Leading the Way to Promote Self-Determination of Individuals with Autism Spectrum Disorder

by

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Abstract

This study explored ways in which the Centre for Autism Services Alberta could exercise leadership to promote self-determination of people with autism spectrum disorder (ASD). I utilized action research engagement and included people with ASD. The study, which employed a neurodiversity lens and added new knowledge relative to self-determination theories, produced the following findings: (a) the need to include the voice of the autistic community in all that affects it; (b) the need to develop an understanding of the construct of self-determination within the Centre; (c) the need to exercise leadership for an organizational culture change to enable staff to build on current good practices and implement new practices; and (d) there are systemic barriers beyond the Centre’s mandate. Recommendations focus on leadership for an organizational culture change as a foundation for work with strategy and policy, training, and the establishment of an advisory group of self-advocates with ASD.
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Chapter One: Focus and Framing

A few years ago, I had a conversation with a parent of a mostly nonverbal teen with autism spectrum disorder (ASD). I had been mentoring her for a number of years; my own son with ASD is 2 years older than her son. We were discussing the future for her son as she was planning for his transition to adulthood when she remarked that she wished she could know what he wants for his life. I started to answer with the standard response that she could watch his behaviour and body language to determine if he was happy and enjoying the activities. She interrupted me to say that no; that was not what she meant. She wanted to know what it was that he wanted, in the same way her other children share their dreams with her. I fell silent and reflected. How can we know what is in the hearts of our children who are unable to tell us of what they dream? I had no idea how to answer this question. I considered my own son who has verbal skills and can express his basic needs but has difficulty thinking and talking about the abstract future. What does my son dream of for his life? How can I know what is in his heart? How can I ensure that my son has a life that he wants, and not one imposed upon him by others? How can I help my friend in her desire to know her son’s dreams? Thus began my journey to find ways to ensure that all individuals with ASD can live the lives of which they dream.

My employer and sponsor of this study, the Centre for Autism Services Alberta (hereafter referred to as “the Centre”), provides services to individuals affected by autism including individuals with ASD, their families, professionals, and other members of the community. Two of the Centre’s key directions in the 2013 to 2018 Strategic Plan are to “deliver services across the lifespan” (Centre for Autism Services Alberta, 2013, p. 1) and to “build an operational model that supports self-determination and independence” (p. 1; see Appendix A). In the fall of 2015,
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the Centre launched CommunityWorks Canada® (Centre for Autism Network, n.d.-a) for youth and Quest for Independence (Centre for Autism Services Alberta, n.d.-b) for young adults as first steps in the fulfillment of the goal to deliver services across the lifespan. This study was designed to inform the process of creating an operational model to support self-determination and independence of individuals with ASD. The *Merriam-Webster* dictionary defined self-determination as “free choice of one’s own acts or states without external compulsion” (“Self-determination,” 2015, Full Definition, para. 1). Wehmeyer (1999) defined self-determination as “acting as the primary causal agent in one’s life and making choices and decisions regarding one’s quality of life free from undue external influence or interference” (p. 56). Self-determination enhances quality of life (Carter et al., 2013; Denney & Daviso, 2012; Shogren, Wehmeyer, Palmer, Rifenbark, & Little, 2015; Wehmeyer, 1999, 2015; Weiss & Riosa, 2015).

The change goal was to provide insight into ways the Centre could become a leader among service providers in Canada in promoting self-determination of people with ASD.

At the time I began this research, I had held a variety of roles at the Centre. During this project, my role was Director of Leadership and then Director of Teen and Adult Programs. I was one of five executive team members responsible for operationalizing strategic issues and overall leadership of the organization. Implementation and oversight of teen and adult services within a model that supports self-determination was part of my responsibilities. This service area was experiencing significant growth. The executive team works collaboratively to achieve the Centre’s goals, and I intended for this inquiry to support the development and implementation of an organizational strategy to promote the self-determination of individuals with ASD across the lifespan. The development of new practice strategies based on the success stories of self-
advocates with ASD demonstrates the Centre’s commitment to its vision (Centre for Autism Services Alberta, 2013), including setting the standard for best practice in autism services through innovative, evidence-based practices.

I also intended for this study to gain insight into how the Centre might encourage a mindset for the self-determination of individuals with ASD such that it becomes an intrinsic part of the organization’s culture, “the way we do things around here” (Deal & Kennedy, 1983, p. 501). One of my roles as an action researcher was to ensure dialogue took place about current and potential practices to promote the self-determination of individuals with ASD. Stringer (2014) stated,

The act of observing and reflecting on our own practices can be an enlightening experience, enabling us to see ourselves more clearly and to formulate more effective ways of working that enhance the lives of the people with whom we work. (p. 41)

Due to my senior position within the organization, I engaged an external party to conduct a focus group session with staff to ensure their anonymity and their ability to grant informed consent to participate without undue influence.

This inquiry was designed to answer the following main question: How can the Centre exercise leadership among autism service providers in Canada in promoting self-determination of people with autism spectrum disorder? The following subquestions also helped to guide the inquiry:

1. What are Centre staff’s current perceptions of self-determination and/or practices that support or hinder the self-determination of people with ASD?
2. What are the stories of self-determined adults with ASD, and how can they inform our practice?

3. What practices can the Centre implement that would promote the self-determination of individuals with ASD?

Significance of the Inquiry

In 2011, Canada ratified the United Nations’ (2006) Convention on the Rights of Persons with Disabilities that confirmed persons with disabilities’ entitlement to the same human rights and fundamental freedoms as persons without disabilities (United Nations General Assembly, 2006, p. 4). The rights include “individual autonomy . . . [and] the freedom to make their own choices” (United Nations General Assembly, 2006, p. 6), or self-determination. The Centre’s vision, mission, values, and the Strategic Plan (Centre for Autism Services Alberta, 2013) all contain elements that support the inherent rights of people with ASD. This inquiry assisted the Centre in actualizing its goals of assisting individuals with ASD to be more self-determined and effective participants in their communities based on their dreams and desires.

According to Autism Speaks (2010), the prevalence rate for ASD was 1 in 5,000 in 1975. Ten years later, the rate was 1 in 2,500 (Autism Speaks, 2010). By 1995, the year my son with ASD was born, the prevalence rate was 1 in 500 (Autism Speaks, 2010). In 2016, the prevalence rate is 1 in 68 (Centers for Disease Control and Prevention, 2014). This significant increase in prevalence of ASD makes the issue of self-determination important to many more at-risk individuals.

Raymaker and Nicolaidis (2013) argued that self-advocates with ASD identify as a minority group that is often the subject of research without being the beneficiaries of the
research. They went on to state, “For the autistic community, questions related to improving quality of life are more germane than causes, cures, and remediation” (Raymaker & Nicolaidis, 2013, p. 178), which are the main foci of current autism research funding. Their study used a participatory knowledge-production model rooted in community-based participatory research to increase the inclusion of self-advocates with ASD (Raymaker & Nicolaidis, 2013, pp. 178–179). The voices of six independent adults with ASD were incorporated into my study, and participants’ words were key to the development of conclusions and recommendations.

Stakeholders for this inquiry included individuals with ASD, their families, staff at the Centre, and the board of directors of the Centre. Wehmeyer (1999) advocated for self-determination as a core dimension of quality of life, and my goal is that individuals with ASD will benefit from this study by becoming more self-determined. As the Centre moves into the next stage of action research, families may benefit by having their loved one with autism become less dependent upon them. However, parents may experience adverse effects if they desire to maintain control over their loved one with autism (van Ingen, Moore, & Fuemmeler, 2008, p. 451). Centre staff may benefit by having specific strategies for increasing self-determination that also remove ambiguity. The board may enhance its public reputation by having staff that demonstrates the stated values of the Centre.

If the issue of self-determination is not addressed, the Centre risks harm to its reputation, as the community may deem that the Centre does not enact its espoused values. With the huge increase in prevalence of ASD, a large number of people could live their lives according to the wishes and desires of others, rather than their own dreams. By fostering self-determination in individuals with ASD, the Centre will be in compliance with the UN Convention on the Rights
of Persons with Disabilities (United Nations, 2006; United Nations General Assembly, 2006), potentially enhancing its reputation. This is of particular importance given that a nonprofit’s greatest asset is often their reputation (Sarstedt & Schloderer, 2010).

**Organizational Context**

The Centre is a nonprofit registered charity with a policy governance board of directors made up of volunteers. The Centre’s vision is that individuals with ASD reach their full potential and its mission is to provide comprehensive, innovative supports and services to those affected by ASD across the lifespan (Centre for Autism Services Alberta, 2013; see Appendix A). The Centre employs approximately 35 salaried staff and 80 hourly staff (S. Gynane, personal communication, November 2, 2015; see Appendix B). My role is the Director of Teen and Adult Services on the executive team. In 2015, the Centre served approximately 200 teens and young adults, and Centre leadership expects this number to grow in 2016. The Centre served an additional 100 children and their families in its largest intervention program, Specialized Services (SS), led by the Director of Clinical Services. Other programs include workshops for parents and professionals, recreational groups, therapeutic groups, summer camp, playgroups, respite care, preemployment programs and transition programs for teens and young adults, and professional workshops. The Centre provides services in the greater Edmonton area and has recently expanded to offer SS to rural areas in southern Alberta. In total, including Teen and Adult Services and SS, the Centre served 1,764 individuals in 2015.

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1 All personal communications in this report are cited with permission.
This inquiry was designed to help the Centre meet its core value of the right to individual choice and self-determination. Other values, key directions, and strategies of the Centre could also be positively affected. For example, building quality programs and services, including an operational model that supports self-determination and increasing connections with community could be facilitated by this study (see Appendix A for a full list of values, key directions, performance indicators, and strategies). A goal of this inquiry was to promote self-determination of people with ASD.

Prior to the beginning of this study, the Centre engaged its management team, consisting of the executive and senior managers, in a collaborative process to create a philosophical framework (D. Allard Usunier, personal communication, May 6, 2016; see Appendix C), including indicators for each key term and each program area. Twelve people lived in Kaner’s (2014) groan zone for several months to reach consensus. Living in the groan zone, where leaders seek to incorporate divergent views and listen until they have developed a shared understanding for sustainable agreements (Kaner, 2014, pp. 4–21), has become part of the culture of the Centre. As leaders, we hold each other accountable to this process by bringing us back to the groan zone when we inadvertently stop listening and start opining.

Through the action research engagement process, staff had an opportunity to develop shared understanding of self-determination and its achievement. Armenakis, Harris, and Mossholder (2009) proposed that a demonstrated need for change, a perceived ability to accomplish change, and active participation in the change process contribute to readiness for organizational change. According to Rowe, Graf, Agger-Gupta, Piggot-Irvine, and Harris (2013), the action research engagement model that was the basis for this inquiry is “based on theoretical
premises about the role of dialogue and participation . . . which are necessary and foundational to a successful change intervention” (p. 6). This inquiry provided an opportunity for staff to participate in the potential change process in an effort to increase their readiness for change.

**Systems Analysis of the Inquiry**

O’Connor and McDermott (1998) defined a system as “an entity that maintains its existence and functions as a whole through the interaction of its parts” (What is a System section, para. 1). Systems thinking involves “seeing interrelationships rather than linear cause-effect chains, and seeing process of change rather than snapshots” (Senge, 2006, p. 73). A process of circular, interconnected thinking allows for visualization of complex contexts to identify potential points of intervention for positive change. Actions can, and likely will, have unintended consequences for which it is difficult to identify the cause-and-effect relationship due to distance in time (O’Conner & McDermott, 1998). A systems perspective enables organizational members to shift from a culture of guilt and blame to “share[d] responsibility for problems generated by a system” (Senge, 2006, p. 78).

The change goal was to provide insight into ways the Centre could exercise leadership among service providers in Canada in promoting self-determination of people with ASD. This study was initiated to create change within the Centre to benefit individuals with ASD. A systems perspective, based on Bronfenbrenner’s (1996) ecological systems theory, highlights the relationships between the Centre, individuals with ASD, provincial and federal governments, and the Canadian culture. Microsystems, the mesosystem, the exosystem, and the macrosystem comprise this model. In Figure 1, I identified only the parts of these systems that relate to individuals with ASD and that fell within the boundary of this study. Individuals with ASD are at
the centre of the model. Their families and/or guardians, the healthcare system, their peers, their workplaces, and the Centre form five microsystems relative to this inquiry. The mesosystem consists of the interactions between the microsystems and/or the individual with ASD. The two major components of the exosystem are the governments of Alberta and Canada. Finally, the attitudes and ideologies of Canadian culture form the macrosystem.

Figure 1. Systems of individuals with ASD.
The Centre’s major funder is the Department of Disability Services of Ministry of Human Services within the Government of Alberta. This department requires that the Centre follow guidelines that include the specific outcomes for adults with disabilities of (a) being actively engaged and involved in their communities, (b) maximizing their independence, and (c) achieving their full potential (Alberta Government, Ministry of Human Services, 2014, p. 6). The Centre’s values align with these guidelines and expected outcomes (Centre for Autism Services Alberta, 2013). The Centre is funded by Alberta Human Services with a block contract and on a fee-for-service basis through families’ individual agreements with the ministry. Disability Services is undergoing reorganization, and the impact on policy, guidelines, and funding is unknown.

Policies of the government in power heavily influence the Centre. For 44 years, the Progressive Conservatives formed the government, but in May 2015, Alberta’s New Democratic Party formed a majority government (“Alberta Election,” 2015). A change in government may have an impact on the Centre’s funding and/or may result in policy changes related to services for people with developmental disabilities. Provincial surpluses or deficits impact the Centre’s funding and the current decline in the price of oil is already placing pressure on service providers to reduce costs. Government policy and the state of the economy also influence donations, on which the Centre relies for most of its program development. All of these factors have a negative impact on the Centre’s ability to respond to the needs of individuals affected by ASD. This funding uncertainty also has an impact on staff morale, although overall, morale is good (S. Gynane, personal communication, May 14, 2015).
Over the year prior to this study, the Centre was developing leadership skills throughout the organization. Team charters are in place to guide interactions and work. Staff members have become better at engaging in dialogue and working through tough issues. The employee engagement survey showed that staff members are proud to work at the Centre, and would recommend the Centre’s services to families impacted by ASD (S. Gynane, personal communication, May 14, 2015). The overall rating indicated that 96% of staff feel satisfied working at the Centre, 96% of staff feel the Executive Director demonstrates effective leadership and communicates openly and honestly, and 100% of staff feel they are treated respectfully by their coworkers (S. Gynane, personal communication, May 14, 2015). This high level of satisfaction and trust could be beneficial to any organizational change project.

The Commission on Accreditation of Rehabilitation Facilities (CARF) has accredited the Centre in the area of “Behavioural Consultation Services – Autism Spectrum Disorder – Children and Adolescents” (Centre for Autism Services Alberta, 2014, p. 7). Accreditation demonstrated that the Centre has met international standards for delivering services that include a commitment to continuous quality improvement, a focus on integrated and individualized services, outcomes measurement, and accountability. The Centre obtained immediate approval upon application to provide services for Alberta Human Services, Persons with Developmental Disabilities (PDD) clients (adults), in part because of its CARF accreditation. This inquiry was in alignment with CARF’s international standards.

Consideration of all parts of the system, as identified in Figure 1, was important in developing recommendations to the Centre. According to O’Connor and McDermott (1998), complex systems are usually stable because they are bound together by many links, but this also
makes it difficult to predict the impact of a change in one part of the system on other parts of the system. The Centre has the ability to influence other parts of the system through its various relationships with government, healthcare, families, and advocacy organizations. The Centre will need to examine any new information within the emerging system context. Adding to the complexity of the system is the relative newness of the inclusion of the autistic community as partners in research (Raymaker & Nicolaidis, 2013). While I prefer person-first language, it is out of respect for the preference of self-advocates with ASD who prefer identity-first language that I use the word autistic when referring to them throughout this thesis.

**Overview of the Thesis**

This chapter provided the context for this study, organizationally and systemically. I also argued the need for the inquiry. Chapter 2 provides a review of the relevant literature about self-determination in general and as it applies to individuals with ASD. The literature review also explores the issue of inclusion of people with ASD in research projects. Chapter 3 contains details of the study methodology, including the theoretical framing, and concludes with a discussion of ethical implications. Chapter 4 details the study findings, featuring the stories of independent adults with ASD. Perspectives of Centre staff members who work with teens and adults with ASD are also incorporated in setting out conclusions. In Chapter 5, I introduce recommendations from the study, including implications for the Centre and ideas for further research. The next chapter will situate the study within the current literature.
Chapter Two: Literature Review

In this literature review, I explore three areas of scholarly research: definitions and perspectives of ASD, with a focus on neurodiversity; self-determination for people with ASD; and inclusion of marginalized voices in research. The review of the literature describing and defining ASD revealed tensions that have arisen as a result of relatively new contributions from self-advocates with ASD. Many authors have contributed to the body of work on self-determination, and I reviewed literature that defined self-determination, discussed prominent theories of self-determination, explored the relationship between self-determination and quality of life, and identified current practices for increasing self-determination of people with ASD. One of this study’s objectives was to hear the stories of self-determined adults with ASD to learn how they could inform the Centre’s practice, so I explored the literature on inclusion of marginalized voices using participatory action research and application within autistic communities.

What is Autism?

Two perspectives. The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) characterizes persons with ASD as experiencing challenges in social communication and social interaction along with restricted, repetitive patterns of behaviour, interests, or activities (American Psychiatric Association, 2013, p. 50). Intellectual impairment may or may not be present. It is a neurodevelopmental disorder (Odom, Hume, Boyd, & Stabel, 2012, p. 271). These definitions place ASD within the medical model of disability that views disabled people as defective or abnormal (Orsini, 2012). The medical model provides the rationale for research initiatives focused on identifying causes, cures, and effective treatments
Much has been written about ASD from the medical model perspective (e.g., Anderson, 2014; Caldwell, 2015; Coplan, 2010; Leaf & McEachin, 1999; Maurice, Green, & Foxx, 2001; Sicile-Kira, 2014).

The neurodiversity movement, in contrast to the medical model, positions autism as a variation in neurology that is part of “normal human difference” (Broderick & Ne’eman, 2008, p. 470). The Autistic Self-Advocacy Network, Autism Network International, the Autism National Committee, the Autism Acceptance Project, and others ascribe to this view of the person with ASD as being within a spectrum of human diversity (Broderick & Ne’eman, 2008, p. 470). “Conditions like autism . . . should be regarded as naturally occurring cognitive variations with distinctive strengths that have contributed to the evolution of technology and culture rather than mere checklists of deficits and dysfunctions” (Silberman, 2015, p. 37). This view of autism places it within the social model of disability, wherein people are disabled because of the lack of accessibility to society and citizenship (O’Brien, 2011a, pp. 109–111).

Broderick and Ne’eman (2008) asserted, “The first step to achieving a level playing field is self-determination: deciding that we can define our own identity, and not let diagnostic criteria define us” (p. 465). The neurodiversity lens positions people with ASD as equal citizens, some of whom will require supports to enact their citizenship (Silberman, 2015; Robertson, 2009), and assists in ensuring promotion of self-determination is for the benefit of people with ASD and not something done to them.

**Impact of the dichotomy.** The dichotomy between the two perspectives is apparent when one looks at the impact of each model. When viewing autism from a medical model, fundraising becomes easier as evidenced by the millions of dollars raised by Autism Speaks
Professionals in the field and family members often take the medical model perspective and focus on fixing deficits. Recently, individuals with ASD have shared their stories of the negative impact on them of the various treatments they were subjected to as children, including Judy Endow (2009) in *The Power of Words* video, Sparrow Rose Jones (Unstrangemind, 2014), Ido Kedar (2012) in *Ido in Autismland*, Amy Sequenzia in an interview with Sydney Parker (2015), and others. These adults advocate for a social model of disability that embraces acceptance of diversity. The use of phrases such as “suffering from autism” and “the heartbreak of an autism diagnosis” has a negative impact on the development of a positive identity for individuals with ASD (Cohen-Rottenberg, 2011, p. 211).

The differing perspectives on ASD also affect the development of autism-related policy. Baker and Walsh (2013) posited that the unknown etiology of ASD is creating tension in finding an appropriate policy home for ASD issues in Canada: education, social welfare, or health (p. 227). One result of not identifying a policy home for ASD issues has been a lack of consensus regarding funding to mitigate the effects of ASD, whether for treatment or supports, creating uncertainty of future funding (Baker & Walsh, 2013, p. 228). Another result is division among those impacted by ASD as to how to situate their advocacy efforts, with parents and professionals often advocating for health policy and independent individuals with ASD usually advocating for social policy and self-determination. The neurodiversity movement advocates for ASD to be regarded as a valuable part of humanity in which some aspects can be disabling without adequate supports (Silberman, 2015, p. 470). The current work of the Canadian Autism Spectrum Disorder Alliance, representing a united voice within the Canadian ASD community,
is attempting to bridge this gap with its advocacy for a National Autism Strategy (Canadian Autism Spectrum Disorders Alliance, 2016b).

**Self-Determination**

**Definition of self-determination and challenges related to ASD.** The *Merriam-Webster* dictionary defined self-determination as “free choice of one’s own acts or states without external compulsion” (“Self-Determination,” 2015, “Full Definition,” para. 1). Wehmeyer (2005) defined self-determined behaviour as “volitional actions that enable one to act as the primary causal agent in one’s life and to maintain or improve one’s quality of life” (p. 117). Wehmeyer and Schwartz (1998b) defined it as “people controlling their own lives and their own destinies” (p. 76). Although these definitions seem simple, the application to people with ASD is more complicated. Exploring self-determination theory helps to explain why.

Proponents of self-determination theory posited, “People are by nature active and self-motivated, curious and interested, vital and eager to succeed because success itself is personally satisfying and rewarding” (Deci & Ryan, 2008, p. 14). However, intrinsic motivation can be adversely affected by factors such as human nature and social environments or context. Autonomy, social-relatedness, and competence are three factors that support intrinsic motivation (Deci & Ryan, 2008). Competence can be a challenge for individuals with ASD. Koegel and Mentis (1985) argued that deficits associated with autism may expose individuals with ASD to frequent failure and high levels of noncontingent reinforcement, which may lead to learned helplessness and extremely low motivation (p. 190). That is, children with autism may not experience sufficient positive reinforcement for attempts at new tasks, resulting in low levels of motivation for further attempts and continued lack of competence. Reinforcing observable
attempts was found to increase motivation and thus improvements in learning and competence (Koegel & Mentis, 1985, p. 186). This has led to the creation of Pivotal Response Treatment® (Koegel & Koegel, 2006), which remains an evidence-based intervention for children with ASD (National Autism Centre, 2015).

Social-relatedness is also a challenge associated with ASD, as indicated by the diagnostic criterion of “persistent deficits in social communication and social interaction across multiple contexts” (American Psychiatric Association, 2013, p. 50). Ryan and Deci (2000) defined social-relatedness as the need to belong and feel connected to others and hypothesized that it promoted intrinsic motivation (p. 68). Socially desirable behaviours can be externally motivated and are more likely to transition to intrinsic motivation when they are reinforced by people to whom the individual being prompted wants to be connected (Ryan & Deci, 2000, p. 73). The National Autism Centre (2015) did not identify any evidence-based interventions to increase social-relatedness and requires research.

Since self-determination “is the product of the individual and the environment—of the person using the skills, knowledge, and beliefs at his/her disposal to act on the environment with the goal of obtaining valued and desired outcomes” (Wehmeyer, Aber, Mithaug, & Stancliffe, 2003, p. 27), people with ASD will experience challenges exercising self-determination. Individuals influence their environments through interaction (Wehmeyer et al., 2003, p. 36). For example, if an individual with ASD is unable to communicate his or her desires, then the people in his or her environment will become less likely to ask for the opinion of the individual with ASD because they are not reinforced for asking. According to Bandura (2001), behaviour results from a complex, reciprocal interplay between individuals and their environment. In the above
example, introducing a contingent reinforcement to the people for asking the individual with ASD what he or she desires may increase the likelihood of the people continuing to ask, resulting in an environment that is more supportive of self-determination for the individual with ASD through more opportunities to practise. Opportunities to practise making choices and decisions could increase the individual with ASD’s competence in making choices and decision. Positive reinforcement for exercising personal control could increase self-determination (Wehmeyer et al., 2003, p. 81).

I found little literature on self-determination of adults with ASD. Indeed, few studies have focused on interventions in general for adults with ASD (National Autism Centre, 2015, pp. 87–88). Instead, studies of effective interventions have focused on children with ASD (National Autism Center, 2015) and studies on self-determination and ASD have focused on transition-age youth. Howlin and Taylor (2015) bemoaned that life for adults with ASD is woefully under researched (p. 771). This presents an untimely gap given the increased incidence of ASD and that more and more children are now or soon to be young adults (Autism Speaks, 2010; Centers for Disease Control and Prevention, 2014).

**Self-determination and higher quality of life.** Wehmeyer and Schwartz (1998a) found that self-determination contributed to a higher quality of life in individuals with developmental disabilities (p. 10), and Lachapelle et al.’s (2005) and Shogren et al.’s (2015) work supported this finding. Schalock (2004) identified a multidimensional structure of quality of life that included eight domains: (a) emotional well-being, (b) material well-being, (c) interpersonal relations, (d) personal development, (e) physical well-being, (f) social inclusion, (g) rights, and (h) self-determination (p. 206), which were used in the study by Lachapelle et al. (2005). Self-
determination was measured using The Arc’s Self-Determination Scale (Wehmeyer & Kelchner, 1995).

Studies have identified that people with ASD have lower quality of life than their peers, including peers with other developmental disabilities. A study by Jennes-Coussens, Magill-Evans, and Koning (2006) found that young men with Asperger’s syndrome (an ASD) had a lower quality of life than their peers. They utilized the World Health Organization Quality of Life measure (World Health Organization, 2016) and semistructured interviews to address levels of independence and income, two of the factors associated with self-determination (Jennes-Coussens et al., 2006). More recently, Weiss and Riosa (2015) identified that youth with ASD and an accompanying intellectual disability had lower levels of thriving than youth with only intellectual disability (p. 2482). This discrepancy is not surprising given the inherent challenges with social communication and interaction and restricted patterns of behaviour and interests associated with ASD (American Psychiatric Association, 2013), and the resulting motivational challenges (Koegel & Mentis, 1985). Weiss and Riosa used a definition of thriving put forward by Benson and Scales (2009) that aligned with Schalock’s (2004) structure of quality of life, thus allowing for extrapolation of the results of lower thriving to lower quality of life.

**Practices to increase self-determination.** In this section I first discuss the theories of practices based in self-determination. Next, I present literature on practices based in the principle of normalization. Then I review self-advocates’ perspectives on self-determination support needs.

**Practices based in self-determination theories.** Since the 1970s, three main theories of self-determination have guided the development of practices to promote self-determination of
individuals with developmental disabilities, including ASD (Wehmeyer et al., 2003, pp. 17–20). Each theory attempts to explain why people experience differences in self-determination and how to intervene to increase self-determination. All three theories “share the overarching conceptualization that self-determination is a psychological construct situated within the broader, organizing structure of theories of human agency” (Walker et al., 2011, p. 8). Human agency refers to the ability “to intentionally make things happen by one’s actions” (Bandura, 2001, p. 2).

The first theory is the social-ecological model of self-determination posited by Abery and Stancliffe (2003). This model considers the individual’s competency in the skills, knowledge, and attitudes and beliefs required for self-determination within the environmental context, recognizing that each can change over time (Abery & Stancliffe, 2003). Also considered is the individual’s desired level of personal control and its importance to the individual. Abery and Stancliffe (2003) identified eight skills that contribute to self-determination: goal setting, decision making, self-regulation, problem solving, personal advocacy, communication, social skills, and independent living (pp. 54–58). They noted four knowledge areas: (a) declarative and procedural knowledge; (b) knowledge of resources, rights, and responsibilities; (c) knowledge of options; and (d) self-knowledge (Abery & Stancliffe, 2003, pp. 62–64). Attitudes and beliefs that promote self-determined behaviour include locus of control, self-confidence and self-efficacy, self-esteem and self-acceptance, determination, feeling valued by others, and a positive outlook (Abery & Stancliffe, 2003, pp. 58–62). Intervening to positively influence any of the knowledge, skill, or attitude and belief aspects has the potential to increase self-determination (Abery & Stancliffe, 2003).
The second theory is Mithaug’s (2003b) self-regulation theory. This theory shows a logical relationship wherein self-regulation leads to self-determined learning, which leads to self-determination (Mithaug, 2003b). This relationship helps explain why some people are more self-determined than others. The ability to self-regulate, to calm down and manage impulses, along with the ability to filter out distractions and avoid sensory overload (Palmer et al., 2013, p. 42), is foundational to self-determination. Mithaug (2003a) identified seven factors that are responsible for self-determination: (a) beliefs about control over circumstances affecting valued pursuits, (b) opportunities or obstacles for gaining something from a circumstance, (c) expectations for gain from engaging an opportunity, (d) choices based on expectations, (e) actions based on choices, (f) results based on actions, and (f) experience of control over circumstances affecting valued pursuits (p. 252). This theory suggests that optimal adjustments and opportunities will increase the prospects for self-determination (Mithaug, 2003a, 2003b).

Finally, Wehmeyer (2003a) proposed a functional theory of self-determination. This is “an integrative theory, drawing from research on self-determination as a motivational construct and theories of human agency to explain how people become self-determined and exert control in their lives” (Wehmeyer, 2003a, p. 175). According to this theory, self-determination is a functional characteristic of people who act autonomously, are self-regulated and self-realizing, and act in a psychologically empowered manner (Wehmeyer, 2003b, p. 182). Self-determination emerges as people acquire the component elements of self-determined behaviour (Wehmeyer, 2003b, p. 182). Wehmeyer (2003a) identified 12 component elements of self-determined behaviour: (a) choice-making skills; (b) decision-making skills; (c) problem-solving skill; (d) goal-setting and attainment skills; (e) independence, risk-taking, and safety skills; (f) self-
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observation, evaluation, and reinforcement skills; (g) self-instruction skills; (h) self-advocacy and leadership skills; (i) internal locus of control; (j) positive attributions of efficacy and outcome expectancy; (k) self-awareness; and (l) self-knowledge (p. 179). The functional theory of self-determination has enabled the development of assessment instruments, the design of instruction models, and the identification of practices and environments that promote self-determination (Wehmeyer, 2003b, p. 201).

Cobb, Lehman, Newman-Gonchar, and Alwell (2009), in their narrative metasynthesis of self-determination for students with disabilities, concluded, “Self-determination as a construct is extraordinarily multifaceted and complex . . . and that positive outcomes seem best achieved or maximized by instructional . . . interventions that contain multiple components” (p. 113). Wehmeyer (2011) suggested self-determination could be enhanced by utilizing “multiple, parallel activities focused on teaching skills related to the component elements of self-determined behaviour and promoting active involvement in educational planning and decision-making” (p. 223). Wehmeyer (2011) suggested the empirically validated Self-Determined Learning Model of Instruction (Wehmeyer & Palmer, 2000) as a teaching and assessment tool (pp. 231–237). Wehmeyer (2011) also recommended the following for students with ASD: (a) the ChoiceMaker Self-Determination Transition Curriculum; (b) Whose Future is it Anyway?; (c) Next S.T.E.P.; (d) The Self-Advocacy Strategy for Education and Transition Planning; and (e) student-led individualized education programs (pp. 239–242). The Self-Determined Career Development Model is designed to support adults with developmental disabilities to make career-related decisions using similar strategies as the Self-Determined Learning Model of Instruction (Wehmeyer, 2004, p. 28) and the Putting Feet on My Dreams
program for young adults was designed by Fullerton (as cited in Fullerton & Coyne, 1999) to develop skills of self-determination. Use of such teaching tools may promote self-determination (Cobb et al., 2009).

**Practices based in the principle of normalization.** In the late 20th century, person-centred planning was developed in response to advocacy by individuals with developmental disabilities (including individuals with ASD) and their allies as institutions were closing and the principle of normalization was gaining traction (O’Brien, 2011b; Wolfensberger & Tullman, 1982). “Normalization implies, as much as possible, the use of culturally valued means in order to enable, establish, and/or maintain valued social roles for people . . . [especially when applied to] . . . people who are devalued by the larger society” (Wolfensberger & Tullman, 1982, p. 131). When providing supports to people with ASD, and there is a choice between doing things in a more socially typical manner or in a less socially typical way, O’Brien (2011b) advised choosing the former, even if it is harder (p. 121). Over time, the emphasis shifted from making people’s lives normal to making settings and services feel normal (O’Brien, 2011b, p. 121). According to Stirks and Sanderson (2012), person-centred practice is evidence based and allows people greater control over their support and the ability to create lives that they desire (p. 9). Person-centred thinking involves support staff looking at what is important to and for the supported individual and finding the balance between the two (Sanderson, Smull, & Harvey, 2008, p. 50). Through staff’s use of these skills, individuals with developmental disabilities can exercise control over their lives (Sanderson et al., 2008, p. 54), enhancing their self-determination. However, more recently, Power, Bartlett, and Hall (2016) observed that personalization has led to fewer opportunities for individuals with developmental disabilities to be together, which has increased
isolation and boredom (p. 15). They advised that “implementation [of personalization] should not ignore the value and importance of being together and speaking out as a group” (Power et al., 2016, p. 15) and proposed peer advocacy as well as self-advocacy.

**Self-advocates’ perspectives on self-determination support needs.** Nonnemacher and Bambara (2011) stated, in exercising self-determination, “environmental influences, including related supports, may be most relevant for adults with intellectual disability” (p. 327). They found that the quality of self-advocates’ relationships with their support staff had a direct impact on their self-determination (Nonnemacher & Bambara, 2011, p. 336). Other key influences included the specific strategies used by support staff, how staff exerted their power, and the settings in which the self-advocates lived and worked (Nonnemacher & Bambara, 2011, pp. 337–338). Although Wehmeyer (2005) described choice making as only one facet of self-determination, self-advocates viewed frequent opportunities for choice making as important (Nonnemacher & Bambara, 2011, p. 337). Self-advocates viewed the use of coercive power by support staff as a barrier to self-determination (Nonnemacher & Bambara, 2011, p. 337). Self-advocates who lived and worked in community settings generally had fewer concerns about staff control than those who lived in congregate settings (Nonnemacher & Bambara, 2011, p. 338).

M. J. Ward and Meyer (1999) supported the inclusion of self-advocates in “all policy-making bodies” (p. 138) and also identified the development of leadership skills as critical to advancing self-determination. However, they argued that professionals are “reluctant to relinquish any of their power to self-advocates” (Ward & Meyer, 1999, p. 137). Like Broderick and Ne’eman (2008), M. J. Ward and Meyer supported a social model of disability versus the medical model (p. 138). The emergence of the Internet advanced the self-advocacy of adults with
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ASD (Ward & Meyer, 1999, pp. 136–137). Hutchinson, Arai, Pedlar, Lord, and Yuen (2007) found that Canadian user-led disability organizations “represented the new social movement, with a focus on quality of life, equality, participation and human rights” (p. 712). User-led disability organizations are increasingly involved in systemic advocacy to influence public policy, enhancing self-determination (Hutchinson et al., 2007). The next section provides greater context on the inclusion of marginalized voices.

**Including Marginalized Voices**

Participatory action research (PAR) evolved from the work of Freire (as cited in Burns, Hyde, Killett, Poland, & Gray, 2014) as a means of emancipation for marginalized groups. Freire (2000) posited that liberating the oppressed requires critical dialogue and reflection to cocreate a new way of being. According to DePoy, Hartman, and Haslett (1999), PAR empowers previously devalued groups through equitable participation in the generation of knowledge (p. 567). The aim of PAR is to “yield discoveries that promote action, refine understanding for future action, and continue to develop members’ capacities” (Parada, Barnoff, Moffatt, & Homan, 2011, p. 125). Through PAR, internal and external stakeholders of an organization can cocreate knowledge for improvement of the organization. The action research engagement methodology (Rowe et al., 2013) utilized in this study supports the principles of PAR by enabling the inclusion of marginalized voices. Action research is an “approach to research that is based on a collaborative problem-solving relationship between the researcher and client, which aims to solve a problem and to generate new knowledge” (Coghlan & Brannick, 2014, p. 43). Action research facilitates organizational development.
The Autistic Self Advocacy Network (2016b) website proclaims “Nothing about us without us” (Overview section, para. 1). The website further states that the Autistic Self Advocacy Network (2016a) “engages in a wide array of policy advocacy and systems change advocacy to ensure that the autistic community is represented whenever autism is discussed in the halls of power” (para. 1). Yet, in a scoping review of the literature on participatory research in ASD and other neurodevelopmental disorders, Jivraj, Sacrey, Newton, Nicholas, and Zwaigenbaum (2014) only found two studies that focused on individuals with ASD and included them as partners throughout the entire research process. Nicolaidis et al. (2011) asserted that autistic self-advocates are a “geographically-dispersed community defined by disability [that] experiences issues in research similar to those expressed by more traditional minorities” (p. 143) and, as such, meet the criteria for community-based participatory research (CBPR) approaches. The autistic community have expressed frustration in the lack of inclusion of autistic individuals in the research process; use of demeaning or derogatory language or concepts; threats to study validity derived from miscommunication between researchers and participants; and the use of findings to advance agendas that opposed community values. (Nicolaidis et al., 2011, p. 143) As an example, many members of the autistic community decry the practices of a major fundraising organization, Autism Speaks, that expends the majority of its research funds to identify causes and cures of ASD and, in their opinion, portrays autistic people as burdens or pitiful (Nicolaidis et al., 2011, p. 146). Nicolaidis et al. (2011) further stated,

Autistic self-advocacy organizations have asked for research and programs to improve quality of life for people on the autistic spectrum, for example, by improving health care,
In conducting this study, I sought ways to increase the self-determination of individuals with ASD, and thus improve their quality of life. In keeping with this intent, I included an independent adult with ASD on my inquiry team and conducted several interviews with independent adults with ASD.

After Jivraj et al.’s (2014) scoping review, Martin (2015) described her research to determine what adults with Asperger’s syndrome needed to live their lives (p. 210). She included three adults with Asperger’s syndrome as coresearchers who were involved in all aspects including development of the focus, design of the survey questionnaire, analysis of the results, design of questions for the focus groups and individual interviews, analysis of the data, and dissemination of the findings prior to publication (Martin, 2015, p. 210). The adults with Asperger’s syndrome were equal partners in all facets of her research (Martin, 2015, p. 222). Nicolaidis et al. and Martin (2015) demonstrated successful inclusion of people with ASD. Through this study, I hoped to add to their success.

**Chapter Summary**

In this chapter, I reviewed relevant literature regarding ASD, perspectives of self-advocates as well as parents and professionals, and the impact of the differing views. I also explored self-determination for people with ASD and other developmental disabilities, and its relationship to quality of life. I examined several practices based in theories of self-determination and in the principle of normalization. Self-determination theory emerged as a critical construct for which I wanted to gather more empirical evidence. Finally, I reviewed literature related to
including marginalized communities in research and the benefits of including individuals with ASD. I conducted this study with the aim of contributing to the dearth of work to date that includes people with ASD. The next chapter describes the methodology I applied to conduct this research.
Chapter Three: Methodology

In this chapter, I describe the chosen methodology and overarching framework of action research engagement as well as the rationale for this approach. According to Rowe et al. (2013), action research engagement is “designed to enhance organizational stakeholder acceptance or readiness for the change phase in action research” (p. 8). Project participants, inquiry methods, study conduct, data analysis, and ethical issues are also discussed. I conducted this study from an appreciative stance using qualitative methods. The inquiry was also exploratory and inductive. By including the voices of people with ASD, I drew on the antioppression work of Freire (2000). I drew on the ethnographic practice to include researcher reflections in the findings, as is consistent with Tedlock’s (1991) work that noted a shift in ethnography from choosing to write about self or others to presenting both together in a single narrative. I chose these methods to answer the following main question: How can the Centre exercise leadership among autism service providers in Canada in promoting self-determination of people with autism spectrum disorder? I also explored the following three subquestions:

1. What are Centre staff’s current perceptions of self-determination and/or practices that support or hinder the self-determination of people with ASD?
2. What are the stories of self-determined adults with ASD, and how can they inform our practice?
3. What practices can the Centre implement that would promote the self-determination of individuals with ASD?
Methodology

The change goal was to provide insight into ways the Centre could exercise leadership among service providers in Canada in promoting self-determination of people with ASD. The study was framed by the action research engagement (ARE) model designed by Rowe et al. (2013). The Centre staff had opportunities to engage in dialogue and to learn more about themselves, colleagues, and independent adults with ASD. They also had opportunities to provide input into the decision on how to move forward to enhance self-determination for individuals with ASD. Rowe et al. asserted that participation in dialogue and sharing perspectives enable acceptance of other viewpoints, new understanding, and generation of visions of cocreated futures (pp. 15–16).

Action research, according to Stringer (2014), “provides a flexible and practical set of procedures that are systematic, cyclical, solutions oriented, and participatory, providing the means to devise sustainable improvements in practice that enhance the lives and well-being of all participants” (p. 5). My sponsor’s support of the plan to include the stories of independent adults with ASD demonstrated the Centre’s commitment to learning and improvement. The participatory nature of action research enhances organizational readiness for change (Armenakis et al., 2009, p. 576). This study’s hoped-for change was a culture in which self-determination for individuals with ASD is expected and thus supported throughout all Centre programs and services. Riel (2016) asserted that action research “forms a path towards a professional ‘adaptive’ expertise” (para. 9). She went on to say that adaptive expertise involves a continual learning process as one’s field evolves requiring innovation, efficiency and deep understanding of practice (para. 10–12). The study was designed to support staff with this ability to adapt.
As the autistic community perhaps has the largest stake in the desired outcome of this study, I included members of that community by utilizing principles of CBPR. According to Israel, Schultz, Parker, and Becker (2001), key principles of CBPR include recognition of the community as a unit of identity, building on strengths and resources within the community, facilitation of collaboration, integration of knowledge and action for mutual benefit, promotion of colearning and empowerment, and dissemination of findings and knowledge gained to all partners (p. 184). Raymaker and Nicolaidis (2013) explained that CBPR “seeks to mitigate the marginalization of minorities in traditional approaches to science while also providing both scientists and community members with the skills, tools, and understanding to generate systems change” (p. 183). I included my reflections and contextual descriptions from the interviews with independent adults with ASD in the findings as a way to enrich their stories and make them come alive for the reader. This ethnographic approach recognizes the intersubjectivity of interviewer and interviewee (Tedlock, 1991, p. 71). Other studies have integrated personal perspectives, reflections, and findings (e.g., Hampshire, Iqbal, Blell, & Simpson, 2014; Ward, 1997). This study aimed to discover new knowledge from the lived experiences of independent adults with ASD.

This inquiry took an appreciative stance that is in alignment with the strengths-based ideology of the Centre. Cooperrider and McQuaid (2012) noted that the appreciative inquiry “process is profoundly strengths-based in its assumptions. It is founded on the premise that we excel only by amplifying strengths, never by simply fixing weaknesses” (p. 73). The Centre aspires to focus on enhancing strengths, rather than solely remediating deficits, for both people served and staff.
Finally, I used multiple data-gathering methods for this study. The initial focus group identified current practices and perceptions of staff. I then interviewed six independent adults with ASD to identify factors that contribute to their self-determination. I had planned a second focus group with the same participants as the first group; however, due to scheduling challenges, I shifted my strategy to an anonymous survey. The survey was designed to determine if there were any changes in staff perspective of self-determination for people with ASD after hearing stories of people with ASD, to identify strategies that the Centre could trial, and to acquire staff perceptions of the Centre’s readiness for implementation (see Appendix D). Qualitative research “focuses on qualities such as words or observations that are difficult to quantify and that lend themselves to interpretation or deconstruction” (Glesne, 2011, p. 283). The use of multiple methods and multiple sources contributed to authenticity and trustworthiness of the data. The inquiry methods and study conduct sections below provide further details.

**Project Participants**

Potential participants in this inquiry included staff at the Centre, the members of the executive team, and independent adults with ASD. An independent adult refers to a nonrepresented adult, as defined in the 2008 Alberta Adult Guardianship and Trusteeship Act (see also Alberta Government, Ministry of Human Services, 2009). That is, an adult who does not have an order appointing a guardian to make decisions on their behalf. According to the Centers for Disease Control and Prevention (2014), 46% of children with ASD and aged 8 years old in 2010 did not have an intellectual disability, which implies that in the future there will be a significant proportion of the adult population with ASD without intellectual disabilities. I chose independent (nonrepresented) adults with ASD to share their perspectives on autism because of
their ability to give freely informed, ongoing consent. The perspectives of adults with ASD who are dependent are also important, but outside the scope of this study as “minimal risk research” (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2014, p. 22).

I invited 15 staff members who work at the Centre with teens and adults with ASD to attend the focus group. Morgan (1997) suggested a range of six to 10 participants as optimal to ensure engaged, focused conversation (pp. 42–43). Due to difficulties with recruitment, the focus group took place with four participants.

To mitigate both my power over and perceived power over some staff members, I used a third party, a colleague from Royal Roads University (RRU), to invite participants to and facilitate the focus group (see Appendices E and F). As noted in the Tri-Council Policy Statement (Canadian Institutes of Health Research et al., 2014), “The influence of power relationships . . . should be judged from the perspective of prospective participants” (p. 34). Staff who worked for me may have felt pressure to participate. For staff members who did not report to me, my position as a director could still have created pressure to participate. To ensure participant anonymity and confidentiality, I employed a third-party team member and a secure, web-based transcription service to transcribe and anonymize the data collected during the focus group prior to my receipt. For the survey portion of the study, I emailed the survey to eligible staff members who responded to a member of my inquiry team to ensure confidentiality (see Appendices D and G).

I interviewed six independent adults with ASD. The flyer in Appendix H was used to recruit interview participants. To minimize travel, the geographical location of recruitment was
restricted to the Edmonton and Calgary area and points in between. I asked all respondents if there was a guardianship order for them or if they were independent. All respondents were independent adults with ASD. They all freely gave informed, ongoing consent (see Appendices I and J). All interviewees lived in Edmonton and were available within applicable timelines. I interviewed all respondents. Interviews took place in person or over Skype™ (Microsoft, 2016) to facilitate the development of rapport (Cridland, Jones, Caputi, & Magee, 2015) and were audio recorded.

I utilized an inquiry team to assist me in conducting this research, as described in the Study Conduct section below. Members consisted of a colleague from RRU, a transcriptionist, the executive team of the Centre, and an independent adult with ASD. The study’s sponsor and the executive team from the Centre have the authority to implement any recommendations arising from this study. All members of my inquiry team signed a confidentiality agreement (see Appendices K, L, and M).

Data Collection Methods

This inquiry used multiple methods of data collection. A focus group explored the first subquestion about Centre staff’s current perceptions and practices supporting or hindering the self-determination of people with ASD. Questions are in Appendix N and were pilot tested with two members of my inquiry team. One strength of focus groups is the “reliance on interaction in the group to produce data” (Morgan, 1997, p. 15). As well, Morgan (1997) posited that data collection could be more efficient when done in focus groups rather than individual interviews, but that the logistics in assembling “enough of the right people” (p. 14) for a focus group may offset the potential efficiencies. My colleague was unable to recruit six participants, so the focus
group was held with four respondents. Morgan (1997) described two weaknesses of focus groups: (a) the presence of a group may influence what individuals say and (b) the participants may be either under or overinvolved (p. 15). The focus group facilitator created a safe environment in which participants could contribute their own thoughts and ideas, remain engaged in the process, and be encouraged to dialogue without dominating the process. For example, the facilitator ensured that each participant was ready to move on before she asked the next question.

The second data collection method was a series of six semistructured interviews with independent adults with ASD. “Qualitative and action research studies require a . . . process . . . that consciously selects people [who are] affected by or have an effect on the . . . issue of interest” (Stringer, 2014, p. 77). I developed the final interview questions in consultation with the independent adult with ASD who was a member of my inquiry team (see Appendix O). Individuals with ASD were included in the research because their lived experience would inform key findings of this study. Self-advocates state, “Nothing about us without us” (Autistic Self Advocacy Network, 2016b, Overview section, para. 1). While my questions followed the interview guide, I allowed space for individuals to tell their story as they chose. Some interviewees answered questions literally and succinctly, while others provided more explanation and context. Their lived experiences of self-determination provided the foundation for this study’s recommendations.

The final method was an anonymous survey of Centre staff (see Appendix D). I sent the invitation to the survey, along with an overview (see Appendix P) and summary of the findings from the first focus group and the interviews with independent adults with ASD (see Appendix
Q), to 12 staff members who work with teens and adults at the Centre. Participants were asked if their perceptions regarding self-determination of people with ASD changed based on the overview and summarized findings. They were asked to identify novel practices that the Centre could implement to promote the self-determination of individuals with ASD based on the data collected and themed from the interviews. Finally, participants were asked to comment on the Centre’s readiness for these changes. Armenakis et al. (2009) explained that active participation in which organizational members learn through their own activities enhances readiness for change (p. 576). The survey results aided in transitioning this study to the implementation of recommendations phase.

I pilot tested all three methods with the assistance of my inquiry team. The independent adult with ASD who was a member of my inquiry team helped me to test the semistructured interview questions. This inquiry team member and I also discussed how to ask the questions to be considerate of any required accommodations to ensure we took into account the unique challenges of individuals with ASD based on the work of Cridland et al. (2015). For example, multipart questions were asked individually. In addition, I advised interviewees that they could request a break at any time.

**Study Conduct**

I gave a presentation (see Appendix R) about my project at a scheduled staff meeting after I received ethical approval from RRU to conduct this research. I also presented the same material to several staff members who were unable to attend the staff meeting. The purpose of these presentations was to introduce my project to staff, advise that I would be using a third-party recruiter and facilitator for the focus group, and reassure them about confidentiality.
I worked with my inquiry team throughout the study. I required an external party to maintain confidentiality for focus group participants. My colleague from RRU served that role. I used a transcriptionist to transcribe the audio recording from the focus group to preserve anonymity and confidentiality of participants; the transcriptionist also created verbatim text documents from the audio recordings from the interviews. The executive team, under the direction of my sponsor, has ability to implement the recommendations and has a stake in the outcomes of this study. This trusted group of coworkers assisted with the analysis and interpretation of anonymized data. An independent adult with ASD assisted in ensuring the interview questions and guides were respectful and understandable. She also assisted in creating questions to take the conversations deeper. My inquiry team assisted me in pilot testing my questions, analyzing the data, and developing conclusions and recommendations.

My colleague from RRU recruited focus group participants via email (see Appendix E) and included the research information letter (see Appendix F). She also received and collected responses, and followed the selection protocol outlined in the Project Participants section of this chapter. As well, she obtained signed consent forms from all focus group participants (see Appendix I) indicating free and informed consent, and facilitated the focus group session. This mitigated the power-over issue related to my position as a director of the Centre.

By answering the interview questions in Appendix O, the focus group explored research Subquestion 1. The focus group was audio-recorded for later transcription. The third-party facilitator transmitted the audio recording via a secure website to the transcriptionist, who transcribed the audio recording verbatim without speakers’ names. Focus group participants received the verbatim transcripts from the third-party facilitator to provide additional comments.
or clarification. The third-party facilitator incorporated changes into the transcripts. I received an anonymized transcript for data analysis.

To recruit independent adults with ASD for interviews, Cridland et al. (2015) recommended the use of less socially demanding methods of contact, such as email, to “encourage better responses rates to the study” (p. 83). This respectful accommodation promoted inclusion by recognizing the needs of individuals with ASD and is consistent with the principles of PAR. Cridland et al. also recommended providing “transparent and detailed information . . . during recruitment . . . [including] study aims, participant requirements, study timeframe . . . and expected benefits to participants” (p. 83), which were incorporated into the recruitment flyer (see Appendix H). I used social media, Autism Edmonton’s monthly newsletter, Autism Alberta’s monthly newsletter, and the disability supports department of the University of Alberta to disseminate information about this study to recruit participants. All interviewees were given the research information letter to review (see Appendix S) and signed consent forms (see Appendix J) indicating free and informed consent. I gave each interviewee the opportunity to ask questions about the study and about the information letter prior to starting the interview.

I conducted six semistructured interviews individually with independent adults with ASD (see Appendix O). O’Reilly and Parker (2012) argued that saturation is not necessary when using an exploratory, inductive approach, as was applied in this research (p. 194). The intention of this study was to generate ideas for the Centre to trial to promote self-determination, not to create generalizable concepts. These interviews generated stories related to the personal experiences of six independent adults with ASD from which themes were developed for use in the anonymous survey, in addition to answering the research questions. A transcriptionist transcribed the
interviews. Transcripts were sent to the interviewees to be checked, and the incorporation of clarifications helped to ensure validity of the data (Glesne, 2011; Stringer, 2014). The data from the interviews were analyzed, themed, and summarized.

An anonymous survey of staff explored the Subquestions 2 and 3 (see Appendix D). Choi and Ruona (2011) posited, “Individuals who experience normative-reeducative change strategies are more likely to have higher levels of readiness for organizational change than those who experience either empirical-rational strategies or power-coercive strategies” (p. 60). The summarized findings from the interviews and focus group were sent via email to staff eligible for completing the survey (see Appendix Q). In addition to the opportunity to suggest strategies for the Centre to implement, the survey also provided an opportunity for staff to comment on any changes in their perspective of self-determination of individuals with ASD and their (staff’s) perceptions of the Centre’s readiness for change.

Throughout this study, I provided updates during biweekly meetings to executive team members, who have primary responsibility for implementation of recommendations. We had ongoing dialogue about the data gathered, emerging themes, and potential recommendations. The executive team has shared responsibility to communicate the need for change and confidence in the organization and in each staff member’s ability to implement recommendations to achieve the change (Armenakis et al., 2009, p. 571).

Data Analysis and Validity

To begin the process of data analysis, I utilized computer-assisted qualitative data analysis software, NVivo (QSR International, 2015), to search for frequently used words. I read and reread the transcripts while highlighting and colour coding the frequently used words and
their synonyms seeking themes. I compared findings from the interviews and focus groups, looking for similarities and differences. I prepared a Microsoft PowerPoint presentation as a way to visualize the themes and refine them. I discussed my emerging themes with the executive team members of my inquiry team and created a matrix of the findings (see the Study Findings section in Chapter 4). I completed further coding of the transcripts based on the matrix as a way to verify the themes and subthemes. This inductive analysis of the data from the interviews informed the creation of the questions for the anonymous survey (Thomas, 2006).

Data analysis continued as I began writing my findings. “Writing [enables] and makes empirically demonstrable our ability to ‘see’” (van Manen, 1990, p. 130). The process of writing and rewriting deepened my understanding of the experiences of self-determination for independent adults with ASD (van Manen, 1990, p. 131).

According to Stringer (2014), “Rigor in action research is based on checks to ensure that the outcomes of research are trustworthy” (p. 92). Creswell and Miller (2000) laid out nine procedures to enhance validity: (a) triangulation; (b) disconfirming evidence; (c) researcher reflexivity; (d) member checking; (e) prolonged engagement in the field; (f) collaboration; (g) the audit trail; (h) thick, rich description; and (i) peer debriefing. Selection of validation procedures from the nine listed depends on two factors: the lens used by the researcher (participants, external reviewer, or self) and the paradigm assumptions (postpositivist, constructivist, or critical). I used the lens of the researcher and the participants within the paradigm assumption of postpositivism for this study, which led to the use of triangulation and member checking as the critical validity procedures (Creswell & Miller, 2000, p. 126). The focus group participants and interviewees reviewed their transcribed data for accuracy and clarity in a
process known as member checking. The use of multiple methods and participants, along with comparing and contrasting the data, assisted in triangulation. Additional procedures that enhanced the credibility of this study included researcher reflexivity, the use of thick, rich descriptions to report on the data, and peer debriefing in which members of my inquiry team reviewed my data analysis.

Researcher bias, or subjectivity, left unacknowledged decreases trustworthiness (Glesne, 2011, pp. 49–50). I have a vested interested in promoting self-determination for people with ASD. I am an adult living with ASD. My son, who is a young man with ASD and a coexisting intellectual disability, struggles with self-determination. I desire to increase his self-determination. I employed two main strategies to mitigate the impact of my subjectivity. First, I used writing to reflect on my subjectivity and clarify my learnings as the process unfolded. Second, in discussions with the executive members of my inquiry team, I acknowledged my subjectivity and sought their feedback regarding its influence on my data analysis and interpretation.

**Ethical Issues**

It was my responsibility as the researcher to ensure adherence to the *Tri-Council Policy Statement* (Canadian Institutes of Health Research et al., 2014) on ethical conduct for research involving humans; core principles of the statement are respect for persons, concern for welfare, and justice. Respect for persons includes “dual moral obligations to respect autonomy and to protect those with developing, impaired, or diminished autonomy” (Canadian Institutes of Health Research et al., 2014, p. 6). To ensure this I utilized a third party to seek focus group participants’ free, informed, and ongoing consent (see Appendices E, F, and I). This protected
potential participants from undue influence related to my position within the organization. I also ensured that interview participants were independent adults with ASD who were able to give freely informed and ongoing consent (see Appendices H, J, and S).

Concern for welfare consists of protecting the potential participants’ quality of life by ensuring they have “enough information to be able to adequately assess risks and potential benefits associated with their participation in the research . . . [and to] ensure that participants are not exposed to unnecessary risks” (Canadian Institutes of Health Research et al., 2014, p. 8). I provided information to potential staff participants regarding the purpose of the study, possible risks and benefits, methods of data collection, confidentiality, sharing of results, and the ability of participants to withdraw from the study to assist them their decision to participate (see Appendices E, F, and I). Independent adults with ASD who chose to participate were given the option to take breaks as needed or end the interview, as noted in the information letter (see Appendix S). I used pseudonyms when quoting study participants.

Justice means treating people with equal respect and concern without unduly benefiting or burdening any particular segment of the population (Canadian Institutes of Health Research et al., 2014, p. 8). Power differentials and vulnerabilities impact the ability to ensure a just process. As noted in the Tri-Council Policy Statement (Canadian Institutes of Health Research et al., 2014), “Participation should be based on inclusion criteria that are justified by the research question” (p. 9). By inviting all staff who work with teens and adults with ASD at the Centre to the focus groups and selecting participants on a first-come, first-served basis, I minimized the opportunity for discrimination. The recruitment and participation of independent adults with ASD required consideration. The use of independence or nonrepresentation served as a proxy
screen to ensure that participants had the capacity to make their own decisions to participate. I asked interviewees whether there was a guardianship order in place for them. Had a guardianship order been in place, the respondent would not have been included in the research. The lived experience of self-determination of independent individuals with ASD could make an important contribution to the body of knowledge to support and enhance self-determination of all individuals with ASD. All staff members who work with teens and adults with ASD at the Centre were invited to participate in the survey.

**Chapter Summary**

In this chapter, I described Rowe et al.’s (2013) ARE methodology and the rationale for utilizing this approach. In this research I applied the principles of appreciative inquiry and CBPR with an emancipation perspective. The active inclusion of independent adults with ASD in this study represented a valuable contribution to the body of existing research. I discussed how I selected the project participants, both staff members from the Centre and independent adults with ASD, as well as the rationale for my choices. I identified the criteria and rationale for the three data collection methods: focus group, interviews, and anonymous survey. I described the study conduct, data analysis, and validation along with ethical issues and mitigation strategies. All aspects were consciously designed with the needs of people with ASD in mind. The next chapter details the study findings and conclusions within the context of the Centre.
Chapter Four: Inquiry Findings and Conclusions

This research study was conducted to answer the following main question: How can the Centre exercise leadership among autism service providers in Canada in promoting self-determination of people with autism spectrum disorder? The following subquestions were asked to provide more details to resolve the main questions:

1. What are Centre staff’s current perceptions of self-determination and/or practices that support or hinder the self-determination of people with ASD?
2. What are the stories of self-determined adults with ASD, and how can they inform our practice?
3. What practices can the Centre implement that would promote the self-determination of individuals with ASD?

This chapter describes the findings from the data collected and relays my conclusions. To emphasize the voices of those traditionally marginalized in ASD studies, I have chosen to first report the findings from the interviews with independent adults with ASD. These findings are summarized in Table 1. I then present the findings from the focus group and survey, which are summarized in Table 2. Lastly, the conclusions are reported.

As Liamputong (2007) noted, “Qualitative research methods allow researchers to be able to hear the voices of those who are silenced, othered, and marginalized by the dominant social order” (p. 7). As referenced in Chapter 2, the dearth of research that includes the autistic community and the community’s request for “nothing about us without us” (Autistic Self Advocacy Network, 2016b, Overview section, para. 1) has compelled me to report the majority of my findings in their words. To maintain anonymity, I used the pseudonyms André, Janine,
Mary, Kevin, Aidan, and Matthew for interviewees and Beth, William, Cathy, and Nadir for focus group participants. As only one staff member returned the survey, I refer to this individual as the survey respondent.

**Study Findings**

**Interviews.** I conducted a total of six interviews with adults with ASD. To maintain participant anonymity, I assigned each participant a pseudonym. The findings from the interviews are presented in the following subsections.

**André.** I walked into the coffee shop to meet André, a university student with ASD who had volunteered to participate in my study. Since we had not met in person, I let him know that I would be wearing an emerald green coat. Immediately upon walking in, André rose to meet me. I was a bit surprised, but delighted to be welcomed. He later told me that he had previously observed a woman entering the café who was wearing a pastel green coat and he was relieved it was not me, as the mistaken description of the colour of my coat would have interfered with his participation in the interview. A young lady was sitting at his table, and I was curious about her presence. André informed me that she was a friend who was present to offer him moral support and she would not participate in the interview. André gave me his signed consent form and I started recording. It was not long into our conversation that I found myself completely enraptured. André’s life experience evoked both empathy and admiration, with his superb articulation of his feelings, challenges, and successes. André and his older sister were raised by a single mom: “My mom taught me how not to die really well; then she was done. How not to die is to make sure that you are safe.” This sense of sink or swim came up more than once
throughout the interviews. Fortunately, André is a strong swimmer, and with guidance from his sister and other mentors, André learned to navigate the often-turbulent waters of the social world.

André is able to create generalizable rules from difficult situations or contexts when he has support from his peers: people he can ask his questions of and be certain of getting a straight answer. André had a story of a time he went to church camp with his mom and sister.

I was listening to [uncool] pop music when a fellow camper tried to socially normalize me with shame, and he’s like, “Why are you listening to that music?” I was confused and thought, “What kind of idiot doesn’t know why I do things? . . . Because [I] enjoy it.” My sister, being who she is, she’s like, “Because he likes the music” and gave him the ‘are there any other dumb questions you’d like to waste our time with?’ look [and] he . . . walked away. From there . . . I realized, if I do anything with confidence and make other people feel dumb, the way they are trying to make me feel dumb, I’m free.

André has cultured an outward image of confidence and being in control. Within the autistic community, this is often referred to as wearing a mask or passing (Willey, 2014). Passing can be a double-edged sword, as illustrated by this story from André:

. . . because I’ve cultured it so well, hurts me sometimes, too. There are times where I’m clueless with other friends. I’ll be doing something, and we’ll come through a problem that, to them, it’s a societal flagstone. You just step on it and keep going. For me, it’s a mountain. . . . I’m like, “I’m staying here until you tell me what we’re doing because I have no clue.” Often times, because I project so very much in control, it turns into a fight. They don’t know why I’m less than they expect me to be. Or worse, they assume I just am mad, and I’m playing a game.
André has developed a model for “how to be, it’s how to learn to understand, how to think” and he graciously shared it with me (see Figure 2). His verbal description of the model left me in awe, that such a young man could have so much insight into himself and the world around him.
Context is everything. Context first. Remember the context, context is important. Context is where we live. It changes, and it’s fluid, and you can’t create a rule to help an ASD person. You can create a rule of how to find context, and then have a friend they can call and just say, “I’m in this context. What do I do?” That’s the closest you can get to a hard rule, though, in my understanding.

You have to start by being acceptable so that you can witness everyone else. So that you can observe, see their values, and choose your own. While you do this, you still have to be acceptable. While you’re doing this, you’re also choosing which parts of everyone else are for you. By necessity, by ideology, for your own presentation, to protect your freedom. While you’re doing this, you still have to be acceptable. You also have to be appropriate to earn your spot to witness them. You have to be appropriate while choosing your parts that you witnessed in them. Those two come from context. You can’t be acceptable without a context. You can’t be appropriate without context.

You also have to choose what you want to be to others, and then you have to run it by somebody who will honestly tell you if that’s a no-no. If what you want to be to others is always in their face, and always in their attention, and always theirs, that’s really not appropriate. Anybody who’s your friend can tell you, “No. If you do that to me, we’re not friends anymore. I need my space.” Okay, there’s other things that I want to do, but I’ve had to learn to be like, “Can I do this?” And people have said no. I’ll be like, “I think this is so inappropriate.”

I literally, in the last month, have turned to someone and been like, “I’m really uncomfortable because this place is noisy.” They’re like, “Thanks for telling me,” and
they took me outside. We hung out outside for 10 minutes, but I’m like, “Wow. You just took care of me because I told you what was wrong.” I thought it was super inappropriate to tell them what was wrong. I was wrong about that. It was good. André had spent time preparing for our conversation and had some astute advice for caretakers.

Show me. This is what I deal with. Teach me. These are the things others have problems with, that we know about, but let me discover for me what I am. Show me here are some coping mechanisms other people use. Tell me what they are. Tell me how I would use them. Give them to me so I can pick them out, not because I have to . . . Don’t pressure me to show you that I’m using them . . . Also, you need to remind me that I can still get help from you if success hasn’t happened yet and I need it. I will show you in my time, what I have succeeded at. It also helps if you define that you value me as the following, because I know you do. You value me as responsible, as kind, as willing to accept your help. I have to find a balance of my certainty of self, my willing to help include you helping me, and my willing to bend on how I act to be on your team because you’re on mine . . . You also need to understand that only I can know what I need. You can suggest it, you can think it, you can probably be right, but only I can know it.

From André I learned the value of mentors, the importance of self-confidence, the relevance of context, the need for willingness to ask for and accept help, the significance of acceptance, the usefulness of being appropriate, and the pertinence of having choice and having knowledge of choices.
Nobody ever told me who I was. . . . They always said, “You can be anything.” So I chose to be nothing, because that’s the only anything that I could hold in my hands. . . .

The biggest part of helping someone with ASD is to show them what they can choose. André, like many university students, is still working out what his future will be. Fortunately, André has many options, ranging from linguistics to law, from which to choose.

**Janine.** Janine was the first person I interviewed for this study. She is a capable, strong, and personable, single mother. She was diagnosed with ASD about three months prior to our conversation. When Janine described her childhood, she talked about having to be self-reliant. Her parents were young, and her father made promises that he did not keep. This “compelled me to do stuff on my own, to figure it out, to get my own car, to get a job so that I had food to eat.” Her father introduced her to volunteer work to which Janine attributes much of her self-determination. “Having the ability to open my own doors and choose my own things to be involved in actually helped with my career, because I learned more doing volunteer work than in school, at university, or at a workplace.” She also credits mentors and a good support network along with confidence for her self-determination. Janine’s story illustrates the need for increased understanding of ASD throughout our communities.

Like André, Janine does not appear at first glance to have ASD. This has caused some challenges for her with people not understanding that she needs support.

Other people . . . I guess when they . . . when they don’t offer support, or, or give the impression that I am self-determined enough to figure things out, it would be, like, they don’t want to talk on the phone about, you know, an issue I might have or some confusion I might have. . . . So other people cutting the lines of communication . . . they
can’t wrap their head around it or provide support. Or they’re just maybe thinking,

“She’ll figure it out.”

Janine talked about the myths associated with ASD and how she feels she has, at times, been misunderstood and/or mistreated by the system. She described a time when she took her children to the emergency department. She “asked for advocacy, because I had Asperger’s, and I would like a social worker and a nurse present, because I can’t multitask with a 2- and a 3-year-old in the room.” Janine expressed frustration that “they turned that into was I had a mental health issue. They put me in mental health. They took my kids away.” At the time of this writing, Janine was still trying to get her children back, and to correct the errors in the various reports that resulted in their apprehension.

Janine described a system that portrays itself to offer many services but that they are “not as useful as they put themselves out to be.” She talked about needing to “navigate the social cracks.” She feels victimized, judged, and misunderstood by the system. “Some nurse made up some stuff at the hospital, and now, when you’re dealing with Children’s Services, it’s like the Gestapo. They can say whatever they want.” She also described the paradox of having a diagnosis of ASD. The label is supposed to enable access to supports, but there are few to no resources, and once you put your diagnosis out there, you cannot take it back.

Frustration is a recurrent theme in Janine’s story. She told me of a time she had been homeless while pregnant. She had just left a bad relationship and was seeking assistance finding housing. This event took place before she had a diagnosis of ASD and she felt forced into claiming she had mental health issues, a claim that would come back to haunt her, to be able to access supports.
They put me up in a Super 8 Motel for seven months, pregnant, with, like, an eight-month-old, right? No kitchen. But that’s what they gave us. So the government’s spending $3,800 a month for me to live in a motel with hardly any services. No access to the bus stop, because there was no sidewalk. It’s in an industrial area. Okay? . . . but they’re refusing to give me maybe a $1,000 towards market rent.

Janine eloquently described the toll it takes to navigate a world designed for neurotypicals:

It’s all this extra mental energy in my life expended trying to understand people. And after a while, you get to know automatically . . . like, I go to my brain, which is like Google, and I know what to apply to certain situations.

In addition, she finds it tiresome to have to educate people about her condition and her rights: “I feel like I’m constantly having to, to guide people to do their jobs.”

When asked about strategies that could help individuals with ASD to be more self-determined, Janine had the following two suggestions: (a) mentors—people to go to who would help you troubleshoot problem situations, people who are committed to helping you in the long term and (b) exposure to personal development—giving people opportunities to learn. Janine’s story brings attention to the inadequate understanding of ASD within the community.

Mary. I met Mary in a coffee shop and, in retrospect, her interview may have been more effective if done via email. Mary answered questions succinctly, and I wondered if she would have preferred to write her responses. A number of individuals with ASD, myself included, prefer written communication to verbal communication (Jones, Quigney, & Huws, 2003).
Mary is proud of the fact that she lives independently: “When I saw other people being independent it made me want to be independent, too.” She currently volunteers in a school library, and she would like to go back to school to become a librarian. Mary identified that she finds it helpful to have a goal to work towards, to have people who encourage her and to have a support group with other adults with ASD. “It’s nice being able to meet people with similar challenges, and [hear] the strategies . . . that they’ve tried,” she commented.

Mary described one of her biggest barriers to self-determination is that people “assume that because I [am] on the autism spectrum I might not be able to become independent.” People sometimes step in to help her before she asks for help, and she feels she should accept their help to be polite. She also gets discouraged when she makes mistakes but has developed a strategy of self-talk reminding herself “it’s how you learn.”

Mary suggested mentors, encouragers, and motivation would help individuals with ASD to become more self-determined. She also proposed having “supports whenever possible.” Throughout our conversation, it was evident that Mary had a strong, innate sense of self-determination and independence. “I always liked being as independent as possible.”

**Kevin.** Kevin is married and has a child. I met Kevin in his home. Like Mary, Kevin’s answers were very to the point. Kevin was not working at the time. He had worked for a flexible and mindful manager who had recently retired. His replacement had little understanding or flexibility regarding Kevin’s diagnosis, so Kevin lost his job. It is not uncommon for people with ASD to have their employment dependent upon the attitude of their supervisor (Wilson-Kovacs, Ryan, Haslam, & Rabinovich, 2008). Kevin remarked,
The problems at work only started when my manager retired, and I had a new person in charge, and they seemed unwilling to acknowledge that it was leadership that could be the issue and it was all focused on me, despite my exemplary performance for the previous 15 years.

Kevin stated, “Growing up in a stable home and having a supporting wife is definitely a big factor in being able to maintain self-determination.” He suggested raising awareness of ASD and having “employer sponsored initiatives to teach people at work how to understand and how to be sensitive to the needs and to respect the people behind the [ASD]” as ways to promote self-determination. Kevin also suggested that training in stress management and social skills would be beneficial for individuals with ASD.

**Aidan.** Aidan is married and was recently diagnosed with ASD. He credited his wife as the impetus for seeking out a diagnosis.

We were having a conversation and I said, “When I walk into a room I always see different. Doesn’t matter who’s in the room or whatever. They are all aliens to me.” She said, “That’s not how I view . . . When I walk into a room I be like, ‘Okay, they’re Caucasian, so I sort of know what their upbringing was like and I can relate to them.’” I’m like, “I don’t have that. I’ve never had that.” That has immediately clued her in that . . . the way I perceive the world is quite different than her. She started looking into autistic spectrum disorders.

It took several years for Aidan to connect with the resources that could do the diagnosis. There are few resources in Edmonton for adult diagnosis of ASD. Getting the diagnosis was positive for Aidan:
Before I got my diagnosis I was aware that I was different. I didn’t feel the world accepted my difference. Because of that I didn’t think there were options open to me. For example, I never thought going to postsecondary until the diagnosis happened.

When we met, Aidan was on a stress leave from his job as a deli manager at a major grocery store. In his words, “The job does not suit my strengths. There’s just too much human interaction.” He is planning to enter postsecondary education to study computers. He has had a positive experience so far with the application process and is grateful for the supports the institution will provide. “I think supports like that are crucial for people who don’t necessarily fit society’s moulds.”

Aidan conveyed a story of a time he had a disagreement with an abusive coworker who was able to evoke sympathy “because they were able to manipulate the emotions” of the boss. He found this to be a frustrating result of his communication challenges. “I have to learn how to communicate with you intellectually because I’m not going to pick up on your body language or your facial expressions et cetera.”

Negativity was part of Aidan’s experience prior to diagnosis. He felt that differences association with ASD should be more positively regarded. Aidan suggested, “having programs designed to celebrate strengths,” programs to teach communication, and more advocacy groups as ways to promote self-determination.

Matthew. Matthew chose to have his interview over Skype™ (Microsoft, 2016). I entered this interview, which was intended to be 30 to 45 minutes in length, with some trepidation as Matthew had informed me during our logistics emails that he felt he would need 2 hours or so to “adequately cover all that you wish to ask me.” Indeed, Matthew had a lot of information to
share with me that exposed many systemic shortcomings, particularly for individuals that are not severe enough to qualify for provincial assistance, but still unable to effectively manage some day-to-day activities. Matthew’s story speaks to a need to reevaluate the criteria used to determine eligibility for provincially funded supports and the need to simplify the navigation of systems of support.

Matthew had an interesting, unexpected answer when I asked his definition of self-determination:

For me, self-determination is being able to live a quality of life without necessarily having to struggle with effects of daily life that cause me hardship to the point where basically I am struggling to figure out, “Is it right for me to be coping with these hardships?”

From Matthew’s perspective, he cannot be self-determined until he has the necessary supports. This perspective initially challenged me. As our conversation progressed, it became clearer. Matthew has excellent self-awareness including a strong understanding of his strengths and weaknesses. He has tried various options to overcome his weaknesses, many of which have failed. The result is that he has a good sense of what he requires for success. Sadly, he has run into numerous barriers along his self-advocacy journey, most of which are beyond his control.

One of Matthew’s biggest desires is to live independently. He currently lives with his mother. To help achieve this goal, Matthew created a nonprofit society to provide wrap-around supports (a term used to encompass assistance with daily living tasks, employment, financial management, etc.) for him and others like him, in a housing cooperative in which he had hoped to purchase a suite. Matthew’s main source of income is Alberta Income for the Severely
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Handicapped (AISH). By the time the proposed housing cooperative had estimated costs for the building plans, he realized he would not be able to afford a suite in this building. He has recently identified a new cohousing project in which he hopes both he and his mother will be able to purchase separate suites, and his nonprofit society will be able to facilitate wrap-around supports in this location. To afford a suite, Matthew will need to supplement his AISH income with employment income.

As Matthew was describing his income challenge, several issues came to light. First, the rules for earning employment income while on AISH are not easily understood. Matthew’s explanation of the rules was inaccurate, yet close enough that I concluded that the AISH documentation is not presented in accessible language.

I would like to work more hours, but AISH regulations . . . mean that I can really only work about 12 hours a week before my AISH gets affected, which to me is almost like they’re for me not to work or to lose my social safety net that AISH provides.²

Second, it is difficult to find suitable housing within the constraints of AISH income. Prospects may improve if Matthew is able to work part time. Finally, Matthew has a difficult time managing his personal finances despite many attempts to learn a software program to assist, and he would like to find an informal trustee. That is, he would like a person or organization to

² AISH regulation allows single recipients to earn $800 per month before their monthly allowance of $1,588 is reduced. Benefits are reduced by $.50 per $1 of employment income between $801 and $1,500 per month effectively keeping the maximum monthly income at $2,338. Eligibility for at least $1 of AISH ensures eligibility for health benefits, so $2,337 can be earned before health benefits are cut off. If health benefits have a value of $150 per month, then a person would have to earn $2,488 per month of employment income to be in the same financial position as collecting AISH and earning $800 per month of employment income (Assured Income for the Severely Handicapped General Regulation, 2007).
manage his funds, including ensuring that bills are paid on time, while maintaining his decision-making rights. He has found such an organization, but he requires a special referral, which he has not been able to obtain. Matthew commented,

They [the people who need to make the referral] are probably thinking that they would be not encouraging me to push myself to improve my own quality of life, and that’s probably why they are [not] electing to fill out the form.

This demonstrates Matthew’s unique understanding of his needs, and his frustration with not being able to choose what type of supports he can get, which in turn, reduces his self-determination.

Matthew identified a number of systemic shortcomings in our conversation. He spoke of his difficulty accessing appropriate dental and health care.

I keep looking at . . . training programs for teaching . . . dentists [and] various other medical support roles . . . how to interact with people on the spectrum. It’s very clear that they’ve tried with one or maybe two individuals on the spectrum before they developed their particular training program and it’s like, that’s only going to help [one] of us, so what about the other 99 of us?

He also described challenges with the public transportation system, upon which he relies. Public transit does not service some places he would like to go that would improve his quality of life, such as a volunteer or recreational locations. He addressed challenges with postsecondary opportunities. Matthew attempted to attend a college program that would lead to a job he had researched and felt suited him. However, the program had some mathematical requirements that
Matthew needed supports to meet. Yet, he was unable to obtain appropriate supports. As a result, he ended up auditing the program and no longer sees himself working in this field.

Matthew would like some legal advice on how to structure his guardianship and trusteeship without giving up control. Currently, his mother handles many of the decisions without Matthew having to give up being his own guardian. He is starting to think about when his mother can no longer do this for him and how he can structure the supports he needs without giving up control, while safeguarding himself from various forms of abuse. “I don’t really know if it’s something that there are lawyers around that I can afford to chat with that have any understanding of how I see parts of these supports supporting me better,” he mused.

Throughout our conversation, it was apparent that Matthew recognizes the dilemma he faces regarding his own self-determination and quality of life. Matthew’s words eloquently summarize the dichotomy:

So much of quality of life for me is linked to self-determination, yet so much of self-determination seems to be taken for granted by a society that has a one-size-fits-all concept of either you want to take 100% of the responsibilities and the privileges that come along with those responsibilities or you want to have 0% regardless of one’s ability to function.

From Matthew I learned the importance of being open-minded and not making assumptions about how others view the world, sometimes having someone else do for you is the best support; real people would benefit if the system could produce individualized supports; and many of the issues are systemic and complex, requiring innovative solutions that are beyond the capacity of any single entity to resolve. I was also reminded that, in taking an appreciative
stance, “The most appreciative thing you can do is listen to people’s stories and the stories do not have to be positive. Before you get to the positive, you have to hear where people are really at, including the negative” (Agger-Gupta, personal communication, July 21, 2015).

**Summary of findings from interviews.** A wide range of enablers of and barriers to self-determination emerged from my interviews with independent adults with ASD. These items were themed as either individual or systemic. As well, the interviewees identified a number of potential strategies to promote self-determination, which also fell into the two themes stated above. A summary is provided in Table 1 on the next page. These findings represent both new and confirmatory knowledge related to the theories of self-determination described in Chapter 2. For example, the access to mentors represents new knowledge whereas exposure to opportunities confirms previous knowledge.

I was struck by the wide range of systemic issues experienced by many of the interviewees. Based on their stories, some commonalities arose, including issues that affect other potentially vulnerable populations. Poverty is a significant issue that was faced by Janine when she was homeless and is faced by Matthew as he tries to find suitable housing. Stereotyping still occurs as evidenced by Janine’s loss of her children when the system deemed she had a mental health issue. The system is not very flexible or creative in generating individualized solutions, and puts people into arbitrary, homogenous categories when assessing need for services, as Matthew has experienced in trying to find a solution to his need for personal financial management support. These are complex problems affecting an already vulnerable population causing further marginalization.
Table 1

*Summary of Findings from Interviews with Independent Adults with ASD*

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<thead>
<tr>
<th>Topic</th>
<th>Individual</th>
<th>Systemic</th>
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<tbody>
<tr>
<td>Enablers of self-determination</td>
<td>• Mentors and encouragers&lt;br&gt;• Personal development courses and books&lt;br&gt;• Support networks&lt;br&gt;• Exposure to opportunities&lt;br&gt;• Acceptance by others&lt;br&gt;• Setting goals&lt;br&gt;• Having a desire to contribute and volunteer&lt;br&gt;• Confidence and motivation&lt;br&gt;• Stable home base</td>
<td>• Job-carving (a process of creating a job description based on the unique skills of a job applicant. It often involves giving the person with ASD the repetitive, detailed parts of a job)&lt;br&gt;• Employer initiatives to train coworkers about ASD&lt;br&gt;• Flexibility&lt;br&gt;• Mindfulness&lt;br&gt;• Attitude of acceptance</td>
</tr>
<tr>
<td>Barriers to self-determination</td>
<td>• Lack of self-confidence and motivation&lt;br&gt;• Stress&lt;br&gt;• Anxiety and depression&lt;br&gt;• Inability to effectively communicate support needs&lt;br&gt;• Inability to effectively advocate for support needs&lt;br&gt;• Feeling powerless&lt;br&gt;• Trauma associated with retelling story&lt;br&gt;• Extra mental energy required to understand social situations&lt;br&gt;• Extra energy required to explain supports one is entitled to&lt;br&gt;• Extra energy to educate people about ASD&lt;br&gt;• Lack of positive example from parents</td>
<td>• Lack of support networks&lt;br&gt;• Judgmental people&lt;br&gt;• Overstimulating environments and lack of understanding of the impact on people with ASD&lt;br&gt;• Overreliance on pharmacological solutions&lt;br&gt;• Insufficient financial supports&lt;br&gt;• Eligibility criteria for services exclude some who need support&lt;br&gt;• Shifting criteria for services cause confusion&lt;br&gt;• Gatekeepers&lt;br&gt;• Perceived misalignment of resources (rigid rules can cause more expensive solutions than necessary)&lt;br&gt;• Professionals (e.g., dentists, family physicians, lawyers) lack knowledge of ASD&lt;br&gt;• Mental health system lacks knowledge of ASD&lt;br&gt;• Lack of appropriate dental and medical care</td>
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LEADING TOWARD SELF-DETERMINATION

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<th>Topic</th>
<th>Individual</th>
<th>Systemic</th>
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<tr>
<td></td>
<td></td>
<td>- Complex rules such as AISH application, eligibility, and employment that are not put into accessible language or explained</td>
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<td></td>
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<td>- Lack of relevant public transportation</td>
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<td>- Lack of access to postsecondary educational opportunities</td>
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<td>- Lack of access to legal advice</td>
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<td>- Time limited supports</td>
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<td></td>
<td></td>
<td>- “Nothing about us without us” (Autistic Self Advocacy Network, 2016b, Overview section, para. 1)</td>
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<tr>
<td></td>
<td></td>
<td>- More advocacy groups</td>
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<td>- Collective education of the community about ASD</td>
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<td></td>
<td></td>
<td>- Increase public awareness</td>
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<td></td>
<td></td>
<td>- Provide workplace accommodations</td>
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<td></td>
<td></td>
<td>- Job-carving</td>
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<td></td>
<td></td>
<td>- Ensure a stable home-base for individuals</td>
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<tr>
<td>Potential strategies to promote self-determination</td>
<td>- Teach skills of self-advocacy</td>
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<tr>
<td></td>
<td>- Ensure a stable home base, where the individual is comfortable</td>
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<td></td>
<td>- Teach communication skills</td>
<td></td>
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<td></td>
<td>- Teach stress management skills</td>
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</tr>
<tr>
<td></td>
<td>- Provide training in social situations</td>
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<td></td>
<td>- Work from an individual’s interests and strengths</td>
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Note. AISH = Alberta Income for the Severely Handicapped; ASD = Autism Spectrum Disorder.

Staff focus group. One of the most interesting occurrences during the focus group was a shift in mental models of some staff members regarding the ability of people with ASD to be self-determined. At the beginning of the group, some participants did not perceive the individuals served by the Centre as capable of self-determination. Beth commented,

I’ve talked with those from the nonverbal right up to the verbal who can express themselves and those who can’t express themselves, who can’t even give you a sign, and I don’t see that they can make that decision for themselves. . . . I’m not saying that we’re
making that decision from a bad point of view. I’m just saying we are making that decision because they can’t express themselves. They can’t do a lot of things for themselves, right?

The individuals being referenced above are more significantly impacted by ASD than the six adults who were interviewed for this study. After about an hour of facilitated discussion, Beth commented,

And maybe how to express [their choice]. Maybe that’s a part of the problem. They’re not able to express it so we know exactly what they want. In other words, finding other strategies or ways to get them to express [what they want].

This shift reinforces the appreciative inquiry belief in the power of inquiry: “We can anticipate that the living organization will ‘respond’ to the questioning process in some way, will indeed be affected and changed by it” (Lewis, Cantore, & Passmore, 2008, p. 24).

Participants in the focus group identified many strategies that are being used in some areas of programming that help build the skills to support self-determination and are shown in Table 2. These strategies could help develop any or all seven of Wehmeyer’s (1999) identified elements of self-determination: choice making, decision making, goal setting, problem solving, self-advocacy, self-management, and self-awareness (p. 59) as referenced in Chapter 2.

Increasing the use of these strategies across all Centre programs could promote the self-determination of individuals with ASD.

The focus group identified a number of potential barriers to self-determination as outlined in Table 2. William commented, “We have one thing in mind, one focus, and that’s to meet this goal and perhaps that may get in the way [of self-determination].” Cathy spoke about culture, “In
some cultures, based on your gender, you’ve already got something planned out for you or based on which family you come from, or status or whatever, for whoever you are that determines your self-determination.” Nadir remarked, “Often times a lack of response is taken as an inability to respond, whereas maybe it’s their [choice].” The following comment from William highlighted the internal conflict faced by staff with regards to *stimming* (a term used in the autism community for repetitive, stereotypical behaviour):

> When you go out in the community, that’s one of the things that you first look into, how could we make the stimming behaviour decrease, or turn it into something more appropriate . . . because when you go out in the community, the first thing that is going to happen is community members or people out there are going to stare, and it’s going to make them feel uncomfortable, it’s going to make you feel uncomfortable, and the person with the special needs is just choosing to walk while they’re flipping their hands. There’s really nothing wrong with that, if you really think about it. They are exercising self-determination in that sense. . . . We all stim. We all do.

Finally, Beth had this to say about others setting goals for individuals with ASD:

> I’m not saying it’s wrong but I’m just saying that they can’t make that decision for themselves to choose those goals, so parents come in, so parents [are] in the way. We are in the way as interventionists, and we don’t mean any harm, but I’m just saying. . . .

When considering strategies for increasing self-determination, and aligned with the principle of normalization, Cathy astutely remarked,

> I think it might be good for people to realize that maybe self-determination for everyone is an ongoing evolving process that is constantly being developed by our experiences and
by the situations that we’re put into. . . . What kind of things people need to be exposed to, to kind of help create that confidence in those pieces that’ll help when they run into the situations again later on, to be able to choose for yourself, because like we said before, like little kids, a lot of parents are determining for them. They don’t have much self-determination, but as they grow through their teen years, you’re getting more freedom and more choice, but if you screw up, it goes back in again, and you’ve got to earn that trust back. . . . There’s going to be all sorts of environments for anyone where you’re not going to be able to be completely self-determined. When you’re at work, you can’t say, “No, see you later.” It’s being aware [of] settings and places, that self-determination is more encouraged in some places than others, and that it’s progressive and that we’re always learning to become more self-determined.

This kind of thinking reflects the attitude that is required for people with ASD to gain and exercise their self-determination. It normalizes a process of becoming self-determined, an important aspect of supporting people with disabilities (O’Brien, 2011b; Wolfensberger & Tullman, 1982). Nadir remarked that one thing we could do to enhance the self-determination of people with ASD is to “shape an environment where their ability to communicate their ideals of self-determination would be a lot more fluent.” The focus group did not identify ways to create such environments.

Staff survey. There was only one respondent to the anonymous staff survey. The survey questions can be found in Appendix D. The respondent believed that people with ASD are capable of self-determination before reading the results of the focus group and interviews and maintained that belief. Two potential strategies were identified: (a) specialized training for
workplace, school, and volunteer organizations and (b) advocating for change and awareness within the provincial and federal funding systems and within the healthcare system. The respondent suggested that a strong training program be created with an effective delivery team that includes people with ASD. Finally, the respondent was unsure about the Centre’s ability to take on the advocacy role, but felt that the Centre could work with advocacy organizations and connect people to those organizations.

Summary of findings from staff focus group and survey. A number of individual and systemic strategies and barriers to self-determination of people with ASD were identified along with some suggested strategies for the Centre to trial. These are outlined in Table 2.

Table 2
Summary of findings from focus group and survey

<table>
<thead>
<tr>
<th>Topic</th>
<th>Individual</th>
<th>Systemic</th>
</tr>
</thead>
</table>
| Current strategies used at the Centre to promote self-determination | • Teaching choice making  
• Having individuals set their own goals  
• Following the individual’s lead  
• Teaching emotional regulation  
• Fading support  
• Teaching self-praise  
• Using strong motivators (reinforcement) | | n/a |
| Perceived barriers to self-determination | • Difficulty with communication | • Hyper-focus by staff or families on singular goals  
• Culture/ethnicity of the family  
• Attitudes toward stimming (such as perception of lack of ability, perception of noncompliance instead of having made a choice) |


<table>
<thead>
<tr>
<th>Topic</th>
<th>Individual</th>
<th>Systemic</th>
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</thead>
<tbody>
<tr>
<td>Strategies to trial at the Centre to promote self-determination</td>
<td>• Shape the environment such that individuals with ASD can communicate their desires more fluently</td>
<td>• Shape environments such that individuals with ASD can communicate their desires more fluently</td>
</tr>
<tr>
<td></td>
<td>• Teaching skills for self-determination</td>
<td>• Training and educating the community about ASD</td>
</tr>
<tr>
<td></td>
<td>• Teach socially acceptable behaviours to replace stimming behaviours</td>
<td>• Collaborate with other organizations to increase advocacy</td>
</tr>
<tr>
<td></td>
<td>• Teach staff to be mindful of developing self-determination for individuals with ASD</td>
<td>• Participate in systemic advocacy with provincial and federal governments</td>
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</table>

Note. ASD = Autism Spectrum Disorder; n/a = Not Applicable.

**Study Conclusions**

Through listening to the stories of independent adults with ASD, I learned that it is vital to include their voices in research because they know what they need to be successful. However, systems and services providers do not always meet their needs. Participants were thoughtful, sensitive, and considerate with their input to this study. Staff members demonstrated their commitment to the Centre’s goal of better meeting the needs of individuals with ASD. The low rate of staff participation may have implications for the implementation of recommendations, as discussed in the next chapter. Based on this study’s findings, I present the following study conclusions:
1. Members of the autistic community need more of a voice in all that affects them, including in research, in development of programs, and in directing their own supports.

2. The construct of self-determination is complex.

3. The exercise of leadership for an organizational culture change will enable staff to build on current good practices and implement new practices.

4. There are systemic barriers to self-determination of people with ASD beyond the Centre’s mandate.

**Conclusion 1: Members of the autistic community need more of a voice in all that affects them, including in research, in development of programs, and in directing their own supports.** Hearing the stories of individuals with ASD confirmed the arguments put forward in the literature that advocates for their participation in all spheres that impact them. As discussed in Chapter 2, opportunities to practise the skills associated with self-determined behaviour, such as making choices, self-advocacy, goal setting, decision making, and problem solving, are integral to the development of self-determination (Wehmeyer, 2011, p. 216). The interviewees in this study were able to identify factors that led to their success in being self-determined as well as barriers, both individual and systemic. Their perspectives personalize the issues, taking situations from theory to reality. To know intellectually that transportation is a barrier to self-determination is only partially helpful, but Matthew’s explanation that he cannot do volunteer work or participate in physical activities that he enjoys because he has no means to travel to the locations animates the issue and provides impetus to solve the problem. People need to hear these kinds of stories again and again to create a movement for change.
Through each person’s lived experiences, the individual learned more about the supports that would have helped him or her to be more self-determined. Janine’s experience of homelessness highlighted a shortcoming in the system solution when she was housed in a hotel room but not supported to live in an apartment. Matthew’s experience with trying to learn a software system to aid in managing his finances taught him that he requires more support in this area, but he has been unable to gain access to this support. Janine’s experience with the health care system and child intervention system highlights the need for better understanding of ASD and how to support individuals with ASD.

Listening to six individuals with ASD describe their experiences reinforced the popular saying in the autistic community, “If you’ve met one person with autism, you’ve met one person with autism” (Shore, 2013, para. 4). Each interviewed independent adult with ASD had achieved self-determination via different pathways. For example, Janine had to swim or sink as a young person, while Kevin described a supportive home base as key to his self-determination. While each interviewee may have had a different definition of self-determination, each was clear in his or her desire to be self-determined. For Mary, self-determination means being independent, having people respect her abilities, and not be too quick to jump in to help her. Having the right supports, as determined by himself, was key for Matthew. André has created a complex model to support his self-determination and to know when to access supports. Promoting self-determination of people with ASD is likely to require creativity and individualization.

**Conclusion 2: The construct of self-determination is complex.** As introduced in the literature review, Cobb et al. (2009) concluded that self-determination is multifaceted and complex, and this is supported by the findings from this study. The preponderance of systemic
barriers identified by both independent adults with ASD and staff at the Centre suggests self-determination is complex. The variety of strategies that promote self-determination posed by study participants is congruent with self-determination as a multifaceted concept and Cobb et al.’s assertion that interventions with multiple components are most likely to be successful (p. 113). Snowden’s (2002) Cynefin framework was designed to enable sense making in a complex world. The framework provides a means to distinguish between simple, complicated, complex, and chaotic systems, to increase leadership awareness of the borders in between these systems, and to adjust their decision making or interventions accordingly. Simple contexts often have one right answer, whereas complicated contexts generally have multiple correct answers, each with different implications (Snowden & Boone, 2007). Snowden and Boone (2007) described chaotic contexts as turbulent, requiring establishment of order. In complex contexts, it is difficult to know the right answers (Snowden & Boone, 2007). Snowden (2002) argued that human systems are complex, and their “components and . . . interactions are changing and can never be quite pinned down” (p. 105). People are only able to make sense of complex systems in retrospect (Snowden, 2002, p. 106). The Cynefin framework may assist in clarifying the construct of self-determination.

Although the consequences of interventions are unknowable and unpredictable (Snowden, 2002), Wheatley (2005) explained that the “primary way to prepare for the unknown is to attend to the quality of our relationships, to how well we know and trust one another” (p. 117). Person-centred practices are one way to know, trust, and relate with the individuals with ASD that we serve. Wehmeyer’s (2003b) functional model of self-determination “predicts that self-determination emerges as people acquire or develop a set of component elements of self-
determined behavior” (p. 182). The implementation of interventions with multiple components is most likely to enhance self-determination of individuals with ASD (Cobb et al., 2009).
Conclusion 3: The exercise of leadership for an organizational culture change will enable staff to build on current good practices and implement new practices. In examining individual readiness for organizational change, Choi and Ruona (2011) proposed, “In order for organizational members’ involvement and participation in the change process to have successful outcomes, they must be knowledgeable, capable, and motivated to make a genuine contribution” (p. 63). The low number of participants for the focus group and respondents for the survey may indicate that staff are not feeling confident in either their knowledge of self-determination or in the Centre’s readiness for change, or that some other unknown factor or factors may be responsible. The Centre leadership team is aware that staff members are experiencing change fatigue, as the Centre’s major funder, Family Support for Children with Disabilities (FSCD), has initiated many changes to expected practices and reporting (D. Allard Usunier, personal communication, June 12, 2015); however, leadership members still overestimated their readiness. Although, the goal for this study was to create of a culture in which the promotion of self-determination of individuals with ASD across the lifespan permeates all services at the Centre, it seemed staff were not ready. The potential lack of readiness for a culture change began to emerge after a staff training session on completing one-page profiles, a tool that promotes self-determination, for the children in the Centre’s SS program. Staff members did not understand its relation to the Centre’s philosophical framework and felt it was just one more task on their to-do list. This may be indicative of a lack of understanding of the construct of self-determination and the Centre’s commitment to promotion of self-determination. In designing this study, my sponsor, the executive team, and I had several conversations about what resources staff need to be able to practise person-centredness, a key philosophy that promotes self-determination of
people with ASD. We thought that what staff needed was to learn how to promote self-determination through person-centred practice, but in retrospect, it seems that we need to back up to generate understanding of the construct of self-determination and why the promotion of self-determination is critical to our work.

An important factor in self-determination, as identified by many authors (e.g., Wehmeyer et al., 2003b; Wolfensberger & Tullman, 1982), is the environment, including the attitudes of the people in the environment. Staff in the focus group and independent adults with ASD also found attitudes to be important. At the beginning of the focus group, some staff did not recognize that the behaviour of individuals with ASD could be the enactment of self-determination. The conversation during the focus group was what caused them to realize behaviour could be demonstration of an individual’s choice. This misunderstanding may also be evidence that more staff do not recognize behaviour as potential enactment of self-determination. Independent adults with ASD spoke of the importance of flexibility and mindfulness of employers as an important factor in maintaining employment. As described in Chapter 2, Aber and Stancliffe (2003) identified attitudes and beliefs as one of the three basic categories required for self-determination. Individuals need to feel valued by others to have trusting relationships. André asked caretakers to value him as responsible, kind, and willing to accept their help. Mary described that sometimes people step in too quickly to help her, which suggests they do not value her ability. Kevin felt devalued when his supervisor blamed him for some challenges at work, ignoring 15 years of “exemplary performance.” As such, the Centre staff may need support to embrace an organizational culture change in order to expand upon existing best practices.
Conclusion 4: There are systemic barriers to self-determination of people with ASD beyond the Centre’s mandate. Many of the barriers to self-determination identified by the independent adults with ASD and staff were systemic barriers and thus will require systemic advocacy. User-led disability organizations are increasingly taking on systemic advocacy (Hutchison et al., 2007, p. 712). While the Centre is not a user-led organization, the addition of a self-advocates advisory group will enable the Centre to work from a user-informed perspective. The Centre will also be in a position to increase the self-advocacy skills of members and service users.

The Centre’s mandate does not include advocacy because the Centre relies on government funding for most of its programs. However, the Centre has positive relationships with its funders and could leverage those relationships to effect change. For instance, the Centre meets quarterly with FSCD, the body that funds the Centre’s largest service area, providing an opportunity to discuss challenges and successes. The Centre collaborates with many partners in delivering services for individuals with ASD. As an example, the Centre has partnered with Edmonton Transit System to deliver a program that teaches youth and young adults to ride the bus independently. This partnership may open other doors within Edmonton Transit System to advocate for alternative solutions to meet the needs of individuals with ASD who rely on transit, yet are unable to access locations that are important to them via transit. Advocacy organizations in Edmonton for individuals with developmental disabilities could also be leverage points for advocacy for individuals with ASD.
Scope and Limitations of the Inquiry

The scope of this study included independent adults with ASD and staff who worked with teens and adults with ASD. Dependent adults with ASD were excluded, which may have resulted in missing information and ideas. Limiting the pool of staff eligible to participate in the focus group and survey likely contributed to the difficulties achieving sufficient numbers for the focus group and the low response rate for the survey.

Limitations of this inquiry include several factors. One limitation was the lack of probing questions during the interviews with independent adults with ASD. This decision was made, in part, to accommodate the needs of individuals with ASD. Although I provided space for interviewees to respond as they wished, more strategies, enabling factors, and barriers may have been identified through additional questioning. I also may have gained additional insight into their experiences of self-determination to inform conclusions and recommendations. Some interviewees may have provided more information if I had used email for the interview, including follow-up emails for probing questions.

Also upon reflection, it may have been beneficial to disclose my own diagnosis of ASD as a way to build rapport and a sense of shared experience. One of the interviewees asked me how I got interested in my field of study and I responded that I had a 20-year-old son with ASD. While this is literally true, in retrospect, it did not feel authentic to the question.

The pool of staff who were eligible to participate in the focus group and survey was small and likely contributed to the inability to achieve sufficient numbers for the second focus group and the low response rate for the survey. Expanding the pool may have increased respondents, thereby providing a greater breadth and depth of data.
Due to power-over or perceived power-over issues, I was unable to participate in any aspects of the focus group. A third-party inquiry team member invited and selected participants and facilitated the focus group. This limited my ability to experience the nonverbal communication of the participants, which could have provided important information for this study. The third-party facilitator was not familiar with my field of practice (ASD intervention), which may have impacted her ability to clarify questions and concepts, resulting in less data.

**Chapter Summary**

By taking action on this study’s findings and conclusions, the Centre will demonstrate leadership among autism service providers in promoting self-determination of people with ASD. Findings garnered from my interviews of independent adults with ASD add to the body of knowledge about self-determination theory and provide evidence of the need to include individuals with ASD in all that affects them. Having self-determination as part of the mindset of staff at the Centre may facilitate the implementation and enhancement of practices to promote self-determination of people with ASD. The next chapter outlines recommendations to achieve these goals, along with implications for the Centre and for future inquiry.
Chapter Five: Inquiry Implications

In this chapter I present the recommendations from this study along with organizational implications for implementation, potential ramifications of not implementing the recommendations, and implications for future study. The recommendations were created in the context of the inquiry question: How can the Centre exercise leadership among autism service providers in Canada in promoting self-determination of people with autism spectrum disorder?

The following subquestions supported the inquiry:

1. What are Centre staff’s current perceptions of self-determination and/or practices that support or hinder the self-determination of people with ASD?
2. What are the stories of self-determined adults with ASD, and how can they inform our practice?
3. What practices can the Centre implement that would promote the self-determination of individuals with ASD?

Study Recommendations

The executive team and this study’s sponsor met to discuss the findings and conclusions from this study within the context of the Centre’s philosophical framework. The following recommendations were agreed upon in that meeting:

1. Provide training for staff on the construct of self-determination.
2. Create an employee working group to focus on increasing staff readiness for organizational culture change that will promote the self-determination of individuals with ASD.
3. Create an advisory group of self-advocates to inform Centre programs for promoting self-determination.

4. Enhance systemic advocacy for inclusion of individuals with ASD in policy setting, development of programs and services, and research.

**Recommendation 1: Provide training for staff on the construct of self-determination.** According to Mithaug (2003b), self-determination is sociopolitical and psychological. The sociopolitical aspect derives from antioppression and acknowledges that everyone has the right to be as free as possible. In order for people to act on their right to be free, “they must have strong desire and substantial ability” (Mithaug, 2003b, p. 120). Wehmeyer (2003b) argued teaching the component elements of self-determination could positively impact an individual’s ability to self-determine. Increasing staff understanding of self-determination may enhance their perceived competence to promote self-determination of individuals with ASD. Competence is a factor in individual readiness for organizational change (Choi & Ruona, 2011). Demonstrating the linkage of promoting self-determination to our vision, mission, strategic plan, and philosophical framework may increase readiness for change by highlighting the need for change (Choi & Ruona, 2011). This study’s sponsor identified that staff are experiencing change fatigue (D. Allard Usunier, personal communication, June 12, 2015); as such, reframing change as development of a learning culture, consistent with the Centre’s strategic plan (Centre for Autism Services Alberta, 2013), may also influence readiness for change (Choi & Ruona, 2011).

**Recommendation 2: Create an employee working group to focus on increasing staff readiness for organizational culture change that will promote the self-determination of individuals with ASD.** Armenakis et al. (2009) argued that one method of creating readiness for...
organizational change is active participation in which employees learn through activities, creating greater trust in the information and enhancing readiness for change (p. 576). An employee working group would provide an opportunity for engagement. One of the tasks of the working group would be to create a toolbox of strategies and practices to promote self-determination, which may include the following: (a) examples of evidence of self-determination (e.g., child-created goals on service plans); (b) perspectives of self-advocates (through written stories and live presentations); (c) samples of evidence of self-determination and/or self-determined goals in service plans; (d) samples of ages and stages evidence of self-determination development; (e) information on how to create opportunities to practise the skills for self-determination; (f) descriptions of what self-determination may look like for an individual whose primary mode of communication is nonverbal; (g) a series of one-page tip sheets for parents, staff, and individuals with ASD; (h) ways to recognize staff for supporting self-determination; (i) ways to alter hiring practices to ensure new staff support self-determination for individuals with ASD; and (j) strategies for engaging individuals with ASD in service planning.

The Centre’s leaders should model and exemplify the philosophical framework, including promotion of self-determination for individuals with ASD. One simple question asked consistently by leadership would promote increased consideration of self-determination of individuals with ASD throughout all Centre programs: How does this (insert goal, activity, objective) promote self-determination for (insert individual’s name)? Keeping self-determination top of mind may facilitate its incorporation into all practices at the Centre (D. Allard Usunier, personal communication, May 12, 2016).
Recommendation 3: Create an advisory group of self-advocates to inform Centre programs for promoting self-determination. In keeping with the autistic community’s request for “nothing about us, without us” (Autistic Self Advocacy Network, 2016, para. 1), a forum for individuals with ASD to provide feedback and input to Centre programs is essential to ensure programs and services are relevant. Independent adults with ASD have valuable information and knowledge about their needs. Optimizing stakeholder engagement is a key performance indicator within the Centre’s strategic plan (Centre for Autism Services Alberta, 2013), yet engaging individuals with ASD has received little focus. In addition to receiving valuable input, the Centre would be demonstrating leadership by providing a venue for individuals with ASD to practise skills associated with self-determination. Lack of skills and competence are barriers to participation in organizational planning for people with disabilities (Radermacher, Sonn, Keys, & Duckett, 2010). Enhancing the skills and competencies of individuals with ASD through participation in an advisory group could increase their involvement in organizational planning, within the Centre and other organizations.

During the executive team’s discussion on ways to engage staff, one member suggested that hearing the stories of self-advocates with ASD could be beneficial and then proposed forming an advisory group of self-advocates with ASD to review the Centre’s programs, as this could assist in ensuring that leadership is focusing on the right things (S. Lynch, personal communication, May 12, 2016). The executive director suggested that staff need to hear from self-advocates multiple times, and this advisory group could be a source (D. Allard Usunier, personal communication, May 12, 2016). The voices of self-advocates could also be heard through reading journal articles and autobiographies during staff time already allocated to journal
review. Identifying candidates for the self-advocates advisory group will be an important next step. Developing this group will be a significant undertaking. The majority of people with ASD that the Centre works with are not independent, resulting in a small pool of people to draw upon for this group. Leadership will need to consider if they will recruit from the broader autistic community. The Centre will be the first autism service provider in Alberta to have an advisory group of self-advocates with ASD. The creation of a self-advocate advisory group will demonstrate the Centre’s leadership and commitment to the inclusion of people with ASD in research, policy setting, and development of programs and services. Hutchinson et al. (2007) found that user-led disability organizations “gave voice to people with disabilities” (p. 701), something for which the autistic community advocates. Although the Centre is not user led, having an advisory group of self-advocates would increase their voice at the Centre. Davidson and Henderson (2010) identified that for individuals with ASD who have learned to pass (a process in which stereotypical autistic behaviours are suppressed and neurotypical behaviours deemed socially appropriate are mimicked), coming out as autistic can be risky (p. 155). According to self-advocates, risks include being pitied, perceived as less capable, and stigmatized (Davidson & Henderson, 2010, pp. 158–159) and some of the individuals I interviewed experienced these risks. Kevin’s boss perceived him to be less capable than did his prior employer, and Mary noted people step in to help her before she asks. Janine was stigmatized by the health system. I was very aware of these risks when I made the decision to disclose my diagnosis of ASD just over a year ago. The two deciding factors for me were a sense of inequity when I openly discussed my son’s diagnosis without sharing my diagnosis, and a
desire to be a positive role model for others with ASD, including my son. Having their voices heard may contribute to the development of positive self-identity for people with ASD.

**Recommendation 4: Enhance systemic advocacy for inclusion of individuals with ASD in policy setting, development of programs and services, and research.** Although advocacy is outside the Centre’s mandate, systemic advocacy is consistent with the governance policies of the Centre. The Centre could use its existing relationships and partnerships to advocate for more inclusion of individuals with ASD by policymakers, service providers, and researchers. The Centre is a member of the Canadian Autism Spectrum Disorders Alliance (CASDA), whose mission includes being “committed to ensuring the implementation of a comprehensive National ASD Strategy that addresses critical gaps in funding and policies, which are preventing individuals with ASD and their families from exercising their equal rights as Canadians” (Canadian Autism Spectrum Disorders Alliance, 2016a, Mission section, para. 1). Through CASDA, the Centre has potential influence with federal and provincial politicians and government. The Centre also could advocate directly with CASDA for the inclusion of individuals with ASD in CASDA working groups and on CASDA’s board of directors.

Other relationships the Centre could leverage include the City of Edmonton (transportation), the health system including mental health, the provincial government (SS, PDD supports, AISH) and postsecondary institutions (inclusive education, professionals’ education, and research). The Centre is connected with two university students’ organizations: one at the University of Alberta and the other at MacEwan University. These organizations raise autism awareness and funds for the Centre at their respective campuses. These groups are potential leverage points for changing attitudes about ASD. The University of Alberta group has an
individual with ASD on their board of directors. The Centre has relationships with several prominent autism researchers that could be points of advocacy for the inclusion of people with ASD in research. Nicolaidis et al. (2011) concluded that autistic self-advocates can successfully participate as partners in research, including those with “diverse communication needs” (p. 143), which is supported by the successful inclusion of adults with ASD in this study. Some modifications were made to my study to ensure successful inclusion, such as restricting the pool of participants to independent adults with ASD, letting the interviewees choose the location or forum for the interviews, and allowing the interviewees the space to answer questions as they wished.

This study supports the Centre’s advocacy efforts with its major funder, FSCD within the Ministry of Human Services of the Government of Alberta, whose current practice is to emphasize parent coaching rather than intervention with the child with ASD. The practice of solely providing parent coaching does not support the self-determination of the child with ASD and is an ongoing area of advocacy for the Centre. The findings from this study support child intervention to develop the skills of self-determination in addition to parent coaching.

**Organizational Implications**

I engaged my sponsor and the executive team in a discussion of study findings and conclusions as a prelude to identifying recommendations. We considered possible means of implementation within the context of the Centre’s philosophical framework (D. Allard Usunier, personal communication, June 19, 2015; see Appendix C). During a lengthy discussion about the philosophical framework, we realized that person-centredness is a new concept for many staff for which the Centre has done minimal training: “How are we [executive and management] going to
message it [person-centred practice] on a daily basis?” (D. Allard Usunier, personal communication, May 12, 2016). The Centre’s philosophical framework defines person-centred as “a philosophy and a set of strategies aimed at promoting self-determination” (D. Allard Usunier, personal communication, June 19, 2015). It took several months of dialogue for 12 executive and management individuals with varying educational backgrounds and experience to reach agreement on the philosophical framework, yet the Centre’s leadership has not put similar effort into engaging the rest of staff. During our recommendations discussion, we acknowledged that other than rolling out the philosophical framework to staff in June of 2015, we have done very little to ensure understanding, acceptance, and implementation. Creating shared understanding is an ongoing challenge for executive members: “We struggle as an executive team . . . to close those loops often. We do great work. We have great ideas and we have great passion, but it is always that last piece, pulling it all together” (D. Allard Usunier, personal communication, May 12, 2016). That is, we do not finish the process by involving other levels of staff. The process of creating individual readiness for change within staff members at the Centre will be lengthy, and achieved by a series of incremental changes. The executive at the Centre is fully invested in this change and committed to implementation of the recommendations.

Throughout the Centre’s next steps and implementation of recommendations, the executive and management will change some of their leadership practices to be successful. I recommend the leadership clearly communicate key messages about the Centre’s philosophical framework and self-determination for people with ASD to staff (D. Allard Usunier, personal communication, June 19, 2015). One accepted leadership practice is to model the way (Kouzes & Posner, 2012, p. 15). As a result of this thesis, the executive and management have begun
discussions on how to put the philosophical framework into action. Mindfulness will assist leadership and staff to change old habits. Demonstration that they are listening to the advisory group of self-advocates with ASD and the employee working group will enhance the leadership’s credibility. Identification of expected operational outcomes for both groups will enable the leadership team to measure success.

The establishment of an employee working group to facilitate readiness for change will assist in gaining the full engagement of staff. Without staff’s full engagement, it is difficult to foresee the Centre successfully promoting the self-determination of individuals with ASD. Next steps will include an interactive session with all staff to begin the work of increasing knowledge of the construct of self-determination and identifying potential candidates for the employee working group. The executive and management team will develop and lead the learning session. Instilling self-determination as part of the culture of the Centre will require many conversations over a long period of time as well as perseverance. Executive and management have demonstrated the ability to persevere with its work to create the philosophical framework.

With regards to systemic advocacy, the Centre’s executive director remarked that the exclusion of the child by FSCD to focus on parent coaching is insulting and dismissive to the child, citing a recent instance in which a 9-year-old child was prevented from participating in service planning (D. Allard Usunier, personal communication, May 12, 2016). Having child-created goals on service plans would promote the development of self-determination, yet the child continued to be excluded by FSCD. Several examples were raised in which Centre staff have included the child, despite the direction given by FSCD, which has resulted in positive outcomes for the child. Positive outcomes include having more understanding of how ASD
impacts the individual and being able to advocate for what he or she wants or needs. FSCD recognizes within their own policy that transitioning to adulthood for children with disabilities is complex and the process should begin as early as 9 years of age (Alberta Government, Ministry of Human Services, 2004, p. 121). The Centre is a member of an Alberta Alliance, which is advocating with FSCD to change their intervention focus to include the child as well as parents.

Through implementation of the four recommendations from this study, the Centre will exercise leadership among autism service providers in Canada in promoting self-determination of people with ASD. As noted earlier, the Centre will be the first autism service provider in Alberta to have an advisory group of self-advocates and to my knowledge, among the first in Canada. Increasing staff knowledge of the construct of self-determination, along with developing discrete practices, will lead the way in promoting self-determination of individuals with ASD. Intentional systemic advocacy is expected to enhance the self-determination of all individuals with ASD, not just those served by the Centre.

**Implications for Future Inquiry**

This study provides new knowledge in three areas on which other researchers could build: (a) the need to include the voices of people with ASD, (b) the need to develop ASD specific strategies to promote self-determination, and (c) the act of including individuals with ASD in research to promote their self-determination. This study included the voices of independent adults with ASD.

Increasingly, self-advocates with ASD are calling for inclusion in autism research. During a live Twitter (2016) chat from the 2016 International Meeting for Autism Research, an autistic self-advocate, tweeted, “Researchers need to find autistic leaders in their communities
and involve them in shaping and running research” (J. Elder Robison, personal communication, May 12, 2016). A special interest group session at the same conference explored the issue of “incorporating autistic intellect in research design and evaluation” (International Meeting for Autism Research, 2016, para. 1). As this study’s principal investigator, I myself am an independent adult with ASD, I included the voices of independent adults with autism within this inquiry, and I included an independent adult with ASD on my inquiry team. This thesis marks one of the first attempts to include the voices of people with ASD within the research and demonstrates how leadership can be enacted in this area. Future inquiries could also include individuals with ASD in all phases of the research, including design and analysis. The voices of nonindependent adults with ASD are also important. It is difficult to learn the perspectives of individuals with communication challenges, as J. K. Y. Lai (personal communication, April 19, 2016) observed. Further research is required to develop effective strategies to ascertain the perspectives of higher-needs people with ASD.

Some of the factors identified in the literature as associated with self-determination, such as self-awareness, self-regulation, and relationships with support staff, are inherently difficult for people with ASD. Strategies for teaching these skills have been developed for people with intellectual or developmental disabilities, but not specifically ASD (Wehmeyer, 2011). Research is needed to find effective strategies for teaching these skills to individuals with ASD, including those with more severe challenges.

Finally, the inclusion of people with ASD in research about self-determination would provide opportunities for those individuals to enact self-determination while studying the construct. This study demonstrated methods to include people with ASD in research utilizing
PAR principles, as evolved from Freire’s (2000) work to overcome oppression of marginalized populations. Research into the effectiveness of including people with ASD in all facets of the research process could support their continued involvement and potentially generate better outcomes for individuals with ASD. Working in collaboration with many different individuals with ASD, including those with more significant challenges than those included in this study, may improve the overall benefits of ASD research for the very community it is designed to support. “Nothing about us, without us” (Autistic Self Advocacy Network, 2016, para. 1).

**Thesis Summary**

This chapter outlined four recommendations for the Centre to enable it to lead the way in promoting self-determination of people with ASD and be in compliance with the *UN Convention on the Rights of Persons with Disabilities* (United Nations, 2006; United Nations General Assembly, 2006). The chapter also discussed organizational implications and outlined suggestions for future inquiry.

This study demonstrated the effective inclusion of independent adults with ASD in multiple facets of research and supports their future inclusion. In addition to the interviews, an adult with ASD was invaluable in the crafting of interview questions. All aspects of this study were designed with the unique needs of individuals with ASD. This research adds to the body of scholarly literature that advocates for partnerships with people with ASD in research (Jivraj et al., 2014; Martin, 2015; Martin, Fox, MacGregor, & Hickman, 2014; Nicolaidis et al., 2011; Nicolaidis et al., 2015). It also adds to the body of knowledge in self-determination theory.

By implementing the recommendations, the Centre will move towards a culture that empowers individuals with ASD to become more self-determined. The Centre will demonstrate
innovation and leadership in the realm of autism service providers with the addition of an advisory group of adults with ASD and add to the organization’s credibility as the Centre’s staff and leadership advocate with and for individuals with ASD. As a member of the executive team at the Centre, as a mother to a young man with ASD, and as an adult with ASD, I will endeavour to keep this change moving forward to benefit all people with ASD.
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LEADING TOWARD SELF-DETERMINATION

http://dx.doi.org/10.1108/13673270210424639


http://dx.doi.org/10.1177/1098214005283748


Appendix A: Strategic Plan: 2013–2018

centre for autism services alberta’s

strategic plan: 2013-2018

**vision:** individuals with autism spectrum disorder reach their full potential

**mission:** Our mission is to provide comprehensive and innovative supports and services to those affected by Autism Spectrum Disorder.

core values

- We value access to supports, services and resources across the full autism spectrum and lifespan
- We embrace person-centered and family-centered practices
- We value meaningful participation of all individuals in every aspect of society
- We believe in the right to individual choice and self-determination
- We value collaboration with all stakeholders
- We are dedicated to continuous quality improvement
- We value accountability and transparency
- We engage in open and honest communication

performance indicators

- Programming meets or exceeds accredited standards
- Stakeholder engagement (external and internal) is optimized
- Percentage of funding from unrestricted sources is increased
- Increased diversity of programs and supports for each life stage

strategies

1. Programs and services meet the unique needs of each stage of life:
   a) Access diverse funding to support lifespan programming
   b) Build strong relationship with government
2. Continue to build and grow a high quality program and service delivery:
   a) Cultivate a culture of self-reflective practice, professional development and lifelong learning
   b) Continuous improvement
   c) Increase opportunities to participate and engage in applied research
3. Develop transitional supports to enable successful community inclusion and maximize autonomy:
   a) Encourage independence for clients, building individual, family and community capacity
   b) Increase connections with other organizations, providers, and community

Appendix B: Organization Chart

Note. From S. Gynane (personal communication, November 2, 2015). Reprinted with permission.
Appendix C: Excerpt from Philosophical Framework

Centre for Autism Services Alberta
Philosophical Framework

**Statement:** We operate under a person/family centered model. Our overriding framework of practice is based on a developmentally informed behavioural approach. Empirically supported practices are incorporated in all activities. Inclusive opportunities and family engagement are maximized.

<table>
<thead>
<tr>
<th>Person Centered</th>
<th>Family Centered</th>
<th>Maximize Family Engagement</th>
<th>Inclusive</th>
<th>Follow a Behavioural Approach</th>
<th>Developmentally Informed</th>
<th>Empirically Supported</th>
</tr>
</thead>
<tbody>
<tr>
<td>A philosophy and a set of strategies aimed at promoting self-determination. It involves understanding each person’s specific context, dreams, and goals; and creating the conditions that will promote their achievement. It includes knowing what is important to the person and for the person and finding the right balance between the two.</td>
<td>A philosophy and method of service delivery that recognizes parents as the experts on their child’s needs; promotes partnerships between parents and service providers; and supports the family’s role in decision making about services for their child. (Rosenbaum, King, Lay, King &amp; Evans, 1998; Shelton &amp; Stepanek, 1995; as cited by CanChild, 2002).</td>
<td>Family involvement and active participation leads to better child and family outcomes.</td>
<td>Ensure and develop appropriate supports and promote acceptance so that all individuals can actively participate in their community.</td>
<td>Promote skill building through the development of measurable and observable goals that are systematically evaluated.</td>
<td>Consideration is given to what is typical for an individual at their chronological age while goals and strategies are also consistent with the individual’s current level of functioning (developmental level).</td>
<td>The use of the best research evidence; professional experience and judgement; and values and preferences of the family and individual. (Sackett, Straus, Rosenberg, &amp; Haynes, 2000 as cited by the National Autism Center)</td>
</tr>
</tbody>
</table>

**Indicators for Teen and Young Adult Services:**

<table>
<thead>
<tr>
<th>Potential evidence includes some or all of the following:</th>
<th>Potential evidence includes some or all of the following:</th>
<th>Potential evidence includes some or all of the following:</th>
<th>Potential evidence includes some or all of the following:</th>
<th>Potential evidence includes some or all of the following:</th>
<th>Potential evidence includes some or all of the following:</th>
<th>Potential evidence includes some or all of the following:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual consent (signature on service plan)</td>
<td>Individual consent</td>
<td>Individual has signed informed consent</td>
<td>Individual attends team meetings</td>
<td>Other family members are invited and encouraged to participate.</td>
<td>Signed informed consent</td>
<td>Ongoing communication between family and team (e.g. TNAC, email, phone)</td>
</tr>
<tr>
<td>Individual attends team meetings</td>
<td>Individual participates in setting goals (goals should be written from the</td>
<td>Individual consent (signature on service plan)</td>
<td>Individual attends team meetings</td>
<td>Other family members are invited and encouraged to participate.</td>
<td>Signed informed consent</td>
<td>Ongoing communication between family and team (e.g. TNAC, email, phone)</td>
</tr>
<tr>
<td>Individual participates in setting goals (goals should be written from the</td>
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<td>Potential evidence includes some or all of the following:</td>
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</tr>
<tr>
<td>Service plans contain information on community activities that individual participates in</td>
<td>Service plan contains goals that will support community inclusion</td>
<td>Service plan contains goals that support generalization of skills across</td>
<td>Service plans contain information on community activities that individual participates in</td>
<td>Service plan contains goals that will support community inclusion</td>
<td>Service plan contains goals that support generalization of skills across</td>
<td>Service plans contain information on community activities that individual participates in</td>
</tr>
<tr>
<td>Learning objectives are clearly defined; can be directly observed; contain measurable objectives; and are appropriately measured</td>
<td>Program plans have a data collection system including graphs that is used to inform decision-making.</td>
<td>Service plans contain information on community activities that individual participates in</td>
<td>Service plan contains goals that will support community inclusion</td>
<td>Service plan contains goals that support generalization of skills across</td>
<td>Service plans contain information on community activities that individual participates in</td>
<td>Service plans contain information on community activities that individual participates in</td>
</tr>
<tr>
<td>✓ motor skills</td>
<td>✓ sensory processing</td>
<td>✓ visual processing</td>
<td>✓ play</td>
<td>✓ motor skills</td>
<td>✓ sensory processing</td>
<td>✓ visual processing</td>
</tr>
</tbody>
</table>

- We actively look to the research and apply it to our clinical practice (document)
- Highly educated staff with specialized training in ASD (documented in HR files)
- Professional development is actively pursued

Appendix C: Excerpt from Philosophical Framework
Note. CQL’s POST = Council on Quality and Leadership’s Personal Outcome Screening Tool; HR = Human Resources; MPOC = Measure of Processes of Care; PRT/DTT = Pivotal Response Treatment/Discrete Trial Teaching; TNAC = Technology North ActiveCare.

Appendix D: Anonymous Survey Questions

My name is Jackie Ryan and this research project, Leading the Way to Promoting Self-Determination of Individuals with ASD, is part of the requirement for a Master’s Degree in Leadership at Royal Roads University. The research includes this survey and is estimated to take 15 to 45 minutes to complete, depending on the level of detail you wish to provide. The information you provide will be summarized, in anonymous format, in the body of the final report. At no time will any specific comments be attributed to any individual. All data received will be kept confidential.

Your completion of this survey will constitute your informed consent.

I confirm that I have read the Information Letter that provides detail of the research (please tick)

1. After reading the PowerPoint slides containing an overview of the findings and the summary of findings from the staff focus group and interviews with independent adults with ASD, has your perspective on self-determination of people with ASD changed? If so, how?

2. Based on the information in overview and summary of findings, and on your personal experience, what are some strategies that could be used to help promote self-determination for individuals with ASD?

3. Do you think the Centre is ready to implement changes like these? If not, what needs to happen first?
Appendix E: Email of Invitation to Focus Groups

Subject: Invitation to Participate in Focus Group about Self-Determination

[Date]

Dear [Prospective Participant],

I would like to invite you to be part of a research project that I am conducting. This project is part of the requirement for my Master’s Degree in Leadership, at Royal Roads University.

In order to create an environment where consent can be given freely, I have asked my colleague from Royal Roads University [colleague’s name] to provide third party assistance.

The objective of my research project is to identify how the Centre for Autism Services Alberta (the Centre) can become a leader among autism service providers in Canada in promoting self-determination of people with autism spectrum disorder.

Your name was chosen as a prospective participant because you work with teens and adults at the Centre.

This phase of my research project will consist of a focus group, estimated to last two hours. The focus group will take place on either January 19, 2016 or January 27, 2016 at 6:30 p.m. at the Centre for Autism Services Alberta, [Address]. NW, Edmonton.

The attached document contains further information about the study conduct and will enable you to make a fully informed decision on whether or not you wish to participate. Please review this information before responding.

You are not required to participate in this research project. If you do choose to participate, you are free to withdraw at any time without prejudice. I realize that due to our collegial relationship, you may feel compelled to participate in this research project. Please be aware that you are not required to participate and, should you choose to participate, your participation would be entirely voluntary. If you do choose to participate, you are free to withdraw without prejudice. If you do not wish to participate, simply do not reply to this request. Your decision to not participate will also be maintained in confidence. Your choice will not affect our relationship or your employment status in any way.

Please feel free to contact me at any time should you have additional questions regarding the project and its outcomes.

If you would like to participate in my research project, please contact my RRU colleague at:
Name: [Colleague’s Name]
Email: [Colleague’s Email Address]
Telephone: [Colleague’s Telephone Number]

Sincerely,  
Jackie Ryan
Appendix F: Research Information Letter for Staff

**Project Title:** Leading the Way to Promoting Self-Determination of Individuals with Autism Spectrum Disorder

My name is Jackie Ryan, and this research project is part of the requirement for a Master’s Degree in Leadership at Royal Roads University (RRU). My credentials with Royal Roads University can be established by contacting Dr. Brigitte Harris, Director, School of Leadership Studies: [email address] or [telephone number].

**Purpose of the study and sponsoring organization**

The purpose of my research project is to identify how the Centre for Autism Services Alberta can become the leader among autism service providers in Canada in promoting self-determination of people with autism spectrum disorder.

**Your participation and how information will be collected**

The research will consist of two focus groups and up to ten interviews with independent adults with ASD. Both methods will use open-ended questions. Each focus group is anticipated to last 2 hours. The anticipated questions for the first focus group include your experience with individuals with ASD exercising self-determination, how you may have contributed, what you think might be barriers to self-determination and what might help overcome those barriers. The second focus group will focus on identifying strategies that would help promote self-determination for individuals with ASD, taking into account the stories of self-determined adults with ASD.

**Benefits and risks to participation**

Potential benefits to participation include the opportunity to contribute to setting the direction for the Centre as regards self-determination for individuals with ASD. The Centre may benefit from your participation by having strategies for increasing self-determination with people with ASD. Individuals with ASD may benefit from your participation by becoming more self-determined. Potential risks include lack of confidentiality of information provided by you or other participants and feeling pressured to participate due to our working relationship. These will be mitigated by use of a third party to recruit participants and facilitate the focus groups, use of a third-party transcriptionist to transcribe and anonymize the audio recording. I will not have any information as to who the participants are for the focus groups, who responded to the invitation, who did not respond to the invitation, nor who was selected to participate. The transcriptionist for the focus groups will work with the third party to transcribe the audio recording. I will only receive a written, anonymized copy of the recording.
Inquiry team

My inquiry team consists of a colleague from RRU, who will recruit participants for and facilitate the focus groups, a transcriptionist, the Executive Team, and an independent adult with ASD. My inquiry team will assist in pilot testing focus group and interview questions, and review my data analysis to assist in managing researcher bias. The Executive Team and independent adult with ASD will only have access to anonymized data.

Real or Perceived Conflict of Interest

As a Director of the Centre, I may be perceived to have undue influence over a staff member’s ability to not participate in this research. For this reason, a third party will be used to both recruit for and facilitate the focus groups. I will have no information as to who participated, nor who chose not to participate. I disclose this information here so that you can make a fully informed decision on whether or not to participate in this study.

Confidentiality, security of data, and retention period

I will work to protect your privacy throughout this study. All information I collect will be maintained in confidence with hard copies stored in a locked filing cabinet in my home office. Staff consent forms will be stored in a locked filing cabinet in my colleague’s home office. Electronic data (such as transcripts or audio files) will be stored on my password protected laptop computer. Focus group audio files will be stored by my RRU colleague on a password-protected computer. Information will be audio recorded and, where appropriate, summarized, in anonymous format, in the body of the final report. At no time will any specific comments be attributed to any individual unless specific agreement has been obtained beforehand. All documentation will be kept strictly confidential. I will not have access to the audio recordings of the focus groups. Data will be retained for two years after the publication of my thesis. Transcripts will be shredded. Audio recordings will be deleted. Due to the nature of group processes, if you choose to withdraw after either focus group, it will not be possible to remove your information. As well, due to the nature of the group process, it will not be possible to keep your comments anonymous from the facilitator or other participants, although they will be kept anonymous from the researcher. Participants are asked to respect the confidential nature of the research by not sharing names or identifying comments outside of the group.

Sharing results

In addition to submitting my final report or thesis to Royal Roads University in partial fulfillment for a Master’s degree in Leadership, I will also be sharing my research findings with the Centre for Autism Services Alberta. My thesis will be published through the Thesis Canada Portal of Library and Archives Canada, and ProQuest/UMI and will be publically accessible. I
may also submit abstracts to leadership or other appropriate conferences or articles for publication to appropriate journals.

**Procedure for withdrawing from the study**

You may withdraw from this study at any time without prejudice. To withdraw, please contact the appropriate recruiter (my RRU colleague). If either focus group has already taken place, it will not be possible to remove your data.

You are not required to participate in this research project. By signing the in-person consent form, you indicate that you have read and understand the information above and give your free and informed consent to participate in this project.

Please keep a copy of this information letter for your records.
Appendix G: Research Information Letter for Staff (Survey)

Project Title: Leading the Way to Promoting Self-Determination of Individuals with Autism Spectrum Disorder

My name is Jackie Ryan, and this research project is part of the requirement for a Master’s Degree in Leadership at Royal Roads University (RRU). My credentials with Royal Roads University can be established by contacting Dr. Brigitte Harris, Director, School of Leadership Studies:

[Email address] or [telephone number].

Purpose of the study and sponsoring organization

The purpose of my research project is to identify how the Centre for Autism Services Alberta can become the leader among autism service providers in Canada in promoting self-determination of people with autism spectrum disorder.

Your participation and how information will be collected

I am inviting you to participate in an anonymous survey, which is the final stage of data collection. This follows a staff focus group and six interviews with independent adults with ASD. The survey consists of 3 open-ended questions. The purpose of the survey is to explore attitudes about self-determination of people with ASD and on identifying strategies that would help promote self-determination for individuals with ASD. Finally, the survey explores perceptions related to the Centre’s readiness for change.

Benefits and risks to participation

Potential benefits to participation include the opportunity to contribute to setting the direction for the Centre as regards self-determination for individuals with ASD. The Centre may benefit from your participation by having strategies for increasing self-determination with people with ASD. Individuals with ASD may benefit from your participation by becoming more self-determined. Potential risks include feeling pressured to participate due to our working relationship. These will be mitigated by use of a third party to administer the survey. I will not have any information as to who the participants are for the survey. I will only receive a written, anonymized copy of the responses.

Inquiry team

My inquiry team consists of a colleague from RRU, who will recruit participants for and facilitate the focus group, a transcriptionist, the Executive Team, and an independent adult with ASD. My inquiry team will assist in pilot testing focus group and interview questions, and
review my data analysis to assist in managing researcher bias. The Executive Team and independent adult with ASD will only have access to anonymized data.

**Real or Perceived Conflict of Interest**

As a Director of the Centre, I may be perceived to have undue influence over a staff member’s ability to not participate in this research. For this reason, a third party will be used to administer the survey, collect responses, and anonymize the responses. I will have no information as to who participated, nor who chose not to participate. I disclose this information here so that you can make a fully informed decision on whether or not to participate in this study.

**Confidentiality, security of data, and retention period**

I will work to protect your privacy throughout this study. All information I collect will be maintained in confidence with hard copies stored in a locked filing cabinet in my home office. Electronic data (such as survey responses) will be stored on the administrator’s password protected computer. Information, where appropriate, will be summarized, in anonymous format, in the body of the final report. At no time will any specific comments from the survey be attributed to any individual. All documentation will be kept strictly confidential. Data will be retained for two years after the publication of my thesis.

**Sharing results**

In addition to submitting my final report or thesis to Royal Roads University in partial fulfillment for a Master’s degree in Leadership, I will also be sharing my research findings with the Centre for Autism Services Alberta. My thesis will be published through the Thesis Canada Portal of Library and Archives Canada, and ProQuest/UMI and will be publically accessible. I may also submit abstracts to leadership or other appropriate conferences or articles for publication to appropriate journals.

**Procedure for withdrawing from the study**

As this survey is anonymous, you will not have the ability to withdraw after you have submitted your survey to the survey administrator, Director of Human Resources.

You are not required to participate in this research project. By ticking the consent box on the survey, you indicate that you have read and understand the information above and give your free and informed consent to participate in this project.

Please keep a copy of this information letter for your records.
Appendix H: Recruitment Flyer for Independent Adults with ASD

Invitation to Participate
Leading the Way to Promoting Self-Determination of Individuals with Autism Spectrum Disorder

Are you an independent adult with autism spectrum disorder or Asperger’s syndrome?
Would you be willing to talk about your experience of self-determination?

The Centre for Autism Services Alberta is sponsoring a study to identify new practices to promote the self-determination of individuals with autism spectrum disorder.

Self-determination is, “people controlling their own lives and their own destinies” (Wehmeyer & Schwartz, 1998, p. 76). Greater self-determination is linked with higher quality of life in individuals, including those with autism spectrum disorder (Shogren, Wehmeyer, Palmer, Rifenbark & Little, 2015; Wehmeyer, 1999; and Wehmeyer and Schwartz, 1998).

Why: To determine ways for the Centre for Autism Services Alberta to promote the self-determination of people with autism spectrum disorder ASD.

Who: Independent adults with ASD (or Asperger’s syndrome)

What: Participate in a 30 to 45 minute interview to share your stories related to your own self-determination. What has helped you to be self-determined? What has hindered your self-determination?

How: Interviews can take place face-to-face in a location that is comfortable for you, or through email, or via Skype. Reasonable expenses to participate may be reimbursed (e.g. parking costs).

For more information contact:
Jackie Ryan, Master of Arts in Leadership Student at [Email Address]

www.centreforautism.ab.ca [Address] [Phone Number]
Appendix I: Research Consent Form – Focus Group

By signing this form, you agree that you are over the age of 18 and have read the information letter for this study. Your signature states that you are giving your voluntary and informed consent to participate in this project.

☐ I consent to participate in the focus group

☐ I consent to the audio recording of the focus group

☐ I commit to respect the confidential nature of the focus group by not sharing identifying information about the other participants

Name: (Please Print): ____________________________________________

Signed: _____________________________________________________________

Date: ______________________________________________
Appendix J: Research Consent Form – Interview

By signing this form, you agree that you are over the age of 18, are an independent adult (i.e. no guardianship order exists), and have read the information letter for this study. Your signature states that you are giving your voluntary and informed consent to participate in this project.

☐ I consent to be interviewed

☐ I consent to the audio recording of the interview

Name: (Please Print): _____________________________________________________________

Signed: ________________________________________________________________

Date: ____________________________________________________________________
Appendix K: Inquiry Team Member Letter of Agreement (Executive Team)

In partial fulfillment of the requirement for a Master of Arts in Leadership Degree at Royal Roads University, Jackie Ryan (the Student) will be conducting an inquiry research study at the Centre for Autism Services Alberta (the Centre) to explore how the Centre can become the leader among autism service providers in Canada in promoting self-determination of people with autism spectrum disorder. The Student’s credentials with Royal Roads University can be established by calling Dr. Brigitte Harris, Director, School of Leadership, at [telephone number] or email [email address].

Inquiry Team Member Role Description

As an Inquiry Team Member assisting the Student with this project, your role may include one or more of the following: providing advice on the relevance and wording of questions, and reviewing analysis of data, to assist the Student and the Centre’s organizational change process. In the course of this activity, you may be privy to confidential inquiry data.

Confidentiality of Inquiry Data

In compliance with the Royal Roads University Research Ethics Policy, under which this inquiry project is being conducted, all personal identifiers and any other confidential information generated or accessed by the inquiry team advisor will only be used in the performance of the functions of this project, and must not be disclosed to anyone other than persons authorized to receive it, both during the inquiry period and beyond it. Recorded information in all formats is covered by this agreement. Personal identifiers include participant names, contact information, personally identifying turns of phrase or comments, and any other personally identifying information.

Bridging Student’s Potential or Actual Ethical Conflict

In situations where potential participants in a work setting report directly to the Student, you, as a neutral third party with no supervisory relationship with either the Student or potential participants, will be asked to work closely with the Student to bridge this potential or actual conflict of interest in this study. Such requests may include asking the Inquiry Team Advisor to produce written transcripts of the focus groups with all personal identifiers removed before the transcripts are brought back to the Student for the data analysis phase of the study and to produce written transcripts of the interviews.

This strategy means that potential participants with a direct reporting relationship will be assured they can confidentially turn down the participation request from their supervisor (the Student), as this process conceals from the Student which potential participants chose not to participate or simply were not selected by you, the third party, because they were out of the selection criteria range (they might have been a participant request coming after the number of participants sought, for example, focus group number 11 when only 10 participants are sought). Inquiry Team members asked to take on such 3rd party duties in this study will be under the direction of the Student and will be fully briefed by the Student as to how this process will work, including
specific expectations, and the methods to be employed in conducting the elements of the inquiry with the Student’s direct reports, and will be given every support possible by the Student, except where such support would reveal the identities of the actual participants.

Personal information will be collected, recorded, corrected, accessed, altered, used, disclosed, retained, secured and destroyed as directed by the Student, under direction of the Royal Roads Academic Supervisor.

Inquiry Team Members who are uncertain whether any information they may wish to share about the project they are working on is personal or confidential will verify this with Jackie Ryan, the Student.

**Statement of Informed Consent:**

I have read and understand this agreement.

__________________________________________   ___________________   __________
Name (Please Print)     Signature     Date
Appendix L: Inquiry Team Member Letter of Agreement (Independent Adult with ASD)

In partial fulfillment of the requirement for a Master of Arts in Leadership Degree at Royal Roads University, Jackie Ryan (the Student) will be conducting an inquiry research study at the Centre for Autism Services Alberta (the Centre) to explore how the Centre can become the leader among autism service providers in Canada in promoting self-determination of people with autism spectrum disorder. The Student’s credentials with Royal Roads University can be established by calling Dr. Brigitte Harris, Director, School of Leadership, at [telephone number].

Inquiry Team Member Role Description

As an Inquiry Team Member assisting the Student with this project, your role may include following: providing advice on the relevance and wording of questions, and reviewing analysis of data, to assist the Student and the Centre’s organizational change process. In the course of this activity, you may be privy to confidential inquiry data.

Confidentiality of Inquiry Data

In compliance with the Royal Roads University Research Ethics Policy, under which this inquiry project is being conducted, all personal identifiers and any other confidential information generated or accessed by the inquiry team advisor will only be used in the performance of the functions of this project, and must not be disclosed to anyone other than persons authorized to receive it, both during the inquiry period and beyond it. Recorded information in all formats is covered by this agreement. Personal identifiers include participant names, contact information, personally identifying turns of phrase or comments, and any other personally identifying information.

Inquiry Team Members who are uncertain whether any information they may wish to share about the project they are working on is personal or confidential will verify this with Jackie Ryan, the Student.

Statement of Informed Consent:

I have read and understand this agreement.

_________________________  ____________________________  _______________________
Name (Please Print)  Signature  Date
Appendix M: Inquiry Team Member Letter of Agreement (Colleague)

In partial fulfillment of the requirement for a Master of Arts in Leadership Degree at Royal Roads University, Jackie Ryan (the Student) will be conducting an inquiry research study at the Centre for Autism Services Alberta (the Centre) to explore how the Centre can become the leader among autism service providers in Canada in promoting self-determination of people with autism spectrum disorder. The Student’s credentials with Royal Roads University can be established by calling Dr. Brigitte Harris, Director, School of Leadership, at [telephone number].

Inquiry Team Member Role Description

As a volunteer Inquiry Team Member assisting the Student with this project, your role will include the following: inviting participants to the focus groups, supporting the logistics of the data-gathering methods, including facilitating focus groups, taking notes, ensuring that the session is audio recorded, transmitting the audio recording to the transcriptionist securely, and answering any questions from the transcriptionist to facilitate anonymous transcription, to assist the Student and the Centre’s organizational change process. In the course of this activity, you may be privy to confidential inquiry data.

Confidentiality of Inquiry Data

In compliance with the Royal Roads University Research Ethics Policy, under which this inquiry project is being conducted, all personal identifiers and any other confidential information generated or accessed by the inquiry team advisor will only be used in the performance of the functions of this project, and must not be disclosed to anyone other than persons authorized to receive it, both during the inquiry period and beyond it. Recorded information in all formats is covered by this agreement. Personal identifiers include participant names, contact information, personally identifying turns of phrase or comments, and any other personally identifying information.

Bridging Student’s Potential or Actual Ethical Conflict

In situations where potential participants in a work setting report directly to the Student, you, as a neutral third party with no supervisory relationship with either the Student or potential participants, will be asked to work closely with the Student to bridge this potential or actual conflict of interest in this study. Such requests may include asking the Inquiry Team Advisor to: send out the letter of invitation to potential participants, receive letters/emails of interest in participation from potential participants, independently make a selection of received participant requests based on criteria you and the Student will have worked out previously, formalize the logistics for the data-gathering method, including contacting the participants about the time and location of the focus groups, conduct the focus groups with the selected participants (without the Student’s presence or knowledge of which participants were chosen) using the protocol and questions worked out previously with the Student, and producing written transcripts of the focus groups with all personal identifiers removed before the transcripts are brought back to the Student for the data analysis phase of the study.
This strategy means that potential participants with a direct reporting relationship will be assured they can confidentially turn down the participation request from their supervisor (the Student), as this process conceals from the Student which potential participants chose not to participate or simply were not selected by you, the third party, because they were out of the selection criteria range (they might have been a participant request coming after the number of participants sought, for example, focus group number 11 when only 10 participants are sought). Inquiry Team members asked to take on such 3rd party duties in this study will be under the direction of the Student and will be fully briefed by the Student as to how this process will work, including specific expectations, and the methods to be employed in conducting the elements of the inquiry with the Student’s direct reports, and will be given every support possible by the Student, except where such support would reveal the identities of the actual participants.

Personal information will be collected, recorded, corrected, accessed, altered, used, disclosed, retained, secured and destroyed as directed by the Student, under direction of the Royal Roads Academic Supervisor.

Inquiry Team Members who are uncertain whether any information they may wish to share about the project they are working on is personal or confidential will verify this with Jackie Ryan, the Student.

**Statement of Informed Consent:**

I have read and understand this agreement.

_________________________  __________________________  ______
Name (Please Print)         Signature                  Date
Appendix N: Focus Group Questions

Merriam-Webster defines self-determination as “free choice of one’s own acts or states without external compulsion” (Self-determination, 2015). Simply put, self-determination is controlling one’s own life without undue influence of others.

1. Do you agree with this definition? Why or why not? If not, how would you change it?
2. Do you think individuals with autism spectrum disorder are capable of self-determination? Why or why not?
3. What are some strategies you have used or are aware of having been used at the Centre that promote self-determination?
4. What do you think gets in the way of self-determination for individuals with ASD?
5. Is there anything else we should know about this topic?
Appendix O: Interview Questions

1. How would you define self-determination?
2. Do you consider yourself self-determined? Why or why not?
3. Do you think it is important to be self-determined? Why or why not?
4. Tell me about a time when you were exercising self-determination. What factors contributed to your ability to be self-determined? What kind of supports, if any, helped you to be self-determined?
5. Were there, or are there still, barriers to your self-determination? What assumptions do you think others make about your ability to be self-determined?
6. What do you think gets in the way of self-determination for some individuals with ASD? How do you think we might be able to overcome those issues?
7. What are some strategies that could be used to help promote self-determination for individuals with ASD who would like assistance? What are some specific skills that could promote self-determination?
8. Is there anything else I should know about your experience of self-determination?
Appendix P: Survey Participants Project Overview

Figure P1. Introductory slide.

Figure P2. Main inquiry question.
The remainder of the slides summarize information from the first focus group and six interviews with independent adults with ASD. Pseudonyms are used when quoting.

Presented by: Jackie Ryan

Figure P3. Setting the context for the research.

Guiding Questions – First Focus Group

Preamble: Merriam-Webster defines self-determination as “free choice of one’s own acts or states without external compulsion” (Self-determination, 2015). Simply put, self-determination is controlling one’s own life without undue influence of others. [Note: we all make decisions with the input from others which is “influence”, “undue influence” refers to taking power away when the individual does not want it taken away]

1. Do you agree with this definition? Why or why not? If not, how would you change it?
2. Do you think individuals with autism spectrum disorder are capable of self-determination? Why or why not?
3. What are some strategies you have used or are aware of having been used at the Centre that promote self-determination?
4. What do you think gets in the way of self-determination for individuals with ASD?
5. Is there anything else we should know about this topic?

Figure P4. Focus group questions.
Emerging Themes – Mental Models

- Uncertain of ability of individuals with ASD to be self-determined at the start of the focus group, with a shift towards the end recognizing a continuum of self-determination.
- Proxy decision-making (guessing what behaviour means)
- Is there a conflict between the behaviour perspective and self-determination?

Figure P5. Focus group themes.

Mary – single with ASD

“and another thing is sometimes people seem to assume that because I was on the autism spectrum I might not be able to become independent but - but then I, then that sometimes made me determined to want to prove them wrong.”

Figure P6. An excerpt from Mary’s interview.
Interviews - Guiding Questions

1. How would you define self-determination?
2. Do you consider yourself self-determined? Why or why not?
3. Do you think it is important to be self-determined? Why or why not?
4. Tell me about a time when you were exercising self-determination. What factors contributed to your ability to be self-determined? What kind of supports, if any, helped you to be self-determined?
5. Were there, or are there still, barriers to your self-determination? What assumptions do you think others make about your ability to be self-determined?
6. What do you think gets in the way of self-determination for some individuals with ASD? How do you think we might be able to overcome those issues?
7. What are some strategies that could be used to help promote self-determination for individuals with ASD who would like assistance? What are some specific skills that could promote self-determination?
8. Is there anything else I should know about your experience of self-determination?

Figure P7. Interview questions.

Overarching Themes – Adults with ASD

- Mindfulness, awareness, open-mindedness (of others and self)
- Dichotomy of the Label – both helpful and limiting
- Decisions, choices, options, independence (opportunities for)
- Self-confidence
- Supportive environments

Figure P8. Overarching themes from interviews.
Figure P9. Individual and internal barriers.

- Lack of self-confidence
- Lack of motivation
- Stress
- Anxiety and depression
- Inability to effectively communicate support needs or advocate for support needs
- Feeling powerless
- Traumatizing to report story again and again

Figure P10. An excerpt from Aidan’s interview.

“I am a deli manager with Save-On...Yeah. I actually burnt myself out. I’m on a stress leave right now because of work pressures. The job does not suit my strengths. There’s just too much human interaction and what-not ...”
Barriers – Individual or Internal

- Extra mental energy required to understand social situations (“brain like Google”, search for previous experience to apply to current situation)
- Extra energy to “guide people to do their jobs”
- Extra energy to educate people about ASD
- Lack of support/positive example from parents forced some individuals to become independent (sink or swim)

*Figure P11. Individual and internal barriers (continued).*

Barriers – Systemic or External

- Lack of support networks
- Judgemental people
- Unfriendly environments (too much stimuli)
- Lack of understanding of the impact of over-stimulation
- Overreliance on pharmacological solutions
- Lack of financial supports

*Figure P12. Systemic or external barriers.*
Barriers – Systemic or External

- Eligibility criteria for services (excludes individuals who need support) and shifting criteria
- Gatekeepers
- Misalignment of resources (e.g. homeless and housed in a motel paid by government but not given money towards renting a home)
- Professionals lack of knowledge about ASD, Asperger’s

Figure P13. Systemic or external barriers (continued).

Janine – single mom

“I have a two- and a three-year-old. Um, my three-year-old has exhibited ... she has an iron deficiency, which I found out last July. She's exhibited, uh, complaints about her legs hurting. So we've seen doctors, and they've, uh, have, uh, concluded that it's an iron deficiency. She has restless legs syndrome. So I took her to the Stollery, and asked for advocacy, because I had Asperger’s, and I would like a social worker and a nurse present, because I can't multi-task with a two- and a three-year-old in the room. What they turned that into was I had a mental health issue. They put me in Mental Health. They took my kids away. Because they don't understand Asperger’s or autism. They think it is a mental health issue. So there's a lot of problem in this city with knowledge.”

Figure P14. An excerpt from Janine’s interview.
Barriers – Systemic or External

- Mental health system and classification, lack of understanding of ASD
- Lack of appropriate dental care/medical care
- Financial – low income as well as challenges managing personal finances
- Inaccurate information being given to people with ASD (e.g. how much can be earned while on AISH, Assured Income for the Severely Handicapped)
- Fear of losing AISH and reapplication process

Figure P15. Systemic or external barriers (continued).

Matthew – single man, lives with mother

“I am fairly active in Autism Edmonton’s Aspires Housing Committee, ... that led me to, with the assistance of one of the other parents on the committee, start this housing pilot project that I have now ironically found myself having to abandon because of various setbacks it’s experiencing in the overall goals of becoming reality.” “Autism Independent Living Association ... is an association that I formed strictly to provide supports [to the pilot project]. ... I hope that I will still be able to take advantage of some of those supports that it will offer its residents, even though I won’t be there, just because there are no other agencies around that will actually do the kind of support work that was my founding vision”

Figure P16. An excerpt from Matthew’s interview.
Barriers – Systemic or External

- Transportation
- Lack of post-secondary educational opportunities
- Lack of access to legal advice
- Time-limited supports

Figure P17. Systemic or external barriers (continued).

Enablers – Individual or Internal

- Mentors
- Self-help books
- Personal development courses
- Support network
- Exposure to opportunities
- Having someone who believes in you and encourages you
- Being accepted

Figure P18. Individual or internal enablers.
"Context is everything. Context first. Remember the context, context is important. Context is where we live. It changes, and it's fluid, and you can't create a rule to help an ASD person. You can create a rule of how to find context, and then have a friend they can call and just say, "I'm in this context. What do I do?" That's the closest you can get to a hard rule, though, in my understanding."

Figure P19. An excerpt from André’s interview.

- Having goals and a desire to contribute
- Confidence
- Stable home base
- Flexibility
- Mindfulness

Figure P20. Individual or internal enablers (continued).
“Right now I would say, it’s really important to me to have a stable home base, to which I can retreat if necessary. Growing up in a stable home and having a supporting wife is definitely a big factor in being able to maintain self determination.”

Figure P21. An excerpt from Kevin’s interview.

Enablers – Systemic or External

- Job-carving
- Employer-sponsored initiatives for co-worker support of people with ASD
- Flexibility
- Mindfulness
- Volunteer work

Figure P22. Systemic or external enablers (continued).
Emerging Strategies – Individual or Internal

- Teach skills for self-advocacy
- Stable home base, a place where they are comfortable
- Teach communication skills
- Teach stress management skills
- Training in social situations
- Figure out individual’s interests/strengths and work from there.

Figure P23. Individual or internal emerging strategies.

Emerging Strategies – Systemic or External

- “Nothing about us without us”
- More advocacy groups
- Collective education of the community about autism
- Public awareness
- Workplace accommodations
- Job-carving
- Stable home base, a place to be comfortable

Figure P24. Systemic or external emerging strategies.
## Appendix Q: Summary of Findings from Focus Group and Interviews

<table>
<thead>
<tr>
<th>Topic</th>
<th>Individual (Internal)</th>
<th>Systemic (External)</th>
</tr>
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<tbody>
<tr>
<td>**Enablers of self-</td>
<td>• Mentors • Self-help books • Personal development courses • Support networks •</td>
<td>• Job-carving • Employer initiatives to train co-workers about ASD • Flexibility</td>
</tr>
<tr>
<td>determination**</td>
<td>Exposure to opportunities • Having someone who believes in you • Having someone</td>
<td>• Mindfulness • Volunteer work</td>
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<td>who encourages you • Acceptance by others • Having goals • Having a desire to</td>
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<td></td>
<td>contribute • Confidence • Stable home base • Flexibility • Mindfulness</td>
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<td>**Barriers to self-</td>
<td>• Lack of self-confidence • Lack of motivation • Stress • Anxiety and depression</td>
<td>• Lack of support networks • Judgmental people • Over-stimulating environments</td>
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<td>determination**</td>
<td>• Inability to effectively communicate support needs • Inability to effectively</td>
<td>• Lack of understanding of the impact of over-stimulation • Over-reliance on</td>
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<td>advocate for support needs • Feeling powerless • Trauma associated with retelling</td>
<td>pharmaceutical solutions • Lack of financial supports • Eligibility criteria for</td>
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<td></td>
<td>story • Extra mental energy required to understand social situations • Extra</td>
<td>services exclude some who need support • Shifting criteria for services cause</td>
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<td></td>
<td>energy required to explain supports one is entitled to • Extra energy to educate</td>
<td>confusion • Gatekeepers • Perceived misalignment of resources (rigid rules can</td>
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<tr>
<td></td>
<td>people about ASD</td>
<td>cause more expensive solutions than necessary)</td>
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### Topic

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<tr>
<th>Individual (Internal)</th>
<th>Systemic (External)</th>
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<tr>
<td>• Lack of positive example from parents</td>
<td>• Professionals (e.g. dentists, family physicians, lawyers) lack knowledge of ASD</td>
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<td></td>
<td>• Mental health system lacks knowledge of ASD</td>
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<td>• Lack of appropriate dental and medical care</td>
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<td>• Financial – low income and challenges managing personal finances</td>
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<td>• Difficulty navigating and understanding rules such as AISH eligibility and employment</td>
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<td>• Fear of losing AISH and the reapplication process</td>
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<td>• Lack of public transportation</td>
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<td>• Lack of post-secondary educational opportunities</td>
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<td>• Fear of losing financial supports</td>
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<td>• Time limited supports</td>
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### Potential strategies to promote self-determination

<table>
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<tr>
<th>Individual (Internal)</th>
<th>Systemic (External)</th>
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<tr>
<td>• Teach skills of self-advocacy</td>
<td>• “Nothing about us without us”</td>
</tr>
<tr>
<td>• Ensure a stable home base, where the individual is comfortable</td>
<td>• More advocacy groups</td>
</tr>
<tr>
<td>• Teach communication skills</td>
<td>• Collective education of the community about ASD</td>
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<tr>
<td>• Teach stress management skills</td>
<td>• Increase public awareness</td>
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<tr>
<td>• Provide training in social situations</td>
<td>• Provide workplace accommodations</td>
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<tr>
<td>• Work from an individual’s interests and strengths</td>
<td>• Job-carving</td>
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<td>• Ensure a stable home-base for individuals</td>
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Appendix R: Project Presentation for Staff Meeting

Master’s Thesis Project

Leading the Way to Promoting Self-Determination of Individuals with Autism Spectrum Disorder

Jackie Ryan, Master of Arts in Leadership Student
Royal Roads University

Figure R1. Introductory slide.

Main Question

How can the Centre become the leader among autism service providers in Canada in promoting self-determination of people with autism spectrum disorder (ASD)?

Figure R2. Main inquiry question.
Centre’s Strategic Plan – Core Values

- We value access to supports, services and resources across the full autism spectrum and lifespan
- We embrace person-centred and family-centred practices
- We value meaningful participation of all individuals in every aspect of society
- We believe in the right to individual choice and self-determination
- We value collaboration with all stakeholders
- We are dedicated to continuous quality improvement
- We value accountability and transparency
- We engage in open and honest communication

Figure R3. The Centre’s core values.

Centre’s Strategic Plan – Selected Key Directions

- Deliver services across the lifespan.
- Continue building quality programs and services
- Build an operational model that supports self-determination and independence.

Figure R4. Overview of the Centre’s key directions.
• Programs and services meet the unique needs of each stage of life
• Continue to build and grow a high quality program and service delivery:
  • Cultivate a culture of...lifelong learning
  • Increase opportunities to participate and engage in applied research
• Develop transitional supports to enable successful community inclusion and maximize autonomy:
  • Encourage independence for clients

Figure R5. Overview of the Centre’s key strategies.

• Organizational Change Project (focused on Teen and Adult Services)
• Action Research (a form of applied research)
  • Inquiry Process
  • Appreciative Stance
  • Community Based Participatory Research
  • Qualitative Research
  • Multiple methods

Figure R6. Overview of the study.
Self-Determination

- Self-determination has been defined as “people controlling their own lives and their own destinies” (Wehmeyer & Schwartz, 1998, p. 76).
- Greater self-determination is linked with higher quality of life in individuals, including those with autism spectrum disorder (Shogren, Wehmeyer, Palmer, Rifenbark & Little, 2015; Wehmeyer, 1999; and Wehmeyer & Schwartz, 1998)

Figure R7. Defining self-determination.

Why this? Why now?

My AHA Moment:

Came during a conversation with another mother of a son with ASD.

How can I know what is in my son’s heart? How can I ensure that he has a life that he wants and not one imposed upon him by others? And further, how can I help others with the same questions?

Figure R8. The impetus for this research.
• Two focus groups (non-management staff who support teens and/or adults with ASD)
  • Management staff will have opportunities to participate in other stages of the project.
• Up to 10 interviews (independent adults with ASD)

*Figure R9. The inquiry methods applied in this research.*

• Between 6 and 10 non-management staff who work with teens and adults with ASD and can attend both focus groups.
• First group will examine current perceptions and/or practices that support or hinder the self-determination of people with ASD.
• Second group will take place after the interviews and will explore and identify novel practices that the Centre could implement that would support self-determination of individuals with ASD.

*Figure R10. Overview of focus group session.*
Figure R11. How confidentiality was maintained within the research project.

Figure R12. Explanation of participation within this inquiry.
LEADING TOWARD SELF-DETERMINATION

**Figure R13.** Overview of the interviews.

- Up to 10 independent adults with ASD
- Independence ensures participants are able to give informed consent
- To explore adults’ with ASD lived experiences with self-determination
  - What can we learn from their experiences?
  - How can we apply that to our practice?

**Figure R14.** Overview of the interviews (continued).

In a scoping review of the literature, Jivraj, Sacrey, Newton, Nicholas and Zwaigenbaum (2014) found:

- only seven studies that were described as partnerships between researchers and individuals with intellectual disability and of those,
- only two focused on individuals with ASD and reported partner involvement throughout the entire research process.
- Community Based Participatory Research
Objectives

- To add to the work of the few researchers who have made it a priority to include people with ASD as partners.
- To make recommendations of strategies and practices to implement at the Centre that will support self-determination of individuals with ASD.

Figure R15. Research objectives.

Selected Benefits

- The Centre may benefit by becoming a leader in promoting self-determination
- The researcher may benefit by being granted a Master’s Degree in Leadership
- The researcher may benefit by gaining access to enhanced opportunities as a researcher/scholar

Figure R16. The benefits resulting from this research.
References


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*Figure R17. Works cited within this presentation.*
Appendix S: Research Information Letter for Independent Adults with ASD

**Project Title:** Leading the Way to Promoting Self-Determination of Individuals with Autism Spectrum Disorder

My name is Jackie Ryan, and this research project is part of the requirement for a Master’s Degree in Leadership at Royal Roads University (RRU). My credentials with Royal Roads University can be established by contacting Dr. Brigitte Harris, Director, School of Leadership Studies: [email address] or [telephone number].

**Purpose of the study and sponsoring organization**

The purpose of my research project is to identify how the Centre for Autism Services Alberta can become the leader among autism service providers in Canada in promoting self-determination of people with autism spectrum disorder.

**Your participation and how information will be collected**

The research will consist of two focus groups and up to ten interviews with independent adults with ASD. Both methods will use open-ended questions. The interviews are anticipated to last between thirty and forty-five minutes. The anticipated questions include your experience with being self-determined; factors that you think may have contributed to your self-determination; what you think might be barriers to self-determination and what might help overcome those barriers; and identifying strategies that would help increase self-determination for individuals with ASD.

**Benefits and risks to participation**

Potential benefits to participation include the opportunity to contribute to setting the direction for the Centre as regards self-determination for individuals with ASD. The Centre may benefit from your participation by having strategies for increasing self-determination with people with ASD. Other individuals with ASD may benefit from your participation by becoming more self-determined. Potential risks include becoming tired during the interview. You may request a break or end the interview at any time.

**Inquiry team**

My inquiry team consists of a colleague from RRU, who will recruit participants for and facilitate the focus groups, a transcriptionist, the Executive Team, and an independent adult with ASD. My inquiry team will assist in pilot testing focus group and interview questions, and review my data analysis to assist in managing researcher bias. The Executive Team and independent adult with ASD will only have access to anonymized data.
Real or Perceived Conflict of Interest

N/A.

Confidentiality, security of data, and retention period

I will work to protect your privacy throughout this study. All information I collect will be maintained in confidence with hard copies (e.g., consent forms) stored in a locked filing cabinet in my home office. Electronic data (such as transcripts or audio files) will be stored on my password protected laptop computer. Information will be audio recorded and, where appropriate, summarized, in anonymous format, in the body of the final report. At no time will any specific comments be attributed to any individual unless specific agreement has been obtained beforehand. Any information that is shared with my inquiry team (e.g. for assistance with data analysis) will be anonymized. All documentation will be kept strictly confidential. Data will be retained for two years after the publication of my thesis. Transcripts will be shredded. Audio recordings will be deleted.

Sharing results

In addition to submitting my final report or thesis to Royal Roads University in partial fulfillment for a Master’s degree in Leadership, I will also be sharing my research findings with the Centre for Autism Services Alberta. My thesis will be published through the Thesis Canada Portal of Library and Archives Canada, and ProQuest/UMI and will be publically accessible. I may also submit abstracts to leadership or other appropriate conferences or articles for publication to appropriate journals.

Procedure for withdrawing from the study

You may withdraw from this study at any time until April 5, 2016, which is two months prior to submission date of my final report, without prejudice. To withdraw, please contact the recruiter.

You are not required to participate in this research project. By signing the in-person consent form, you indicate that you have read and understand the information above and give your free and informed consent to participate in this project.

Please keep a copy of this information letter for your records.