwork is getting to know the person and what they can and cannot do (IDD participant 1).

Part of learning about the "whole persona" of the IDD was learning all aspects of the IDD, which included getting to know them in the areas of 1) strengths and skill sets in relation to occupational performance, 2) the environments impacting their health (social and physical environments), and 3) employment and health related issues in the context of their environments and strengths. While IDDs initially sought out advocacy support regarding employment related issues, all IDDs felt there was enough trust with their advocates to share other aspects of their life, such as their medical history, social history, and environmental conditions impacting their day-to-day functioning. All OTs felt that it was necessary to obtain a rounded collection of information of the individual's life before proceeding to help that individual work towards a goal or change.

Acceptance and a nonjudgmental approach were described as significant descriptors that facilitated the "trust process". When IDDs felt the advocates were accepting of their (IDDs) illness, limitations, and place in life, the IDDs also believed their advocates were also personable, supportive, caring, encouraging, understanding, nonjudgmental, and compassionate. OTs reassured the client that it is okay to ask for help and encouraged them to ask questions, stating,

…Showing them (IDD/ client) what kind of questions are okay to ask and there's no silly question, really. As long it's clarifying what you need to know. That's the important thing" (Therapist 3).

Another part of the trust factor within the IDD/ advocate relationship was the ability of the IDD to entrust their advocate to speak to others on their behalf. IDD participant 1 described trust as,

> Level of trust is very important, if somebody is going to advocate on your behalf you, have to trust them because they are talking to someone that you do not know at that point in

time, have no idea what the other person is all about, and so you certainly you do have to trust the person advocating for you is acting in your best interest (IDD participant 1).

While OTs encouraged their clients to self-advocate and be active participants within the advocacy process, OTs also believed that part of the advocacy process was being supportive of their clients who struggled with their illness, and providing hope that life can get better. Therapist 4 described how therapists can be the vision for the client within the advocacy process, stating,

> Acknowledging that when we first we meet our clients, because they may have a new diagnosis or some sort of trauma or something significant happen to them, they don't necessarily have that vision and, or they can't,…or they had a vision of what, especially like say a younger client newly diagnosed, they had a vision of what that story was going to play out for them and now it's been stolen from them in a way and they don't have that ability to see what life could be like for them as they recover and with you know or experience clinically and life experience and seeing, having walked many other clients through before, you can be that vision for them until they see it for themselves (Therapist 4).

IDDs held the same perspective that their advocates provided a realistic lens for them in challenging negative thought processes or misperceptions associated with depression. IDD participant 3 stated, " …So to have somebody who recognizes that, recognizes the thinking, the behaviour, and is able to challenge your thoughts, and bring you around to the…to reality… that's really important (IDD Participant 3).

Credibility of the advocate contributed to the establishment of the trust within the IDD/ advocate relationship. Advocates were described as having credibility when they demonstrated knowledge of the health/ employment systems, ability to respond to questions, were available to meet with the IDDs as issues arised, and demonstrated abilities navigating the health/ employment systems with the IDDs.

Only one IDD participant (participant 4) did not identify the IDD/ advocate relationship as the main component within the advocacy process; rather he/ she placed more importance on the availability of any advocate in moments of need. He/ she indicated that he/ she shared information with different advocates depending on the advocate's availability and what life situations were happening at those moments in time when she had appointments with those advocates.

2. Navigating the system: Core component of the advocacy process.

Navigating the health and employment systems was described as the core component of the advocacy process. Both IDDs and OTs identified mental health stigma, accessing appropriate resources, fragmentation in services, bureaucratic red tape, lack of funding, and limitations in scope of practice as the issues that contributed to the complex nature of the health and employment systems. All IDDs struggled navigating the mental health and employment systems and expressed significant frustration with trying to access resources. One IDD participant encountered many roadblocks in his/ her experiences with finding advocacy supports, particularly around the lack of cohesiveness in community resources and connecting with the services to meet his/ her needs. He/ she also struggled with knowing programs offered and names of programs, which further contributed to the frustrations of navigating the health and employment systems. IDD participant 3 stated,

> When you start trying to find out like you have to you have to find them on your own and how are you supposed to do that when you don't know the names. It's like trying to find a word in the dictionary when you don't know what the word is (IDD participant 3).

Occupational therapists also experienced similar frustrations within the health and employment systems, particularly with being aware of current resources and communicating with personnel. Therapists struggled with connecting with various agencies due to full voicemails, lack of returned phone calls, and a lack of reliability among some organizations in providing a response within appropriate time frames. While OTs were trying to advocate for their clients, limitations on the existing health and employment systems hindered the progress of the advocacy process. Therapist 3 emphasized the importance of being patient while navigating these systems, indicating,

> And for whatever reason when you're working with these systems or trying to get a hold of people or connect kind of thing, it can be little setbacks. It's just…at the, the advocacy piece is…we need to work through the system. We need to be patient (Therapist 3).

Being up to date with current resources was also a challenge for some therapists. Resources were always evolving, changing, and being added to the wealth of existing health and employment services. Because resources were always being added or changing, therapists identified learning about community resources as an ongoing learning process.

Both IDDs and OTs felt that navigating the health and employment systems was also about accessing resources, specifically around ensuring basic health necessities were secured and stabilized prior to pursuing occupations such as employment. IDD participant 6 indicated that the advocacy process was about addressing essential health needs, such as pharmacare drug

prescriptions, debt issues, and dental care that would have been neglected had the advocate not be involved. IDD participant 6 strongly identified the advocate role as one that successfully helped him/ her manage basic necessities by helping him/ her navigate the health system:

> They (advocate) help me like pull all these pieces of my life together sort of thing. Like, … get in on the pharmasave drug plan because I'm on CPP disability. I have no benefits and stuff so they help me get set up with that. .. I hadn't found my income tax return in a while and they sent me to a place, … I got my taxes done so I got all caught up on all my taxes. … they got me hooked up somewhere where I could get some dental care that wasn't too expensive. Um, they helped me with getting my student loans forgiven. ….I needed some ID, they helped me with that... .They helped me, get a few things that I needed like to sort of get straight in my life .. stuff I, needed to do (IDD participant 6).

Occupational therapists navigated these systems with their clients by clarifying which individuals/ agencies need to be involved in the advocacy process, helping them problem-solve through situations the IDDs identified as challenging, attending systems meetings where other stakeholders were going to be present (i.e. manager, human resources, other health professionals), and explaining systemic processes. Therapist 3 described the navigation of the systems as a means of connecting the IDD to the appropriate personnel and informing the IDDs of all the potential choices to manage a difficult situation. The amount of individuals that needed to be part of the advocacy process also complicated matters because sometimes a large number of individuals from different agencies wanted to be part of the process. Part of the role of the advocate specific to navigating the health and employment systems, is including the necessary stakeholders in negotiating employment goals/ accommodations.

Mental health stigma.

Negative perceptions and stigma were significant issues within the advocacy process. Mental health stigma added a layer of complexity to the advocacy role, as clients feared disclosing their illness to others, especially to employers. Therapists stated that their clients feared disclosing their illness to employers, which in turn made it difficult for therapists to advocate for change in the workplace. However, at the same token, IDDs wanted to have someone speak on their behalf because they felt unheard and powerless in many aspects of their lives. Often, therapists needed to deal with clients' underlying fears before they could actively engage in advocating to promote changes in the workplace for their client.

Therapists needed to use a variety of their skill sets (as therapists and advocates) to effectively help their clients face their fears yet validate their emotions at the same time. Therapist 4 validated her clients' fears of disclosure by reiterating that it was not necessary for others to know about their health information; but at the same time try to challenge their thinking by discussing strategies of how to disclose their illness when the individual was eventually ready:

> When they wanna disclose and they wanna, ready to share and tell the world and they're feeling empowered is letting them know how they can do that, how to do it safely, and then on the flip side, when people aren't ready, you know, how do you plan for it and, almost validating for them that not everyone needs to know your business. You don't have to tell everyone where you've been and you don't have to explain it and it is your private information, you share it when you're ready and with whom you're ready, right. So sort of walking that line of preparing but validating at the same time (Therapist 4).

Some participants had their own beliefs about what employers thought about individuals with depression being employed. One therapist struggled with advising her clients whether they should disclose their illness to employers as she believed individuals with mental illness were discriminated from work opportunities when they disclose they have a mental illness. One IDD participant believed that job security would be compromised if one were to disclose they had a mental illness and request job accommodation options. Therefore, this participant opted to not discuss mental illness with employers for fear of losing his/ her job. He/ she internally struggled with the risks and benefits of disclosing mental health issues with his/ her employer due to his/ her own personal beliefs that employers fired IDDs from the workplace, stating, "…there's lot of people that wait for that job, so that's why it's hard" (IDD participant 5).

While some study participants felt that the decision to disclose mental illness to others (e.g. employers) should be carefully considered, other participants indicated a need to openly discuss mental illness to address mental health stigma, increase public awareness, and educate employers about mental illness. One participant described the progression and positive publicity regarding breast cancer awareness (physical health related condition) and how mental health needs to progress in the same direction as well. IDD participant one felt that advocates need to have open discussions about mental illness with both employers and the general public to promote mental health awareness:

> The main purpose is to get people talking about mental health…We need to do what mental health, what we did with breast cancer 30 years ago. Up until 30 years ago in Canada, we didn't talk about breast cancer. Then we started to talk about it. And now you see the pink ribbon, you see the dragon boat races, you see cancer survivors speaking up etcetera etcetera. Cancer rates in women are dropping significantly and it's because we

made it okay to talk about it and we made it okay for women to ask about it and get treatment. We need to do the same thing with mental health. Have to talk about first before you can get anything else going (IDD participant 1).

OTs in this study worked in mental health settings and identified mental health stigma among their colleagues as a prominent issue.In these situations, advocacy became two fold; 1) OTs advocating and justifying to colleagues why they were assisting clients with certain goals, 2) OTs advocating with and for their clients to help them (client) achieve their goal. Therapist 2 described her frustration with having to justify IDDs' rights to engage in occupations related to exploring employment:

…As far as the interdisciplinary team at the hospital is concerned, I find sometimes, that I need to, advocate for the client for them to even participate in vocational rehab, like in, pursuing of occupation, of paid employment or volunteering. I find a lot of the old school, thoughts of the team can sometimes be a hindrance to the patient and will be working so hard on, on a resume or preparing to go back to work and then the rest of team says well why are you bothering? They're just gonna get sick again, for example. And, it could be ….defeating…(Therapist 2).

Mental health stigma complicated many aspects within the advocacy process; therefore increasing mental health awareness was identified as a strategy to ameliorate inaccurate negative perceptions of mental illness and perceptions about individuals with mental illness, including depression.

Providing "just right" challenges.

Providing "just right" challenges within the advocacy process was only identified by occupational therapists. Occupational therapists described providing "just right challenges" as the therapist's/ advocate's abilities to engage the client in risk-taking. Risk taking involved encouraging the IDDs/ clients to extend beyond their comfort zones to either engage in a new activity, learn a new skill, or face a fear, which would then cause elevated levels of anxiety. Providing "just right" challenges was essentially described as advocating in such a way that was supportive of the client, knowing how to be their "realistic voice", knowing the client's current skill sets, and exploring how to proceed with the client in expanding their skills sets to promote personal growth. Therapist 2 described providing "just right" challenges as a:

> … Need to know what they're capable of and be able to push them in a good way, towards their goal that they have set out. I feel like encouragement is one of the most important, like the ability to encourage the client in a way that they that works for them (Therapist 2).

Providing "just right challenges" was also about the advocate being knowledgeable about the overall recovery process from depression, knowing what stage the IDD was within the recovery process, and the IDD's readiness for change. Having this core set of knowledge facilitated the advocate in implementing "just right challenges". However, one therapist indicated that some individual clients may be reluctant to change and will require a firmer approach to work towards change. Therapist 4 emphasizes that while a firmer approach is necessary with some clients to work towards change, the approach is still based on the relationship with that client and still facilitating the process in a supportive way based on the client's readiness level. Therapist 4 described the process as walking alongside the client:

> I think it goes back again to your relationship with the client and how well you know them and knowing what their skill sets are and their function is to actually be able to say, well…they won't do it on their own. So I'm gonna walk along with them even if it's like pulling teeth sometimes (Therapist 4).

Many of the therapists agreed that change was attainable when they encouraged their client to step out of their comfort zone. Providing "just right challenges" from the advocate perspective required the advocate to have excellent communication and negotiation skills, specifically when trying to support their clients to engage in risk taking behaviours towards making a change in their lives.

Theme 3: Addressing both health and employment issues as part of the advocate role

There was a consensus among all the IDD and OT participants that health and employment must be discussed together. While advocacy for employment was the focus of the study, it was clear that being employed and having employment played a small role in the big scheme of the IDDs' overall health. Employment was identified as an important and meaningful occupation by both sample groups; however obtaining employment was only realistic if certain skills in two areas (managing basic health and developing pre-employment skills) were acquired. Participants in both sample groups described that working towards employment goals required a series of sequential steps, which involved the following three steps: 1) "Maintaining healthy mental health," 2) "Exploring employment issues & acquiring pre-employment skills", and 3) "Obtaining and maintaining employment".

A) Maintaining healthy mental health.

All participants (IDDs and OTs) shared the similar perspective that employment was not a realistic goal if individuals were not physically and/ or emotionally stable. Both IDDs and OTs described a stabilized mental health as a prerequisite and the foundation to realistically explore employment. Awareness of depressive symptoms, insight into one's depression and triggers of symptoms, and a stabilized cognitive functioning contributed to one's mental health. One IDD participant described the importance of challenging one's own thinking as perception or interpretation of situations can be skewed by distorted thinking associated with depression. He/ she says,

> …I think you have to be the point where you are aware enough of your depression that you're able to catch it. say to yourself, oh no, this is not true, you know. This is depression. So yes, you sort of have to get at that point cuz a person who is extremely depressed, you know how it is with depression ,when you're extremely depressed, you don't even know you're depressed. You know? And you're practically delusional. or …. even hallucinate so if you're at that point,…..like personally I don't think… ….you know whose so depressed where they're hallucinating, I don't see how they could even be having a job (IDD participant 3).

All OTs emphasized assessing the individual's current functional skill set as a baseline to determine readiness for employment, which included obtaining a baseline of the IDD's cognitive status, mood component, management of medications, and managing day-to-day functioning. One therapist described the advocate role of obtaining this baseline/ starting point to help clients establish realistic goals, indicating,

> It's looking at where they are at skill wise …and using that as a starting point. sometimes medications or the depression itself has a whole lot of cognitive impact and that precludes people from sometimes getting back or finding work. So, sometimes it's taking people back from that point and seeing well, where is this affecting you and then how could we help you in your work situation or what kind of work can we help you gear you towards so that you can, can manage (Therapist 5).

Maintaining health and sustaining a stabilized health was identified as important by both IDDs and OTs, regardless if the individual was employed or not. Maintaining health was defined by all study participants as managing areas of physical well-being (such as having healthy sleep hygiene, exercise, and physical health), emotional wellbeing (such as adequate coping skills, healthy self-esteem, effective stress management skills, and connecting with spirituality domain), basic necessities (such as housing, medications, health benefits, and financial supports) and cognitive abilities (insight into depression, awareness of triggers, acceptance of relapse, and challenging negative thinking).

IDD participant two believed that exploring employment opportunities would only be realistic if one was not actively working on other goals related to improving mental health. However, he/she indicated that it might be possible for some individuals to work on employment and health issues simultaneously only if that individual experienced stable mental health. He/she stated, "…I guess for me... I would say it's been super important to look at the mental health stuff first kind of and make sure that's in place and then being able to look at …. work situations" (IDD participant 2).

All study participants indicated that establishing the foundational base of IDD maintaining health was a requirement before employment could be a viable option.

B) Exploring employment issues & acquiring pre-employment skills.

Both IDDs and OTs also identified the importance of IDDs developing relevant skills specifically related to being employed. These skill sets, also referred to as pre-employment skills included: resume writing, interview preparation, completing a job interview, and applying for jobs. Therapists described their advocacy role as focusing on helping clients develop pre-employment skills and facilitate community linkages to resources that would help them in securing employment. Many therapists indicated that it was outside of their job description scope of practice to work with clients to carry through the processes of client's successfully obtaining employment therefore they often made referrals to other agencies who could advocate for employment with clients on a longer term basis.

IDDs identified the importance of having the ability to cope with work stress and co-workers with challenging personalities to prepare for readiness for employment. Learning to regulate their (IDD) moods and behaviours within the environmental conditions of work stress and with co-workers were skill sets IDDs wanted to develop before they actively pursued employed opportunities.

One of the IDD participants struggled with poor emotional and impulse control, specifically in managing anger towards co- workers with challenging personalities. As a result, this individual recognized he/ she was not ready to be in the workplace as there were expectations of employees to work harmoniously with other co-workers, indicating,

> I think a person has be able to commit themselves to…what their employer….would require…to be ready for the environment itself, working around people that you may, not agree with ….having self-control and patience …being able to, turn away from things that maybe you hear and see that that could offend you ….without continuing that offence (IDD participant 4).

Disclosure of mental illness to employers was another challenging issue that both IDDs and OTs struggled with and all study participants believed there were negative implications with disclosing this personal information. Mental health stigma and workplace discrimination against IMI were two identified factors (according to IDDs and OTs) that contributed to difficulties in IDDs obtaining and maintaining employment. Some of the OTs struggled with advising IDDs to disclose their illness to employers due to their own personal beliefs that individuals with depression are discriminated by employers in successfully obtaining or sustaining employment. However, despite the OTs personal beliefs, the OTs felt it was important to discuss the pros and cons of IDDs disclosing their illness with employers before they entered the workplace setting (pre-employment) to provide a realistic picture of anticipated issues that may arise due to the disclosure.

One of the OTs role played with her clients how a job interview may be conducted and integrated questions around mental health disclose. She stated,

> One of the, questions that I get asked most often when clients are nervous about their resume or about an interview for example, is how do I explain why I haven't worked for these periods of time and how do I not tell them that I have a mental illness …. Trying to figure out what can you say, what can't you say, …what is the employer allowed to ask you and what aren't they allowed to ask you because …some employers will…., will make a point of not hiring you based upon the interview if you reveal or disclose that you do have a mental illness, so ….that's something that I find that I struggle with right alongside with my clients…Is how to negotiate that (Therapist 2).

Awareness of employees' rights and entitlements (i.e. income sources through assistance programs and disability programs) was another pre-employment issue that all participants felt should be explored prior to IDDs entering the workplace setting. IDDs often struggled differentiating whether their perceptions of situations/ information were based in reality or distorted thinking, therefore identified the important need for advocates to help them be made aware of their rights, what processes were typical when pursuing employment, and what steps are need to be taken to go from being unemployed to being employed. IDD participant 2 found it very helpful when his/ her advocates provided education around employment rights to clarify normalized processes, stating,

> … Definitely helps (education) in the way, knowing what my rights are and like talking me cuz I think a lot of times, you just have so many questions and like what is this, is this right, am I taking this wrong, do I understand this right? And it really helps to have someone just being able to…yeah who understands more of what is, yeah what is normal in a job situation and what is normal, in getting on social assistance…(IDD participant 2).

Awareness of employment rights and entitlements also had its drawbacks as discontinuation of disability benefits caused anxiety for some IDD participants. One IDD participant was always worrying how he/ she was going to pay for day-to-day expenses if he/ she were to get cut off from the income received through disability benefits before securing employment. He/she felt that imposed deadlines and pressures to find a job within certain time frames as outlined by disability policies was anxiety provoking, stating,

> …You always have that thought… that you may get cut off of disability and so your finances will be less than what they are now…or that you might have to go back to work

and that part,... is a little scary cuz I don't really know if I'm ready to go back to work yet (IDD participant 6).

Acquiring pre-employment skills, in conjunction with skills related to managing depression, were essential as the basic building blocks for IDDs to realistically explore employment opportunities.

C) Obtaining and maintaining employment.

Obtaining and maintaining employment was the main goal for all IDD participants; and OTs worked with many IDDs whose primary goal was to secure employment. However, obtaining and maintaining employment was not possible if individuals were not managing their depression well or did not have the pre-employment skill sets to successfully secure employment or cope with anticipated challenging scenarios in the workplace. Fifty per cent of the IDD participants were employed at the time of the study and these individuals emphasized that the success of maintaining employment was dependent on how well that individual was maintaining their health. All participants re-iterated the need to maintain those foundational skill sets (managing depression and pre-employment skills) even if the IDDs were successful in securing employment. Both IDD and OT participants indicated that IDDs addressing different performance components, such as their ability to manage their physical and emotional health, learn and maintain coping skills to manage work-specific situations, while maintaining employment is addressing the "holistic" person, which all are relevant when advocating for successful employment for IDDs. IDD participant 2 described his/ her perception that health and employment related issues cannot be separated, indicating,

> I guess I see it in a very like a holistic manner that like if I'm healthy enough person and am doing enough well emotionally then like I am able to work and I'm able to like do like.. I think it's hard for me to like separate them (health issues and work issues) (IDD participant 2).

Occupational therapists also identified the connection between an IDD maintaining their health, IDDs' previous work experiences, and skill sets within the pre-employment domain in relation to an IDD successfully obtaining and maintaining employment. Therapist 5 highlights how current functional abilities and previous return to work experiences impact the success of IDD's re-integration into employment:

> I think it also depends where somebody is at in the recovery…how, debilitated by their depression…and for some people its whether they've had other experiences with their depression and what return to work has been like. So that's sometimes colours the return to work (Therapist 5).

All IDD participants strived to achieve employment as employment was perceived as part of "normal culture", provided a primary sense of purpose and meaning to life, and meant being integrated into society. Employment was important for IDD participants because a primary goal for IDDs was to fit within this "normal culture". According to two IDD participants, being employed meant that one was part of "normal culture", that was one part of the "real world", and that one was productively contributing to society. One participant went so far as to say that all individuals who have employment should be happy because they have work. He/ she also believed there was an

expectation for all individuals to have employment regardless if one was sick, describing the difficulties he/ she had with seeing other people work when he/ she was unable to work, stating,

> Yeah, of course. Its, very hard to see on that daily basis people that you meet on every, in every area, at the post office, the doctor, people are doing their daily jobs and they don't know how happy they are that they are healthy and they can do it. So I always feel,… I feel happy for them and I ask them myself am I going to be able to go back to normal life? That's….what every normal person wish for themselves. Yeah, it's hard….hard to wish to do something and then you see you can't do it….that's part of every life. Like even if, if we sick we have to work. (IDD participant 5).

Both IDDs and OTs indicated that exploring employment for IDDs was only realistic if basic necessities, healthy level of health, and skills in pre-employment skills were already established.

OTs advocated with their clients by taking the time to explore various options with the client, including job accommodations. Before therapists initiated or encouraged change, or developed action plans, therapists spent a significant amount of time hearing the client's story about their goals, preferences, fears, and tolerance and threshold levels for managing work stress. Therapists took these factors into consideration as part of their overall assessment before integrating any workplace changes. Therapist 5 described her approach of inquiring what the client's issues are and how the client would want to overcome the challenges affiliated with the client's issues.

> Kind of the stresses that were inherent as part of the work environment before you (IDD) left,…..what things do you think that you could handle going back to, what things are still

> huge barriers to you and how do, I mean, do you have those tasks when you go back initially or, or can your job be re-assigned? What are the options for you? Or is it just increasing your comfort level? And then feeling that yes I can do those tasks again I think. I think the time you take to tease it apart with that person (Therapist 5).

The long term goal of many IDDs was to obtain and maintain employment and specifically sought out advocacy support to receive direction as to how to successfully work towards achieving employment. Therapists, on the other hand, assessed the IDD's entire situation, collaborated with the IDDs, and problem-solved together how issues will be resolved. The advocacy process for employment, as described by both IDDs and OTs, required a completion of a sequence of steps in a certain order to facilitate realistic planning to successfully obtain employment.

Theme 4: Outcomes of advocacy: "The advocacy process is about outcomes and accomplishments"

Advocacy leads to intrinsic and extrinsic outcomes.

Successful advocacy was described by all study participants as forward movement, progression towards change, improvement in one's life situation, orientation towards achieving a goal, and a positive change in health and/ or employment status. Both IDDs and OTs emphasized that the effectiveness of advocacy was directly linked to an outcome and finding the right types of support to help achieve employment. All participants described the outcome as a positive change, as IDD participant 2 stated,

> I guess I know that advocacy has, is having an impact if I see positive change in my life. Like if I see in its you've got to maintain my goals and … getting to a better place, that I'd get into a better place …emotionally…. (IDD participant 2).

Therapists supported the stance that the advocacy process was about meeting the clients' goals and facilitating a change that wasn't in existence prior to the advocate's involvement; more specifically enabling the client to accomplish a new task or engage in a new occupation that they previously could not engage in.

Therapist 5 knew her advocacy role was successful when she was able to see her clients succeed in participating in activities that they previously were unable to complete, stating,

You can measure it (effectiveness of advocacy) if… someone's doing something that they tried before and it just didn't work so…All of a sudden, you see, wow, they got into somewhere and volunteer and that's because I phoned or that's because I went in there. (Therapist 1).

While participants equated successful advocacy as leading to an outcome, there was also a general consensus that a lack of change or outcome was the absence of effective advocacy. One participant questioned whether the relationship between the IDD and advocate impacted the lack of success of the advocacy process. This participant felt strongly that advocacy was based on the foundation of the relationship and indicated that if the relationship was not a good "fit" between the IDD and advocate, then the next step was to find another advocate who could assist the IDD successfully facilitate change and help them accomplish their goal. IDD participant 2 indicated," I was thinking well maybe that it's not advocacy if it's not …. If it's not supporting that person in obtaining their goal …. yeah, it could be that it's not the right fit" (IDD participant 2).

All study participants identified specific outcomes of advocacy, which have been categorized as intrinsic or extrinsic outcomes of advocacy. Similar outcomes were identified by both IDDs and

OTs; however it was evident that IDDs identified the advocacy process as leading to more extrinsic outcomes whereas the OTs identified more with intrinsic outcomes of advocacy for their clients.

Intrinsic outcomes.

Examples of intrinsic advocacy process outcomes identified by both IDDs and OTs included: instilling hope within the IDDs, facing barriers through navigating the health and employment systems, facilitating opportunities to be heard, enabling individuals to have choices, and IDDs learning effective coping strategies to manage stress/ anxiety, facilitating personal growth within the IDDs, helping the IDDs learn about recovery from depression, establishing a relationship, and providing opportunities for the IDD in making a decision.

1. Facilitating hope.

Instilling hope was the most significant and positive outcome of the advocacy process identified by both IDDs and OTs. IDDs expressed difficulties in managing day-to-day functioning due to the persistent stigma surrounding them held by the general public, peers, or family members and relied significantly on their advocates to be their voices, help them cope with challenging situations that others without depression do not have to endure, and validate their experiences. One participant described hope as the "engine for the car" (IDD participant 2) because having hope helped IDDs strive to continue to live their lives despite the challenges of their depression. Therapists also believed that the advocacy process was about instilling hope through validating client experiences and providing an objective/outsider perspective about the challenges of living with depression. This therapist compared her role of providing hope for her clients as being an external source of vision when her clients had lost all hope and could not foresee a positive future. She stated:

> And acknowledging that when we first we meet our clients, they may have a new diagnosis or some sort of trauma or something significant happen to them, they don't necessarily have that vision and, or they can't,….they had a vision of what that story was going to play out for them and now it's been stolen from them in a way and they don't have that ability to see what life could be like for them as they recover …..you can be that vision for them until they see it for themselves (Therapist 4).

Providing hope for the clients also facilitated client opportunities for personal growth, change, and client engagement in meaningful occupations despite the individuals' diagnosis of depression. IDDs expressed their struggles with self-esteem and confidence level, therefore IDDs often experienced self- doubt and feared taking risks because of their lack of self-confidence. IDDs described advocacy as being effective when IDDs became hopeful about their situations and began believing that change is possible, which was demonstrated through the IDDs' abilities in taking risks and believing in themselves. IDD participant 2 recognized advocacy was starting to have an impact when he/ she became more hopeful and started to have more self-confidence:

> Realizing that..it's not as hard as you had thought or it's not as or… or you can, you can ask those questions and they can be fearful but you can handle it, you know, like it's okay its it'll, yeah that you can, …yeah maybe that there's a lot of fear there but you can still you could still handle that fear. You know, like it'll, yeah, you can still work and still be okay. But perhaps a big part of it is trying it out (IDD participant 2).

Instilling hope was one of the most important outcomes of advocacy as identified by both IDDs and OTs.

2. Personal growth.

The advocacy process was described as a process that led to change; within that evolution of change, both IDDs and OTs experienced personal growth. While the OTs described the advocacy process as enabling the IDD in participating in a meaningful occupation and facilitating a change, the OTs also felt they benefited from the advocacy process as well. When the OTs were able to facilitate personal growth within their client, assist with improving the client's quality of life, and/ or enable participation in a new occupation, the OTs felt their job as an occupational therapist and advocate was successful. One therapist also shared that the personal growth of her clients contributed to her personal growth as a therapist, indicating, "I believe advocacy leads to ongoing learning and growth. Not only for the client but also for the therapist working with the client" (Therapist 3).

Personal growth was also described by IDDs as being accepting of their limitations, being able to challenge their situations, and being open to receiving help as a result of their (IDD) limitations. Recognizing one's limitations meant IDDs accepting that they were struggling in one aspect of their life, a willingness to share these limitations with someone, and accepting help from others. IDD participant 2 described the personal growth as a difficult experience, as it required the individual to be vulnerable and accept there were flaws within them as an individual as well as flaws within their situations:

> I think it's been a tough one in…. I guess there's two sides to it, … I think it's been really, challenging me, asking for help, and you have to be like be willing, for someone to help you know a person like advocate for me or supporting me so I can self-advocate, I think that's been its been challenging to…… to do kind of both to accept the help … but at the same

time, knowing that it is been a very its its good for me to, I guess it's been challenging in that way but it's also it's something I know I need… (IDD participant 2).

The advocacy process was successful and/ or effective when the outcomes led to any type of change; change, inherently causes personal growth according to all study participants.

3. Insight into recovery from depression.

Effective management of depression and stability of emotional/ physical health was the foundation of the advocacy process. Learning about the recovery from depression, being realistic about the progression of depression, and being aware of the potential relapse in health was an important part of the advocacy process. While advocacy was described as a process that led to change, both IDDs and OTs indicated that advocating for change would be very difficult to achieve if an individual did not have good insight into their depression or did not have the insight to effectively manage their depression. OTs felt that their advocacy role was successful when they were able to not only educate their clients about the recovery process, but also validate their clients' challenging experiences of progressions and regressions within their health and life circumstances. Helping their clients accept the recovery process of depression contributed to the personal growth of their clients. While it was important for OTs to help clients be hopeful about working towards making positive change in their life, it was also important for clients to have realistic expectations of their recovery. Therapist 3 validated her clients' experiences by

Reassuring individuals that, that story or that book or that path, there's gonna be banana peels along the way. There's going to be slips, there's going to be times when you're going to go ten steps forward and maybe five or six back so to be aware that that's a part of that process too, in the recovery. And, that it's okay to reach out for help, it's okay to ask for

> some assistance,….it's okay to let someone else to take your hand for a while. It's okay to go back into the hospital if you need to. … the hope is that one would not need to come back, you know through this door, through this path again, however, if one needs to, that's okay. (Therapist 3).

Another part of IDDs teaching their clients about the recovery process of depression; was also teaching individuals that they were human beings separate from their mental health diagnosis. OTs acknowledged that stigma is often attached to depression but OTs felt that helping IDDs recognize their own self-worth despite having depression was a positive outcome of advocacy. Therapist 4 helped IDDs develop insight by,

> Helping them (IDDs) accept that there can be stigma, they don't have to live with it… …But then also giving them faith in themselves that they can handle it and walking them through possible answers… …just sort of giving them faith in themselves that what their diagnosis is isn't what they have is okay. And they're more than that, they're a lot more than that. ... (Therapist 4).

Similarly, IDDs also identified successful advocacy as having an advocate help them accept their difficult situations and help IDDs identify their strengths. IDDs described being in less than desirable situations (e.g. poor income, limited resources, and poor social network) however, effective advocates were able to help IDDs recognize their own strengths while in the midst of difficult circumstances. IDD participant 6 described his/ her experience of recognizing his/ her self-worth after working with an advocate over a long period of time. He/ she stated,

> For the past two years, it's sort of helped me focus getting a direction where I'm trying to get on track at least being able to,…to sort of live with myself? You know what I mean? Live with my situation, or make the best of my circumstances (IDD participant 6).

From the perspective of IDDs in this study,IDDs' acceptance of the recovery process and development of self- worth was not easy to achieve; IDDs were required to do a lot of self-reflective work to accept the difficult circumstances they were in and to maintain a hopeful perspective that positive changes was possible despite the presence of their depression.

4. Opportunities to be heard.

Validation of experiences and providing opportunities to be heard was another intrinsic outcome of advocacy . Hearing the client's story was a significant part of the OT and advocate role. IDDs within this study did not identify having many social supports, therefore having someone be available and present for them was an uplifting experience. One IDD indicated that effective advocates made themselves available to answer questions and help IDDs break down tasks into realistic steps so that the IDD was not so overwhelmed. IDDs also described effective advocates as being positive influences who motivated, encouraged, and believed in the IDDs. IDD participant 6 described advocates as:

> Having people who, help you along the way, who are positive and give you some direction and maybe say try this or go here kind of thing. Or do that kind of helps me move along… Or do that kind of helps me move along… (IDD participant 6).

Frustrations with navigating the health and employment systems was a common theme among all study participants, including OTs who worked within the health system. OTs felt that part

of their role as an advocate was not only to validate the IDD's frustrations with the health and employment systems, but also allowing the IDDs the vent out their frustrations. OTs also validated their (IDD) experiences by empathizing with them, informing them that they know what frustrations they have experienced because they, as health professionals, have come across similar barriers as well. Therapist 1 empathized with her clients:

> It helps too, also to, just, to be honest, and to validate someone's feelings and validate someone's experience. Example, just to express frustration with an organization and say, no this isn't the way it usually works so that they (client) feel that their expectation was also, you know, on, on the right track there. (Therapist 1).

5. Establishing a relationship.

Establishing a collaborative and trusting relationship between an IDD and advocate was another intrinsic outcome of advocacy identified by both IDDs and OTs, especially since the IDD/ advocate relationship established the foundation of the advocacy process. One therapist identified developing a collaborative partnership with the client as her ultimate measure of successful advocacy. She described collaborative partnerships as the ability to empower the client to make decisions and allowing the client to feel like a "non-patient". While she agreed that enabling employment was a successful measure of advocacy, she valued client empowerment more heavily as an advocacy outcome as empowerment provided for their clients to be in control within their life. She described advocacy as,

> ….ultimate success if they (client) felt that they (client) were in a partnership, whether they got back to work or not… if they felt that they experienced…made them not feel like a

patient,…in that they have ability to make choices…and even choosing to do nothing is a choice….that's important for me (Therapist 5).

All IDDs valued the opportunities to be heard, validation of their experiences, and hope instilled within them, all of which are inherently part of establishing a relationship with their advocates.

Extrinsic outcomes.

Obtaining employment, overcoming systemic barriers, promoting healthy workplaces, and facilitating access to employment and health resources were the extrinsic outcomes identified by both IDDs and OTs as a result of the advocacy process. The most obvious extrinsic outcome of advocacy was obtaining or securing employment, especially when the IDDs' primary goals were to obtain employment. However many OTs indicated that obtaining employment was not a good outcome measure of the work/ progress was made during their involvement. While the OTs may have been assisting the IDDs in securing employment, OTs stated that a lot more advocacy outcomes are achieved even before the IDDs secure employment.

1. Improved self-care.

Managing basic self-care and depression was identified as the most important aspects of an individual's wellbeing, even if the IDDs' primary goal was obtaining employment. Obtaining employment was not a realistic goal unless IDDs were managing their emotional and physical health. Maintaining self- care and well-being became significantly important when the IDDs began to engage in new occupations or develop new skill sets. For one participant, the individual became much more productive when he/ she learned to manage his/ her time more effectively as a result of having regular meetings with his/ her advocate. Within these scheduled meetings, the IDD and advocate would negotiate what goals (often self-care related) needed to be accomplished within a

certain time frame, which helped the IDD in successfully achieving them. IDD participant 6 found the regularity in meetings with the advocate helped prevent a decline in his/ her self-care and overall health:

> Having the regular…now I have….the work to go to, that'll, that'll help but I find, not working is easy to get into this, this rut of not working and your, your times are filled. You know, you can easily sleep away the day, the week, a month (IDD participant 6).

Therapists also described improved self-care as a success of the advocacy process. Inpatient therapists in particular, indicated that a significant outcome measure in an inpatient setting was acknowledging clients' achievements in addressing basic needs, such as learning effective time management skills, adequate management of self-care tasks, and managing stress. These skill sets were just as important as they provided the stepping stones to bigger goals such as finding employment.

An inpatient therapist recognized the success of her role as an advocate when she saw improvements in her client's routine and abilities to manage their self-care:

> Like perhaps the client is now able to get up and get dressed and ready for the day before ten a.m. which is a huge step for some people specifically and people with depression so sometimes you have to make your successes smaller (Therapist 2).

All therapists shared the same perspective that even if their involvement as an advocate did not lead to their clients successfully obtaining employment, therapists felt that any type of positive change within an IDD's situation was an outcome of successful advocacy.

2. Access to resources.

Knowledge of existing resources and accessing resources was a barrier identified by all participants, particularly the IDD participants. Individuals recognized they required assistance to help sort out health or employment related issues, however did not know which organizations provided what services and who to approach. Many of the IDDs encountered the appropriate services by chance; either by seeing an advertisement about a resource centre in a newsletter or bulletin board, initiating phone calls to various agencies and continuously asking questions; or hearing about ideas through informal support groups.

One IDD participant in particular felt that community resources were poorly advertised and not well known about, even from health care providers. While his/ her experiences with the employment system had been successful in obtaining vocational training funding due to his/ her diligence and perseverance with finding advocacy supports, he/ she felt that other IDDs would not necessarily have the abilities to endure the challenges of accessing appropriate resources:

> It's very hard, the average person doesn't know about what resources are out there. It's almost like they're hidden And, when you start trying to find out like you have to, find them on your own and how are you supposed to do that when you don't know the names. … How are you supposed to find that? And, when you start to locate organizations that you think should have the information especially….they don't have the information. They should and they don't.…The employees within those organizations haven't got a clue (IDD participant 3).

Accessing community resources or programs were not the only types of resources IDDs struggled in connecting; sometimes it was accessing basic necessities/ resources (such as a bank account, access to phone or fax machine, or monies for pharmacare) to manage day-to-day

functioning. When IDDs were able to connect to the appropriate support systems, whether it be an agency or an individual advocate, these individuals felt that they had overcome a significant barrier.

Similarly, therapists acknowledged the abundant amount of resources in the community and that it was not possible for anyone to know of all of the available supports. OTs indicated that organizations were either changing names of programs, offering different supports, changing the focus of the agency, and/ or were being canceled/ closed. Therapists indicated that they were constantly learning from others, including their clients, of new resources or new services being provided by agencies. One therapist in particular recognized that she was more knowledgeable about mental health resources but was always looking for other types of resources as her client's often were either looking for resources unrelated to mental health or could not afford some of the existing resources due to limited funds. Therapist 5 indicated that part of her role as an advocate, was to go seek out relevant information regarding community resources outside of her scheduled work time. Therapist 5 described how she was continuously learning new information due to the constant evolution of community programs:

> ... all the resources that there are and they're always, changing.. you know, this spring, I found a new resource I didn't know was out there. And it's free and quick access..I'm always looking for other options rather than just the tried and true main,…mental health programs..And so, I think..always talking to, to other people about what did you see or if I'm in the mall and I see a display up, you know, I'll pick up pamphlets…we all do that kind of thing because we know that we don't have all, the knowledge and it's always changing or, organizations are renaming themselves or having different focuses (Therapist 5).

In order for OTs to effectively advocate for their clients in accessing resources, they first had to learn and become aware of the various community resources before they could increase IDD access to resources and/ or facilitate community linkages.

3. Learning new skills & enabling occupations.

When IDDs were able to do something new that they previously were not doing, engagement in the new occupation and / or learning new skills were outcome measures that demonstrated a positive change. IDD engagement in new tasks identified by both IDDs and OTs included: managing self-care, having a daily routine, volunteerism, attending groups, initiating conversations with family, friends, and/ or employers about important issues, and being able to engage in social surroundings.

One therapist summarized her measure of success as an advocate when she had a direct impact on enabling occupations:

> Someone's doing something that they tried before and it just didn't work so…All of a sudden, you see, wow, they got into somewhere and volunteer and that's because I phoned or that's because I went in there (Therapist1).

Both IDDs and OTs agreed that learning a new skill or engaging in a new activity was evidence of successful advocacy.

4. Improved quality of life.

Both IDDs and OTs described the essential concept of the advocacy process as facilitating a positive change, which inherently contributes to the improvement in quality of life for an IDD. The outcomes previously discussed (e.g. improved self-care, accessing resources, learning new skills, enabling occupations, personal growth, etc.) all contribute to improving an IDD's improved quality

of life. Working towards improving a situation and/ or aspects of one's life was a key motivator for IDDs in seeking advocacy support.

Advocacy is about "fighting the good fight"

"Fighting the good fight" (IDD participant 4) was one of the outcomes unique to the OT perspective between the two sample groups. Three therapists (therapists one, three, and four) described advocacy as an overall process of facing and overcoming barriers with their clients. Therapist four described facing challenges as "fighting the good fight" and indicated a need for advocates to be "gutsy", "feisty" and "extroverts" for clients who are marginalized and have difficulties standing up for their own rights or speaking up for themselves. She also described the advocacy role as "sticking up for other people", especially for individuals who would or could not advocate on their own.

Therapist one described the advocacy process as the willingness of a therapist/ advocate to "how far somebody will push" and further provided two examples of personality types within therapists: a) those that accept no as an answer and leave issues along or b) others who would fight "City Hall":

> Actually I think that the level of advocacy that you offer is actually related to your personality and I would think that the quality and quantity of advocacy is gonna be related to how far somebody will push. So, say for example, there may be someone that just willing to accept that no is an answer and that's what they communicate back to the client that the answer is no. And other people who are in fact going to fight City Hall. So I think it's dependent on, the therapist's own skill set and personality (Therapist 1).

Therapists described the advocacy process a challenging venture because advocacy challenged ideas and people. On one hand, therapists challenged their clients to take risks, which sometimes felt like "pulling teeth" process. On the other hand, therapists faced some tension with organizations, especially if they challenged responses (i.e. "no" or a refusal of a request) given to them by organizations. Some therapists also faced tension among their colleagues in situations where the colleagues would disagree with the OT's decision in addressing issues such as employment with clients, as some colleagues did not think individuals who had frequent hospital admissions were capable of managing employment.

One therapist described her interpretation of what fighting the good fight looked like:

> About that facing a challenge, like advocacy I think, like fighting the good fight, that's the way I see it is sort of a polished scrappy. Like you're willing to kind of get in the ring and get dirty but you're gonna do it as a professional and role model it for the client and role play it with them all those things (Therapist 4).

5.0 Discussion

This study explored the concept of advocacy in the context of the advocate role and experiences within the advocacy process. Valuable insights and perceptions were obtained from two different sample groups, which data was then used to see if there were similarities and/ or differences between these perceptions.

The relational components of advocacy

The relationship between the IDD and advocate was described as foundational to the advocacy process. Both the IDD and OT participants in this study describe the IDD/ advocate relationship as consisting two major components: 1) Trust, which was described as the ground

work of the IDD/ advocate relationship, and 2) Navigating the health and employment systems. Trust between the IDD and OT advocate and the navigation within the health and employment systems were identified as the components that made up the advocacy relationship. Figure 5 depicts the components of the IDD/ advocate relationship and the elements within those components. Please refer to figure 2 which conceptualizes the relational components of advocacy. "Trust" and "navigating the systems" are the two main and required components of the IDD/ advocate relationship; both of which have a dynamic impact on one another whereby establishing one component inherently builds on the other component. Figure 2 outlines the elements that comprise both the trust component and "navigation" component.

Trust is described as the process component whereby trust is developed over time through dynamic behaviours between both the IDD and advocate. Examples of dynamic behaviours, which contribute to the trust component, include: effective communication between the IDD and advocate, ongoing contact, exchange of information/ knowledge, and being available when questions and needs arise. These dynamic behaviours demonstrate dependability on one another, nonjudgment towards each another, implementing a hopeful attitude towards the future, and an invested interest towards working on achieving realistic and goal-oriented outcomes such as obtaining employment. Trust enables the parties (IDDs and advocates) to rely on one another to follow through with their part/ role within a working relationship Navigating the health and employment systems is described as the task component whereby specific physical or verbal task oriented actions were initiated in order to explore answers or seek solutions to overcome barriers which hindered IDDs' occupational engagement in meaningful activities. Both the "trust" and "navigating the systems" components are required to establish an effective IDD/ advocate relationship. As trust developed within the IDD/ advocate relationship, IDDs and advocates were able to work cohesively together to navigate the health and employment systems. Similarly, as

IDDs and OTs navigated the health/ employment systems, the trust between the IDD/ advocate was further expanded. Several studies (Corrigan, 2002; Tse, 2002) indicate the importance of the interpersonal relationship as a central factor in assisting someone with mental illness with their recovery journey, especially as it relates to implementing hope, helping the individual recognize their strengths, and helping the individual accept their illness.

IDDs in this study described that once there is an initial level of trust, their attention focused on the importance of the advocate in navigating the health/ employment systems with and for them. For example, IDDs relied on the advocate to access relevant information for them, connect them with appropriate resources/ services that can assist with their employment-related goals, and assist them with securing basic health needs that would enhance their quality of life. Provide some examples here. Furthermore, when advocates were able to demonstrate successful navigation in the health and employment systems within the advocacy process, IDDs were able to trust their advocates. Once the initial trust was established between the IDD and advocate, the IDD/ advocate relationship continued to be an important aspect, however the navigating the system became the primary focus for the IDD.IDDs described effective advocates as individuals who obtained a genuine understanding of their story and helped them overcome challenges within the health and employment systems that hindered them (IDDs) in participating in meaningful occupations. Their (IDDs) significant reliance on their advocates was based on the perception that they (IDDs) lacked the abilities to speak on their own behalf, mental health stigma in the workplace, and limited skill sets in navigating the health systems. Because IDDs faced a number of complex issues, (i.e. stigma, previous negative experiences with employers or within the health system, poor self-esteem) they relied on their advocates to be their voices, stand up for them, provide solutions for them, and navigate the health/ employment systems for them, which is consistent with McColl's definition of advocacy. McColl (2003) defines advocacy as "initiatives taken by a therapist

on behalf of a client, to pursue change in the environment that will ultimately enhance occupation", which has largely been criticized for not addressing the collaboration between the client and therapist. However, IDDs do not emphasize the collaboration between the IDD/ advocate relationship. IDDs' interpretation of the advocacy process is also consistent with the process outlined by Sheafor & Horejsi's (2003) indicating that the advocacy process is a set of actions to carry out a plan based on which advocacy strategies will be implemented to overcome opposing views. From the IDD perspectives, IDDs expected the advocates to carry out the set of actions for them in order to overcome barriers or opposing views.

OT participants in this study described focusing on empowering the IDDs to self-advocate, therefore OTs' emphasis within the IDD/ OT relationship was enhancing the trust component by focusing on identifying the IDD's strengths/ skill sets and helping the IDDs utilize these strengths to become their own self-advocates rather than on navigating the system for them. OTs believed that as advocates, they needed to work within the parameters of the IDDs strengths in order to work towards IDDs being independent and learn how to be a self-advocate.

Several authors (Chima, 2005; Ingram et al., 2008; Townsend, Langley, & Ripley, 2003) indicate the role of an advocate is to empower individuals in learning to be their own self-advocates.

OTs' belief systems, as described by their perception of the advocacy process are consistent with the empowerment approach (Chima, 2005; Ingram et al, 2008), therefore OTs believed that if they helped their clients develop self-advocacy skills, their clients would then utilize these skills to independently navigate the health and employment systems (Chima, 2005; Funk et al., 2005; Koch, 2000). Moreover, if IDDs are able to self advocate their future reliance on advocates may decrease. Occupational therapists believe that when an individual views

themselves as having skills to advocate on behalf of oneself they may feel empowered and hopeful about themselves even when they have not successfully gained employment.

On the other hand, OTs expected more of a collaborative process where clients were more engaged in the dialogue and decision-making process. OTs acknowledged their skill sets in navigating through the health and employment systems and expertise in facilitating occupational performance, however, the majority of OTs indicated that the advocacy process of navigating through the systems was a joint-learning experience with their clients. The OTs described their advocacy role as engaging their clients in decisions, promoting increased autonomy, and increasing client responsibility, which is consistent with the recovery model core concepts (Frese et al., 2001;Jacobson & Greenly, 2001). Furthermore, OTs emphasized the importance of empowering their clients in learning the skill sets so that the IDDs can engage in advocating for themselves throughout the advocacy process. OTs' perspectives were consistent with Chima's (2005) description of the advocacy process whereby clinicians assist individuals in developing appropriate skill sets so that individuals are more engaged in the process of working towards employment-related goals. The majority of OTs perceived the advocate role as being consistent with the practice philosophy of client-centredness (Restall & Ripat, 2008; Townsend & Polatajko, 2007) where health services are tailored around the client's preferences, goals, and desires. Two of the six therapists felt strongly about facilitating opportunities for clients with mental health issues to make decisions, even if those decisions involved refusing health services.

Only one of six OTs indicated the need to speak on behalf of her clients or make decisions in the best interest of her clients due to her client's cognitive impairment and unrealistic expectations of being employed. This perception varied greatly in comparison to the other OTs who indicated their role as assisting their clients in achieving their goals. However, the significant difference between the one of the six OTs is that this one OT worked primarily with individuals with

schizophrenia. Individuals with schizophrenia present with more cognitive impairment than individuals with depression (Fabian, 1992); therefore individuals with greater cognitive impairment (i.e. individuals diagnosed with schizophrenia) would require more direction and assistance from health professionals in navigating the health and employment systems than individuals with less cognitive impairment (i.e. individuals with depression).

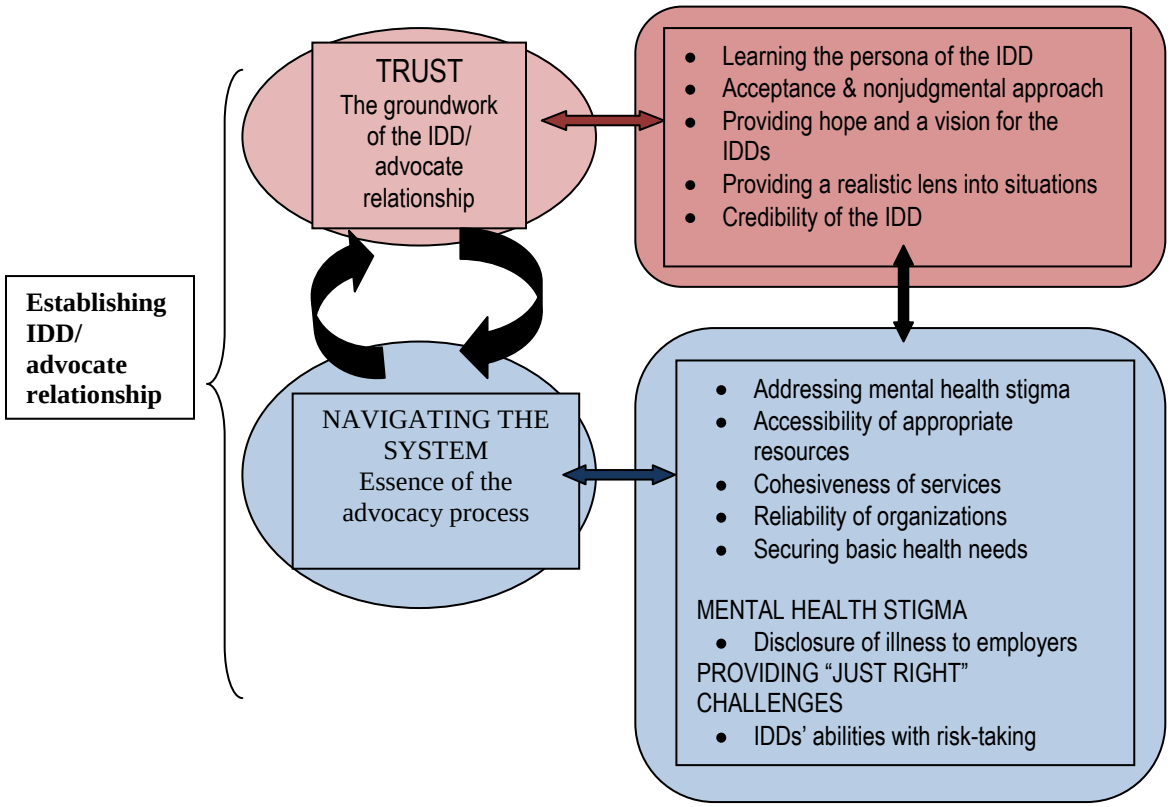
IDDs and OTs both identified these same components of the relationship (trust and navigation of systems) however emphasis on different components was evident in their description of the IDD/ advocate relationship.

Role expectations within the context of the IDD/ advocate relationship was the central issue identified by all IDDs and OTs regarding the advocacy process and advocate role. Expectations, power dynamics within the IDD/ advocate relationship, and perception of who led the advocacy process contributed significantly to how occupational therapists integrated advocacy in their clinical work and what IDDs expected of their advocates when seeking health services.

Therefore, there were major differences in the expectations of the advocate role, which also explains why both IDDs and OTs perceived the advocacy process differently.

There is a need to address the gaps and differences of the relational components among IDDs and OTs because emphasis on one relational component versus the other implicates the expectations within the advocate role. Therefore, if OTs and IDDs emphasize different relational components, then it is clear that OTs and IDDs hold very different expectations of the OT role within the advocacy process. The differences in perception of the advocate role indicates a gap between how OTs see their role as advocates and what IDDs expect from advocates when seeking health services. There is a need to address this practice gap if OTs want to facilitate client centredness philosophies within their OT practice.

Figure 2. The relational components of advocacy



Readiness progression towards employment goals

Readiness and preparation for employment is described by both IDDs and OTs as a process which entails a progression of skills. Obtaining and maintaining employment requires complex skill sets, which means that individuals striving to work towards employment need to have a set of foundational skills as prerequisites before exploring employment is a realistic goal. The primary set of foundational skills required of an IDD include the ability to maintain a healthy level of physical and emotional health (step 1 in figure 3). As outlined in figure 3, IDDs and OTs described four areas of health which defined healthy level of health, which included components of physical wellbeing (adequate exercise, physical health, adequate sleep hygiene), emotional wellbeing

(coping skills, self-esteem, stress management, spirituality), basic necessities in place (housing, health benefits, financial supports, medications), and presence of cognitive abilities (insight into depression, awareness of triggers, acceptance of relapse as part of recovery process of depression, and ability to challenge negative thinking).

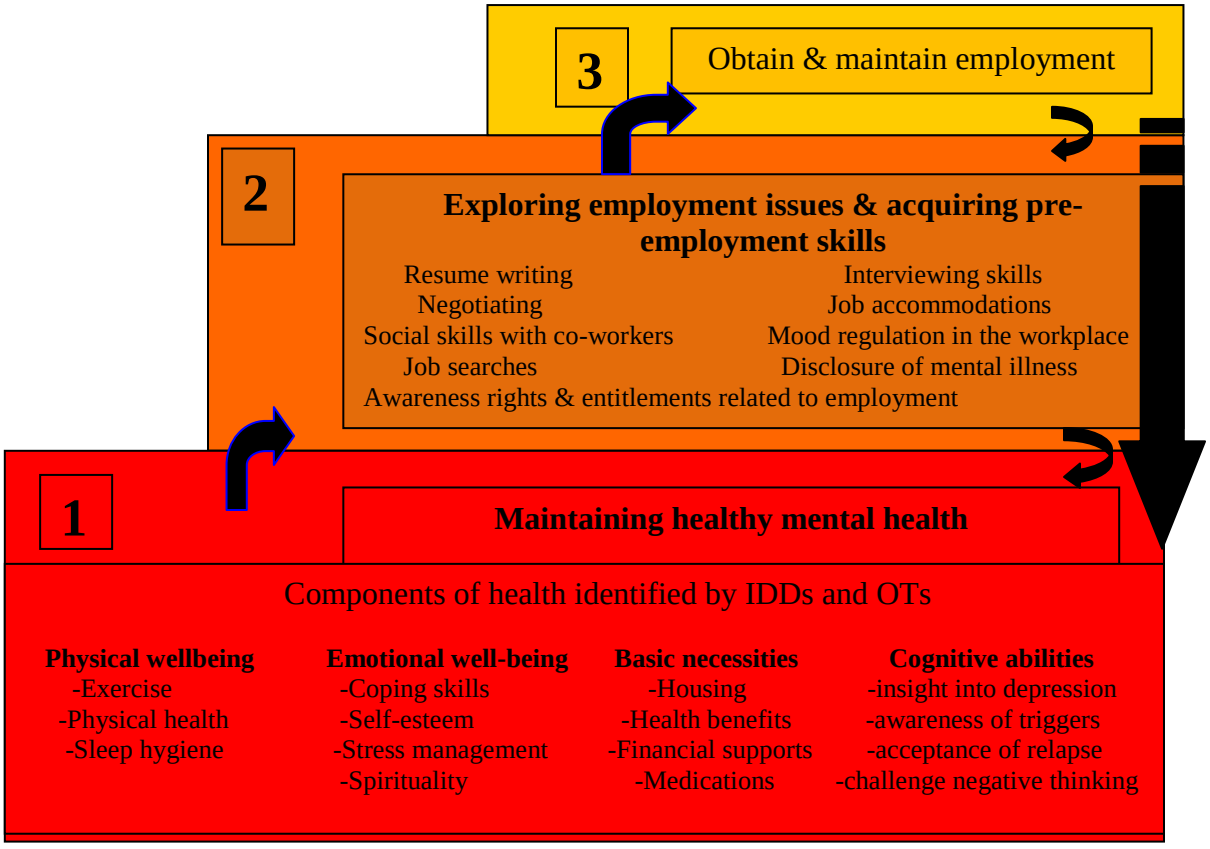
Maintaining healthy level of physical and emotional health described the foundation of an individual pursuing any type of goal, regardless if the goal was employment related or not. If IDDs were managing their health relatively well, then acquiring pre-employment skills and exploring employment related issues (step 2 in figure 3) would be the next set of skill sets to develop when IDDs were specifically pursuing employment related goals. Pre-employment skills include: developing resume writing skills, learning how to complete job searches, learning how to participate in a job interview, and exploring readiness/ comfort in disclosing one's mental illness to employers. Exploring employment related issues included developing effective communication skills such as assertion and negotiation skills with employers, learning one's rights and entitlements related to employment, exploring job accommodations that would be suitable for the individual, and exploring strategies in regulating the IDD's mood in the workplace. The IDD's ability to regulate their mood in the workplace included their capabilities in managing their emotions around working with co-workers with challenging personalities and managing workplace stigma. IDDs identified workplace bullying, educating employers on mental illness, and developing effective communication skills with co-workers as significant issues that required further enhancements in advocacy practices.

When IDDs possessed skill sets in both managing their physical and emotional health (step 1 in figure 3) and acquired pre-employment skills and skills related to managing employment issues (step 2 in figure 3), only then was it possible for IDDs to realistically pursue goals specifically aimed at obtaining and maintaining employment.

Obtaining and maintain employment was described as a complex ability consisting of a number of skill sets in steps 1 and 2, therefore a breakdown in skills related to maintaining health (step 1) and/ or pre-employment skills/ employment issues(step 2 in figure 3) would result in difficulties in maintaining and/ or obtaining employment. Therefore, as portrayed in figure 3, if individuals were struggling in step 2, the IDD would then have to focus on ameliorating the issues related to pre-employment skills. Similarly, if individuals were previously able to maintain employment but then began to struggle with health componenets in step 1 that were compromising their ability to maintain employment, that individual would need to go back and address health related issues (step 1 in figure 3) and make subsequent steps to obtain/ maintain employment.

All IDDs and OTs agreed that each step contributed as a foundation to the next step/ stage, therefore OTs/ advocates working with IDDs need to be aware of what skills are required so that advocates can realistically assist IDDs in achieving vocational goals and optimizing success with these goals.

Figure 3. IDDs and OTs description of progression readiness towards employment



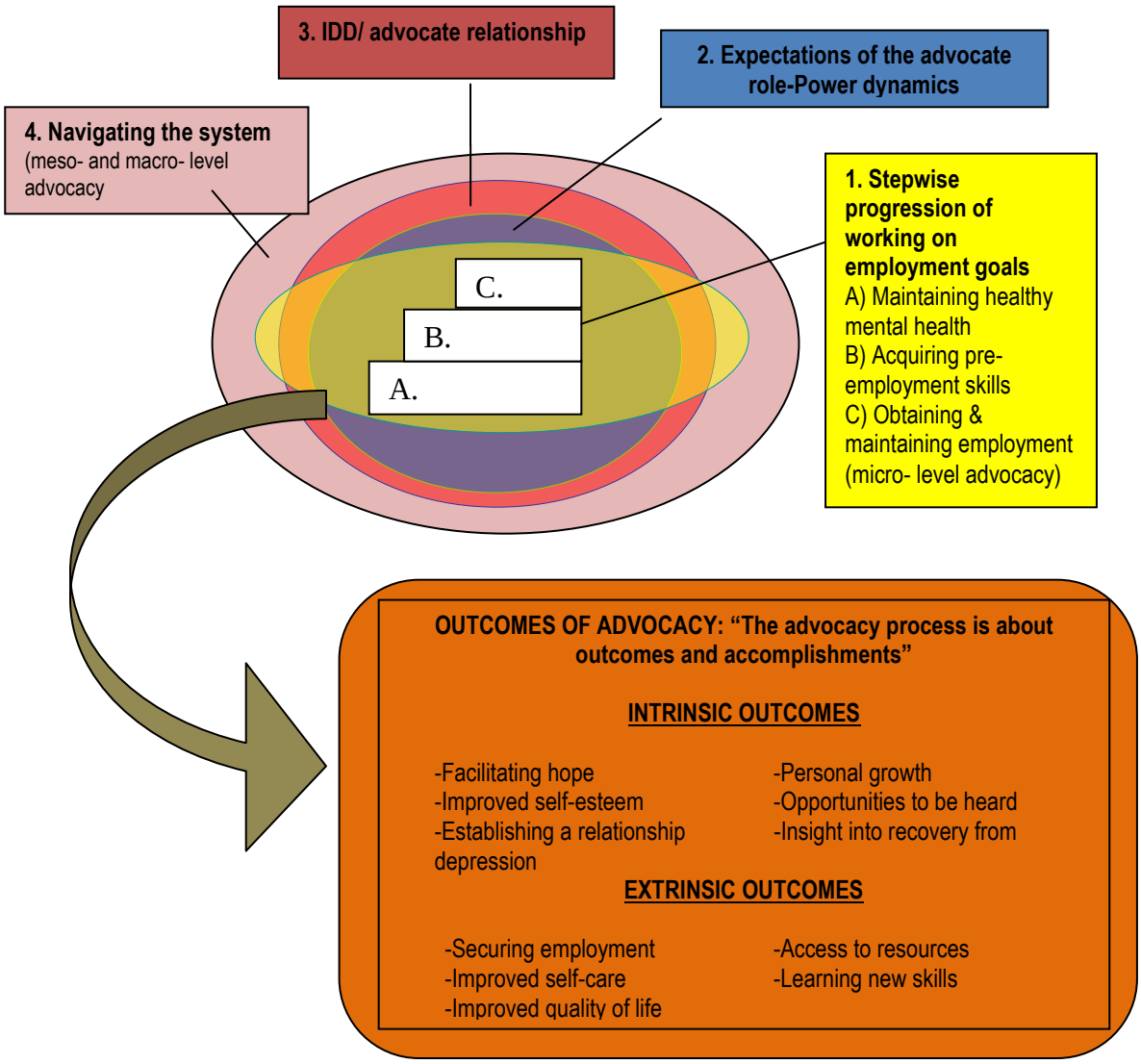
The advocacy process is comprised of many components

The advocacy process is described as a process that always leads to an outcome. However, before outcomes are achieved, the advocacy process is carried out including a number of components. As described by both IDDs and OTs, the advocacy process can be carried out at either the micro-, meso-, and micro- levels. Figure 4 conceptualizes the components of the advocacy process. At the centre of the advocacy process is the micro- level advocacy that occurs between the IDD and advocate. Advocates work with each individual in establishing the readiness progression of how IDDs will work towards obtaining and maintaining employment (first inner layer as portrayed in figure 4). As advocates work with each individual, both the IDD and advocate work together in establishing the expectations and role responsibilities of one another (second inner layer in figure 4) within the context of the developing the IDD/ advocate relationship (third outer layer in figure 4). Advocates assist the IDDs in navigating the health and employment systems (fourth outer layer) to address the barriers that hinder the IDDs engagement in employment. Navigating health and employment systems, depending on the impact of the advocacy, can be advocacy at the mirco-, meso-, and macro- levels.

Effective advocacy always leads to an outcome. Outcomes can either be categorized as an intrinsic or extrinsic outcome. If an outcome is not achieved as a result of the advocacy process despite the best efforts of the advocate, then either the components within the advocacy process need to be modified or the advocate needs to change.

As described by all study participants, advocacy is about forward progression and change, therefore it is imminent that advocates assess the efficacy of their advocacy work through reviewing the progress made with the individuals they are working with.

Figure 4. The advocacy process leads to an outcome



Use of the word "advocacy"

Both participant groups rarely used the word "advocacy" throughout their responses in the discussions, despite the focus of the study exploring the phenomenon of advocacy. Both IDDs and OTs associated the word "advocacy" with someone who took the leadership role within the IDD/ advocate relationship. As a result, OTs preferred not using the term "advocate" when explaining their role in providing occupational therapy services due to a number of reasons. These reasons

included:1) OTs personal beliefs that they do not "lead" the process or are the decision-makers within the client/ therapist relationship 2) did not want to give their clients the impression that they (OTs) were going to be doing everything for their clients. The OT participants opted to use terms such as 'strategies', 'empower', 'educate', 'encouraging', 'collaborate', and examples of interventions or treatments to describe the advocacy process they implemented in their clinical practices. Advocacy was also perceived as outside of the scope of realistic practice in occupational therapy and therapists identified the advocacy phenomena to occur primarily at the meso- and macro- levels as opposed to advocacy within an individual context. If OTs did not openly identify advocacy as a process that occurred at the individual level, this could explain why therapists infrequently used the term advocacy in their discussions in the focus groups.

For different reasons, IDDs also did not use the word "advocacy" in their discussions. Reasons for lack of use of the word "advocacy" was not explored, however, one IDD participant felt that the word 'advocacy' was used more in research studies rather than in the practical world. Despite IDDs' limited use of the word advocacy, all IDD participants consistently interpreted the advocate as the "expert", "boss", and someone with authority to effectively make changes. The IDDs' consistent interpretation of the advocate role and their expectations of the advocate in delivering health services indicate that they are familiar with the concept of advocacy. Based on the literature search, no research studies were found that explored the reasons for use/ non-use of the term advocacy.

Since neither participant group used the term 'advocacy' in their responses, the PI ensured advocacy was always incorporated in each of the questions to clarify that the information provided by the study participants was about the advocacy process and role.

Meso- and macro- level advocacy

Implementing the advocacy process within the meso- and macro- levels were identified as an important area of practice by both IDDs and OTs. Both Restall & Ripat (2008) and Stergiou-Kita et al. (2010) identified the importance of meso- and macro- level advocacy as a strategy to ameliorate incidences of social injustices and inequities, which is consistent with the findings in this study.

All IDDs described their experiences of the advocacy process as yielding positive results (i.e. improvement in their physical and mental health, accessing resources, obtaining employment) however all IDD participants indicated a need for advocates to address meso- and macro- level issues such as workplace bullying, promoting healthier workplace environments, increasing access and availability of employment related resources, and education around mental illness in the workplace.

Similarly, OT participants also identified a need to address issues within a larger global context, such as educating employers on mental illness, writing letters and proposals to government/ parliament, and engaging in developing policies. OTs expressed minimal difficulties in advocating with their clients at the micro- (individual) level, which is consistent with findings from occupational therapists who participated in Restall & Ripat's (2008) study. However, therapists in this current study identified limitations within their advocate role and implementing the advocacy process beyond the micro- level, which were contributed to difficulties in defining their team role, lack of autonomy in the workplace, and scope of practice issues. Ingram et al. (2008) indicated that the advocacy process is more likely to be carried out depending on the individual's work setting, autonomous work positions, and perception of having a leadership role within the work setting; therefore if health professionals lacked workplace autonomy and perceived limitations in their leadership role, then implementing advocacy beyond the micro-level would be very limited.

Implementing the advocacy process

Implementing advocacy is a challenging and complex process that requires the careful consideration of the IDDs' functional capabilities, the stigma that exists within the IDDs' environments, the IDDs' goals, IDDs' access to resources, and structural policies within the health and employment programs where health services are being delivered (Baron & Salzer, 2002; Dhillon et al., 2010; Hellwig et al., 2003; King et al., 2006; Kirsh et al., 2009; Tse, 2002). Depending on the workplace setting, the implementing the advocacy process varies greatly depending on the health setting, expectations of the advocates, and the abilities of both the IDD and OT.

Mental health stigma and fears about mental illness disclosure was a significant barrier to IDDs exploring employment opportunities. A primary role of an advocate is to ameliorate barriers, including mental health stigma, which continues to be a significant issue for IDDs accessing employment opportunities (Corrigan, 2002; Funk et al., 2005; Gutman et al., 2009; Kelly, 2006; Townsend & Wilcock, 2004).

Advocacy within the inpatient setting versus outpatient setting

Inpatient therapists identified with being confined to practicing advocacy at the micro- level because their involvement with a client could only remain while clients were hospitalized. Furthermore, inpatient therapists expressed more dissatisfaction in their role as an advocate because colleagues were not supportive of the inpatient therapist advocating in exploring employment opportunities for IDDs.

OTs working within inpatient settings identified more limitations to their overall advocacy role compared to their counterpart outpatient OTs due to limitations in autonomy, role expectations within their teams, acute symptoms of inpatient individuals and stabilizing depressive symptoms that take precedence over working on goals such as obtaining employment, and limited timeframe to work with their clients (during inpatient hospitalization) . Limitations of the advocate role within

an inpatient setting is supported by Baron & Salzer's (2002) findings that institutional policy generally prioritizes medical issues over longer-term rehabilitation issues and that time constraints in certain work settings impede focus allocated to advocacy for issues such as addressing employment issues.

Political barriers, (such as resistance to change, stigma among colleagues in the workplace, and lack of funds inhibiting the advocate role) made it very difficult for inpatient therapists to advocate with and for their clients within hospital settings. Literature also supports the perspective that political barriers and conflict in the culture of the hospital system or work environment is incongruent with advocating to address structural barriers (such as poverty, stigma, discrimination) that impede occupational engagement (Baron & Salzer, 2002; Dhillon et al., 2010; Hellwig et al., 2003; Jugessur & Iles, 2009; King et al., 2006; Tannous, 2000).

Findings from the inpatient OTs from this current study are very similar to the results in Negarandeh's (2006) study who explored inpatient nursing perspectives on advocacy, in that both health professional groups identified sense of powerlessness in the workplace, lack of support from their managers, time constraints to work with their clients, and frustration with their work as barriers to implementing advocacy practice. Funk et al.'s (2005) findings that advocacy for change in policies or within organizations is highly unlikely without the involvement of a group of mental health consumers and/ or mental health organizations. If the mandate within the inpatient setting is to focus on efficient recovery of individuals with acute mental health symptoms to facilitate discharge from inpatient hospital settings once acute symptoms have subsided, then there is no time to address systemic barriers or issues such as stigma, as these issues require time. Ingram et al. (2008) also indicates that a core function within community health workers is to address structural issues and health inequities such as poverty, employment, housing, and discrimination

which cannot be addressed within a hospital admission stay where the goals are very different from inpatient setting goals.

Self-advocacy within the advocacy process

IDDs and OTs held different perceptions of the concept of "self-advocacy" in the context of the advocacy process. The perception that recipients of health services should learn self-advocacy skills so that health consumers can advocate for themselves was not held by all study participants.

OTs believed their advocate role involved teaching their clients self-advocacy skills to facilitate individuals in being empowered and speaking on their own behalf. OTs within this study also felt it was important for their clients to engage in behaviours related to self-advocacy, such as participating in conflict resolution, communicating assertively with others, negotiating with employers, which is supported by literature findings that emphasize these same benefits of self-advocacy (Funk et al., 2005; Koch, 2000;Townsend et al., 2003; Tse, 2002).

However, the majority of IDD study participants did not express a priority to learn self-advocacy skills. While the IDDs did not deny that learning self-advocacy skills was a relevant and important skill set, IDDs seeking advocacy support intended to have an advocate speak on their behalf and an advocate to provide direction to improve areas of their life (i.e. obtain employment, improve health) because the IDDs felt voiceless and were experiencing difficulties in navigating the health and employment systems. IDDs also emphasized the need to be heard, understood, having hope, and not be judged within the IDD/ advocate relationship, which Tse (2002) also indicates that providing hope for individuals is important within the advocacy process. IDDs' description of their perception of the advocate role is more consistent with the legal definition of advocacy; in that IDDs rely on others to make decisions on their behalf to exercise their rights and protect them from social exclusion (Jugessur & Iles, 2009; Stylianos & Kehyayan, 2012).

On the other hand, OTs perceived advocacy as facilitating occupational performance by modifying environmental conditions and enabling client participation within the advocacy process (Restall et al., 2003;Townsend et al., 2007; Townsend et al., 2010). OTs within this study strongly felt that the advocacy process was about having a partnership, a collaborative relationship, and a joint-learning experience with their clients.

Based on this current study results, there there are significant differences in perception around the reliance on an advocate versus individuals in learning to be self-advocates to independently advocate for themselves. Establishing expectations of the advocate role is a critical part of the IDD/ advocate relationship to outline clear boundaries of the advocate role (Chima, 2005; Jugessur & Iles, 2009). An individualistic approach to establishing the advocate role and expectations may need to be tailored to each individual. The individual approach may be dependent on the IDD's circumstances, the IDD's level of willingness and functional capacity to actively engage with self-advocacy within the advocacy process, and IDD's overall goals. Other factors will need to be taken into account to determine how realistic it is for the IDD to learn self-advocacy skills and engage in employment, such as: 1) IDDs' cognitive functional abilities (Baron & Salzer, 2002; Kelly, 2005; King et al., 2006; Kirsh et al., 2009), 2) IDDs' social functioning (Baron & Salzer, 2002; Kelly, 2005; King et al., 2006) and 3) IDDs' previous experiences within the health and employment systems (Baron & Salzer, 2002) . All study participants within both sample groups recognized that the stability of the IDDs' physical and emotional health is the foundation and pre-requisite to client's exploring employment opportunities.

Implementing an individualistic advocacy approach may also require the OT to be flexible within their advocate role in that the OT may need to accept more responsibility within the advocacy process and promote self-advocacy skills within the IDD as the IDDs show readiness to engage more as a self-advocate (Chima, 2005). While the majority of the IDD participants within

this study did not identify the concept of self-advocacy as part of the advocacy process, each IDD recognized that advocates could not do everything for them and that some level of responsibility was required of them. The definition and concept of self-advocacy needs to be further explored so that various stages and level of responsibilities of IDDs capture their level of engagement as a self-advocate.

Skill set of the advocate

Credibility, knowledge of and navigation through the health and employment systems, ability to understand and hear and individual's story, assertive communication, and knowledge of legislation around human and employment rights were identified as important skill sets as identified by all study participants. All of the listed skills are consistent with Stergiou-Kita et al. (2010) and Hellwig, Yam & DiGiulio (2003) account of relevant skills required of an advocate. Additional skill sets specifically identified by OTs in this study include: the therapists' value of the advocacy role, therapists' commitment to implementing advocacy, therapists' employment, therapists' perceived role within their work setting, therapists' tolerance for ambiguity, and OTs' personality and willingness to go the "extra mile". This supports the study by Holtrop et al.'s(2000) which indicates that individuals engaged more with meso- and macro- level advocacy (ie. changing public policy) if they had the interest and knowledge in public policy.

Individuals with education in areas of leadership training and engagement in activities such as marketing, collaborating with government, and participating in political practices and policies are more likely to engage in advocacy beyond the micro-level (Ingram et al., 2008; Restall & Ripat, 2008). Integrating educational opportunities so that health professions can further develop leadership skills, engaging with governmental and legislation activities, may increase health professionals' engagement in meso- and macro- level advocacy practices. If a primary role of an advocate is to address structural barriers that hinder occupational engagement in meaningful

occupations for individuals with depression, then occupational therapists must obtain the skill sets and experiences to further engage in meso- and macro- level advocacy. Leadership training and advocacy training should be incorporated within OT educational programs so that OTs can further develop and become more comfortable with practicing advocacy at the meso- and macro- levels.

Advocacy in relation to the recovery model and CMOP-E

Recovery model.

Enhancing occupational performance by facilitating individual autonomy.

Frese et al. (2001) described recovery within the recovery model framework, as the personal experiences of an individual in which they are empowered to take ownership of their health to lead satisfying lives. OTs within this study emphasized the importance of their advocate role to empower their clients to actively engage and take more responsibility in working towards achieving their goals. The OT perception of how the advocacy process is carried out is consistent with the core elements of the recovery model of enhancing individual autonomy, facilitating client empowerment, and increasing client a minimum of responsibility in working towards change (Frese et al, 2001; Funk et al, 2005). OTs discussed their role in facilitating their client's occupational engagement in meaningful occupations by addressing barriers that hindered their client's performance and/ or engagement within these activities. On the other hand, some OTs described the advocacy process as "fighting a good fight" and backing up individuals who could not speak up on their own behalf, which required the OT advocate to provide more advocacy support if the individual client could not do so. Chima (2005) supports the stance that health professionals should be advocating for individuals who are oppressed through injustices. While all OTs expressed that the advocate role was about increasing client empowerment within the advocacy process, all OTs also agreed that if the clients lacked the cognitive or social functioning to engage within the advocacy process, then the advocate role is to assist them in "fighting the good fight" to ameliorate

barriers hindering occupational engagement. However, many of the therapists also indicated that while they may provide direct assistance in doing tasks for their clients in circumstances where the client was unable to do the task (ie.making a phone call for them to speak to others for them), OTs typically negotiated with clients on how that client will increase their independence the next time a similar situation arises. In situations where there was an increased dependence on the advocate to do or speak on their behalf, the primary goals of the OTs within this study were to work towards the client being independent.

IDDs depend on their advocates.

The IDDs' expectations of the advocacy process are slightly different than the core elements of the recovery model. While IDDs perceived the advocacy process as an individualistic approach based on their strengths and a need to address areas of their life to improve their overall quality of life, all IDDs felt that a big component of the advocacy process is having the advocate "be their voice to speak to others on their behalf". IDDs agreed that self-advocacy and being empowered were important however their initial intentions when seeking assistance from health professionals were not aimed at learning how to self-advocate. A number of complex issues contributed to the IDDs' inabilities to speak on their own behalf, such as 1) mental health stigma in the workplace 2) previous negative experiences, which was also contributed by the IDDs experiences of being stigmatized 3) poor self-esteem and 4) fears related to disclosure of their depression. Due to these complex issues, IDDs rely significantly on their advocates to "stand up for them" as they (IDDs) were unable to effectively make changes on their own. These findings support advocacy within healthcare is primarily related to working with a vulnerable and marginalized group of people (Juggesur & Iles, 2009; Funk et al., 2005) and that health care professionals should advocate to defend, intervene, and recommend course of actions on the basis of addressing the social inequities (Chima, 2005).

IDD participants' readiness to be autonomous from their advocates came at later stages within their recovery. Based on the discussions with the IDDs, IDDs began to be more independent from their advocates after a lengthy period of time (closer to at least one or more years) of working with the advocates and when they had established skills in effectively managing their depression, developed pre-employment skills, and gained better confidence in dealing with challenging situations. While the premise of advocacy in health care is about working with individuals who have difficulties in standing up for themselves, Chima (2005) indicates that advocates should be working towards teaching their clients to self-advocate and be more independent from the advocate.

The recovery model as a lens to explore the advocacy process and role.

Both IDDs and OTs identified facilitating hope, increasing access to appropriate resources, and addressing human rights as important components of the advocacy process, which are also elements of the recovery model. Utilizing the recovery model as a lens to establish research questions and interpret the data was a good fit for the study for a number of reasons.

1) The recovery model is a framework that is used within mental health (Juggesur & Iles, 2009); therefore clinicians working with individuals with depression should have a good working knowledge of the core elements of the recovery model. In addition, elements of the recovery model, such as focusing on the individual's skill sets and strengths, working within the context of the individual's environments, collaborating with the individual to increase autonomy and enhance client responsibility are consistent with concepts of client-centred practice, which is also a common practice approach within occupational therapy. Based on study results, utilizing the recovery model as a lens to obtain and analyze data was a good fit as elements of the recovery model (i.e. facilitating hope, promoting client empowerment, increasing client autonomy) were all concepts that OTs perceived as components of the advocacy process and advocate role.

2) individuals with depression often struggle with hope, mental health stigma, have various coping strategies in managing day-to-day functioning, and have their own interpretation of what recovery from depression means to them. The recovery model was an appropriate lens as elements of hope, improving quality of life, accessing appropriate supports/ resources, addressing human and employment rights, and focusing on individual's strengths were all components IDDs identified relevant to the advocacy process and part of the advocate role.

struggle with hope , have difficulties identifying with strengths, and struggle with mental health stigma in their day-to-day life. The recovery model is an appropriate framework when working with individuals with a mental illness including depression.

Canadian model of occupational performance and engagement (CMOP-E).

The advocacy process, as identified by both IDD and OT participants within this study, is based on pursuing choices and changes that are centred on the IDDs' goals, preferences, and interests within a relationship between the advocate and IDD, all of which are core concepts of the CMOP-E. Consistent with the CMOP-E's belief that engagement in meaningful occupation is the dynamic interaction between the person (cognitive, affective, physical, spiritual), occupation (self-care, productivity, leisure), and environment (cultural, institutional, physical, social) (Baptiste, 2003; Law, Baptiste, & Mills, 1995), both IDDs and OTs agreed that the advocate role takes into consideration the best avenue to advocate for another individual by assessing the individual's strengths, the occupations in which they desire to engage, and the environments in which the occupations occur. The CMOP-E was a good fit to utilize as a lens to establish research questions and analyze data because the essence of the advocacy process and advocate role was described as about being client-centred and considering various facets of the individual's life (strengths, life experiences, environmental conditions) when advocating for a change.

Researcher's clinical experience

Despite all measures to ensure rigour in data collection and analysis, the researcher's clinical experience and own biases always has an impact on the overall research findings (Finlay, 2002). The researcher's initial biases towards the concept of the advocacy process evolved throughout the course of the study, especially since the researcher's clinical roles have changed from being an inpatient occupational therapist to a community case manager. The researcher's belief systems around the advocate role and advocacy process have remained consistent despite the varied clinical roles. However the researcher feels more strongly that clinicians in the community setting have more opportunities to advocate with clients in the meso- and macro-levels. Furthermore, the investigator also believes that meso – and macro- level advocacy is imbedded within the scope of practice of community clinicians whereas inpatient settings have a narrow focus and place limitations on clinicians to practice within the micro- level despite the inpatient clinician's desire to work within the meso- and macro- levels. While inpatient OTs have some opportunities to engage in advocacy roles, their primary roles are assisting with stabilizing health to promote occupational performance in daily basic tasks such as getting dressed, taking medications, eating, and going to the bathroom. Once acute symptoms have subsided and clients are re-engaging in basic tasks in day-to-day basic occupations, then clients are then discharged from the inpatient setting into their communities. Inpatient OTs do not have the time to address the client's long term issues (employment, financial difficulties, lack of access to resources, etc.) unless the therapists are able to follow the client on a long term basis as an outpatient.

As a current case manager now from an inpatient occupational therapist, the investigator has had greater work autonomy and greater exposure to advocacy opportunities as the case manager's role is to address structural barriers, such as risks of losing housing, limited accessibility to financial and community resources, and complex issues impeding efficient

integrative health services along their continuum of complex health needs. Based on Ingram et al.'s (2008) study, community clinicians have greater work autonomy and self-perception of leadership roles, which increases facilitation of implementing advocacy, which are consistent with investigator's clinical practices.

The investigator's current clinical experiences with the advocate role and advocacy process has expanded significantly since the inception of this current research study, therefore the researchers initial perceptions of the advocate role and advocacy process have evolved throughout the duration of the study. It is important to note that data collection was completed before the investigator became a community case manager; therefore interview questions may have been potentially different if the interviews occurred when the investigator was practicing clinically in the community. As Finlay (2002) indicated, the investigator is a central figure who inherently has an influence on the collection, selection, and interpretation of the data, therefore the investigator's current experiences with integrating advocacy practice and advocacy roles are much greater than when practicing as an inpatient OT, which would have a different influence that at the time the interviews ensued.

As a clinician working in the community, there are greater opportunities to engage in activities that work towards organizational and behavioural change because those types of activities are embedded within the advocate role in case management.

Limitations of the study

Recruitment process.

The investigator encountered several challenges throughout the recruitment of both IDD and OT participants. Many individuals with a mental illness expressed interest in participating in the study but were declined due to an absence of a diagnosis of depression. Furthermore, the investigator was in an awkward position of contacting the individuals to indicate to them that they

did not fit the study criteria despite their strong belief they had depression. The investigator thanked these individuals for their interest in participating in the study, informed that the study was focusing on a very specific population group, and was told they may be contacted for future studies. Another limitation to the recruitment process of IDD participants was that less than half of the IDD participants were employed. To increase participation of individuals already employed, the investigator would distribute the recruitment packages and advertisement posters to various employers throughout the province.

A second limitation to the recruitment process was that a very small group of occupational therapists volunteered to participate in the study. The intent of the study was to recruit OTs with a broad range of clinical experience working in various settings within Manitoba. However, only OTs within Winnipeg working exclusively within mental health volunteered to participate in the study. The recruitment packages were sent to all Manitoban OTs registered with the College of Occupational Therapists of Manitoba, however the recruitment packages were only sent to Winnipeg clinics. Distribution of the recruitment packages to the hospitals and main clinics within all of Manitoba, including rural areas, would have been ideal to obtain a greater target population of both IDDs and OTs. However due to very limited resources, packages were only sent in Winnipeg.

Interviewing the research participants.

The first half of the interviews with the IDD participants was spent gaining trust and rapport between the researcher and IDD, which is not uncommon in mental health (Corrigan, 2002). Therefore, information obtained was more within a superficial level versus obtaining an in-depth account of the IDDs lived experiences with the advocacy process. To obtain a richer account of IDDs' experiences with the advocacy process and allow a lengthier process to establish rapport, it would have been beneficial to set up multiple interviews with the same IDD participants. However, due to time limitations and limited resources, it was not possible to set up the study this way.

The format of the focus groups for the occupational therapy participants was conducive to collecting very valuable insight as to how occupational therapists perceived the advocate role and advocacy process as the group discussions facilitated discussion among OTs who worked within the same practice settings and who provided health services to a similar clientele group (with the exception of one therapist). While the investigator's intent was to recruit occupational therapists practicing in varied practice settings, the data yielded specific strengths and limitations to the advocacy role within OT practice particularly for mental health, which adds to the body of literature in mental health. Advocacy within the occupational therapy (OT) role need to be clearly defined (Stergiou-Kita et al., 2010) as lack of clarity in the advocate role, specifically in mental health, and advocacy processes contribute to the difficulties in occupational therapists in advocating effectively and consistently in their clinical practices (Jugessur & Iles, 2009).

A benefit of this study is that the clinicians who participated in this study are exclusively OTs practicing in mental health in one geographical location, therefore research findings add to the body of mental health literature.

Initial purpose of the study

During the initial stages of developing the study, the initial purpose of the study was to obtain a common definition of the concept of advocacy among IDD and OT participants. However, within the first few interviews, it was apparent that study participants had difficulty in responding to the open ended questions due to the complex nature of the concept of advocacy such that it was very difficult to respond to a broad question such as "what does advocacy mean to you?" Discussing advocacy and deconstructing the concept of advocacy into the "process" of advocacy and "roles" of the advocate simplified the data collection process because questions became more comprehensive, at least as what was observed when questions were modified into inquiring advocacy in terms of advocacy process and advocate roles.

6.0 Conclusion

Policy and practice implications to OT practice

The advocacy process is described as the facilitation of individuals engaging in meaningful occupation while addressing structural barriers that hinder occupational engagement and performance in occupations, which is the core belief within occupational therapy. All research participants identified the need for the advocate role to take into consideration the individual's strengths, environmental conditions, and desired occupations when providing advocacy support, which is consistent with the OT theoretical model of CMOP-E in that occupational engagement is the interaction between the person, environment, and occupation. Advocacy is a role within the OT scope of practice within both inpatient and outpatient settings, however the degree of involvement of the advocate role and implementation of the advocacy process vary greatly due to role descriptions and expectations within those workplace settings.

There are more opportunities for occupational therapists working in the outpatient/ community settings to engage within meso- and macro- level advocacy. Advocating for employment related issues specifically for individuals with depression is also relevant within occupational therapy as OT clinicians are experts in task analysis and promoting occupational performance. OTs have the skill set to assess the individual's functional abilities and complete a clinical breakdown of how the client's desired goals could be realistically achieved to carry out the advocacy process.

Conclusions

Individuals with depression identify employment as part of 'normal' life that provides a sense of productivity, identity, structured routine, and source of income. This study contributes to the existing body of literature as this study describes the advocacy process and advocate role as perceived by IDDs and OTs. The study is unique in design that it is one of the only studies that explores the concept of advocacy from two different perspectives (health providers and health

users) along the continuum of health services. The advocacy process and advocate role are consistent with the core concepts of the recovery model and CMOP-E. Utilizing an individualistic approach to pursue a change, instill hope, work towards improving quality of life, and promoting occupational engagement that is hindered by either mental stigma or limitations in the individual's abilities to speak on their own behalf, is the essence of the advocacy process as described by both IDDs and OTs. The advocate role is to implement the advocacy process using a client-centred approach. However, there were major differences between expectations of the advocate role and advocacy process between therapist and IDDs perceptions. There was an expectation from the IDDs' perception that the advocate would lead the process as the "experts" as the IDDs preferred the in making the decisions for them, speaking on their behalf, and navigating the health and employment systems for them. IDDs' reliance on their advocates was significant. OTs, on the other hand, expected the IDD to engage much more within the advocacy process by being autonomous and participating in the decision-making process. Differences between the perceived advocate role indicate a need to establish an advocacy framework of practice that meets the expectations of the advocate role and process by both IDDs and OTs.

Recommendations for future research

Future recommendations for conducting this study again include: 1) exploring how the participants define the word advocacy, whether it is a term they often use or hear within health care, and discuss reasons behind why they use or disuse the word. Defining the term advocacy would contextualize the process of advocacy and provide an in-depth description of how research participants perceive advocacy. 2) Conduct multiple interviews with the same research participants, particularly individuals with depression given the length of time required to establish rapport with IDDs. The set up of this research study did not facilitate an in-depth exploration of the research topic because the first half of the interviews were spent establishing and gaining trust.

Establishing practice frameworks and policies

Future research is indicated to establish a consistent definition of advocacy and establish a framework for carrying out the advocacy process. A consistent definition and advocacy framework would provide OTs a frame of reference in implementing the advocacy process. Furthermore, advocacy processes within all levels of (micro-, meso-, and macro- levels) should be integrated into OT scope of practices to further enhance the practice of advocacy across an individual's continuum of health. If increased education, leadership training, and mentorship programs with seasoned clinicians increase likelihood of implementing advocacy (Ingram et al., 2008; Restall & Ripat, 2008) then OTs should be engaging in continuing educational opportunities to further develop self-advocacy skills. If advocacy is to be a role within occupational therapists, courses that focus on developing meso- and macro- level advocacy skills should be part of the post-secondary curriculum.

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Appendix A

Screening Questions

Individuals diagnosed with depression

- How old are you?
- Have you been given a diagnosis of depression by a psychiatrist or a family physician?
- Do you identify work/ employment to be important to you?
- Are you agreeable to having your interview audio taped? Part of the taping process is to ensure all the information from your interview is accurate and having the interview taped allows the primary investigator to re-listen to the interview again.
    1. If you are not comfortable having your interview taped, would it be okay to have a research assistant present to take notes during your interview?

Occupational therapy clinicians:

- Do you work with individuals with a diagnosis of depression?
- Do you work with mental health clients who identify getting employment as important for them?
- Do you facilitate clients in returning to work and/ or actively assist them towards obtaining paid work such as offering job placements, accompany them in interviews, assist with applying process, etc?

Interview Guide

Definition of advocacy that will be provided at the beginning of all of the individual interviews and focus groups:

"Advocacy is any actions that you take or another person or group takes on behalf of an important issue. These actions are done to influence positive changes in one's lives based on their needs,

rights, and wants. A person who advocates can be advocating for themselves (also known as a self-advocate) or can be advocating for others".

Individual interviews -For individuals with a mood disorder

Main questions

- Who are your advocates? Describe your advocate and what is your relationship like with that advocate?
- What kinds of work has your advocate done for you? Was this helpful? Why/ why not?
- What are the important factors that make a good advocate?
- Has being able to self-advocate lead to obtaining or successfully re-entering work?
- Has having an advocate lead to obtaining or successfully re-entering work?

Sub-questions

- What was the process of advocacy like for you?
- How long does it take for advocacy to feel like it's having an impact?
- How do you know when advocacy is having an impact?
- In the process of returning to work, how do you overcome some of the challenges of being employed/ re-employed?
- How do you recognize when someone is being an advocate?

Additional questions to subsequent interviews based on emergent data collected from previous interviews

- Can advocates who assist with mental health issues also be advocates for employment issues?
- How did you know when to ask for help and accept help?
- Was it difficult for you to come to that acceptance (of requiring help)?

- Does a mental health advocate have the same qualities as an advocate for employment related issues?
- Is it helpful to have more than one advocate when dealing with employment?
- What information do you share with your advocate?
- How do you know when changes or improvements are happening when working with an advocate?

The following is a list of guiding questions for the focus group for the occupational therapist sub group guide:

Focus group- Questions for occupational therapists

Main questions

- Describe your advocacy role? What do you think are your primary roles/work is as an advocate? What are the challenges of being an advocate?
- How does one advocate or become an advocate?
- Has being able to advocate for your clients lead to your clients obtaining or successfully re-entering work?

Sub-questions

- What changes would you make in the health care system regarding advocacy towards obtaining employment for IMD would you make?
- How do you provide advocacy support to your clients when exploring paid employment?
- How do you overcome some of the challenges related to advocacy and challenges related to getting your clients connected with paid employment?
- When do you know advocacy is having an impact?
- What would you say are the important factors that make up advocacy?

- How do you teach your clients to be self-advocates?

Examples of additional questions that were added to the discussion guide for the focus groups included: Baron & Salzer, 2002

- Do your colleagues support your role as an advocate at work? If so, how, and if not, why?
- Does your team support your role of promoting employment? If so, how, and if not, why?
- Where does the role of advocacy fit within the occupational therapist's role?
- Do you use the word advocacy when working with your clients? Why or why not? How do you describe advocacy to your clients?
- What challenges have you experienced when advocating for your clients, particularly when promoting employment?

Appendix B

September 2011

To Whomever it concerns,

My name is Shirley Ramos and I am a researcher currently recruiting individuals to participate in a study. The title of the study is "A qualitative study on advocacy in mental health: Employment for individuals with depression". The purpose of this study is to explore the concept of advocacy. I will be interviewing two sets of different groups, including 1) Individuals with a diagnosis of depression who identify employment as important to their recovery 2) Occupational therapists who have worked/ are working with individuals with a mental illness, specifically individuals with depression to obtain competitive employment opportunities or facilitating return to work.

I am sending you this letter to invite you to participate in this study as you have been identified as an occupational therapist who works with clients who may identify work as important and wish to seek employment.
If you have worked as an occupational therapist for a minimum of 3 months and worked with an individual who has been diagnosed with depression expressing interest in employment, you meet the criteria for this study.

The format of the study will be participating in a one-time focus group with 3-7 other individuals. Length of the focus group will range between 60- 90 minutes, depending on the course of the group discussion. All participants who participate in the study will be rewarded with a gift certificate as a token of appreciation for volunteering their time.

The aim of this study is to further explore advocacy in the area of employment for individuals with depression. In order to further enhance and make positive changes to current practice and policies so that individuals with a mental illness have equal access to employment, voices need to be heard from individuals who receive and provide vocational services.
Your contribution and participation in this research study will help working towards this goal.

If you are interested in participating in this study, please contact me at (204) 787-7416 or email me at sramos@hsc.mb.ca. Please leave me a voice mail to express your interest in the study if I am out of the office. Arrangements for the time of the focus group will be followed up once contact is made with you and other interested participants.

Thank you for your time!

Regards,

Shirley Ramos, O.T. Reg. (Mb)
Graduate student researcher (primary investigator)
Occupational Therapist

June 2011

To Whomever it concerns,

My name is Shirley Ramos and I am a researcher currently recruiting individuals to participate in a study. The title of the study is "A qualitative study on advocacy in mental health: Employment for individuals with depression". The purpose of this study is to explore the concept of advocacy. I will be interviewing two sets of different groups, including 1) Individuals with a diagnosis of depression who identify employment important to their recovery 2) Occupational therapists who have worked/ are working with individuals with a mental illness, specifically individuals with depression to obtain competitive employment opportunities or facilitating return to work. I am sending you this letter to ask your assistance in identifying appropriate clients for this study as you provide psychiatric follow up to clients in the outpatient clinic.

I am currently looking for participants who have been diagnosed with a mood disorder, speak and read English, are eighteen years of age or older, those who are competent to make treatment decisions, and who identify work as important to their recovery. While previous employment experience would be ideal, it is not required that the client has work experience.

If you are working with a client and they meet the above criteria, please inform them of this study and direct them to the advertising poster that has been attached to this letter. If they express interest in participating in the study, they are encouraged to independently contact the primary investigator.

The format of the study will be participating in a one-time individual interview. Length of the interview will range between 45- 75 minutes, depending on the course of the interview. All participants who participate in the study will be rewarded with a gift certificate as a token of appreciation for volunteering their time.

The aim of this study is to further explore advocacy in the area of employment for individuals with a psychiatric disorder. In order to further enhance and make positive changes to current practice and policies so that individuals with a mental illness have equal access to employment, voices need to be heard from individuals who receive and provide vocational services.

Participation in this research study will help working towards this goal.

Please contact the primary investigator at (204) 787-7416 if you have any questions regarding this study. Clients who express their interest in participating in the research study should also be redirected to call the primary investigator. Arrangements for the time of the focus group will be followed up once contact is made with participants and other interested participants.

Thank you for your time!

Regards,

_____

Shirley Ramos, O.T. Reg. (Mb)
Graduate student researcher (primary investigator)
Occupational Therapist

Appendix C

Title of research study:

A qualitative study on advocacy in mental health: Employment for individuals diagnosed with depression

Are you:

- **An individual who has been diagnosed with depression?**
- **An individual who identifies employment as meaningful and important to your recovery?**

Do you want to have your voice heard about your experiences with working toward employment?

If you answered YES to the above questions, you are invited to participate in the study.

Please contact the primary investigator at (204) 787-7416 or email at sramos@hsc.mb.ca. More information and arrangements to follow!

Participants will be given a small gift certificate as a thank you for their participation in the study.

Your participation in this study may make positive changes to help improve equal access to employment and quality of life for individuals with a mental illness.

Title of research study:

A qualitative study on advocacy in mental health: Employment for individuals diagnosed with depression

Are you:

- **An occupational therapist who works with individuals with a mental illness, specifically individuals diagnosed with depression?**

- **An occupational therapist who provides vocational services to help your clients obtain employment in the competitive job market or help them return to work?**

- **An individual who identifies employment as meaningful and important for the clients you work with?**

Do you want to have your voice heard about your experiences with helping your clients with working toward employment?

If you answered YES to the above questions, you are invited to participate in the study.

Please contact the primary investigator at (204) 787-7416 or email at sramos@hsc.mb.ca. More information and arrangements to follow!

Participants will be given a small gift certificate as a thank you for their participation in the study.

Your participation in this study may make positive changes to help improve equal access to employment and quality of life for individuals with a mental illness.

Appendix D

Release of information consent form

I, _____, hereby consent the primary investigator,
(name of participant)

Shirley Ramos, to contact my (psychiatrist/ physician/ other clinician), whose name is
(please circle one of the above)

_____, to obtain information regarding my diagnosis and
(name of psychiatrist/ physician/ other clinician)

ability to make decisions that is pertinent to my participation in the study titled "A qualitative study on advocacy in mental health: Employment for individuals with depression". I fully understand that the information will be kept confidential and any identifying information, such as my name, employment history, or location where I receive psychiatric follow up will not appear in the research study.

Participant's signature_____Date:_____
(day/month/year)

Participant's name (Printed)_____

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their consent

Printed Name:
_____Date_____
(day/month/year)

Signature: _____
Role in the study: Primary investigator

Consent forms to have interviews or the focus group audio taped

I, _____, hereby consent the primary investigator,

(name of participant)

Shirley Ramos, to audio tape the interview or focus group in which I participate. The purpose of recording the discussions is to allow the researcher to go back to the interviews to use the important information I provided at a later time. This allows the researcher to obtain a more accurate description of the information I shared on my interview.

Please place a check in one of the sections

_____ **Yes,** I do agree to have the interview or focus group I participate in be audio taped.

_____ **No,** I do not agree to have the interview or focus group I participate in be audio taped.

In the event I do not consent to having my interview be audiotaped, I do agree to have a second person present during the interview so that there is another individual writing down notes on the information provided on my interview.

_____ **Yes,** I do agree to have a second person be present during the interview

_____ **No,** I do not agree to have a second person to be present during the interview

Participant'ssignature_____Date:_____(day/month /year)

Participant's name (Printed)_____

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their consent

Printed Name: _____Date_____

(day/month/year)

Signature: _____

Role in the study: Primary investigator

Appendix E

RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM

Title of Study: "A qualitative study on advocacy in mental health: Employment for individuals diagnosed with depression

Principal Investigator: "Shirley Ramos, 771 Bannatyne Ave., 787-7416"

You are being asked to participate in a research study. Please take your time to review this consent form and discuss any questions you may have with the primary investigator. You may take your time to make your decision about participating in this study and you may discuss it with your friends, family or (if applicable) your doctor before you make your decision. This consent form may contain words that you do not understand. Please bring this form with you at the next meeting with the primary investigator. Please ask the study staff to explain any words or information that you do not clearly understand.

Purpose of Study

This research study is being conducted to study and explore the concept of advocacy and people's experiences with advocacy and how advocacy relates to finding and maintaining employment with and for individuals with a mental illness. The study is aiming to study advocacy from perspectives of two separate groups. These separate groups include people who have been diagnosed with depression and occupational therapy clinicians. Ten to twelve individuals with depression is anticipated to participate in individual interviews and five to seven occupational therapists anticipated to participate in a focus group.

Study procedures

The first stage will include attending a scheduled individual interview or a focus group, depending on the sub-category the participant falls within. Individual interviews will be conducted with individuals who have a diagnosis of depression and the focus group will be conducted with occupational therapy clinicians. Duration of the interview or focus group will be dependent on how much each of the participants share in the discussions. Individual interviews will be approximately forty-five to seventy-five minutes in length and the focus group will be approximately sixty to ninety minutes in length. The discussion will focus on what advocacy is according to each participant, their experiences with advocacy, specifically around obtaining competitive employment for individuals with a diagnosis of depression.

Within a week after the focus group and individual interviews have been completed, the primary investigator will mail you out a copy of the transcript transcribed form the interview or focus group. The primary investigator will contact you a week afterwards to clarify and summarize the content of the discussion.
A summary of the study findings will be made available to you after completion.

If you take part in this study, you will have the following procedures:

- Receive a phone call from the primary investigator to ensure you qualify to participate in the study.

- If you are an individual with a diagnosis of depression, the primary investigator will contact your physician/ psychiatrist/ or other clinician to confirm your diagnosis and ability to participate.

- Attend either a forty-five to seventy-five minute individual interview or a sixty to ninety minute focus group (again depending if you are a mental health consumer or occupational therapist clinician). Location of the interviews and focus group will occur in a group room (Room # R110) located at the University of Manitoba on 771 McDermot Avenue or in a seminar room at the Mood Disorders Association of Manitoba located on 4 Fort Street. Date and time of the individual interview or focus group has been determined to be held on _____.

- The primary investigator will contact you within one to two weeks of you completing the interview or focus group and once the information has been transcribed. You will have the opportunity to review the transcription of the interviews or focus group as it will be mailed/ emailed to you within a week of completing your interview or focus group. The primary reason for this process is to ensure that the summary of the discussion is accurate.

- The primary investigator will contact you again once the information from all the interviews and focus group have been analyzed to ensure there is some agreement with the study results.

Participation in the study will be for

- 15 minutes for the screening interview to be held over the phone
- 1 day to attend the individual interview or focus group (45- 75 minutes for the individual interviews; 60- 90 minutes for the focus group)
- 1 day to review the transcription from the interview or focus group (60 minutes)

- 1 day to discuss accuracy of data information obtained from the interviews or focus group(10- 30 minutes)
- 1 day to discuss findings and information relating advocacy and its role with leading to obtaining and maintaining paid employment. Discussion to be held over the phone

You can stop participating in the study at any time. However, if you decide to stop participating in the study, we encourage you to talk to the primary investigator first. If you need to talk to someone about your reasons for withdrawing from the study or if the topic is a sensitive issue for you, you are encouraged to immediately approach the primary investigator to discuss your concerns. If you have any questions or concerns throughout the process, you are welcome to contact the researcher to discuss them.

You will be receiving a community newsletter after the completion of the study summarizing the research findings and outcomes.

Risks and Discomforts

There are minimal risks in participating in this study. There is a slight chance that sensitive topics may arise from the interviews or group discussions which may cause you some emotional discomfort or anxiety. You are encouraged to share only what you are comfortable sharing. If at any time you need to stop or leave the interview or focus group, please notify the researcher as soon as possible. A list of contacts will be readily available should you require immediate counseling services.
Some participants (the occupational therapy clinicians) will be participating in focus group discussions with other individuals they may or may not know in a personal context. While the primary investigator will re-enforce confidentiality, it cannot be guaranteed. Therefore, if you become uncomfortable with being in the group for the reason of knowing someone else from the group, please inform the primary investigator of this reason.

Benefits

Participating in this research study will allow you to share your experiences with advocacy. We hope the information taken from this study will aid in making changes to practice in order to work towards social inclusion for employment opportunities for individuals diagnosed with depression and other psychiatric conditions. Results from this study will also add to the literature regarding advocacy in mental health.

Costs

All the procedures, which will be performed as part of this study, are provided at no cost to you. Bus tickets or payment for parking in order to attend the focus groups will be reimbursed.

Payment for participation

You will be given a five dollar gift certificate as a thank you for your participation in the study. As indicated above, bus tickets and payment for parking will be provided to you so that you can attend the interview or focus group for the study.

Confidentiality

Information gathered in this research study may be published or presented in public forums, however your name and other identifying information will not be used or revealed. Despite efforts to keep your personal information confidential, absolute confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law. All information gathered on the individual interviews or focus groups will bear only your assigned number. The only copy of the document with your assigned number and your name will be locked away in separate, locked cabinets in the researcher's locked office.

In the interviews and focus groups, it will be strictly enforced that all disclosed information in the group is to be held in confidence and not to be repeated outside of the interaction.

Any information gathered from your physician/ psychiatrist/ nurse therapist will be treated as confidential in accordance with the Personal Health Information Act of Manitoba.

The University of Manitoba Health Research Ethics Board may review records related to the study for quality assurance purposes.

All records will be kept in a locked secure area and only those persons identified will have access to these records. If any of your medical/research records need to be copied to any of the above, the researcher will remove all identifying information.

Voluntary Participation/Withdrawal from the Study

Your decision to take part in this study is voluntary. You may refuse to participate or you may withdraw from the study at any time.

We will tell you about any new information that may affect your health, welfare, or willingness to stay in this study.

Medical Care for Injury Related to the Study

In the case of emotional discomfort resulting from this study, a list of counseling contacts will be readily available for you should you require immediate counseling services.

Questions

You are free to ask any questions that you may have about your rights as a research participant. If any questions come up during or after the study or if the study causes emotional stress, contact the primary investigator: Shirley Ramos at (204)787-7416.

For questions about your rights as a research participant, you may contact The University of Manitoba, Bannatyne Campus Research Ethics Board Office at (204) 789-3389.

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

Statement of Consent

I have read this consent form. I have had the opportunity to discuss this research study with Shirley Ramos and her study staff. I have had my questions answered by them in language I understand. The risks and benefits have been explained to me. I believe that I have not been unduly influenced by any study team member to participate in the research study by any statements or implied statements. Any relationship (such as employer, supervisor or family member) I may have with the study team has not affected my decision to participate. I understand that I will be given a copy of this consent form after signing it. I understand that my participation in this study is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this research study.

I understand that information regarding my personal identity will be kept confidential, but that confidentiality is not guaranteed. I authorize the inspection of any of my records that relate to this study by The University of Manitoba Research Ethics Board, advisor and advisory committee members of the researcher for quality assurance purposes. I also consent to having my interview being audiotaped for data collection purposes.

By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

_____ *[Optional]* I agree to be contacted for future follow-up in relation to this study,
Yes _ No _

Participant signature_____

Date _____
(day/month/year)

Participant printed name: _____

I, the undersigned, attest that the information in the Participant Information and Consent Form was accurately explained to and apparently understood by the participant or the participant's legally acceptable representative and that consent to participate in this study was freely given by the participant or the participant's legally acceptable representative.

Witness signature_____

Date _____
(day/month/year)

Witness printed name: _____

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their consent

Printed Name: _____

Date _____
(day/month/year)

Signature: _____

"Role in the study: Primary investigator