

Amplifying Autistic perspectives: Learning from and with Autistic adults to support their
autonomy

by

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ABSTRACT

Self-determination enhances a person's quality of life and is a fundamental human right. Yet, Autistic individuals experience fewer opportunities for self-determination than their non-autistic peers, including peers with other developmental disabilities. This is often due to professionals exerting external control over Autistic individuals, especially those with co-occurring intellectual disabilities. However, some professionals are striving to support self-determination for Autistic people. While research about the lived experiences of Autistic people is increasing research on the lived experience of Autistic people with intellectual disabilities (ID) remains limited. Intellectual disability should not affect an Autistic young adult's ability to be self-determined but will affect the level of support the person needs. Autistic people and autism researchers have both proposed that including Autistics in research as collaborators or co-researchers can enhance the relevance of autism research, support the self-determination of Autistic individuals, and improve their quality of life. According to Self-Determination Theory, autonomy is one of three basic psychological needs that must be met for someone to experience self-determination.

This work is comprised of five chapters, including an introductory chapter, three manuscripts that represented independent research with integrated learnings to support self-determination, and a discussion/conclusion chapter. Each project in the three manuscripts was conducted using a community based participatory research (CBPR) approach. A CBPR approach with Autistic people enhances self-determination by ensuring that the research is relevant to the Autistic community, attending to social inequalities, and by increasing the knowledge and skills of the Autistic partners. The first manuscript describes the development of *Research 101, Effective Collaborators* to enhance the ability of Autistic people to participate in research as co-

researchers. The second manuscript investigates what autonomy means to Autistic adults with ID and how they want to be supported to be autonomous. The third manuscript explores how staff at an autism service provider support autonomy for the Autistic participants with ID and what knowledge, skills, and abilities they and the Autistic participants need to promote greater autonomy.

This dissertation contributes new knowledge on supporting Autistic people, including those with ID, to be more self-determined. This work has implications for researchers, professionals, clinicians, disability support workers, and other autism practitioners. This work contributes to methodological and ethical discussions about conducting research with Autistic adults with ID.

Keywords: autism, autonomy, self-determination, intellectual disability, Autistic, participatory research

PREFACE

This thesis is the original work by Jacalyn Gowin Ryan. The research project, of which this thesis is part, received research ethics approval from the University of Alberta Research Ethics Board, *Research 101 “Effective Collaborator” Training Development: Increasing Autistic Adults' Engagement in Participatory Autism Research*, PRO00119538, May 17, 2022. The research project, of which this thesis is part, received research ethics approval from the University of Alberta Research Ethics Board, *Understanding autonomy and autonomy-support from the perspective of Autistic people with intellectual disabilities: Community based participatory research to enhance self-determination*, PRO00103146, Nov 18, 2020.

DEDICATION

This work is dedicated to the Quest for Independence program participants, particularly, Justin, Kent, Lily, Peter, Lamont, Dax, Brody, and Gabe (all pseudonyms), who participated in this study. It was a joy to spend time with you and to learn from you! You are all terrific young adults and so much fun.

“If you're always trying to be normal, you will never know how amazing you can be.”

- Maya Angelou

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care of our home when we went overseas, you provided company for Sean when I was too busy. Sean, you are the inspiration for this work. I know there were days when you would have rather had me than my research. You've had tough days as we figure out what adulthood is going to be like for you which keeps me looking for solutions. Andrew, you are the love of my life. Without you, this journey would not have been possible.

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CHAPTER ONE – Introduction

Situating Myself in the Research

I was initially inspired to explore self-determination for Autistic people when a friend expressed a desire to know what her non-speaking Autistic son truly wanted for his life. I have an Autistic son with an intellectual disability (ID), and I had the same desire. This desire led me to study self-determination for Autistic people during my master's program completed in 2016 (Ryan, 2016). During this time, I was diagnosed as Autistic which made the exploration of self-determination even more relevant. After all, I had every opportunity to be self-determined and I wondered what limits I may have faced had I been diagnosed earlier in my life. My Autistic son was nearing the end of high school and we were trying to figure out what was next for him. Although my son speaks, he has a difficult time expressing his inner thoughts, and thinking about the future. So how could we learn what he wanted for his adult life?

In the fall of 2017, I read an article on autonomous goal setting with this sentence “we noted many statements that suggested that professionals felt that the Autistic adolescents were not able to identify ‘appropriate’ or ‘correct’ goals” (Hodgetts et al., 2018). I was intrigued and immediately wondered what we could do to change that perception. I met with the author of the paper, Dr. Hodgetts, who is now my doctoral supervisor. I initially thought that my studies would focus on creating a tool to assist professionals to involve Autistic adolescents and young adults in setting their own goals. As is usual in the doctoral process, I am told, my final research evolved to learning from Autistic adults with ID about what autonomy means to them and how they wanted to be supported to be autonomous.

I intended to use a participatory approach and I sought the opportunity to learn from an experienced participatory autism researcher. This led to a study abroad term in the DART Lab at

the University of Edinburgh, during which I had the opportunity to co-create, co-pilot, co-evaluate, and revise Research 101 training for Autistic people with Prof Sue Fletcher-Watson. This revised training was the starting point for the *Research 101, Effective Collaborators* training project, which we decided to incorporate into my thesis because we believe that it aligns well with self-determination, and it is one step towards equipping Autistic people with the knowledge and skills to be recognized as active agents and experts in matters that relate to their lives.

Philosophical Orientation

This work is conducted within a constructivist paradigm, which aims to understand phenomena and the construction of the social world through the subjective view of participants (Ponterotto, 2005). Ontologically, this means that I believe that there are multiple constructed realities and that this work presents just one possibility (Ponterotto, 2005). Epistemologically, I believe that reality is socially constructed, and a result of the interaction between researcher and participant. In other words, the understandings garnered in this dissertation were co-created by me, the participants, and the ACP. I also brought a critical autism perspective in which I attempted to attend to the imbalance of power between researchers and participants, with the goals of emancipation and advancing new, enabling narratives of autism (Davidson & Orsini, 2013). Finally, the axiology to which I ascribe is that the researcher's values and lived experience cannot be separated from the research process (Ponterotto, 2005).

Literature Review

Next, I will explore six key topics to further situate the three studies that comprise this dissertation: (1) community based participatory research with the Autistic community, (2) a neurodiversity, human rights perspective of autism, (3) autonomy and self-determination theory and (4) approaches to include perspectives of Autistic adults with ID, (5) current approaches to

support autonomy for Autistic adults with ID and (6) creating autonomy supportive environments. This chapter ends by identifying the research problem and research objectives.

Community Based Participatory Research with the Autistic Community

Autistic self-advocates have expressed frustration with the lack of inclusion of Autistic individuals in autism research (Nicolaidis et al., 2011). Autistic people are not usually recognized as experts on autism; a scoping review found only two instances where Autistic people were involved as partners in participatory autism research (Jivraj et al., 2014). Pellicano, Dinsmore and Charman (2014) found that autism researchers were reluctant to engage the Autistic community in research due to differences in priorities, challenges with communication, the diversity of views within the community, and the perception that disputes were unlikely to be resolved. Community based participatory research (CBPR) is an action research approach “committed to conducting research that will benefit the participants either through direct intervention or by using the results to inform action for change” (Israel et al., 1998, p. 175).

CBPR’s nine principles are: (1) community is a unit of identity, (2) build on strengths and resources in the community, (3) collaborative and equitable involvement of all parties in all phases of the research (4) integrate knowledge and action for mutual benefit of all partners, (5) promote a co-learning and empowering process that attends to social inequalities, (6) cyclical and iterative process, (7) address health from both positive and ecological perspectives, (8) involve all partners in disseminating findings and new knowledge, and (9) is a long-term commitment by all partners (Israel et al., 2001). The Autistic community is a geographically dispersed community for which a growing number of technological platforms can facilitate collaboration (Nicolaidis et al., 2011). There is a need to increase the involvement of Autistic individuals in research to enhance the relevance of autism research, to support the self-

determination of Autistic individuals, and to improve their quality of life. This involvement is critical as “action research is emancipatory; it leads not just to new practical knowledge but also to new abilities to create knowledge” (Bradbury & Reason, 2008, p. 227). CBPR is one action research approach to enhance the involvement of Autistic people and increase their self-determination. We included five Autistic community partners on our research team as described below.

Positionality of Autistic Community Partners

The research team included five Autistic community partners, HB, AB, CD, AK, and AL. HB is an Autistic professor who researches thriving and belonging for Autistic people. AB is an Autistic person, a parent of an Autistic child, and an advocate for child and disability rights for people of all abilities. CD is an Autistic Registered Social Service Worker who has just completed a second Bachelor's degree in Disability Studies and Psychology. AK is an Autistic Linguist who has found a calling caring for Autistic people with higher needs than my own. AK is also a student, a caregiver, and an advocate on a daily basis, often using language, paralinguage, and physical communication to help people who need it. AL is an Autistic university alumnus with a Bachelor's degree in computer science. Their unique perspectives greatly benefitted this research.

Autism: A Neurodiversity, Human Rights Perspective

DSM: Helpful or Harmful?

Autism Spectrum Disorder, according to the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text revision (DSM-5-TR), is a life-long neurodevelopmental disorder manifested by “deficits in social-emotional reciprocity, ... deficits in nonverbal communicative behaviors used for social interaction, ... deficits in developing, maintaining, and understanding

relationships, ... and restricted, repetitive patterns of behavior, interests or activities” (American Psychiatric Association, 2022). Fletcher-Watson and Happé (2019) acknowledged that “although we know autism has a genetic foundation, leading to neurobiological differences, ... no reliable biological marker has been found” (p. 30). Therefore, autism is diagnosed behaviourally using the criteria in the DSM-5-TR¹ (American Psychiatric Association, 2022). But is this descriptor helpful or harmful?

The first edition of the DSM was released in 1952 as a new classification system of mental disorders to formalize and standardize nomenclature of psychopathological conditions (Kawa & Giordano, 2012). In the first two editions, autism appears only in the descriptions of Schizophrenia, childhood type (Kawa & Giordano, 2012). The third edition, DSM-III, represented “an attempt to re-medicalize American psychiatry” (Kawa & Giordano, 2012, p. 5). The DSM-III impacted psychiatric practice, research, and teaching including rejuvenating American governmental and pharmaceutical companies’ funding of related research (Kawa & Giordano, 2012), and was the first edition in which autism appears as a separate diagnosis, Infantile Autism. The next three versions expanded the number of disorders under the umbrella of autism (Barahona-Corrêa & Filipe, 2016) and finally, the most recent edition, DSM-5 and its text revision, DSM-5-TR, collapsed the other disorders back into a single diagnosis, Autism Spectrum Disorder (American Psychiatric Association, 2022).

While not publicly acknowledged by the American Psychiatric Association, each revision of the DSM has been politically influenced (Kawa & Giordano, 2012). For example, political influence was demonstrated by the gay community’s successful advocacy for the removal of homosexuality from the third edition of the DSM (Rosenberg, 2002). The development of the

¹ Other manuals exist, such as the International Classification of Diseases, but for the purposes of this thesis I will only refer to the DSM-5.

fifth edition of the DSM “was the newly organized Autistic community’s first opportunity to weigh in on the criteria that governed who the medical community considered Autistic” (Kapp & Ne’eman, 2020, p. 169). The DSM-5’s proposed Autism Spectrum Disorder diagnostic criteria was significantly changed due to lobbying by the Autistic Self-Advocates Network, including removal of “recovery criteria” that was proposed by the Workgroup, reframing of the severity scale to support needs, and removal of “fixated interests” from the restricted and repetitive behaviours domain (Kapp & Ne’eman, 2020).

Noted historian of medicine Charles Rosenberg (2002) stated, “Everywhere we see specific disease concepts being used to manage deviance, rationalize health policies, plan health care, and structure specialty relationships with the medical profession” (p. 238). The presence of autism in the DSM-5-TR lends credibility to the notion of treatment and normalization (Gillespie-Lynch et al., 2017). This has led to an industry of autism pseudoscience including chelation, hyperbaric oxygen therapy, omega-3 fatty acids supplementation, and Miracle Mineral Supplement protocol, all of which can be harmful, both physically and financially (Thyer, 2019). Some evidence-based treatments such as Applied Behavioural Analysis (ABA), have been criticized by Autistic adults as harmful (Kapp et al., 2013; Kupferstein, 2018; Orsini, 2012). ABA gained popularity with the publication of Lovaas’s 1987 study in which he reported that “47% of the experimental group achieved normal intellectual and educational functioning” (p.7) and that “school personnel describe these children as indistinguishable from their friends” (p. 8) giving rise to the notion that Autistic people could and should be made to look more neurotypical. Many Autistic adults consider ABA an intervention to teach Autistic people to pass as neurotypical (Fletcher-Watson & Happé, 2019). Camouflaging comes at great cost to Autistic people including physical and mental exhaustion, depression, anxiety, and potentially, suicidal

ideation (Cage & Troxell-Whitman, 2019; Raymaker et al., 2020). Furthermore, Autistic adults condemn the suppression of self-stimulatory behaviour (stimming) as removing an important coping or regulatory skill (Kapp et al., 2019). These impacts, if left unmitigated, can have life-long negative impacts on the quality of life of Autistic people.

A Neurodiversity Perspective

The concept of neurodiversity grew out of an online discussion group of Autistic people in 1996 and simply means that all human minds are different in much the same way humanity has ethnic, gender, and other diversities (Dekker, 2023; Walker & Raymaker, 2020). The term neurodivergent was coined in 2000 by Kassiane Asasumasu, a multiply neurodivergent neurodiversity activist, and refers to having a mind that differs significantly from what society has deemed to be ‘normal’ (Walker, 2014). The neurodiversity movement is a civil rights movement that advocates for the rights of neurodivergent people using a framework that values the full constellation of differences (Kapp, 2020) and acknowledges both the strengths and challenges of being Autistic (Robertson, 2009). In fact, Autistic individuals, including Autistic researchers, consider some of the DSM-5-TR deficits associated with autism to be strengths. For example, the criteria of “restricted, repetitive patterns of behaviour, interests, and activities” (American Psychiatric Association, 2022) is viewed as a strength when considered as hyper focus that allows an Autistic person to remain engaged in an activity of interest or solving a problem of interest as explicated by the monotropism theory of autism (Murray & Lawson, 2005).

Milton’s (2012) Double Empathy Problem (DEP) posits that challenges with social communication and interaction are caused by both neurodivergent and neurotypical parties lacking an understanding of the other’s social norms. That is, the challenge does not only lie

within the Autistic person, but within the non-autistic communication partner as well. Crompton, et al. (2020) provided empirical evidence for the DEP through an experiment utilizing a “diffusion chain paradigm” (p.5) that found there was no difference in the transfer of information in chains of Autistic people, or in chains of neurotypical people; both chains experienced a similar rate of decline. However, they found a steeper decline in information transferred in mixed chains of Autistic and neurotypical people (Crompton et al., 2020). This would suggest that the challenge with social communication is a two-way problem wherein neurotypical individuals have difficulty understanding Autistic people and Autistic individuals have difficulty understanding neurotypical people (Milton, 2012). Milton’s DEP also suggests that Autistic people benefit from opportunities for social relatedness with other Autistic people.

Autonomy and Self-Determination Theory

Self-Determination

According to Merriam-Webster.com, self-determination is the “free choice of one’s own acts or states without external compulsion” (n.d.). 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). Self-determination enhances quality of life, including for Autistic individuals (Carter et al., 2013; Denney & Daviso, 2012; Shogren et al., 2015; Wehmeyer, 1999, 2015; Weiss & Riosa, 2015). However, Autistic individuals have lower levels of self-determination than their non-autistic peers, including peers with other developmental disabilities (e.g., Chou et al., 2016; Hodgetts et al., 2018; Nonnemacher & Bambara, 2011; Weiss & Riosa, 2015). Autistic individuals with ID are the least self-determined (Cheak-Zamora et al., 2020).

Self-Determination Theory

According to Deci and Ryan (1985), self-determination is “the capacity to choose and to have those choices, rather than reinforcement contingencies, drives, or any other forces or pressures, be the determinants of one's action” (p. 38). Deci and Ryan’s self-determination theory (SDT) posits that all people, including people with disabilities, have three basic psychological needs (autonomy, competence, and relatedness), that when satisfied lead to self-determination and wellbeing (2017). The satisfaction of a single need can have a positive impact toward the satisfaction of the other two needs (Ryan & Deci, 2017). Additionally, “When there is support for autonomy, people are also more able to seek out and find satisfactions for both competence and relatedness, as well” (Ryan & Deci, 2017, p. 247). Next, I review the three basic psychological needs.

Competence.

Competence refers to the feeling of mastery and accomplishment. Perceived competence can be negatively impacted when considering autism only within the medical model of disability, which describes autism based on deficits. Koegel and Mentis (1985) argued that deficits associated with autism may expose Autistic individuals to frequent failure and high levels of noncontingent reinforcement, which may lead to learned helplessness and extremely low motivation (p. 190). Instead, they recommended reinforcing observable attempts to increase motivation and improvements in learning and competence (Koegel & Mentis, 1985). However, rather than the use of reinforcement or evaluative praise, Ryan and Deci (2017) recommended the use of positive informational praise to facilitate internalization of motivation as competence is achieved. That is, the use of external rewards such as tangibles or evaluative praise can change behaviour in the short term but will have a long-term negative impact on motivation. Further,

according to Ryan and Deci's mini theory of Cognitive Evaluation, introducing extrinsic rewards for an activity that is already intrinsically motivated, can cause the activity to become viewed as being externally controlled, decreasing a sense of autonomy, undermining intrinsic motivation and feelings of competence. Utilizing intense interests is a positive strategy to mitigate reliance on extrinsic rewards, thus avoiding amotivation. Amotivation contributes to poor performance in school, low self-esteem, and problem behaviours (Ryan & Deci, 2017).

Relatedness.

Relatedness refers to feelings of belonging and connectedness. According to the DSM-5-TR's diagnostic criterion of "persistent deficits in social communication and social interaction across multiple contexts" (American Psychiatric Association, 2022, p. 56) relatedness is an inherent challenge associated with autism. However, as noted earlier, Milton's DEP (2012) belies this assumption. Ryan and Deci (2000) hypothesized that relatedness promotes intrinsic motivation (p. 68). They also argued that 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 wants to be connected (Ryan & Deci, 2000). Autistic self-advocates advised caution when promoting neurotypical social skills with neurodivergent people so as to not suppress their natural self-regulatory tools (e.g. self-stimulatory behaviours) which can result in increased anxiety (e.g. Angulo et al., 2019; Milton, 2012; Robertson, 2009).

A key factor in achieving the positive effects of relatedness is autonomy. That is, both parties need to be in the relationship for autonomous reasons, rather than out of a sense of obligation (Ryan & Deci, 2017). "People are sensitive to evidence concerning whether others' interests in them are volitional" (Ryan & Deci, 2017, p. 302). I have had first-hand experiences of the consequences of inauthentic engagement of support staff with my son. He expresses

anxiety and dislike of being with that staff. Autonomy supportive partners can take the perspective of each other, conveying empathy and respect, thus strengthening the relationship, and leading to healthy interdependence (Ryan & Deci, 2017).

Autonomy.

Autonomy refers to the experience of an action as in accord with one's interests and values and is facilitated when the person is aware of their interests and needs (Ryan & Deci, 2017). Although autonomy has been defined as the freedom to make one's own choices (United Nations, 2006), it can encompass making a choice or decision with input from someone else as long as one agrees with the choice or decision made (Ryan & Deci, 2017). Autonomy is not synonymous with being independent, which according to Merriam-Webster.com (n.d.) means "not requiring or relying on others," nor "looking to others for one's opinions or for guidance in conduct." Within the context of this dissertation, we use autonomy as synonymous with volition which is defined as the "act or power of making one's own choices" (Merriam-Webster, n.d.).

Ryan and Deci's (2017) Goal Contents Theory (GCT) posits that intrinsic goals contribute to well-being of the individual whereas extrinsic goals lower an individual's well-being. Intrinsic goals are set by the individual and are usually developed in congruence with one's values whereas extrinsic goals are usually outwardly focused outcomes, such as money, fame, or power (Ryan & Deci, 2017). Extrinsic goals can be set by the individual but have been found to be less satisfying of the basic psychological needs. Further, GCT proposes that people whose basic psychological needs have been thwarted are more likely to set extrinsic goals to bolster their sense of worth (Ryan & Deci, 2017). Hodgetts et al., (2018) found that professionals, such as occupational therapists, speech language pathologists and educators, verbalized that they value autonomy, yet often did not include Autistic people in goal setting, or

did not support the goals they identified. Shogren and Shaw (2016) found that autonomy was an important factor for better quality of life outcomes in adulthood for individuals with disabilities. Yet, educators often exert more external control with students with disabilities instead of providing an autonomy-supportive environment (Ryan & Deci, 2017). “When there is support for autonomy, people are also more able to seek out and find satisfactions for both competence and relatedness, as well” (Ryan & Deci, 2017, p. 247).

Approaches to Include the Perspectives of Autistic Adults with ID

While there is a body of research that includes the perspectives of people with ID (e.g., Bigby et al., 2014; Frankena et al., 2015 & Schleien et al., 2013), this work is primarily based on those who communicate through verbal speech. While research about the perspectives of Autistic adults without ID is increasing (e.g., den Houting et al., 2020; Raymaker et al., 2020), it remains limited (Nicholas et al., 2019) and the lack of inclusion of Autistic adults with ID remains a significant gap. One reason for the gap is that qualitative research largely relies on focus groups and interviews which tend to exclude people who are unable to express their inner thoughts with verbal communication² (Nicholas et al., 2019). Nicholas et al. (2019) identified several promising methods for including Autistic people with ID and/or communication differences including (1) graphic or arts-based approaches to elicit perspectives from participants, (2) deep assessment, and (3) participant observation. Nicholas et al. (2019) argued for inclusion of a variety of approaches to represent the diversity of autism more fully.

Photovoice is an arts-based method typically used in participatory research, however the approach still relies on verbal communication to explain the photographs (Cheak-Zamora et al.,

² Verbal communication refers to communication using words which includes spoken and written words.

2016; Ha & Whittaker, 2016). Photovoice involves participants taking photographs that represent an issue important to them and to solve problems (Wang & Burris, 1997).

Talking Mats is a picture sorting activity that is useful for determining likes, dislikes, and in-between, however it often requires verbal communication for deeper meaning (Bunning et al., 2017). Pictures are sorted by the participant into three piles according to likes, dislikes, and in-between, usually on mats designed for this purpose (Germain, 2004). Likewise, deep assessment is particularly useful to determine likes and dislikes while not providing information about an individual's inner thoughts (Lyons et al., 2015). Deep assessment consists of three stages: (1) behaviour state observation, (2) triangulated proxy reporting, and (3) startle reflex modulation measurement (SRM; Lyons et al., 2015). Behaviour State Observation looks to determine an individual's readiness to engage and their optimal level of alertness, to ascertain the best time to engage with the individual (Lyons et al., 2015). Triangulated Proxy Reporting seeks authentic input from those who know the individual best and attempts to verify their reporting through direct observation (Lyons et al., 2015). Finally, SRM will provide confirmation (or not) of the results of the Triangulated Proxy Reporting (Lyons et al., 2015). SRM is a reliable measure of emotional valence in that a stronger eye blink is indicative of a more negative inner state and a weaker eye blink is more indicative of a pleasant inner state (Lyons et al., 2015).

Participant observation focuses on observing participants over a period of time, recording descriptions of the environment, including people and activities, and describing participants' emotional and affective responses (Raber et al., 2010). Observation usually takes place over multiple sessions of varying length to form an understanding of the participant (Raber et al., 2010). Raber (2010) used participant observation to determine preferences and interests of

people with dementia and noted that one must be attuned to the participant's behavioural expressions to gain the best understanding of the participant.

Approaches to Support Autonomy for Autistic Individuals with ID

Moran et al. (2020) conducted a systematic review of studies that implemented self-determination interventions with Autistic students. They found nine intervention studies that included Autistic students (Moran et al., 2020). Of the nine studies, two only included Autistic students without ID; three included Autistic students with ID but not all Autistic students had ID; in four studies it was not possible to discern if the Autistic students had ID or not (Moran et al., 2020). To the best of my knowledge, only one intervention has been specifically adapted for adults with ID, although not specifically for Autistic adults, the Self-Determined Learning Model of Instruction (SDLMI). The adapted version is the Self-Determined Career Development Model (Shogren et al., 2016).

Kuld et al. (2023) conducted a systematic review and meta-analysis of interventions to promote self-determination of people with severe or profound ID. Most of the studies were on interventions to enhance the individual's ability to make specific choices such as time delay and prompting, Picture Exchange Communication Systems, preference assessments, and microswitches, which the authors' concluded seemed to lack volition of the participant (Kuld et al., 2023). Studies in the review that were deemed to support the volition of the participants are discussed below.

Interventions for Individuals

SDLMI.

The SDLMI is an evidence based model of instruction designed to embed teaching of self-determination component elements within ongoing curricula (Hagiwara, 2020). Through

iterative processes of setting a goal, taking action, and adjusting the goal or plan, students develop component elements of self-determination (Raley et al., 2018). Component elements include (1) choice-making skills, (2) decision-making skills, (3) goal-setting skills, (4) problem solving skills, (5) planning skills, (6) goal attainment skills, (7) self-management skills, (8) self-awareness, (9) self-knowledge, and (10) self-advocacy skills (Shogren et al., 2017). Use of the SDLMI has been found to enhance self-determination (Moran et al., 2020).

Whose Future Is It?

Whose Future Is It (WF) is an evidence-based curriculum with 15 chapters in three themes: (1) Getting to Know Your Individual Education Plan (IEP), (2) Decisions and Goals, and (3) Your IEP Meeting (Shogren et al., 2018). The WF was designed to guide teachers in the teaching of specific self-determination skills to enable students to direct their transition planning process (Shogren et al., 2018). An earlier version of the curriculum, Whose Future Is It Anyway, was found to increase students' self-determination (Wehmeyer et al., 2011). Interestingly, the implementation of the SDLMI and the WF together was found to have a greater impact on student self-determination than either model alone (Shogren et al., 2020).

The Navigation of Social Engagement (NOSE) Model.

The NOSE model was designed to improve social problem solving skills and increase self-determination for Autistic students (Chou, 2020). It is a three phase intervention: (1) developing a logical sequence of steps, (2) applying the steps to vignettes, and (3) applying the steps to a scenario the student is likely to experience (Chou, 2020). A novel feature of NOSE is its use of the student's circle of support in all three phases (Chou, 2020). The NOSE model was found to increase self-determination in the Autistic junior high students participating in Chou's study.

Project TEAM (Teens Making Environment and Activity Modifications).

Project TEAM is a 12-week intervention that includes goal setting, a group curriculum, and peer mentoring (Kramer et al., 2018). The intervention was co-designed with young people with developmental disabilities (Kramer et al., 2018). The intervention was implemented in four schools and three community agencies and resulted in increases in self-determination as reported by participants and parents (Kramer et al., 2018).

Interventions Targeted at the Environment, Including People

Person-Centred Active Support (PCAS).

PCAS was developed in response to deinstitutionalization as a means to increase participation of individuals with severe disabilities (Murphy et al., 2017). It has been found to increase individuals engagement in meaningful activities and social relationships, have more contact with staff, have more social interactions with community members, have more opportunities for choice, and more likely to have their choices respected (Beadle-Brown et al., 2021). PCAS is an intervention to change staff behaviour in supporting individuals using four pillars: (1) every moment has potential, (2) little and often, (3) graded assistance, and (4) maximizing choice and control (Murphy et al., 2017).

Family Centered Transition Planning.

Hagner and colleagues (2012) introduced a three-component model for transition planning for Autistic youth transitioning from school to adult life. The first component involved group training with the families of the Autistic youth on person-centered planning (Hagner et al., 2012). The second component consisted of facilitated person-centered planning for each youth (Hagner et al., 2012). The third component comprised facilitator follow-up to assist families and

youth to enact their plan (Hagner et al., 2012). The intervention resulted in significant increases in self-reported self-determination (Hagner et al., 2012).

Miscellaneous Staff Training to Modify the Environment.

Chatterton (1999) trained nurses to adjust their communication with individuals with ID specific to the individual and to improve the general communication environment. Haakma et al. (2017) provided training to teachers to enable them to be more need-supportive (autonomy, competence, and relatedness) to increase student motivation and engagement. Ogletree et al. (2015) trained four support staff on how to support expressive communication of an adult with severe ID use of an AAC. All of these interventions were specifically designed for the specific environments of implementation.

Creating Autonomy-Supportive Environments

According to SDT, people with disabilities, including autism, will flourish more fully in an autonomy-supportive environment, yet professionals more often use controlling techniques (Ryan & Deci, 2017). This is despite research that shows that when professionals use autonomy-supportive techniques participants had more engagement and skill development (e.g. Cheon et al., 2020; Reeve, 2006; Shogren et al., 2012).

Staff who create autonomy-supportive environments use the following techniques: (1) listen carefully; (2) create opportunities for individuals to work in their own way; (3) praise signs of improvement and mastery; (4) encourage effort and persistence; (5) offer progress-enabling hints when individuals seem stuck; (6) respond to individuals' questions and comments; (7) communicate clear acknowledgement of individuals' perspective; (8) provide opportunities to talk; and (9) arrange the environment so individuals can manipulate objects and conversations rather than passively watch and listen (Reeve, 2006; Reeve et al., 1999; Reeve & Jang, 2006;

Ryan & Deci, 2017). Conversely, controlling behaviours include: (1) monopolizing the learning materials; (2) giving solutions before individuals have time to work on problems independently; (3) telling individuals the right answer without giving them time and opportunity to discover it; (4) giving demands and directives; (5) using 'should,' 'have to,' 'must,' and 'got to' statements; and (6) using controlling questions as a way of directing individuals' work (Reeve & Jang, 2006; Ryan & Deci, 2017). It is reasonable to hypothesize that these results would be similar in learning environments with Autistic adults (Ryan & Deci, 2017).

Research Rationale

Clearly, there is much work to be done to enhance the engagement of Autistic people in things that matter to them, including in autism research and in daily life experiences. More specifically, three problems provide a rationale for this research:

1. Autistic people have expressed a desire to participate in research as more than subjects; they also want to be collaborators or co-researchers (Chown et al., 2017; den Houting et al., 2020, 2022; Gillespie-Lynch et al., 2017; Kapp et al., 2019; Milton, 2014; Nicolaidis et al., 2011). However, most Autistic people outside of academia lack knowledge about research processes, which limits their ability to move from consultation to true partnership in research (Arnstein, 1969; den Houting et al., 2020; Fletcher-Watson et al., 2021). One way to increase the research literacy/knowledge of Autistic people is to provide direct training on research processes and collaboration (Fletcher-Watson et al., 2021). This was the first problem my research aimed to address.
2. Autistic people experience lower levels of self-determination than their non-autistic peers (Chou et al., 2016; Hodgetts et al., 2018; Nonnemacher & Bambara, 2011; Weiss & Riosa, 2015). Furthermore, according to caregiver report, Autistic individuals with ID are

even less self-determined than Autistic individuals without ID (Cheak-Zamora et al., 2020). This was the second problem my research aimed to address.

3. While research about the lived experiences of Autistic people is increasing (e.g., den Houting et al., 2020; Higgins et al., 2021; Raymaker et al., 2020, 2022), there remains limited literature regarding the lived experience of Autistic people with ID and almost no research that prioritizes their perspectives (Nicholas et al., 2019). This was the third problem my research aimed to address.

Objectives of this Research

In response to the above problems, this research had the following objectives:

1. To explore the perceived strengths, benefits and recommendations for changes related to a training program designed to enhance research literacy/knowledge of Autistic people from the perspective of Autistic adults.
2. To learn from Autistic people with ID what autonomy means to them and how they want to be supported to be autonomous.
3. To learn from staff of an autism service provider how they support autonomy for its Autistic participants with ID and what specific skills and abilities staff perceive that Autistic adults with ID need to enhance their autonomy.

Dissertation Structure

This work is comprised of (1) this introduction to the broad topics that informed this dissertations, as well as the research problems addressed, research objectives and dissertation structure, (2) three manuscripts as outlined below (chapters two-four), and (3) an integrated discussion, that address the three problems outlined above and are linked together by their focus on approaches that can support autonomy and self-determination for Autistic adults with ID.

In chapter two, I present the development and results from a series of pilot studies related to *Research 101, Effective Collaborators*. The development of this training program and qualitative descriptive study of perceived strengths, benefits and recommendations for changes addresses the lack of involvement of Autistic people in research that matters to them.

In chapter three, I present *Being able to be myself: Understanding autonomy and autonomy-support from the perspectives of Autistic adults with ID*. This study presents what autonomy means to Autistic adults with ID and how they want to be supported. It addresses the problem of lower levels of self-determination experienced by Autistic adults and contributes knowledge to increase their self-determination. It also addresses the problem of limited research that prioritizes the lived experiences and perspectives of Autistic people with ID.

In chapter four, I present “*It’s really who they are and what they want*”: *Staff perspectives on supporting autonomy for Autistic adults with ID*. This study presents strategies that professionals at one autism service provider used to support the Autistic participants’ autonomy, and what knowledge, skills, and abilities they and the Autistic participants needed to promote greater autonomy. It addresses the problem of lower levels of self-determination of Autistic adults and contributes new knowledge to support increased levels of self-determination.

Chapter five discusses and concludes the dissertation. Here, I attempt to integrate learnings across the presented studies and with existing literature. I present strengths and limitations of my work, and implications for supporting the involvement and self-determination of Autistic adults with ID in things that matter to them. Finally, directions for future research are presented.

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CHAPTER TWO – Research 101, Effective Collaborators: Co-design and evaluation of a training program to support participatory autism research³

INTRODUCTION

Autistic people and autism researchers have both proposed that including Autistics in research as collaborators or co-researchers can enhance the relevance of autism research, support the self-determination of Autistic individuals, and improve their quality of life (Chown et al., 2017; den Houting et al., 2020, 2022; Jivraj, 2014; Kapp et al., 2019; Milton et al., 2014; Nicolaidis et al., 2011). Participatory approaches to research aim to increase the quality of life for the affected community (Israel et al., 2012) and have become more common since the early 2000's, especially in research with minority communities (Macaulay, 2017). Participatory research holds great potential in autism research, yet it remains rare with the Autistic community. Autistic people are most frequently involved in consultative or advisory roles rather than in leadership or co-production roles (Cassidy et al., 2018; Fletcher-Watson et al., 2018; Jivraj et al., 2014; Milton, 2019; Pellicano et al., 2014a). This type of involvement means that Autistic people do not have any power to influence how or when the research is conducted, what the research is about, nor who is involved in the research (Fletcher-Watson et al., 2018).

Pellicano, Dinsmore and Charman (2014a) found that autism researchers were reluctant to engage the Autistic community in research due to differences in priorities, challenges with communication, the diversity of views within the community, and the perception that disputes were unlikely to be resolved. In particular, non-autistic autism researchers have expressed concerns that social communication disabilities make collaboration difficult (Hollin & Pearce, 2018; Pellicano et al., 2014a). The double empathy problem posits that social communication is

³ A version of this chapter will be submitted for publication with the following authors: J. Ryan, S. Thompson-Hodgetts, Heather M. Brown, A. Borden, C. Devlin, A. Kedmy, A. Lee, L. Hull, and S. Fletcher-Watson.

challenged between mixed neurotypes due to a mismatch of salience (Milton, 2012). That is, just as Autistic people have difficulty understanding the social communication of non-autistic people, non-autistic people are also challenged to understand the social communication of Autistic people (Milton, 2012). It is important to address and resolve the communication gap, rather than allow it to be a reason to limit collaboration. Using the double empathy model, the responsibility for resolving the differences lies with both non-autistic and Autistic people involved in a project (Milton, 2012).

Another identified barrier is that there is no singular agenda within the autism community⁴ (Pellicano et al., 2014a). Autistic people have become more vocal in the last decade about the mismatch between the traditional focus of autism research identified by non-autistic researchers, such as investigating causes for autism, versus research topics that Autistic people want and need to improve their quality of life (den Houting & Pellicano, 2019; Pearson et al., 2022; Pellicano et al., 2014b; Poulsen et al., 2022; Roche et al., 2021). Priority setting exercises can aid in setting a common research agenda. For example, Autistica, a UK autism charity, conducted a James Lind Alliance priority setting exercise (James Lind Alliance, 2021) with Autistic people, family members, and professionals to identify the top ten questions for autism research that represented all stakeholder groups (Cusack & Sterry, 2016). There is also a discrepancy between what researchers perceive to be the involvement of Autistic people and what Autistic people perceive as their involvement, leaving Autistic people feeling tokenized (Pellicano et al., 2014).

Limited guidance is available for autism researchers who wish to develop collaborations with Autistic people. However, some researchers have published guidelines for conducting

⁴ Autism community refers to Autistic people, non-autistic family members, researchers, professionals, and service providers whereas the Autistic community refers only to Autistic people.

research with the Autistic community (Chown et al., 2017; Fletcher-Watson et al., 2018, 2021; Nicolaidis et al., 2019). The Academic Autism Spectrum Partnership in Research and Education (AASPIRE) conducts action research to improve the lives of Autistic adults using community based participatory research (CBPR). AASPIRE has published practice guidelines for engaging Autistic people as partners in research, which include being clear about goals, having clearly defined roles, having processes for communication and power-sharing, focusing on building and maintaining trust, collaboratively disseminating findings, fairly compensating community partners, and building community capacity (Nicolaidis et al., 2019). Similarly, the Inclusive Practices for Neurodevelopmental Research guide (Fletcher-Watson et al., 2021) contains many actionable recommendations including setting clear expectations, including people with lived experience, having community-specific (e.g., Autistic) inclusion accommodations, including people with intersecting identities, empowering community partners, and up-skilling community partners.

Even with these new approaches, most Autistic people outside of academia lack knowledge about the research process, which also limits their ability to move from consultation to true partnership in research (Arnstein, 1969; den Houting et al., 2020). One of the reasons for the lack of knowledge is that enrolment rates in postsecondary education, a context in which people often learn about research, are low for Autistic people (Sansosti et al., 2017) and of those that enrol, only about 35% will graduate (Scheef et al., 2019). Participatory research becomes emancipatory when lay (e.g. Autistic) partners gain new knowledge and skills as a result of the project (Biggeri & Ciani, 2019).

One way to increase the research literacy/knowledge of Autistic people is to provide direct training on research processes. As such, a training course for Autistic people was

developed to support Autistic people to become effective collaborators in research (<http://dart.ed.ac.uk/research/learning-about-research/>). Having a shared understanding and vocabulary related to the research process is beneficial to research partnerships. Here, we aim to describe this training and present findings from a formative, pilot evaluation of the acceptability, feasibility, and appropriateness of the training, including perceived strengths and benefits of participation in this program, and recommendations for changes from the perspective of Autistic adults.

METHODS

Methodological Approach

This qualitative descriptive study (Sandelowski, 2000) used a CBPR approach throughout the process, consistent with the desires of the Autistic community (Chown et al., 2017; den Houting et al., 2020; Israel et al., 2010; Kapp et al., 2019). Although some interpretation inevitably occurs, we align with qualitative description as we stayed close to the data and were not highly interpretive or theoretical (Sandelowski, 2000). A CBPR approach enabled us to make the training relevant to Autistic people. Four Autistic Community Partners (ACP; AK, AL, AB, CD) and one Autistic Associate Professor (HB) were part of the research team. We fairly compensated the non-academic members of the ACP for their time. Our ACP were integral to the research process.

Development of Research 101, Effective Collaborators

The *Research 101, Effective Collaborators* training course was developed through an iterative process that engaged Autistic people within and outside of research and non-autistic researchers. We intended for participants in this course to understand the research process, what

being a collaborator in research means, and provide useful strategies for collaboration. Ethics approval was not sought at the initial stage, but the initial processes are outlined here.

Initially, an Autistic PhD student (JR) and an autism researcher (SFW) created a draft outline for training. The draft outline formed the basis of a marketing-style survey of Autistic people within and outside of research and non-autistic researchers to prioritize the proposed outline topics and suggest changes (see Tables 1 and 2). Then, the draft outline was updated and circulated for feedback from a selected sample of Autistic researchers to create the final outline. Initial training materials were then developed based on this outline. The initially developed program was informally piloted with seven Autistic adults who had varying experiences with participatory autism research. Feedback about the content, length, relevance, understandability, distribution of time between lectures and group work, was collected informally from these participants using Likert scales and open-ended questions. Participants were also asked about their confidence to participate as an effective collaborator in research and if there were any ways in which the training could be improved. Changes were made to the training based on these evaluations, including dividing the full-day 6-hour format into three 2-hour sessions, providing handouts prior to training sessions, adding structure to each training session by linking the content to the research process, and increasing the content on being a collaborator.

Draft Outline Topics	Included in Final Outline for Pilot
How long does it take to get ethics approval?	No*
What are the steps to get ethics approval?	Yes
What is grant funding and what restrictions come with grants?	Yes
What are key research terms and jargon?	Yes
What is meeting etiquette?	Yes
How to give and receive feedback.	Yes
Troubleshooting your collaboration.	Yes
How is data analyzed?	Yes

How are results and conclusions determined?	Yes
What is the publication and peer review process?	Yes
How is authorship determined?	Yes
What are common research careers and how do they affect the research process?	No*
How should I contact academics?	Yes
What is “Open Science” and why does it matter?	Yes
Open Answer Suggestions	
Research Integrity, data protection, confidentiality, etc.	Yes
Stages of research process	Yes
What is and isn’t within scope of research/researcher’s role	No
Examples of great collaborations	Yes
Establish the work dynamic at the beginning of the project, follow the principles of respect and fairness, and create it together.	Yes
Intersectionality	No
The messiness of research and good reflective/reflexive practice	Yes
The messiness of research and good reflective/reflexive practice	Yes
Developing research questions, operationalize key concepts/variables, etc.	Yes
Being paid for your time and how this can impact on benefits	Yes
General expectations (extension of meeting etiquette)	Yes

Table 1. Topics included in draft outline and their inclusion in the final outline. * These topics were excluded because they were rated of low importance.

Delivery Method	Included in Final Outline for Pilot
Lecture	Yes
Discussion	Yes
Small group activities	No
Individual activities	Yes
Role Play	No
Case studies	No
Panel presentations	Yes
Open Answer Suggestions	
E-learning/discussion	No
Pre-assigned readings	No
Asynchronous online forums	No
Whole group activities	Yes
Written handouts	Yes

Include non-speaking Autistic people and those with high support needs	No
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Table 2. Delivery methods and their inclusion in the pilot training.

The revised *Research 101, Effective Collaborators* training was then formally piloted with three groups of Autistic adults (n=17); two groups (n=7) were already involved in research as ACP and one group (n=10) was comprised of Autistic adults who were not yet involved in research. The two groups of ACP were in Edmonton, Canada, and the group of 10 were in Bristol, UK. JR led all training sessions, assisted by LH for the Bristol group and HB for the Edmonton groups. Training consisted of three, 2-hour, synchronous online sessions. Session topics included: (1) *introduction*, (2) *being a collaborator*, (3) *getting to the research question*, (4) *answering the research question*, (5) *practical details*, (6) *outcomes, publications, and implementation*, and (7) *next steps*. Breaks and time for discussion and questions were also integrated throughout each training session, as desired, for a total session length of two hours. See Table 3 for a summary of topics and learning objectives and Figure 1 for a sample of the original slides. The University of Alberta's Research Ethics Board 1 and the University of Bristol Ethics Committee approved this study.

Topic	Learning Objective	Length (minutes)
Session 1		
Introduction	Welcome, vision of the course, ground rules	30
Being a Collaborator	To gain understanding of working as a team, including the skills of working together, setting mutual expectations, conflict resolution techniques. To explore excellent examples of research partnerships	25
Research Process 1: Getting to the Research Question	To gain an understanding of the process from idea to research question, to getting funding including barriers to funding.	40

Session 2		
Research Process 2: Answering the Research Question	To understand the research process, opportunities within the process for collaboration, and the steps within the process	45
Research Process 3: Practical Details	To understand the details of implementing a project from hiring staff, applying for ethics, participant recruitment, data management, and problem solving	40
Session 3		
Outcomes, Publications, and Implementation	To gain an understanding of where and how research gets published, who or what determines authorship, and how does research become practice or policy.	45
Next Steps	To learn practical ways to connect with researchers to become collaborators.	40

Table 3. Topics and learning objectives

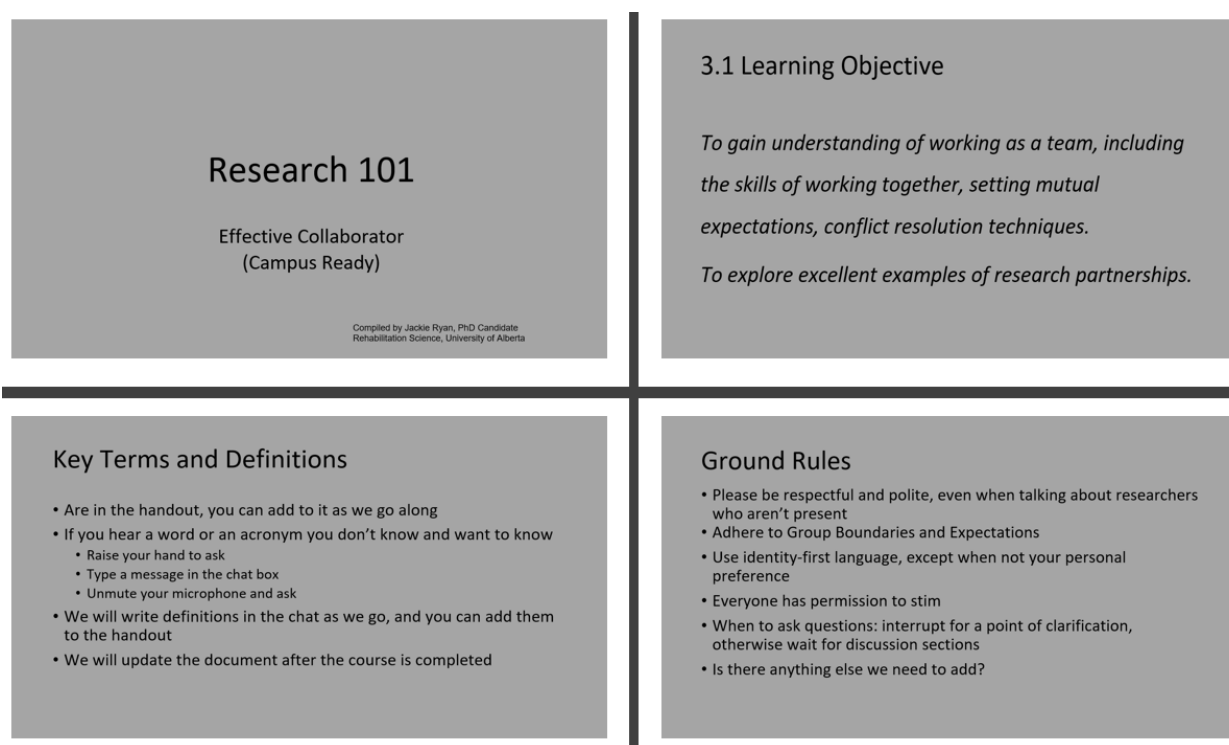


Figure 1. Sample of original slides

Recruitment

We invited trainees to participate in the research via email following each completed three-session training. JR emailed the research invitations to the seven trainees in Edmonton, Canada and LK emailed the research invitations the 10 trainees in Bristol, UK. Trainees were given the options of attending a focus group or having an individual interview to discuss perceived strengths and benefits of, as well as weaknesses and recommended adjustments for, the training. Invitees who chose to participate emailed JR (Edmonton) or LH (Bristol) to let them know of their interest. Importantly, trainees did not have to agree to participate in the research project to participate in the training.

Participants

Seven out of the 10 trainees in Bristol agreed to participate and seven out of seven ACP trainees in Edmonton agreed to participate, for a total of 14 participants. All participants identified as Autistic and were capable of actively participating in the training without external support. We did not collect other demographic information from participants.

Data Collection

Participants were interviewed individually (n=10) or in a group (n=4), with LH conducting the focus group and three interviews in Bristol and JR conducting seven interviews in Edmonton. The focus group and interviews were all conducted online. Guiding questions are in Appendix 5. Several questions were closed ended and we encouraged interviewees to expand upon their initial response. We audio-recorded and transcribed verbatim all interviews.

Data analysis

Data analysis, guided by Braun and Clarke's (2019) six-stage approach to thematic analysis, involved an iterative process of coding and theme development. Initially, two authors

(JR, STH) read all transcripts multiple times, and coded each transcript line by line. Then, they compiled codes into preliminary themes (n=3) and sub-themes (n=10). These initial themes and sub-themes were then reviewed and agreed upon by two additional team members (LH, SFW). Finally, these themes and subthemes were reviewed and refined with the remaining team members, including the ACP (HB, AB, CD, AK, and AL), resulting in two themes and four subthemes.

RESULTS

We identified two themes, which addressed perceived benefits and strengths of, as well as pragmatic suggestions for, *Research 101, Effective Collaborators*. The first theme, **opportunities for connectivity**, reflects participants’ feedback of the perceived strengths and benefits of the training generally, which emphasized the perceived importance of connecting with other Autistic people. The second theme, **recommendations for program content and structure**, reflected participants’ pragmatic feedback about recommended concrete changes to the existing training, as well as options to tailor the training to different participant needs.

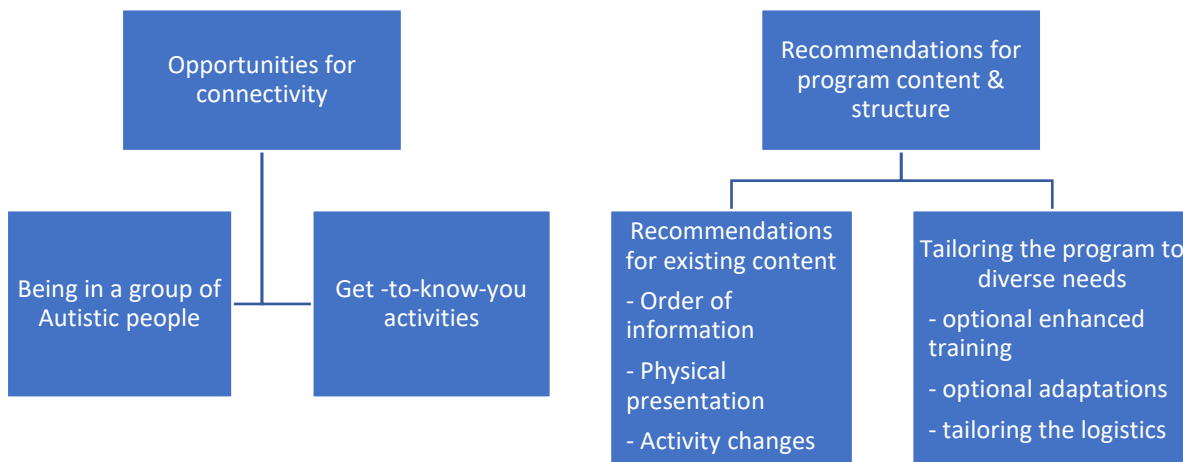


Figure 2. Themes and subthemes

Theme 1: Opportunities for connectivity

The first theme, **opportunities for connectivity**, includes participant feedback on being in a group of Autistic people and ‘get to know you’ activities. Overall, participants indicated that they *enjoyed being in a group of other Autistic people*. They appreciated that the training was developed specifically for Autistic people. Participant comments included, “It’s nice to meet other Autistic people”; “I’m still in contact with one of the other participants and we became friends”; “I love working with other Autistics and I love meeting new ones”; “just being able to feel less filtered and having to wear a ‘mask’ [camouflage] while engaging with others that are Autistic”; and

like if I compare it to when I’m in class, being in ... an Autistic group is easier than being in a ... neurotypical group so ... it was easier to ... listen and learn and then ... when people were asking questions ... I could relate and see where they were coming from, whereas I have ... a hard time, sometimes with ... other classes.

These comments demonstrate the value of having Autistic people learn together to develop group cohesion. Participants wanted more opportunities to interact with each other, including *activities to get to know each other* as well as icebreaker activities. One participant commented, “So I would have liked to have more time to, more interactivity.” Another participant shared that they would like “an icebreaker at the start a meeting and just like a roundup, summary like check in or activity to conclude the session.” Interestingly, the Autistic participants from Bristol made more mention about opportunities to get to know each other, possibly because the training was the first time they met each other.

There were varying responses to the section on collaboration, with some people thinking it was valuable and others describing it as just common sense. Trainees identified that their knowledge of research processes was increased, which enhanced their confidence to be a collaborator. However, they also acknowledged that their ability to collaborate in autism research would be impacted by the non-autistic researchers' attitudes and knowledge of how to collaborate with Autistic people.

Theme 2: Recommendations for program content and structure

This theme refers to participants' pragmatic recommendations to improve the program content and structure and make Research 101 more valuable for them. In our first subtheme, ***recommendations for existing content***, they discussed ideas related to the program content, order, physical presentation, and activities. In our second subtheme, ***tailoring the program to diverse needs***, participants shared ideas of how the program could be adapted or tailored to meet the needs of diverse participants.

Subtheme 1. Recommendations for existing content.

Participants had multiple recommendations to improve the content and delivery of the existing training. They reinforced that the titles of the training slides needed to be clear and directly related to the slide content. For example, in relation to one section titled 'answering the question,' a participant said, "It seemed to me more that it was showing people how to get a research grant as opposed to being a collaborator." Other participants also reinforced that they wanted training specific to their responsibilities on the research team, rather than content about research funding, "And more perhaps instead of about this sort of theoretical budgeting and hiring, how you get funding, ... (more) about ... the academic structure of ...research."

Participants discussed the need to be very careful in choosing examples used during training. For example, although it wasn't intended to be provocative, one of the examples related to life expectancy caused distress to one participant, "I didn't like it when it suddenly was announced that people on the spectrum have shorter life expectancy. Now, maybe that's me just being naive, but I didn't realize that." Multiple participants also recommended an opportunity to interact with a panel of Autistic people who have collaborated in autism research, either in-person or on video, suggesting "it would have been amazing if we could have heard from [an Autistic person] who has conducted research ... I would have loved to ... hear their personal experience of it and how they got along and heard encouraging words."

Participants also reinforced the need to ensure that the *order of information* made sense, and to make this clear for participants. For example, one participant noted that the slides, "they didn't all necessarily link up in a way, I couldn't quite remember why things were in certain places, and I couldn't quite remember what linked to the slides." Changes to the *physical presentation* were recommended. For example, participants were not fond of our original gray scale slides, "presentation was a bit visually unappealing if that makes sense." Finally, participants recommended multiple *activity changes*, often related to modifying the activities to either a case study or a real-life example. In general, the activities were well received, however as one participant noted: "they were relevant to what we were learning, but ... they weren't really well connected in terms of the flow chart of how the research process goes." Another participant would have like more structure for the group activities, as they clearly stated, "I just wish the group activities were a bit more structured." Another suggestion was for the opportunity to work "in groups where there's all sorts of individuals [and] you do work on the little fake project together."

Subtheme 2. Tailoring the program to diverse needs.

This subtheme refers to suggested ways that trainers could adapt the training to accommodate their trainees. These included several ideas for **optional enhanced training**. One suggestion was for *optional pre-reading*, as noted by a participant, “I would have been happy to sort of read that through before, to study the sort of the content before the meeting.” A participant suggested that *interactive videos* could be nice, “after the lecture format discussion format that we did ...there could be an interactive video component where we did exercises and answered questions to apply more of experience to apply what we learned.” Another participant would have liked optional *online modules* to “delve a little bit more deeply, and maybe it could be where some people would want to attend the first one [session] and then other people who wanted to expand could do the module, and then attend a next one.”

There were several ideas for **optional adaptations**. One suggestion was to have *knowledge checks or quizzes*, as expressed by a participant, “knowledge checks, or a little quiz, even if people would feel childish ... it could just be self-assessments that we can use just to check our knowledge.” Another idea was to *add a session to practice the research process from idea to write-up*. For example, a participant suggested, “what would be amazing, although you’d need like an extra session will be like if, as a group, or in small pairs or whatever you could practice coming up with your own research idea and plotting out or planning your paper.”

Participants also provided a multitude of ideas for **tailoring the logistics** of the training to suit the unique needs of different trainees. They recommended that information about and permission to make these logistical changes be clearly outlined in a training manual. Participants recommended *to tailor examples to be relevant to the geographic location and research environment*. One UK participant advised that “I would like there to be more about the UK

context of research.” They also recommended tailoring *breaks to the needs of the group*. We found differing needs for breaks between groups, and they could be adjusted for the preference of the group, as noted by this participant, “more frequent, super short breaks, just so I can heat up my tea, etc. and not miss anything.” Another participant found the breaks helpful because “I don't know when I need to take breaks.” The ability to *tailor the activities* to the preference of the participants was also recommended. For example, one participant did not like the group activities at all; when asked what the worst thing about the training was, they answered, “the group activities.” Another participant commented that, “Well, I must admit, the group activities, I think it maybe derailed a bit into casual conversation.” However, another participant wanted more group work as they stated, “this is where I would say it would benefit from a bit more like interactivity and group work.” Some participants found there was not enough time for the activity as one participant noted, “I felt like the discussions were kind of cut short and that would have been really valuable and interesting and I think like it would have been fun to have discussed people and brainstorm with people's individual ideas like how they could expand on it and really bounce off each other and that opportunity was kind of wasted.” See Table 2 for sample activities.

Session	Activity	Guiding Questions
1	Develop a research question.	<ol style="list-style-type: none"> 1. Start with a big topic that interests you e.g., camouflaging. 2. What do you already know about this topic? What is in the literature about this topic? What are some keywords associated with the topic? 3. Ask an action question that is answerable and not a yes/no question
2	Discuss as a group to find potential answers to problems that can arise.	<ol style="list-style-type: none"> 1. The community collaborator disagrees with an academic project partner.

-
2. The video camera breaks halfway through data collection.
 3. An email is accidentally sent to all participants in CC instead of BCC.
-

Table 4. Sample activities

Suggestions were offered to *tailor the length of sessions*. All sessions were two hours long. Some participants wanted longer sessions as indicated by this comment, “it could have been longer.”

Other participants felt the sessions were too long as related by this comment, “the sessions were too long.” Finally, participants suggested having an *option to respond to questions and activities anonymously* as suggested by this comment, “one of the things it would have been helpful, useful, to see would have been like using ... online tools ... just for people to share their comments anonymously.”

To summarize, we identified edits we need to make to the existing training, optional adaptations to include in the training manual, and ways to enhance connectivity between trainees that will also be included in the manual. Importantly, we learned that trainees appreciated the training however they still felt that the attitudes of non-autistic participatory researchers will affect their comfort in collaborating with them.

Next Steps

Information from this pilot study was and will continue to be used to further improve future workshop delivery and resources. Concrete changes recommended to the existing training, such as content and order changes, physical presentation, and activity changes, will be reflected in revisions to the training PowerPoint presentations. We engaged an Autistic graphic artist⁵ to create images and slide templates to make the presentation more visually appealing (see Figures

⁵ Katcha Smile Studio

3 and 4). Adaptations to tailor training for different individuals and groups, such as optional training activities, and information about tailoring logistics such as breaks, session length, and tailoring activities for whole or small group participation will be outlined in an in-depth training manual.

The final version of Research 101, including editable slide decks, additional resources based on these pilot study findings, and the manual will be made freely available for use, for example, for researchers to share with potential Autistic research collaborators or for Autistic people interested in seeking these opportunities, on a website hosted by the Salvesen Mindroom Centre for Research at the University of Edinburgh.

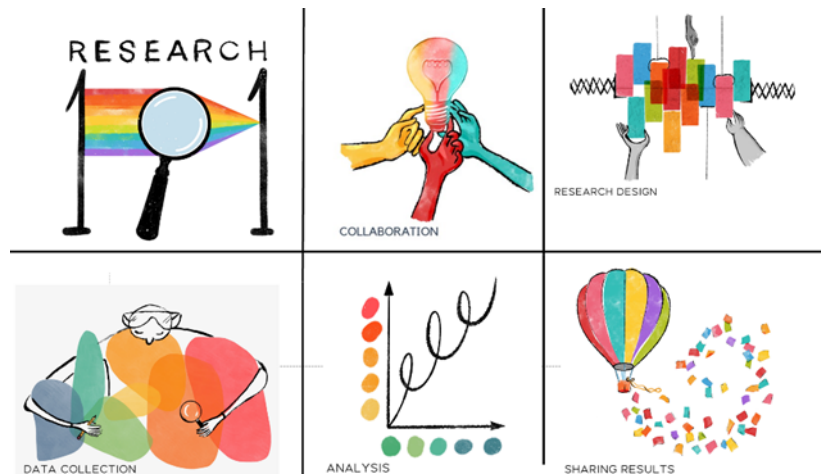


Figure 3. Graphic designs

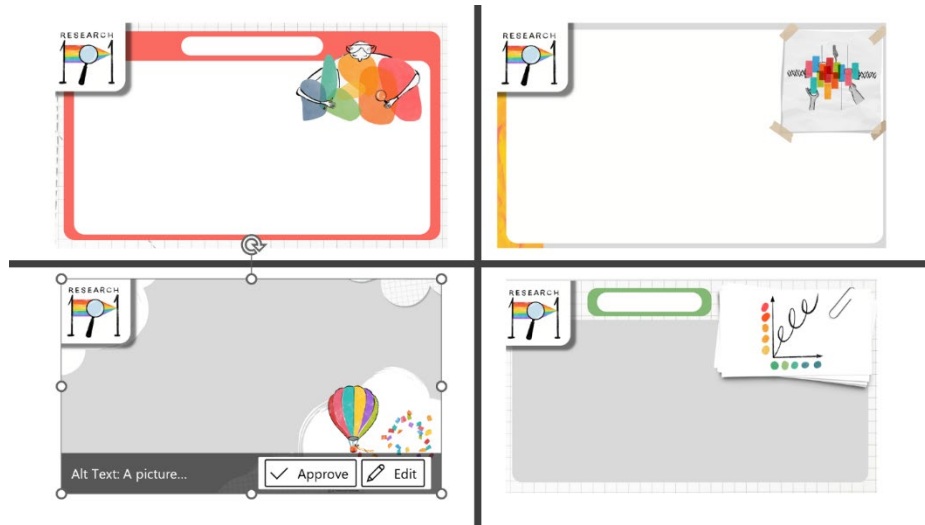


Figure 4. Sample of new templates.

DISCUSSION

Including Autistic people as collaborators in research has many benefits yet remains rare (Cassidy et al., 2018; Fletcher-Watson et al., 2018; Jivraj et al., 2014; Milton, 2019; Pellicano et al., 2014a). We developed the *Research 101, Effective Collaborators* training course to help remove a barrier to participatory autism research by increasing Autistic people’s knowledge of the research process and enhancing their collaboration skills. Having a shared understanding of the research process and vocabulary is an essential component for collaboration (Nicolaidis et al., 2019). In this study we aimed to evaluate this training with the goal of improving future workshop delivery and resources. We used a CBPR approach to both develop and evaluate the training course. One of the principles of CBPR is to promote “co-learning and building capacity among all partners” (Israel et al., 2012, p. 10). Our CBPR approach to evaluate *Research 101, Effective Collaborators* training enhanced the capacity of our ACP in two ways: (1) by engaging as community partners in all stages of the research project from conception to dissemination; and (2) by receiving the training.

Concerns with social communication differences is one barrier to engaging Autistic people as collaborators in research (Hollin & Pearce, 2018; Pellicano et al., 2014a). The training was delivered three times, two times by two Autistic facilitators and once by an Autistic and non-autistic facilitator. Trainees appreciated that the training was developed by and for Autistic people and indicated that they enjoyed being in a group of Autistic people. Milton's (2012) double empathy problem suggests that Autistic people find it easier to communicate with Autistic people. Participants felt they did not have to mask in the training setting and were grateful to be allowed to stim, two factors that support feelings of safety for Autistic individuals. Feeling safe and secure are needs for learning (Lacoe, 2020; Ryan & Deci, 2017).

In designing training for adult learners, it is important to consider adult learning theories. A review of adult learning theories identified five main principles: (1) adults need to know why they are learning, (2) adults are motivated to learn by the need to solve problems, (3) adults' previous experience must be respected and built upon, (4) adults need learning approaches that match their background and diversity and (5) adults need to be actively involved in the learning process (Bryan et al., 2009). The *Research 101, Effective Collaborators* course had clear learning objectives, was designed to address the problem of the lack of participatory autism research, provided opportunities for the learners to share their experiences with research and/or CBPR, and included active engagement of the trainees.

Guidelines have been created for autism researchers, most of whom are non-Autistic, on how to engage Autistic community partners in research (Fletcher-Watson et al., 2021; Nicolaidis et al., 2019). In addition to considering adult learning theories, our training utilized strategies from these guidelines. We also explicitly included information on these guidelines so potential Autistic collaborators have an understanding of what they should expect from autism researchers

in research collaborations. We hope that providing information about all perspectives (Autistic collaborators, Autistic researchers, and non-Autistic researchers) will help to decrease some of the issues related to perceived differences in priorities, diversity of views, and the perception that disputes will not be resolved (Pellicano et al., 2014a). This knowledge will help Autistic people to make informed decisions about collaborating in autism research.

Implications for practice and research

The *Research 101, Effective Collaborators* training course has the potential to increase the frequency and effectiveness of participatory autism research, improving the relevance of autism research to the Autistic community and fostering more research that responds to community needs. Increasing participatory approaches to autism research can mean that more research will be conducted to improve the quality of life and wellbeing of Autistic people *now*, in contrast to much traditional research. Autism researchers are invited to use this training course with their Autistic community partners.

Limitations and directions for future research

Although the learning approaches were designed for Autistic people, we did not consider other or intersecting diversities. For example, we did not include Autistic people with intellectual disabilities. Future research could include tailoring the training for Autistic people with intellectual disabilities and evaluating the training from their perspective. Additionally, many Autistic people experience difficulties with executive functioning including working memory and planning (Xie et al., 2020). While this training was designed for Autistic people, based on the feedback from trainees, we could have done more to support executive functions of working memory and planning. Paying careful attention to aligning the agenda items, learning objectives, and slide titles would support working memory and planning for Autistic learners. Importantly,

the open-access training package that will be available will allow for modification to support tailoring to different participant needs.

CONCLUSION

The *Research 101 Effective Collaborators* training course is a powerful tool, with a focus on preparing Autistic people to be informed and empowered community partners in research. The training course will be finalized as an open-access resource hosted by the University of Edinburgh, Salvesen Mindroom Research Centre. This revised training will increase both the capacity of Autistic adults to contribute to research as collaborators as well as autism researchers' willingness to conduct participatory autism research.

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CHAPTER THREE - Being able to be myself: Understanding autonomy and autonomy-support from the perspectives of Autistic adults with intellectual disabilities⁶

INTRODUCTION

Self-determination plays a vital role in improving an individual's overall well-being (Ryan & Deci, 2017), including for Autistic individuals (Shogren et al., 2015; Wehmeyer, 1999; Weiss & Riosa, 2015). It is a fundamental human right, universally applicable regardless of disability (United Nations, 2006). Self-determination refers to “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” (Wehmeyer, 1996, p.177). Self-determined behaviours encompass a wide range of activities such as making choices, decisions, problem-solving, goal setting, planning, achieving goals, self-management, self-advocacy, self-awareness, and self-knowledge (Shogren et al., 2017). The cultivation of self-determination is a crucial element for one’s personal growth and ability to thrive (Ryan & Deci, 2017).

Self-Determination theory (SDT) asserts that all individuals have three fundamental psychological needs to experience self-determination: (1) competence, the belief in one's ability to effectively perform tasks and acquire skills, (2) relatedness, the sense of belonging and connection with others, and (3) autonomy, feeling in control of one's life, making choices, and acting voluntarily (Ryan & Deci, 2017). People with mild to borderline intellectual disabilities (ID) experience greater well-being in environments that support their autonomy (Frielink et al., 2018). However, professionals often exert external control rather than promoting the autonomy of individuals with ID (Ryan & Deci, 2017).

⁶A version of this chapter will be submitted for publication with the following authors: J. Ryan, H. Brown, A. Borden, C. Devlin, A. Kedmy, A. Lee, B. Kingsley, and S. Thompson-Hodgetts.

Autistic individuals tend to be less self-determined compared to their non-autistic peers, including those with other developmental disabilities (Chou et al., 2016; Hodgetts et al., 2018; Weiss & Riosa, 2015). Autistic individuals may have less opportunities and support to engage in self-determined behaviours than their non-autistic peers (Moran et al., 2020; Wehmeyer et al., 2010). Autism is diagnosed primarily based on deficits in social communication (American Psychiatric Association, 2022). However, evidence for the Double Empathy Problem (Milton, 2012) suggests that it is a mismatch between the way non-autistic people and Autistic people understand each other, not simply deficits of Autistic people (Crompton, 2020). This suggests that there is as much need for non-autistic people to learn to relate to Autistic people as there is for Autistic people to learn to relate to non-autistics (Milton, 2012). While research about the lived experiences of Autistic people is increasing (e.g., den Houting et al., 2020; Raymaker et al., 2020) research on the lived experience of Autistic people with ID remains limited. Intellectual disability should not affect an Autistic young adult's ability to be self-determined but will affect the level of support the person needs (Cheak-Zamora et al., 2020). Cheak-Zamora et al. found that caregivers reported many opportunities for self-determination, but low capacity for self-determination for their Autistic young adults, especially for Autistic young adults with ID. This gap highlighted the need to investigate whether Autistic young adults with ID are truly receiving the support that they need to be self-determined (Cheak-Zamora et al., 2020), especially because an estimated 50% of Autistic people have ID (Russell et al., 2019).

This study aimed to address this knowledge gap by exploring autonomy and autonomy-support from the perspective of Autistic adults with ID. Autonomy was the area of focus because Ryan and Deci (2017) suggested that “when there is support for autonomy, people are also more able to seek out and find satisfactions for both competence and relatedness, as well” (p. 247).

Specific objectives were: (1) to understand the meaning of autonomy and choice from the perspective of Autistic people with ID, and (2) to learn how Autistic people with ID want to be supported to be autonomous and make autonomous choices.

MATERIALS AND METHODS

Methodological Approach

Interpretive description (Thorne, 2016) was chosen as a methodological approach because it allows investigators to exploring meanings and explanations that may yield practice implications (Thorne et al., 2004). A community-based participatory research (CBPR) approach informed the research process from study conception to dissemination (Fletcher-Watson et al., 2018; Nicolaidis et al., 2011, 2019). CBPR is aimed at ensuring the relevance of research to community needs and minimizing barriers to implementation (Hacker, 2017), both of which support self-determination. A group of five speaking Autistic adults without ID, the Autistic Community Partners (ACP), played a crucial role in the research process. While the ACP were not directly representative of the community whose self-determination we wanted to influence, they were indirectly representative as Autistic people who could talk about their experiences of being Autistic. They were involved in all stages of the study and were fairly compensated for their time. The ACP received Research 101, Effective Collaborators training (Ryan et al., in preparation) to learn about research processes and collaboration, as well as training in Reflexive Thematic Analysis (Braun & Clarke, 2019; Byrne, 2022). The University of Alberta's Research Ethics Board 1 approved this study.

Positionality Statements

The first author has deep personal connections to the autism community. She is Autistic and also the mother of an Autistic young adult who participates in the autism service provider's

(SP) program. Furthermore, she is employed at the SP and is the creator of the studied program, although she has not been directly responsible for it for the past five years. To ensure objectivity and address any potential biases, she maintained accountability throughout the research process by seeking feedback on her positionality from her PhD supervisor (STH), the ACP (HB, AB, CD, AK, AL), her supervisory committee, and other trusted colleagues, and keeping a reflexive journal about her own perspectives and potential influences.

HB is an Autistic professor who researches thriving and belonging for Autistic people. AB is an Autistic person, a parent of an Autistic child, and an advocate for child and disability rights for people of all abilities. CD is an Autistic Registered Social Service Worker who has just completed a second Bachelor's degree in Disability Studies and Psychology. AK is an Autistic Linguist who has found a calling caring for Autistic people with higher needs than my own. AK is also a student, a caregiver, and an advocate on a daily basis, often using language, paralanguage, and physical communication to help people who need it. AL is an Autistic university alumnus with a Bachelor's degree in computer science. Their unique perspectives greatly benefitted this research.

Program Description

This study was conducted within an innovative post-secondary transition program offered by a prominent Canadian non-profit organization that supports Autistic people and their families. The program focuses on empowering Autistic adults with ID to actively participate in their communities. It had a total of 19 participants, aged 20 to 27 years, all of whom receive provincial disability support funding. The program maintains a high staff-to-participant ratio (approximately 1:2). The program operates in a large city, utilizing three apartments located in a walkable community with access to public transportation, and a practice apartment in the main

center. It runs Monday to Friday, six hours/day, and offers a diverse range of activities such as learning modules (e.g., applying for a job, gym etiquette), leisure activities (e.g., going to the gym, going for coffee), volunteer work (e.g., food bank, Meals on Wheels), apartment maintenance (e.g., cleaning), and paid employment (upkeep of shared areas of the apartment building). One of the program's key goals is to foster self-determination, supported by its design as an environment that supports autonomy (Reeve, 2006).

Recruitment

Because of the first author's affiliation with the SP, a program manager distributed and collected all information letters and consent forms. The first author did study information sessions for parents/guardians, and then for program participants for whom their parent/guardian had provided initial consent. Assent forms, available in accessible formats (e.g., easy to read and/or pictorial), were required for participants. Ongoing assent of participants was monitored via verbal and/or behavioural check-ins, and a participant did leave the study area twice.

Participants

Consent/assent was obtained from eight of the SP's program participants (42% of total program participants). The SP's eligibility criteria require participants to have an autism diagnosis and all participants in the program receive provincial funding for which eligibility criteria includes having an ID. All participants had some level of spoken communication. Two were fluent speakers and the remainder of the participants primarily used short phrases, vocalizations, gestures, and body language to communicate.

Data Collection

Descriptive and demographic data

All participants lived with their parents and received provincial disability funding for adults with a permanent medical condition that substantially limits their ability to earn a living. They had all received certificates for completing high school. Additional relevant demographic information, including age, gender as defined by the participant, and age of autism diagnosis are provided in Table 5.

ACP data

Meetings of the Autistic Community Partners took place monthly over Zoom, beginning eight months prior to submitting the proposal for ethics approval. We discussed the proposed research questions, data collection methods, data analysis and interpretation methods, and dissemination strategies. Once ethics approval was received, all meetings were recorded with documented consent from the ACP.

Name*	Age	Gender**	Age of autism diagnosis (years)
Justin	26	Male	2
Kent	20	Male	5
Lily	24	Female	13
Peter	26	Male	3.5
Lamont	24	Man	5
Dax	22	Male	3.5
Brody	24	Male	3
Gabe	27	Male	4

Table 5. Descriptive and demographic information. *Pseudonym. **As stated by participant.

Participant data collection

To assist in getting to know the participants and to help guide activity choice, we reviewed the one-page profiles that were compiled by the participants, their parents/guardians,

and program staff as part of the regular program. The profiles provided information about their likes, how they prefer to be supported, what is important to them, what others like and admire about them, and their hopes and dreams for the next few months.

Participants were divided into two groups, G1 (n=3) and G2 (n=4), and one participant preferred to engage with a researcher on their own. Weekly, one-hour sessions were held over several months (G1=16 sessions; G2=13 sessions; individual participant=7 sessions), led by the lead author and a research assistant who are both Autistic. Each session was framed around a guiding question (see Table 6) to gradually build a “picture” of the experience of autonomy and choice. Guiding questions were developed by JR and STH, reviewed, and finalized with the ACP. Data collection for some questions occurred over multiple weeks. Data collection stopped when we felt that all guiding questions had been answered and we were not getting new data (Braun & Clarke, 2021).

Study participants chose the mode they used to provide data. A diverse range of art supplies was made available in each group session, including sculpting clay and tools, fuse beads, LEGO® bricks, LEGO® dots, paper, colored pencils, coloring pictures tailored to participants' interests, magazines, and construction paper. While some participants opted not to utilize the art supplies, they actively remained within the group and willingly responded to any questions as they saw fit.

Participant observation was the primary data collection method. Participant observation is a useful technique when participants are unable to discuss the study topic (Merriam & Tisdell, 2016). Observations took place during researcher-led conversations, defined as verbal language, as well as non-verbal cues such as body language, facial expressions, vocalizations, and laughter, that occurred during the activities. Participants shared their thoughts on their creative process and

expressed their desires for autonomy support. Relevant artefacts created during the sessions were also utilized as additional sources of data. One participant chose to engage in a series of interviews conducted during community walks alongside an Autistic research assistant. All data collection sessions were recorded through audio and video, except for the community walk interviews, which were solely audio recorded. Comprehensive field notes were kept about who was present, the activity for the session, how the activity was chosen, and the guiding questions for the session. Researcher impressions and reflections of the data collection sessions were documented in reflexive journals following each data collection session.

Guiding questions

1. Activities
 - a. What activities do you like to do?
 - i. Do you get to do them as often as you would like?
 - ii. Who do you do them with?
 - b. Do you do any activities where you lose track of time or become less aware of what is happening around you?
2. Choices
 - a. Do you get to make choices (choose) in your day?
 - b. Who lets you choose?
 - c. Is there anyone who never lets you choose?
 - d. What kinds of choices (choosing) are important to you?
 - e. How do you like to be supported to choose?
 - f. Are there times when being able to choose is not important to you?
 - g. Do you get tired of choosing?
 - h. When does this happen?
 - i. How can someone help?
3. People
 - a. Who do you like to spend time with?
 - b. Do you feel accepted by the people around you?
 - c. Do people take your feelings seriously?
4. Boss for the day (A Really Good Day)
 - a. You are the boss for the day – what will you do?
 - i. What does a good day look like for you?
5. Being Happy
 - a. What makes you happy?
 - b. What is a comfortable environment like, sounds, tastes, textures, smells, visual, people, pace, etc.

Table 6. Guiding questions for data collection sessions

Data Analysis

The research team, which included the ACP, collaboratively used Reflexive Thematic Analysis to identify patterns in the data that were meaningful (Braun & Clarke, 2019; Byrne, 2022). Videos were watched multiple times and data codes and themes were discussed over multiple meetings. By working collaboratively, we were able to explore multiple assumptions and interpretations of the data to achieve richer interpretations.

Community Involvement

The research was led by an Autistic researcher and included team members from the Autistic (n=6) and autism (n=2) communities.

RESULTS

Our two objectives were to (1) understand the meaning of autonomy and choice from the perspective of Autistic people with ID, and (2) to learn how Autistic people with ID want to be supported to be autonomous.

Overall, our data support that participants define autonomy as **being able to be themselves**. In line with Ryan and Deci's (2017) conceptualization of autonomy, this definition reflects participants' desire to live authentically and feel in control of themselves and their lives. Data also support three themes that participants perceive enable them to be autonomous: (1) **having choice and control**; (2) **being able to communicate in their own way**; and (3) **being in safe environments**. Within each theme, we identified corresponding strategies for supporting Autistic people with ID to be autonomous, from *their* perspective. We also identified an overarching support strategy, **having Autistic facilitators**. Each of these themes and strategies is described in detail below, supported by quotes or images from our data. Figure 5 summarizes the themes and corresponding strategies.

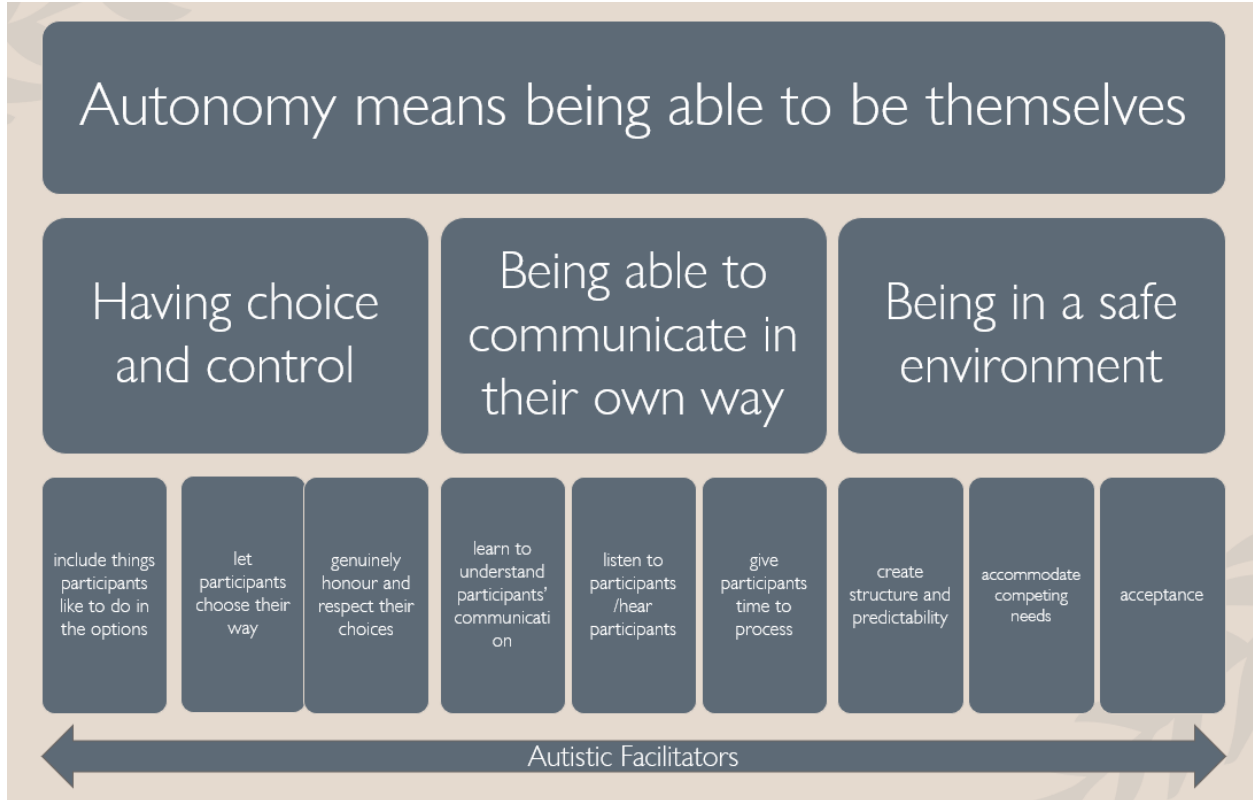


Figure 5. Meaning of autonomy and strategies to support

Theme 1: Having choice and control.

This theme highlights the significance of providing meaningful opportunities for participants to exercise choice and control, and respecting their capacity to do so. Some participants enthusiastically selected preferred activities from the offerings presented to them. However, others made different choices. For example, instead of opting for an art activity, Brody brought along a story he was actively working on. Peter sometimes chose to remain with the group while abstaining from participating in any art-related endeavors. Similarly, Gabe opted to embark on community walks alongside a researcher instead of engaging in art activities.

The first strategy we identified to support choice and control is to **include things participants like to do in the options**. Having preferred choices available was important, however, we noted that participants reinforced that choosing not to do a presented option should also be interpreted as a choice. For example, for five sessions Peter did not choose any of the art activities offered and we wondered why. Once we introduced the option of looking at magazines, Peter actively made a choice and engaged with the group. Furthermore, he exercised his autonomy by selecting the specific magazine he wanted from a variety of options (Figure 6).

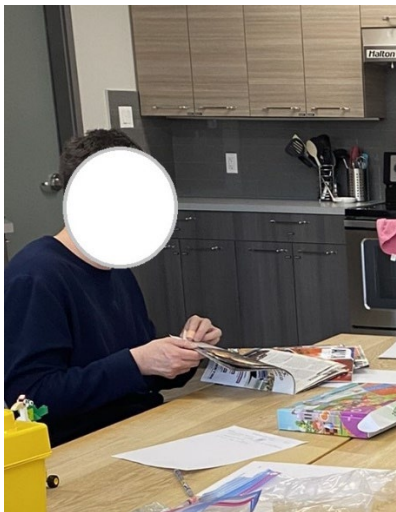


Figure 6. Peter leafing through a magazine

The second strategy to support choice and control is to **let participants choose their way**. Our observations revealed a multitude of examples showcasing the participants' individuality in decision-making and the specific support they required. For example, Brody preferred to approach the activities bin and select an activity in response to the researcher's cue to "show us with his hands." In one activity each participant was tasked with describing their ideal day using any format they preferred. Lamont chose to respond to this open-ended question by compiling a list of activities in which he would engage (Figure 7). Considering our knowledge that Peter enjoyed browsing through magazines, we provided him with a magazine-

like booklet containing pictures depicting various activities, allowing him to browse and select the things he would include in his “awesome day”. Peter went on to cut out the chosen pictures and affixed them to construction paper (Figure 7). In contrast, Gabe did not respond to the researcher’s questions about what he would like to do on an awesome day, but he did respond to the alternate question, “what makes Gabe happy?” by saying, “Movie, Mario Kart, big comfy chair.”

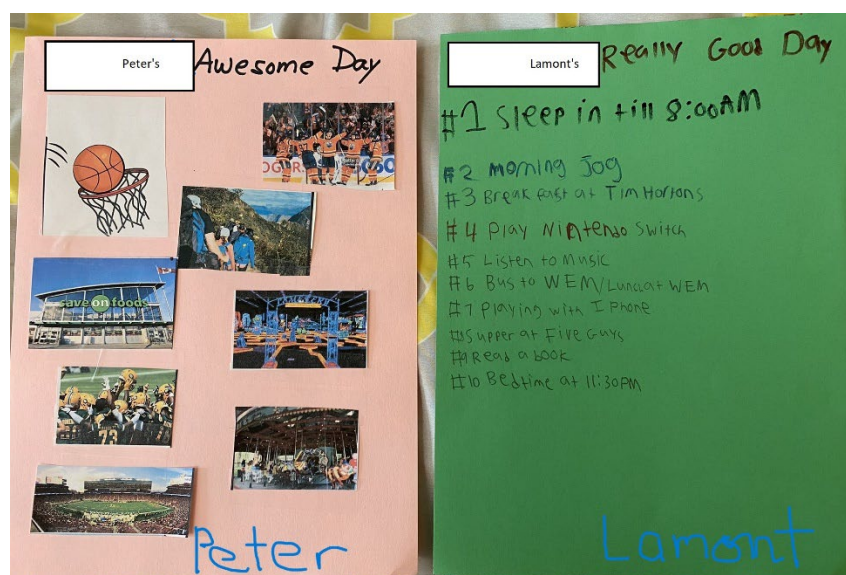


Figure 7. Peter and Lamont’s lists of things to do on an awesome day

Lily and Justin expressed choice and control by creating vision boards using a website. Lily's vision board depicted various elements she aspired for in her future. She described, “I want to live in a house in the city and have a garden, have lots of friends, have a job, and be busy, but happy busy, not sad busy” (Figure 8). Justin’s vision board represented the importance of travel in his future with many different destinations, including outer space (Figure 8). Thus, the second strategy for supporting choice and control let individuals choose their own paths and empowered them to express their choices in diverse ways. This approach recognized the uniqueness of each participant and the varying support they required.

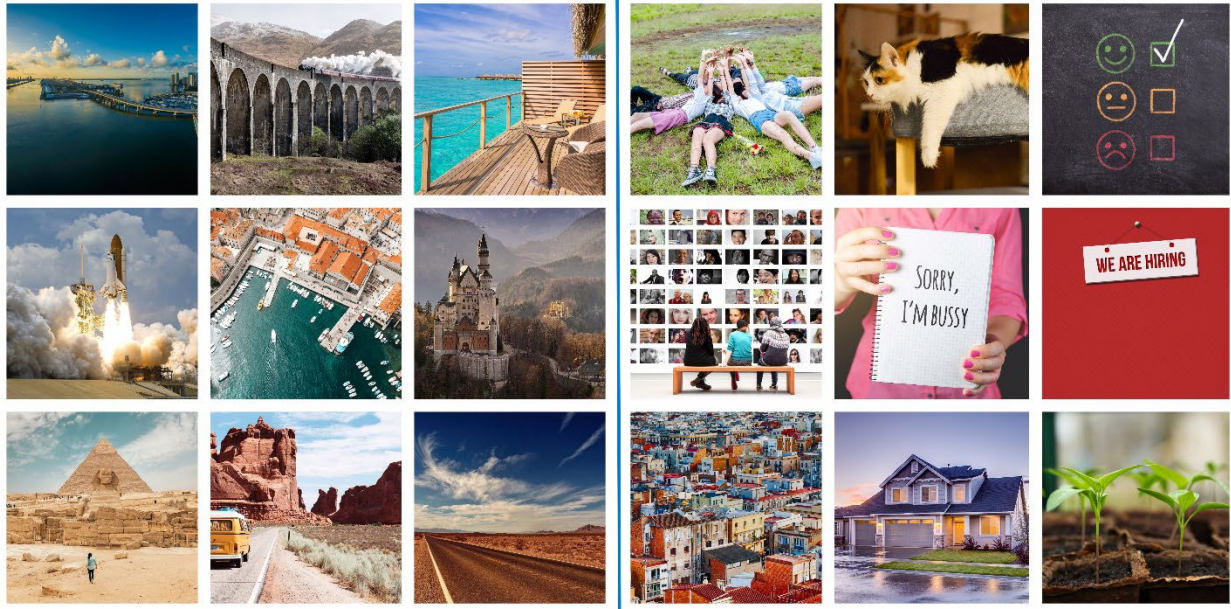


Figure 8. Justin (left) and Lily’s vision boards

The third way to support choice and control is to **genuinely honour and respect their choices**, both by allowing them and by accepting them, even if they differ from your own preferences. We came to recognize the significance of this strategy through instances where researcher actions fell short of our desired standards. These experiences shed light on the importance of maintaining a respectful and accepting attitude towards participants' choices, irrespective of whether they align with our own. For instance, a researcher once suggested a particular approach for Lily to undertake a task, but Lily decided to pursue an alternative path. In response, the researcher said “your choice” in a tone of voice that conveyed an unintended negative connotation, which Lily interpreted as disapproval of her decision. Although the researcher technically honored Lily's choice, the underlying tone displayed a lack of respect towards the participant's autonomy. Similarly, Justin expressed his desire to engage with LEGO® bricks, but a researcher persistently suggested alternative activities. Justin, undeterred, repeatedly responded with “LEGO” to each suggestion until the researcher finally accepted his

preference. Justin should not have been required to display unnecessary persistence to have his choice honoured. These instances highlight the significance of allowing participants to make their own choices and genuinely accepting and respecting those choices.

Theme 2: Being able to communicate their way.

This theme reflects the importance of working to understand the unique way in which each participant communicated, what each participant was communicating, and ensuring that they understand your communication.

The first strategy to support participants to communicate their way is to **learn to understand participants' communication**. This refers to the need to take time and put effort into ensuring that participants and researchers or staff understand each other because they communicate in different ways. For example, Brody sometimes communicated his needs and desires by repeating a line from a movie or show. In one session he said “no, Eleanor, don't be upset” when he was becoming dysregulated. In another example, a researcher asked Gabe, “What is a comfortable place to be?” and Gabe responded, “At the chair.” The researcher needed more details, so then asked, “Which chair is the best chair?” Gabe answered, “Big comfy chair.” Dax spoke very quickly, and we sometimes required him to repeat himself several times to understand him. Although tedious at times, the extra requests ensured that Dax's intent was understood. These examples illustrate the variety of communication forms that researchers and facilitators need to attend to.

The second strategy in this theme, **listen to participants/hear participants**, refers to the need to recognize and ‘listen’ to all forms of communication including verbal, body language, movement, facial expressions, and vocalizations. For example, Dax asked to take a picture of one of the researchers because Dax uses photographs to communicate with others and wanted to use

that picture to show people what he did that day. In another session, Dax wanted his picture taken with his clay creations. The researcher quickly recognized that a photographic record of this event was important for Dax because photos were how he organized his memories (Figure 9).



Figure 9. Dax and his creations, ice cream cone and hot dog

The third strategy, **give participants time to process**, refers to allowing time for participants to respond or make a choice. For example, Brody often took so long to answer a question that we thought he was not going to answer. During the ‘Would You Rather’ game, the question was ‘Would you rather have to walk while in a sleeping bag or sleep in a bathtub?’ All participants had answered except Brody and the researcher was about to ask the next question when Brody responded, “sleep in a bathtub.” This was an important reminder for the researchers about the importance of allowing the participants time to respond.

Theme 3: Being in a safe environment.

This theme refers to the importance of creating a physical and social environment that is comfortable and safe for participants. We observed that participants were able to make clearer choices and remain regulated when they were comfortable and calm.

The first strategy is to **create structure and predictability**. For example, Justin hit his head and appeared agitated when the researchers announced unexpected changes to the questions for that session. This unpredictability interfered with Justin's ability to safely advocate for himself, for example by saying no or leaving the session. The researcher reverted to the expected questions for the session and gave Justin a printed copy of the new questions that would be asked at the next session so that Justin would feel prepared. This helped Justin stay calm and regulated and take part in the activities at the next session. Dax had a routine that he did before he sat in a chair. Once he had done the movements and made the sounds, he sat and was then able to engage in the research activity. The researchers and participants did not interfere with Dax's routine, helping him to feel safe in conducting his routine. Another example of creating structure included having the sessions on the same day of the week at the same time of day in the same location. When we needed to change any of the three elements, we informed the participants the prior week to allow them time to mentally prepare for the change.

The second strategy, **accommodate competing needs**, refers to instances when participants have opposing needs. For instance, during one session, Dax unintentionally hit his small clay baseball into Brody's area using a small clay bat. Brody firmly refused to return the ball to Dax. In response, the researchers asked Lamont to assist and return the ball to Dax. This approach honored both Dax's desire to retrieve his ball and Brody's wish to refrain from returning it. The researcher then suggested to Dax that he hit the baseball in a direction away

from Brody. The allowed Dax to continue engaging with the baseball in a way that would not infringe upon Brody's space or preferences.

In a second instance, an issue arose when Lamont's LEGO® bricks scooter entered Brody's space, which Brody did not like. Recognizing this concern, Lamont agreed to discontinue his actions, demonstrating a willingness to respect Brody's boundaries. To further address the issue, the researchers took proactive measures in the next session by arranging for a larger table, ensuring that everyone had more personal space. These examples highlight the importance of actively responding to participants' needs and concerns, fostering an environment where their preferences and boundaries are acknowledged and accommodated. By addressing conflicts and making practical adaptations, we fostered an environment that was characterized by harmony and respect. This environment upheld the autonomy of participants and enhanced their overall experience.

The third strategy, **acceptance**, refers to holding space for participants to be themselves and express their true interests. For example, Kent said, “maybe when I live on my own, I’ll buy some beer.” This was a recurring topic for Kent who also expressed a desire to get his driver’s license, watch action movies, get married and have two children. The Autistic researchers accepted Kent’s comments even though we never identified if it was sincere or if he was teasing us (Kent liked to tease people). Attending to both what is being said and what is not being said is crucial. In another session, Brody started jumping up and down, waving his arms, and making loud vocalizations. This activity risked the environment becoming unsafe for people around Brody. Without judgement and with Brody’s permission, one of the researchers led him through a deep breathing exercise to help him to calm. When Brody was calm, we determined that he was

being asked too many questions as part of the session’s activity, so we did not ask Brody any more questions in that session.

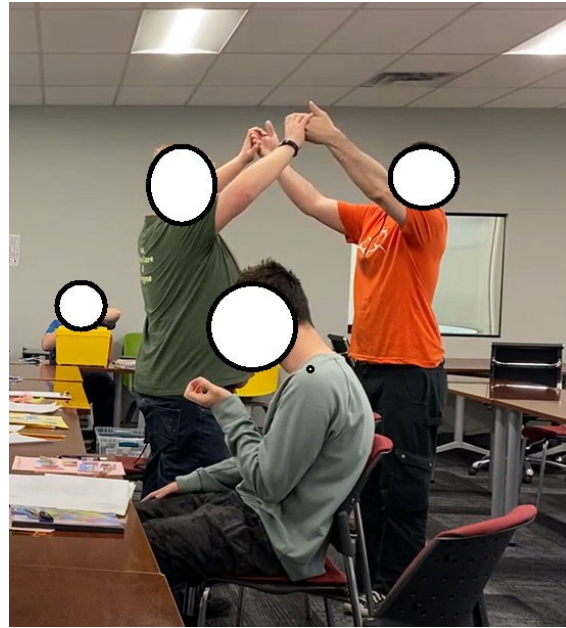


Figure 10. Brody and researcher co-regulating

Finally, we identified an overarching strategy that supported the participants’ autonomy, **Autistic facilitators**. Having Autistic researchers strengthened the project, because there were shared understandings and a unique connection between the Autistic researchers and participants. For example, when Lily expressed her perception of letters resembling shapes and one researcher explained their personal association of the letter ‘y’ with a sweater, Lily flapped her hands in excitement, exclaiming, “You get it!” We found common ground in our love for puns, palindromes, and the enjoyment of creating words from car license plate letters. These shared interests and connections allowed for meaningful conversations and interactions. Lily also candidly expressed the significance of engaging with fellow Autistic adults, stating, “It’s nice talking to other Autistics. I never really have before. I’ve never been open with other people. She also remarked, “I didn’t know a woman on the spectrum could be so independent!” These sentiments highlighted the positive impact of Autistic role models and the value of building

connections within the Autistic community. Engaging in playful activities with the participants, such as the ‘Would You Rather’ game, with a mix of serious and lighthearted questions, resulted in an abundance of laughter, fostering a joyful and inclusive environment.

During an ACP meeting, a partner commented on the remarkable nature of watching videos from the data collection sessions. They marveled at the Autistic researchers’ abilities to lead the discussions with people who communicate in non-traditional ways and swiftly comprehend the subtle forms of communication employed by the Autistic participants,

[To] see two Autistic people leading the discussion, and tapping in right away to the indirect communication that the Autistic participants are putting forth such as saying villains, right away, picking up on the echolalia right away, ... [not only] picking up on it, [but also] reflecting back what the person might be feeling, [and] de-escalating everything.

The partner went on to emphasize the beauty observed in this distinct communication style, attributed to this unique and intuitive Autistic mediator response versus what might typically occur from a neurotypical mediator. In summary, Autistic facilitators played a vital role in shaping our interactions and experiences throughout the study. The genuine connections, shared understanding, and appreciation for Autistic perspectives and communication styles fostered a profound and enriching autonomy-supportive environment for all involved.

DISCUSSION

There is a dearth of research that includes the perspectives of Autistic adults with ID (Nicholas et al., 2019). Cheak-Zamora et al. (2020) called attention to the need to learn how Autistic young adults themselves define and display self-determination. To our knowledge this study is the first to explore the meaning of autonomy and choice, and how they want to be

supported to be autonomous, directly from the perspectives of Autistic people with ID. Research suggests that Autistic people are less self-determined than others (Chou et al., 2016; Hodgetts et al., 2018), yet our findings suggest that Autistic adults with ID can be and want to be self-determined.

Our findings align with conceptualizations of self-determination related to being the primary causal agent in one's life (Wehmeyer, 1999). Participants were more engaged when choosing activities that they genuinely liked, including beyond the offered suggestions. When acting autonomously, consistent with SDT, participants were intrinsically motivated and experienced joy (Ryan & Deci, 2017). A systematic review on promoting self-determination of individuals with severe or profound ID found that existing interventions mainly focused on choice-making skills and training caregivers to interpret and respond to individuals "natural modalities of preference expression" (Kuld et al., 2023, p. 32). We found that we were better able to support participants' autonomy after learning to understand each participants' communication. Communication level (e.g., non-speaking, verbally fluent) predicts caregivers' perceptions of Autistic young adults' ability to be self-determined (Cheak-Zamora et al., 2020). We learned from our participants through their spoken words, and their actions and demeanours. Autistic people with ID may show their self-determination through actions, and it is incumbent on others to learn to interpret and respect these actions to support Autistic people with ID to be self-determined.

Milton's (2012) double empathy problem proposed that Autistic people may not have deficits in social communication, but rather, problems may arise from a mismatch between Autistic and non-autistic communication. Relatedly, Crompton et al. (2019) studied rapport in dyads of Autistic, non-autistic, and mixed (Autistic and non-autistic) groups. Both Autistic and

non-autistic raters gave poorer ratings of rapport for mixed neurotype pairs than for matched neurotype pairs. Our ACP observed uniqueness in how the two Autistic researchers who conducted the data collection sessions responded to the Autistic participants with ID, offering support for a double empathy problem and that there is an empathetic strength in having Autistic people working with Autistic participants. Indeed, having other Autistic people in supportive roles, for example as researchers and as support staff, might be important in supporting self-determination of Autistic adults with ID (Capozzi et al., 2019; Dwyer et al., 2022; Lawrence, 2019; Shaw et al., 2021). However, there is a dearth of research in this area. In fact, a systematic review of peer mentorship programs in postsecondary education found only one study that had Autistic peer mentors (Duerksen et al., 2021).

Self-regulation, which involves emotional and behavioural responses that are appropriate for a situation, develops through interactions with caregivers and the broader environment and can support one's ability to make autonomous decisions (Smith & Douglas, 2022). Our participants desired structure and predictability and accommodation of their competing needs to feel regulated. Most Autistic people have sensory processing differences that can influence their ability to self-regulate and participate in daily activities (Loh et al., 2023; Tomchek & Dunn, 2007). When our participants were dysregulated due to a stressor in the environment, such as loud noise or limited personal space, co-regulation was an effective strategy to assist participants to re-regulate so they could continue to engage in the sessions in a meaningful way. Order and predictability can help Autistic people to feel secure in their environment, feel regulated, and make their needs known (Krieger et al., 2018), and supported their ability to make autonomous choices.

Limitations and directions for future research

Limitations of this study are our small sample size, that data were collected from within only one autism service provider. A different or larger sample may have yielded different results. However, our approach aligns with the interpretive methodology and constructivist perspective that guided this research, and we believe that this study makes a meaningful contribution to knowledge given its novelty. We did not consult parents/guardians about their interpretation of their adult children's communication; rather, we relied on our prolonged engagement with participants to learn and understand their communication. It is possible that parents/guardians may have interpreted their adult children's communication differently. However, given that our research topic was self-determination, we felt that it was appropriate to centre the participants. Future research could involve parents and staff to triangulate communication interpretations. Finally, although we engaged the ACP throughout the research, we did not include an Autistic adult with ID on the ACP, nor did we take our interpretation of results back to the participants for input. Future research could take the results back for review, input, and confirmation.

Implications for practice

We found that Autistic adults with ID can and want to be self-determined. Kuld et al. (2023) suggested that future studies should focus on supporting relationships with others by providing a need-supportive environment where the three basic psychological needs of competence, relatedness, and autonomy can be fulfilled with the support of others. Indeed, opportunity for choice-making is a component of self-determined behaviour that can be directly increased by support staff and others around the Autistic adult. Service providers can play an important role in facilitating this by creating need-supportive environments. Building secure relationships between Autistic adults with ID and those who support them is critical as it

enhances communication, contributes to better co-regulation, and supports autonomy for participants. Strategies include letting participants make choices in their own way, being sure to include things they like in the choices and honouring their choices. It also means learning to understand participants' methods of communication, a process that often includes holding space and giving participants time to process information and decisions. Structure, predictability, and routine were key for participants to be regulated, and researchers and participants benefited from co-regulation strategies and creating an environment that accommodated competing needs among participants. Finally, service providers should consider hiring Autistic staff as including Autistic facilitators in programming can also enhance the ability of Autistic adults with ID to be self-determined.

CONCLUSION

People with ID will likely need more support to be self-determined, but ID does not negate their ability to be self-determined (Cheak-Zamora et al., 2020). Our participants indicated that autonomy meant being able to be themselves and included having choice and control, communicating their way, and having a comfortable environment. These findings reinforce that Autistic adults with ID desire to be and are capable of being autonomous with appropriate support. We hope that this work inspires others to consider how they can best support Autistic people with ID to be autonomous, ultimately enhancing self-determination and quality of life.

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CHAPTER FOUR: “It’s really who they are and what they want”: Staff perspectives on supporting autonomy for Autistic adults with intellectual disabilities⁷

INTRODUCTION

Self-determination is defined 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” (Wehmeyer, 1996). It is a fundamental human right, as stated in the 2006 United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006), which was ratified by Canada in 2011, and is known to enhance an individual’s quality of life (Ryan & Deci, 2017), including for Autistic individuals (Denney & Daviso, 2012; Shogren et al., 2015; Wehmeyer, 1999; Weiss & Riosa, 2015). It refers to “both the right and capacity of individuals to exert control over and direct their lives” (Wehmeyer, 2004, p.23). As such, self-determination requires having opportunities to be self-determined, such as being involved in transition planning from high school to postsecondary education, choosing what leisure activities to participate in, and deciding where to live. It also requires having the skills, knowledge, and abilities to engage in self-determined behaviours, such as goal setting, problem solving, and planning skills. However, where an individual lacks the skills, knowledge, and/or abilities to be self-determined on their own, appropriate supports can be provided to mitigate these challenges (Kuld et al., 2023).

Self-Determination Theory (SDT) is a macro-theory of motivation that posits that individuals require the fulfilment of three basic psychological needs to be intrinsically motivated and experience well-being: competence, relatedness, and autonomy (Ryan & Deci, 2000).

Competence refers to the feeling that one can effectively perform tasks as required. Relatedness

⁷A version of this chapter will be submitted for publication with the following authors: J. Ryan, H. Brown, A. Borden, C. Devlin, A. Kedmy, A. Lee, D. Nicholas, and S. Thompson-Hodgetts.

refers to the sense of belonging and connection with others. Autonomy refers to behaviour congruent with one's true interests and values. SDT researchers have demonstrated that these three needs are universal including for individuals with disabilities (Ryan & Deci, 2017). However, the satisfaction of each of the three needs exists on a continuum; competence can range from perceived incompetence to perceived competence, relatedness can range from rejection to acceptance, and autonomy can range from controlled to autonomous (Ryan & Deci, 2006). Within SDT, autonomy is not synonymous with independence; one can be "autonomously dependent or forced into independence" (Ryan & Deci, 2006, p.1562). A person can be externally influenced and still concur with the action, thus acting autonomously (Ryan & Deci, 2006).

Despite self-determination being a human right for everyone, Autistic individuals experience lower levels of self-determination than both their non-autistic peers and those with other developmental disabilities (Chou et al., 2016; Hodgetts et al., 2018; Nonnemacher & Bambara, 2011; Weiss & Riosa, 2015). Furthermore, Autistic people with intellectual disabilities (ID) are amongst the least self-determined people overall (Cheak-Zamora et al., 2020; Chou et al., 2016).

Professionals who work with individuals with ID, including those with co-occurring autism, often "respond to learning difficulties ... as if they were motivational deficits and attempt to change outcomes by exerting more external control" (Ryan & Deci, 2017, p.365). What the individuals usually need instead is more structure, which is autonomy-supportive (Ryan & Deci, 2017). Furthermore, professionals express that they value self-determination for Autistic youth, yet they rarely include Autistic youth in the goal-setting process (Hodgetts et al., 2018). A recent study on supporting the self-determination of Autistic students in transitions at

school (e.g., between grades and schools, as well as daily transitions during school) found that Autistic students are usually just given information, which is passive involvement, rather than being actively involved in planning and implementation (Webster et al., 2022). Passive involvement is not likely to develop self-determination.

People with intellectual disabilities (ID) experience greater well-being in environments that encourage autonomy (Frielink et al., 2018, p.43). Reeve (2006) described strategies to create autonomy-supportive environments that could be applied to Autistic people, including those with co-occurring ID. Autonomy-supportive environments have staff that: (1) listen carefully; (2) create opportunities for participants to work in their own way; (3) provide opportunities for participants to talk; (4) arrange the environment so participants manipulate objects and conversations rather than passively watch and listen; (5) encourage effort and persistence; (6) praise signs of improvement and mastery; (7) offer progress-enabling hints when participants seem stuck; (8) respond to participants' questions and comments; and (9) communicate a clear acknowledgement of participants' perspectives (Reeve, 2006). Conversely, Reeve described the following behaviours as indicative of a controlling environment: (1) monopolizing the learning materials; (2) giving solutions before participants have time to work on the problem independently; (3) telling participants the right answer instead of allowing them time and opportunity to discover it; (4) giving directives and commands; (5) using 'should,' 'have to,' 'must,' or 'got to' statements; and (6) using controlling questions as a way of directing participants' work (e.g., 'Can you do what I showed you?') (Reeve, 2006, p. 231). Bigby and Beadle-Brown (2018) identified 44 propositions about what makes a difference to outcomes for adults with ID in supported living situations. One proposition is that staff practices reflect Active Support, which is a framework for support staff to enhance participants' engagement and

participation in meaningful activities. Active Support has four essential components including the importance of choice and control, a factor known to enhance autonomy (Mansell & Beadle-Brown, 2012).

Clearly, strategies to support self-determination of Autistic adults, including those with ID, exist yet are frequently not implemented. This qualitative descriptive study, guided by Ryan and Deci's (2017) SDT, aimed to explore staff perspectives on approaches to enhance the self-determination of Autistic adults, including those with ID. Ryan and Deci (2017) explained that "[w]hen there is support for autonomy, people are also more able to seek out and find satisfactions for both competence and relatedness, as well" (p. 247). As such, we chose to focus on autonomy, rather than competence, relatedness, or all three basic psychological needs. Our specific aims were to learn from staff of an autism service provider (ASP) about (1) how they support autonomy for its Autistic participants, and (2) the specific skills and abilities they perceive are required by Autistic adults with ID to enhance their autonomy.

MATERIALS AND METHODS

Methodological Approach

Interpretive description (Thorne, 2016) was chosen as a methodological approach because it allows investigators to exploring meanings and explanations that may yield practice implications (Thorne et al., 2004). A community-based participatory research (CBPR) approach informed the research process from study conception to dissemination (Fletcher-Watson et al., 2018; Nicolaidis et al., 2011, 2019). CBPR involves engaging community members as part of the research team to ensure that the research is relevant to their needs and to overcome barriers to translation (Israel et al., 2010). We engaged with five Autistic Community Partners (ACP) and two representatives from the ASP, the Executive Director, and the Program Manager, who all

played vital roles in the CBPR process. The ACP consisted of four non-academic Autistic individuals (AK, AL, AB, CD) and one Autistic Associate Professor (HB). The non-academic members of the ACP were compensated fairly for their time. The University of Alberta's Research Ethics Board 1 approved this study.

Positionality statements

The first author of the study, JR, has personal ties to the autism community, including being Autistic herself and being the mother of an Autistic young adult who is a participant in the ASP's program. Additionally, she works at the ASP and is the creator of the ASP's program, although she has not had direct responsibility for it for five years. She is a current member of the Executive Team at the ASP. She acknowledged the unique advantages of her position and used it to conduct a thorough and impassioned study. To address any potential biases, she maintained accountability throughout the research process by keeping a reflexive journal and seeking feedback on her positionality from her PhD supervisor, the ACP, her supervisory committee, and other trusted colleagues.

HB is an Autistic professor who researches thriving and belonging for Autistic people. AB is an Autistic person, a parent of an Autistic child, and an advocate for child and disability rights for people of all abilities. CD is an Autistic Registered Social Service Worker who has just completed a second Bachelor's degree in Disability Studies and Psychology. AK is an Autistic Linguist who has found a calling caring for Autistic people with higher needs than my own. AK is also a student, a caregiver, and an advocate on a daily basis, often using language, paralanguage, and physical communication to help people who need it. AL is an Autistic university alumnus with a Bachelor's degree in computer science. Their unique perspectives greatly benefitted this research.

Program description

This research was conducted within the innovative post-secondary transition program of a major Canadian, non-profit, multi-disciplinary ASP, which aims to equip Autistic adults with ID with knowledge and skills to engage in the community. One of the program's anticipated outcomes is increased self-determination, supported by its design as an autonomy-supportive environment (Reeve, 2006). The ASP's principles emphasize the right to self-determination and the freedom to make decisions.

The ASP program primarily runs out of three apartments in a walkable community within a large city with access to public transportation. The program also utilizes a practice apartment in the ASP's main centre. The ASP program operates from Monday to Friday for six hours per day. Throughout the day, the Autistic adults participate in various work and leisure activities. Related to work, the adults engage in learning modules such as time management and applying for jobs; volunteer at a food bank and Meals on Wheels; and engage in paid employment such as maintaining the apartment building's shared areas. In terms of leisure activities, the adults go to the gym, swimming, on community walks, and attend festivals. They also engage in related learning modules such as gym etiquette and staying cool in hot weather.

At the time of data collection, the program had 19 participants, ranging in age from 20 to 27 years (n=17 identified as men and n=2 identified as women) and all received provincial disability support funding. We acknowledge that parents usually directed participants to the program, which could be perceived as contrary to self-determination. However, participants needed to know about the program and what it offered to be able to make an informed decision about attending. Most program participants chose to stay in the program once they had joined.

To support individualized skill development, the program maintained a high staff-to-participant ratio of approximately 1:2.

Recruitment

Due to the first author's relationship with the ASP, a manager at the ASP distributed the invitation to the Information Session to program staff. The first author led the Information Session and answered any questions the attendees had. Following this session, the manager provided interested staff with consent forms and answered any additional questions, including those regarding confidentiality. The manager also collected the consent forms.

Research Participants

Staff participants were recruited from the ASP's program staff (n=9, 82% of total staff). Each staff participant (hereafter called 'staff' or 'staff member') provided relevant demographic information, including age, gender, years worked at the program, years worked as a disability support worker outside of the program, and educational background. Individualized staff information is presented in Table 7. Additionally, each staff member completed the Utrecht Work Engagement Scale-9 (UWES-9), a brief survey used to assess work engagement. The UWES-9 has been shown to have good internal consistency ($\alpha=.80$) and test-retest stability coefficients at one year between .61 and .73 based on data collected from over 14,000 adult employees in various employment settings across 10 countries (Schaufeli et al., 2006). Unfortunately, specific data for employees who work with Autistic individuals are not available. The UWES-9 consists of nine questions that are rated on a 6-point Likert scale (0=never, 6=always) and takes approximately 10 minutes to complete. The surveys were distributed and collected by the manager, and the anonymous results were then summarized by the first author. The aggregate results of the UWES-9 indicate that staff are more engaged than the norm across

all three areas: vigor (ASP staff: 4.38; normative data 4.18), dedication (ASP staff: 5.29; normative data 4.28), and absorption (ASP staff: 4.48; normative data 3.68).

Age (years)	Mean	30
	Range	24-43
Identified gender (n)	Woman	8
	Man	1
Educational attainment (n)	High school	2
	College diploma	1
	Undergraduate degree	4
	Graduate degree	2
Years in with Service Provider	Mean	2.67
	Range	1-6
Years in disability services	Mean	7.78
	Range	2-15

Table 7. Demographics

Data Collection

A focus group with six ASP staff was conducted over Zoom by an external facilitator, guided by the questions in Appendix A. The guiding questions were developed by JR, reviewed, and finalized with STH and the ACP. We used Zoom because the focus group took place during COVID-19 restrictions. We used an external facilitator who was not part of the ASP or the research team to eliminate any perceived power imbalance due to the role of the first author in the organization. The focus group was recorded and transcribed, and the transcript was made anonymous before being sent to the first author for analysis. The remaining three staff were interviewed by the same external facilitator in a group interview with two staff and a single interview with the other staff member. The focus group and interviews were between 60 and 90

minutes. The transcripts from the group and single interviews were merged to decrease potential identification based on participant responses, anonymized, and sent to the first author. Therefore, analysis was based on two in-depth transcripts.

Additionally, meetings of the ACP took place monthly, beginning eight months prior to submitting the proposal for ethics approval, where we discussed the proposed research questions, data collection methods, data analysis and interpretation methods, and dissemination strategies. Once ethics approval was received, all meetings were recorded with documented consent from the ACP. Analyses was also informed by the recorded ACP meetings, as well as the lead author's reflexive journal.

Data analysis

We used reflexive thematic analysis to analyze the data (Braun & Clarke, 2021). Initially, both the first author, her supervisor (STH), and an ACP member reviewed both transcripts, highlighting notable data and reflecting on it. The ACP members' reflections were crucial for the first author to acknowledge any biases related to her and her son's involvement in the program. Next, the first author engaged in an iterative process of reading the transcripts, identifying significant portions of data, and proposing themes. Drafts of theme generation were reviewed multiple times by four separate groups: (1) the ACP, (2) the Research Team, (3) program staff, and (4) program management. After each review, the first author re-examined the transcripts and incorporated feedback from each group, keeping an audit trail of all versions. Multiple iterations, discussions, reviews, and final consensus between the ACP, researchers, and staff resulted in two themes and 10 subthemes (described as factors and areas below).

RESULTS

Our first objective was to gather information from staff regarding their strategies and approaches in promoting autonomy for the Autistic adults. We identified an overarching theme of the **importance of relationships** as well as six key factors necessary for promoting autonomy. The first four factors referred to the staff themselves and included the importance of staff (1) **knowing the participants**, (2) **caring about the participants**, (3) **tailoring choice making**, and (4) **feeling supported by the organization**. The last two important factors included (5) **the ability to support families as they foster self-determination** and (6) **the cooperation of the local community**.

Our second objective was to gather perspectives from staff regarding the specific skills and abilities essential for fostering autonomy among Autistic adults with ID. Within the overarching theme of **staff perceptions of skills needed to enhance autonomy**, we identified four key areas as crucial in this regard, including **self-advocacy**, **interoceptive awareness**, **working effectively in a group**, and **identifying the potential natural results of their choices** (see Figure 11).

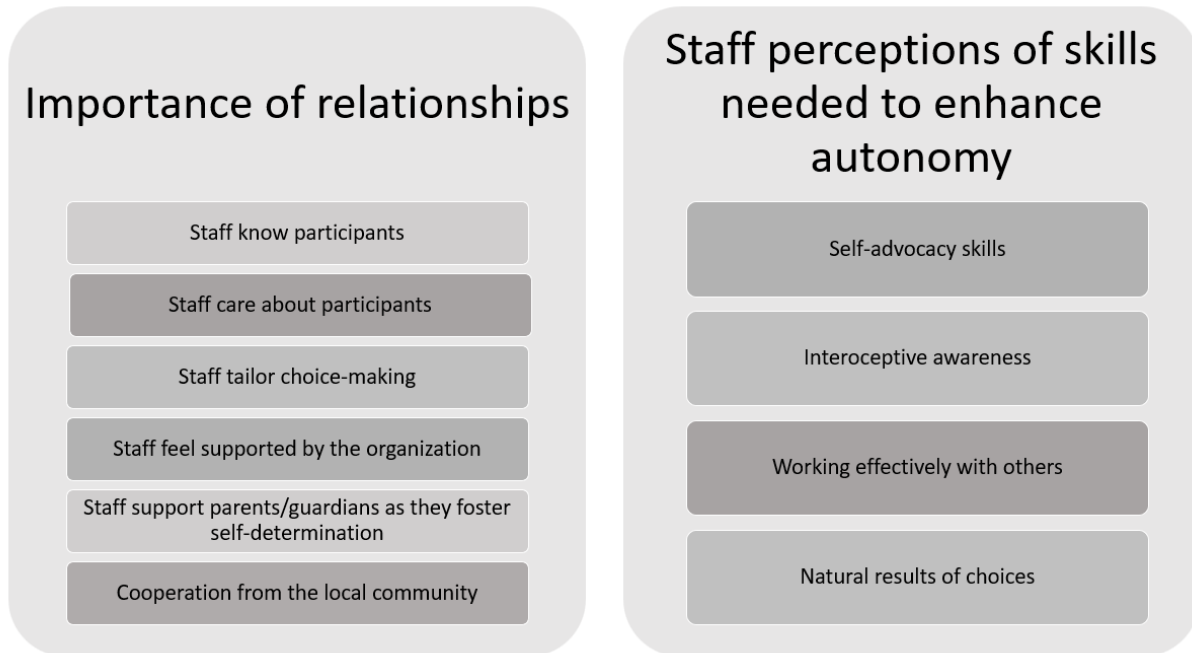


Figure 11. Themes and subthemes

Theme 1: Importance of relationships.

This theme refers to the need for strong relationships between staff and Autistic adults to foster the self-determination of Autistic adults with ID. Significant time was required to build relationships between ASP staff and participants. Staff felt that allowing this time was crucial for staff to really get to know the participants, so that autonomy support could be provided in the most meaningful way for each participant.

At the time of data collection, the program was understaffed, and staff expressed concerns about being overburdened. For example, one staff member commented, “We're always stretched thin, and our staff often doesn't receive the training we believe is necessary.” Despite being understaffed, staff prioritized developing and maintaining relationships with participants.

The first factor related to theme 1, **staff know the participants**, underscores staff appreciation for the individuality of each program participant and reflects the staff's belief in the

importance of developing a deep understanding of the participants. This high level of familiarity further enabled and promoted personalized autonomy support. However, staff emphasized that it takes time to get to know each participant as shown in the following comment,

And sometimes the people I've worked with for a long time, I feel like I could read their minds. So, I think we just have that really strong desire to get to know the people that we're supporting. ... I think that's kind of at the heart of what makes this program successful - having staff that care.

Unfortunately, the low wages in the disability services field, which is publicly funded, means high staff turnover that impacted the program participants, as reflected in this staff member's comment, "We're all here because we genuinely care but that doesn't pay our mortgages, so it can be challenging." The integration of new staff into the program required a dedicated period for them to establish relationships and familiarize themselves with the participants. However, this transitional phase was thought to temporarily limit the self-determination and opportunities for autonomous decision-making among program participants.

The second factor, **staff care about participants**, describes the importance of staff being open, responsive, empathetic, and non-judgemental to support the autonomy of program participants. Staff also brought a sense of warmth and high regard for each participant. These traits were articulated by managers as well as front-line staff as demonstrated in this comment by a supervisor,

All of them [referring to staff] really care about the participants and they don't necessarily only care in the way that 'this is my job, and this is the percent I'm helping.' They care about that these people's lives are awesome, and they're having a great day and are furthering their goals.

Indeed, when asked about their own experience of autonomy and choice-making and its influence on their well-being, a staff member revealed that the pandemic-induced limitations on their social life heightened their empathy for program participants who may have fewer chances for autonomy and choice-making. Throughout the interviews, staff expressed their desire to improve Autistic adults' lives, and prioritize Autistic perspectives, including perspectives of minimally or nonspeaking Autistic people, to know what participants *really* want in their lives. One staff member remarked that it is about,

genuinely understanding who the people around us are and the things that they hold dear so that we can facilitate that process in a way that honours who they are, and it's not an extension of us or an extension of even, you know, their parents or the program. It's really who they are and what they want.

Staff create a safe space for program participants to learn and test their self-determination. One staff member commented, “you [referring to the program participants] make a radical decision and it blows up in your face, we’re still going to be there to make sure you’re okay and you’re safe.”

The third factor, **staff tailor choice-making**, refers to the use and perceived benefits of individualized support for making choices. Staff indicated that they use the four essentials of Active Support: (1) little and often, (2) maximizing choice and control, (3) graded assistance, and (4) every moment has potential (Mansell & Beadle-Brown, 2012) as a structure to support each program participant by maximizing their choice-making opportunities. One staff member's comment exemplified the use of all four essentials,

[by] giving as much information as possible and giving it in a way that can help them (program participants) understand the concept of each choice [*graded assistance*]. ... [We're] practising making choices all the time [*little and often*]. Even with little things like having water or soda [*every moment has potential*], or we are going to work on this huge goal or this huge goal [*maximizing choice and control*]. And then you frame it in different ways [*graded assistance*], and that also comes from us knowing the participants too.

Another staff member commented that staff, “support...them in whatever way they need you to in that moment to be the best version of themselves, essentially.”

The fourth factor, **staff feel supported by the organization**, refers to the culture of the ASP which enabled them to try new things, make mistakes and learn from them. Staff felt encouraged “to dive into that interest [of the program participant] and to follow that desire,” even if it was something they had not tried before. This encouragement was also reflected by a comment from a supervisor,

The team, they don't meet each other with judgement. They share their successes; they share their mistakes as staff and the environment is so supportive and learning-based that nobody's worried about saying ‘I messed this up big time.’ And everybody is so supportive, and they just do something different next time. And that attitude seeps into the participants too.

This culture of acceptance freed staff to find new ways to support participants’ self-determination and help participants to explore their interests.

Two additional factors within the overarching theme of “the importance of relationships” were identified as crucial in fostering self-determination among Autistic adults with ID. The fifth

factor, **staff support parents/guardians as they foster self-determination**, refers to staff's need to have direct, open conversations with participants' families/guardians about their young adult's need to progress toward typical adult responsibilities and experiences within the safe environment of the ASP's program.

Some staff expressed frustration on account of the current ASP practice that all communication with parents/guardians goes through program management. They perceived that this resulted in communication that was not always accurate as demonstrated by this comment,

I think the way a family receives information coming from [manager] versus the way they receive it coming from one of us is a hundred percent different, even if [manager] is just telling them the words that we told her.

This frustration about communication breakdown was particularly obvious in the staff's stated desire to talk directly with parents/guardians about areas of instruction that they felt the program participants needed and wanted but that parents/guardians had previously discouraged or prohibited, such as sexuality. In such cases, a participant may have been trying to choose one direction but were thwarted from that option as it contradicted the persuasion of the parent/guardian. As a staff member commented, "so many of our families grew up with their adult in that [protective] paradigm that they really, really struggle to let go of that control." Staff also emphasized that the autonomy of parents/guardians was often prioritized over the autonomy of the program participant, especially when the desires of parents/guardians conflicted with the program participants. For example, some participants wanted to watch an action movie rated 14A but were not able to because their parents did not provide consent.

Staff also highlighted the importance of being able to have frank discussions with parents/guardians about what is important to the participant. As one staff put it,

I think so many of our families, their hearts are in the best possible place. They love their adults so profoundly and they just want the best for them. But realistically, perception of best practice and what best looks like has changed. It's really, really hard to overcome a lifetime of understanding in a really small amount of contact that we have with families.

One staff member recommended that researchers develop a body of research for supporting the self-determination of Autistic adults with ID and,

make it widely accessible to Autistic people themselves and also to support people in their lives. Information is so powerful, and it gives people the opportunity to advocate for themselves when they have that information, but also gives other people the opportunity to make better informed choices for the people that they are advocating for.

The sixth factor, **cooperation from the local community**, refers to the need for understanding and acceptance from the community to better support program participants' autonomy. Staff spoke about stigma and ableism faced when doing activities in the community. One staff member remarked, "there's definitely widespread community ignorance" that leads to "people not knowing how to respond to us or participants or, you know, behaviours that might be exhibited."

One staff gave an example of a recent trip to a coffee shop, "we're at [a coffee shop] waiting to order drinks and there's a line of 25 people ... and people are starting to get mad that we're taking too long...". The staff member then described her struggle to support program

participants in local community, “we all work really hard at finding that balance where, you know, we’re not antagonizing community members and kind of facilitating a negative perception of the people we’re supporting.” Staff’s anxiety about receiving social censure from the community seemed to interfere with their ability to advocate for program participants to have enough time to complete transactions independently, interfering with their self-determination. These data demonstrate that relationships with participants, community members, and families are important to support and enhance the self-determination of program participants.

Theme 2: Staff perceptions of the skills needed to enhance autonomy.

This theme refers to knowledge and skills that staff think program participants need to enhance their autonomy. There were four key areas that staff felt were important to enhance participants’ autonomy: self-advocacy; interoceptive awareness; working effectively with others; and natural results of choices.

The first key area identified by staff was the need to develop participants’ **self-advocacy skills**; that is, participants’ abilities to effectively make their preferences, needs and choices known to others. For example, one staff member stated, “self-advocacy [is] something that we’re always working on, right? The ability to say, ‘I want’ or ‘I need,’ or ‘yes’ and ‘no’ to things is so, so important.”

The second area, **interoceptive awareness**, refers to the ability to identify internal feelings within one’s body such as hunger, the need to urinate, when one’s heart is racing, and feelings such as anger, embarrassment, and fear (DuBois et al., 2016). As one staff member remarked, “it’s really hard to identify and label wants, needs, desires, hopes, whatever, ... if you’re not able to understand what is happening in your own body or your own mind.”

Increasing interoceptive awareness for program participants could also benefit their self-advocacy by helping them to recognize their internal needs.

The third area, **working effectively with others**, is related to the program taking place in groups and the requisite skills required for successful group participation. For example, one staff member commented, “[it] is like a democracy. We have to respect everybody's choice, but it's also a group so we have to kind of also get a democratic vote quite often, to lead to some kind of choice.” Inherently, participants needed to recognize that working with others means that they will need to compromise at times, as not everyone can get their choice at all times. A staff member noted that, “when it comes to getting everyone's input, we try to shine a light on how others might feel like ‘hey, you pick this game every time we pick a game. How would you feel if you never got to pick the game?’”

Conversely, the nature of program participants being in groups allows for peer-to-peer support as evidenced by this comment, “we have a few participants who are starting to support their peers quite a bit more, they are thinking about them, they are including them, they are bringing them into conversations.” Having skills for working effectively with others could benefit program participants in other settings such as employment.

The fourth subtheme, **natural results of choices**, refers to helping program participants make informed choices by understanding the impact of those choices. One staff member said, “There are a lot of factors that go into making a choice and I feel like we make a really concerted effort to explore those factors and why they matter or if they matter.” Another staff member suggested they help program participants by asking “what happens when you make those decisions? How does it affect the people around you?” Staff said that they also worked on understanding how a choice may impact how the participant feels, “if you don’t sleep at night,

you're gonna be tired all day and you have to deal with that.” This knowledge could help program participants make choices that are aligned with their values, goals, and desires, which fosters self-determination.

In summary, the analysis of staff data highlighted the importance of relationships, knowing and caring about program participants and providing individualized support to benefit program participants' autonomy. Staff data also identified opportunities to enhance program participants' autonomy including providing support to parents/guardians and gaining greater cooperation from the local community. Finally, we also learned from staff the skills that they felt program participants needed to learn to be autonomous, including advocacy skills, interoceptive awareness, working effectively with others, and the natural results of their choices.

DISCUSSION

Many services for Autistic people do not support self-determination (Hodgetts et al., 2018; Mansell & Beadle-Brown, 2012; Webster et al., 2022). This research aimed to learn from the staff of a unique post-secondary transition program about how they support autonomy for its Autistic participants with ID, as well as staff insights regarding the specific skills that staff felt would support Autistic adults with ID to enhance their autonomy and ultimately, their self-determination. We used a CBPR approach with the intent to ensure the research was relevant to Autistic people and to increase the likelihood that the knowledge gained would be integrated into practice for the benefit of the Autistic program participants (Israel et al., 2001). Staff spend a significant amount of time with participants, and their perceptions may differ from parent and/or program participant perceptions. Furthermore, opportunities to be self-determined are essential, and staff are able to create (or not) autonomy-supportive environments. Therefore, garnering

their perspectives is one important component in enhancing supports and services to promote self-determination for Autistic adults with ID.

Although we had conceptualized this study with a focus on autonomy, our findings relate to all three basic psychological needs that Ryan and Deci (2017) propose are necessary for self-determination. Skill development, as suggested by staff, would promote the basic psychological need for competency. According to Ryan and Deci (2017), competence refers to feelings of mastery and accomplishment, and developing the skills identified by staff may support both the Autistic adult's ability to make their choices known and also staff's confidence that they are accurately interpreting the Autistic adult's desire. We identified the overarching importance of taking the time and effort to development meaningful relationships with program participants as a core part of current practices of the ASP's program staff, which is aligned with SDT's basic psychological need for relatedness (Ryan & Deci, 2017). These relationships were deemed to be key to supporting program participants' autonomy. Staff asserted that knowing and caring about the program participants enabled them to personalize their support for enhancing participants' autonomy. That staff members felt supported by the organization enhanced their willingness and capacity to develop relationships with program participants.

However, it takes time to build relationships, and staff turnover interferes with establishment of relationships. In exploring factors that influenced job retention for staff working with people with ID, Murray and colleagues (2022) found that staff ranked their relationship with program participants highest in supporting retention, followed by pay. Low wages are known to be problematic in the disability service sector and contribute to high turnover across countries such as the United States of America, Canada, Australia, England, and Hong Kong (Breen et al., 2022; Macdonald et al., 2018; President's committee for people with intellectual

disabilities 2017, 2017; Stevens et al., 2021; Xun, 2019). However, Murray and colleagues (2022) findings that relationships were deemed even more important than pay reinforces the importance of organizational support for relationship building, and suggests that, even though this time may seem inefficient, it may be cost-effective due to increased staff retention. Additionally, attainment of the skills identified by staff could mitigate the lost time for building relationships when new staff are hired as the participants may require less support to enact their autonomy in ways that staff will understand.

In the ASP's program, tailoring choice-making to program participants' needs and abilities is one component that is intended to maximize choice and control, thus enhancing both opportunity and capacity for self-determination. Maximizing choice and control is one of four essentials of Person-Centred Active Support that has been shown to increase program participants' levels of engagement and autonomy (Felce et al., 2000; Mansell et al., 2003; Stancliffe et al., 2007). By individualizing choice-making for each participant, staff are helping to ensure they can honour program participants' choices. However, staff cannot facilitate autonomy and self-determination on their own. Parents/guardians are the primary people in program participant's lives. Thus, they have significant influence over opportunities to be self-determined. A history of having one's choices respected is one of four elements of real choice (Murphy et al., 2017). Staff expressed a desire to support parents/guardians in their journeys toward helping to increase self-determination for their Autistic young adults with ID.

Being dependent and living with parents is a common feature of young adulthood, regardless of disability, with independent living, long-term relationships, and clear career paths emerging later (Wood et al., 2018). The ASP's program participants are part of the stage of life in which parents are often still engaged in parenting their non-autistic children who are still

living with them (Nelson et al., 2011). Therefore, it is reasonable that parents of program participants are continuing to exert some parental control over them. However, ongoing controlling behaviour may lead to poor autonomy and relatedness outcomes (Liga et al., 2017), and decreased self-determination. Staff also expressed a desire to help parents/guardians understand what is important *to* their Autistic young adult versus what their parent/guardian thinks is important *for* them. In supporting autonomy, it is necessary to strike a balance between what is important to the person being supported and consideration of their health and safety (Sanderson & Lewis, 2012). Staff can support parents/guardians to allow more autonomy for their Autistic young adults to aid program participants' autonomy, self-determination, and future well-being.

The capacity to be self-determined, along with adequate support when needed, is also important (Cheak-Zamora et al., 2020). Staff identified four areas for program participant skill development which could reduce their need for support: (1) self-advocacy skills, referring to the ability to “speak out” (recognizing different ways of communicating) on behalf of oneself (Wehmeyer et al., 2003), (2) interoceptive awareness, which refers to the ability to pay attention to and understand internal signals (Mahler, 2017), (3) working effectively with others, and (4) understanding the natural results of choices. These areas of skill development are often neglected in adult support programming (Bigby et al., 2014, 2017; Bigby & Beadle-Brown, 2018; Stefánsdóttir et al., 2018). Adult support programming often instead focuses on mitigating generic challenges commonly associated with autism, such as social skills training or job interview training, rather than considering the diverse needs of individuals (Lorenc et al., 2018). Together, increased skills and awareness in the areas identified by the staff in this study are likely to have a positive impact on self-determination. Working effectively with others included

using democratic methods or voting, to make group choices. In addition to providing opportunities through voting, program participants must understand their needs, including internal needs recognized through interoceptive awareness, to effectively self-advocate for those needs (Schena II et al., 2022; Mahler et al., 2022). This, in turn, will help to ensure that their desires are included in the democratic method for making group choices.

Implications for practice and service delivery

Although this study was situated within one service provider, many of our learnings are generalizable to other service providers who want to support self-determination for Autistic people with ID. Service providers can support self-determination by adopting programs such as Active Support as a framework to ensure that program participants have opportunities for making choices and are engaged in meaningful activities and relationships (Mansell & Beadle-Brown, 2012). They can also educate themselves on interoception, recognized to influence behaviour and cognition for Autistic people (DuBois et al., 2016), and incorporate activities to increase interoceptive awareness into programming (Mahler, 2017). Service providers can teach self-advocacy as a component element of self-determined behaviour using programs such as the Self-Determined Learning Model of Instruction (SDLMI; Shogren et al., 2012, 2017; Wehmeyer, 1997), including the use of the SDLMI to assist program participants to set their own goals.

Service providers can also explore non-voting methods of group choice-making, such as participatory or consensus methods (Kaner, 2014) or nominal group techniques (Owen et al., 2016). These methods, which would require instruction and practice, could lead to more satisfactory, individualized choices for the program participants. Service providers can help program participants to generate ideas for ways to fund activities other than using program participants' discretionary funds to increase access to activities that are not cost-free.

Service providers can provide training on supporting self-determination to parents/guardians of program participants. One evidence-based approach is the La Trobe Support for Decision-making Practice Framework (Douglas & Bigby, 2020). The efficacy of this approach was demonstrated in a recent study with parents/guardians of adults with ID (Bigby et al., 2022). This could be a parallel training for parents/guardians while teaching self-advocacy skills to program participants.

System advocacy is required to address the issue of low pay in this sector. There may be ways to engage other stakeholders, such as parents and advocacy organizations, to undertake this advocacy. Resolving the issue of pay is critical to the retention of staff and thus to the quality of life for program participants.

Autistic people are often stigmatized which harms their wellbeing (den Houting et al., 2021). People who do not have an Autistic family member or close friend often have only stereotyped knowledge of autism, including attributes such as difficult personalities or behaviour, poor social skills, being weird and awkward, low intelligence, and being withdrawn (Treweek et al., 2018). Training is one method to increase autism knowledge that could enhance cooperation from the community (Gillespie-Lynch et al., 2015; Jones et al., 2021; Waisman et al., 2023).

Limitations and directions for future research

One limitation of this study is that we only recruited staff from one service provider. Interviewing staff from other service providers may have had different results, especially because the program in which these staff work is designed as an autonomy-supportive environment (Reeve, 2006). However, we believe that our findings can generalize to other organizations by suggesting strategies that programs that are not yet autonomy-supportive can

use, or validating approaches that autonomy-supportive programs are using. Another limitation is that all data are based on staff reports and perceptions, with no direct observation of the program in action. Future research could also include direct observation within the program environment to provide context for staff perceptions by observing staff and program participants as they engage in daily activities. Our findings reinforce the importance of wrap-around approaches in which programs and parents/guardians encourage autonomy. However, there is a gap in research on how best to support parents/guardians to enhance autonomy. Future research could explore the efficacy of implementing both the La Trobe Support for Decision-making Practice Framework for parents/guardians along with the SDLMI for Autistic adults with ID.

CONCLUSION

This study revealed key elements for autonomy and autonomy-support for Autistic adults with ID from the perspectives of staff at a post-secondary transition program. Relationships between staff and Autistic adults with ID were critical. We learned that direct communication between stakeholders, including staff, parents/guardians, program participants, and the broader community, would support staff to promote autonomy. Finally, we learned of several skill areas that staff perceived would benefit program participants to enhance their autonomy. This is all crucial information for supporting self-determination for Autistic adults with ID. It also points to the need for more of this type of research, across geographic and cultural borders, with an Autistic-centred and inclusive perspective on quality-of-life issues for this population.

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CHAPTER FIVE – Discussion, Implications, and Conclusions

Integrated Manuscripts: Telling a Story

Throughout my doctoral studies journey, I had two personal goals: (1) to increase participatory autism research; and (2) to advocate for Autistic human rights. Aligned with this, I also knew that I wanted to conduct research that could have a positive influence on increasing self-determination for Autistic adults. These goals influenced my doctoral studies and are reflected in the objectives of this research:

1. To explore the perceived strengths, benefits and recommendations for changes related to a training program designed to enhance research literacy/knowledge of Autistic people from the perspective of Autistic adults.
2. To learn from Autistic people with ID what autonomy means to them and how they want to be supported to be autonomous.
3. To learn from staff of an autism service provider how they support autonomy for its Autistic participants with ID and what specific skills and abilities staff perceive that Autistic adults with ID need to enhance their autonomy.

This dissertation contributes: (1) a training program to enhance Autistic adults capacity to participate in research, which could increase their self-determination; (2) new knowledge on what autonomy, a basic psychological need for self-determination and wellbeing, means to Autistic adults with ID and how they want to be supported to be autonomous; and (3) staff perspectives on autonomy for Autistic adults with ID and how this could transfer to other autism service providers.

Discussions unique to each of the three studies that comprised this dissertation are included in each chapter. In this integrated chapter, I aim to succinctly summarize key findings

from each of the three studies, discuss some emerging insights related to ethical considerations and the methodology and methods used, and integrate findings across studies where applicable. I will highlight research and clinical implications that are drawn from this work, and end with concluding remarks.

Summary of Findings

In the first study (Chapter Two), *Research 101, Effective Collaborators*, we developed training on the research process and collaboration skills for Autistic people to enhance their capacity to collaborate in research and to increase their confidence in collaborative research. We used an evaluation process to understand how we could improve the training. Research participants appreciated that the training was developed specifically for Autistic people and delivered in a group of all Autistic people. They also made recommendations for program content and structure, including pragmatic edits to content, layout, and activities, as well as optional adaptations to tailor the training to meet the needs of diverse participants. Next steps include incorporating the recommendations into the training and preparing it for open access. The training was useful for the ACP for this series of studies and in turn the ACP provided feedback contributing to the refinement of the training.

In the second study (Chapter Three), *Being able to be myself: Understanding Autonomy and Autonomy-Support from the Perspectives of Autistic Adults with ID*, we learned from participants that autonomy means being able to be themselves, to have choice and control, to communicate in their way, and to be in safe environments. We also learned that it is important to have Autistic facilitators. Strategies they suggested to support choice and control included ensuring things the participants like to do are in the options presented, letting participants choose their way, and genuinely honouring and respecting their choices. Within the theme of

communicating their own way, strategies included learning to understand participants' communication, listen to and hear participants, and let participants have time to process. Finally, strategies suggested for safe environments included having structure and predictability, accommodating competing needs of participants, and acceptance. This new knowledge will help staff, families, caregivers, professionals, and researchers to support the basic human right of Autistic adults with ID to be self-determined.

In the third study (Chapter Four), *"It's really who they are and what they want": Staff Perspectives on Supporting Autonomy for Autistic adults with ID*, we learned from staff how they currently support autonomy for program participants, Autistic adults with ID, and specific skills that program participants need to learn to enhance their autonomy. We learned the importance of relationships including staff knowing the participants, staff caring about the participants, staff tailoring choice-making for each participant, staff feeling supported by the organization, having staff support parents/guardians as they foster self-determination in their Autistic young adults, and staff needing to build cooperation and acceptance within the local community. Staff identified skills that would assist participants to be more autonomous including self-advocacy skills, interoceptive awareness, teamwork, and natural results of choices.

Reflections on Ethical Considerations in using a CBPR approach with Autistic adults

Researchers have identified a number of ethical issues that can arise in the conduct of CBPR (e.g. Fadem et al., 2003; Flicker et al., 2007; Kwan & Walsh, 2018). Ethical issues that were relevant to this research can be summarized as follows: (1) issue selection when a community is deeply divided; (2) inclusion and exclusion in research team composition, and sample selection; (3) power imbalance on research teams; and (4) using the findings to unite and strengthen the community.

Issue Selection when a Community is Deeply Divided

The autism community is divided on research priorities. The majority of autism research has focused on biology, causes, and treatments (den Houting & Pellicano, 2019). Autistic self-advocates have been clear that they do not desire research to find a cure for autism (Nicolaidis et al., 2011; Pellicano et al., 2014). Furthermore, the Autistic community has identified broad priorities such as physical and mental healthcare, education and employment (Pearson et al., 2022). For this research, we chose to focus on issues identified as priorities by Autistic people: (1) autonomy and self-determination, as they impact wellbeing; and (2) increasing capacity of and opportunities for Autistic people to be involved in participatory autism research recognizing that there are transferable employment skills involved.

While we acknowledge that our primary motivation to focus on these topics stemmed from support for Autistic people and have articulated their potential benefits, we believe that this work will also have many benefits for the broader research and clinical autism communities. For example, understanding the intentions of Autistic people with ID can be difficult, and our findings can be used to enable people in the broader research and clinical autism communities to feel more equipped to support autonomy and choice-making for Autistic people with ID. Additionally, stakeholders, including Autistic and non-autistic people in a variety of roles in the autism community, have expressed a need to better “bridge the gap” between scholars and the Autistic community (den Houting et al., 2022). *Research 101, Effective Collaborators* will provide autism researchers who do, or want to, use participatory research methods with a freely available and accessible tool that can promote competence in their Autistic collaborators and co-researchers.

Inclusion/Exclusion in Research Team Make-Up and Sample Selection

McCoy et al. (2020) raised the issue of full representation of the autism spectrum in advocacy contexts as opposed to partial representation by only Autistic adults with the ability to verbally communicate their thoughts and ideas and participate in decision-making. A potential solution for representation of the autism spectrum could be to ensure that as many perspectives as possible are represented as part of the research process. We opted to only have Autistic individuals who were able to represent themselves through verbal and/or written communication for the Autistic Community Partners (ACP). CBPR with the Autistic community is an emerging field and we made a conscious decision to minimize communication challenges. For the study presented in Chapter Three, we were interested in Autistic individuals with ID's perspectives and/or thoughts, so we decided to not use proxy reporting. Instead, we used prolonged engagement with participants, video and audio recordings, and interpretation by a group of seven researchers, six of whom were Autistic and one who was not Autistic. We identified our personal biases and held each other to account when we noticed that personal biases were creeping into data interpretation.

Power Imbalance

There is an inherent imbalance of power between academia and community, including the Autistic community, with academia holding the bulk of the power. Nicolaidis et al. (2019) suggested creating processes to effectively share power such as a structured process for decision-making, providing materials in advance of meetings, allowing enough time for partners to process information, and fairly compensating community partners for their work. We aimed to incorporate all of these strategies into this work. For example, even though the use of startle reflex modulation measurement (Lyons, 2015) was approved by my dissertation committee, we

did not use this technique based on feedback from the ACP. This technique involved placing electrodes on participants' faces, and, early in the research process for this study, the ACP had a thoughtful discussion and was united in their perception that this technique would be perceived as uncomfortable and invasive. As such, we opted to remove the technique. This helped to develop trust between all members of the research team. We used an anonymous, structured process for decision-making that was an adaptation of Nicolaidis et al.'s process for when we did not reach clear consensus. We provided materials in advance, whenever possible (Nicolaidis et al., 2019). Importantly, the ACP was fairly compensated for their work on these studies.

Uniting and Strengthening the Community

Taking a strengths-based approach can help to avoid re-stigmatizing a marginalized community such as the Autistic community (Tuck, 2009). The work in this dissertation was conducted from a strengths-based perspective. The ACP approved each of the manuscripts, which were written from a strengths-based perspective. The third study, presented in Chapter Four, was also reviewed by the staff from the autism service provider that took part in the study. Although staff were not part of the Autistic community, it was important to get their feedback, as one objective of this research was to enact change to enhance autonomy for Autistic individuals with ID and staff do hold power in enacting these changes.

Reflections on Quality and Rigour

Qualitative researchers have suggested various criteria to determine and describe quality and rigour in qualitative research. For example, Stringer (2014) asserted that rigour in action research is:

based on checks to ensure that the outcomes of research are trustworthy – that they do not merely reflect the *particular perspectives, biases or worldview of the*

researcher [emphasis added] and are not based solely on superficial or simplistic analyses of the issues investigated (p. 92).

Lincoln and Guba (1986) identified four key attributes to establish trustworthiness: (1) credibility which refers to the integrity of the study; (2) transferability, which refers to the possibility of applying the outcomes of the study to other contexts; (3) dependability, which refers to study procedures that are clearly defined and transparent; and (4) confirmability, which refers to evidence that the procedures described were actually followed. Morse et al. (2002) argued for investigator responsiveness, methodological coherences, appropriate sample, collecting and analyzing data concurrently, thinking theoretically, and theory development to ensure rigour. Mayan (2009) provided a useful set of strategies that combines suggestions from multiple authors, including the authors referenced above, to ensure rigour including the strategies we used as outlined in the next sections.

Membership of the ACP

Each member of the ACP was intentionally selected for their variety of lived experiences and perspectives, including being unique from each other and from me. AB is an Autistic parent of an Autistic child and a member of her local Autistic rights community. CD brought a disability studies lens to the project. AK is a linguist who used language, paralanguage, and physical communication in the research. AL brought his lived experience as an Autistic university graduate. HB is an Autistic professor who researches thriving and belonging for Autistic people.

Prolonged Engagement

In seeking to understand what autonomy means to Autistic people with ID and how they want to be supported, we spent between seven and sixteen hours with our participants to learn

from them. We watched the video recordings several times to understand what the participants were telling us, both verbally and non-verbally.

Researcher Responsiveness

Researcher responsiveness refers to the need for researchers to be open to the data and to set aside preconceived ideas about what the data will show. We spent a lot of time with the data, including working with it and then setting it aside for a few days before coming back to the data to see if our analysis still resonated. We spent many ACP meetings discussing the data and determining the meaning of the data.

Thinking Theoretically

This concept refers to working with the data from both macro and micro perspectives. This involved an iterative process of moving between looking at the data in detail and at a big picture level. This process helped us to refine themes and subthemes ensuring that they represented the data.

Peer review

Peer review is the process of engaging other researchers in discussions about the data and our process of working with the data. As themes and subthemes were identified, all seven members of the research team reviewed and contributed to refining the themes and subthemes.

Reflexivity

As insider researchers, being aware of our own perspectives, biases, and worldview was important when conducting CBPR with the Autistic community. One of the complaints leveled by the Autistic community about research without Autistic partners, is the misinterpretation of the data, in part due to not taking into account an Autistic tendency for literal interpretation of language (Nicolaidis et al., 2011). Each of the ACP identified their biases and shared them with

the team. I kept a reflexive journal about my own perspectives and potential influences. I discussed these with my supervisor, the ACP, my supervisory committee, and other trusted colleagues.

Audit Trail

A record of all iterations of data analysis has been kept electronically. All meetings of the ACP took place over Zoom and were recorded. Most decisions were made during ACP meetings thus we have record of them.

Adequacy of Data

We agree with Braun and Clarke's (2021) assertion that determining the adequacy of data is a subjective decision. For Study 2, we stopped data collection after we felt that all guiding questions had been answered and we were not getting new data.

Integration of findings across studies

This dissertation is comprised of three distinct studies that aligned in their focus on enhancing autonomy and self-determination for Autistic people. However, as we dove deeply into analyzing data, we realized that there was meaningful overlap in findings in the perceptions of the different stakeholders represented in studies 2 and 3 (presented in Chapters Three and Four). The importance of relationships was a strong finding across both studies. Autistic adults with ID indicated that they want to communicate in their own way in a safe environment which requires staff to know and care about them. Furthermore, Autistic adults with ID told us that they want to have choice and control, including being able to choose in their own way and having things they like included in the options which was supported by staff indicating that they tailor choice-making for each program participant.

Our research team also conducted a third related study, which was not part of my dissertation, that can be integrated to present a wholesome understanding of how to support autonomy for Autistic people. This related study asked Autistic adults without ID about their experience of self-determination. We learned that they wanted safe and supportive environments, to have their choices respected, support with executive functioning such as time to process, and clear communication (Thompson-Hodgetts et al., 2023). This aligned with our findings from Autistic adults with ID; they wanted safe environments, to be understood in their communication, and time to process.

Implications for Practice

We found that Autistic adults with ID can and want to be self-determined. Indeed, opportunity for choice-making is a component of self-determined behaviour that can be directly increased by support staff and others around the Autistic adult (Shogren et al., 2017). Service providers can play an important role in facilitating this by creating need-supportive environments. Building secure relationships between Autistic adults with ID and those who support them is critical as they enhance communication, contributes to better co-regulation, and supports autonomy for participants (Ryan & Deci, 2017). We found that strategies included letting participants make choices in their own way, being sure to include things they like in the choices and honouring their choices. Strategies also include learning to understand participants' methods of communication, a process that often includes holding space and giving participants time to process information and decisions. Structure, predictability, and routine were key for participants to be regulated, and staff and participants benefited from co-regulation strategies and creating an environment that accommodated competing needs among participants. Finally,

service providers should consider hiring Autistic staff as including Autistic facilitators in programming can also enhance the ability of Autistic adults with ID to be self-determined.

Service providers can support self-determination by adopting programs such as Person-Centred Active Support as a framework to ensure that program participants have opportunities for making choices and are engaged in meaningful activities and relationships (Mansell & Beadle-Brown, 2012). They can also educate themselves on interoception, recognized to influence behaviour and cognition for Autistic people (DuBois et al., 2016), and incorporate activities to increase interoceptive awareness into programming (Mahler, 2017). Service providers can teach self-advocacy as a component element of self-determined behaviour using programs such as the SDLMI (Shogren et al., 2012, 2017; Wehmeyer, 1997), including the use of the SDLMI to assist program participants to set their own goals. Service providers can provide training on supporting self-determination to parents/guardians of program participants. One evidence-based approach is the La Trobe Support for Decision-making Practice Framework (Douglas & Bigby, 2020). The efficacy of this approach was demonstrated in a recent study with parents/guardians of adults with ID (Bigby et al., 2022). This could be a parallel training for parents/guardians while teaching self-advocacy skills to program participants.

System advocacy is required to address the issue of low pay in this sector. There may be ways to engage other stakeholders, such as parents and advocacy organizations, to undertake this advocacy. Resolving the issue of pay is critical to the retention of staff and thus to the quality of life for program participants. Autistic people are often stigmatized which harms their wellbeing (den Houting et al., 2021). People who do not have an Autistic family member or close friend often have only stereotyped knowledge of autism, including attributes such as difficult personalities or behaviour, poor social skills, being weird and awkward, low intelligence, and

being withdrawn (Treweek et al., 2018). Training is one method to increase autism knowledge (Gillespie-Lynch et al., 2015; Jones et al., 2021; Waisman et al., 2023). Advocacy is needed to encourage the community to participate in autism training.

Implications for Research

The *Research 101, Effective Collaborators* training course has the potential to increase the frequency and effectiveness of participatory autism research, improving the relevance of autism research to the Autistic community and fostering more research that responds to community needs. Increasing participatory approaches to autism research can mean that more research will be conducted to improve the quality of life and wellbeing of Autistic people *now*, in contrast to much traditional research. Autism researchers are invited to use this training course with their Autistic community partners.

The data collection methods utilized in *Being able to be myself: Understanding Autonomy and Autonomy-Support from the Perspectives of Autistic Adults with ID* could be used to include Autistic adults with ID in future research. They represent a portion of the autism constellation frequently left out of research (McCoy, 2020). Creating a need-supportive environment for conducting research could also facilitate the participation of Autistic adults with ID in research (Kuld et al, 2023).

Directions for Future Research

Future research could include tailoring the *Research 101, Effective Collaborators* training for Autistic people with ID and evaluating the training from their perspective. Suitable training could facilitate their collaboration in research, both enhancing their self-determination and providing opportunities to influence research in the direction they want.

When seeking the perspectives of Autistic people with ID who have difficulty expressing their inner thoughts and ideas, future research could involve parents and staff in addition to researchers to triangulate communication interpretations. When exploring staff perspectives, future research could also include direct observation within the program environment to provide context for staff perceptions by observing staff and program participants as they engage in daily activities. There is a gap in research on how best to support parents/guardians to enhance autonomy. Future research could explore the efficacy of implementing evidence-based tools such as the La Trobe Support for Decision-Making Practice Framework for parents/guardians to give parents the tools to support their (adult) child's autonomy (Bigby et al., 2022).

Finally, this dissertation focused on day-to-day choices, for which I argue that promoting individual (as opposed to supported) autonomy should be prioritized. We did not consider autonomy in making life choices or difficult decisions for which a lens of Supported Decision-Making theory would be useful (Harding & Taşcıoğlu, 2018). Within that context, an exploration of Relational Autonomy theory would be appropriate (Oshana, 2020). Relational Autonomy refers to a “variety of conceptions of personal autonomy, all of which are united in the belief that autonomous beings are, of necessity, socially situated and interdependent” (Oshana, 2020, p. 1). Future research could explore supporting these more complex choices and decisions.

Concluding Comments

This dissertation provides a pathway to increased autonomy for Autistic people. The *Research 101 Effective Collaborators* training course will prepare Autistic people to be informed and empowered community partners in research. As such, they will have opportunities to influence future autism research. We learned from Autistic participants with ID that autonomy means being able to be themselves and includes having choice and control, communicating their

way, and being in a comfortable environment, and having Autistic facilitators. They told us how we can support them to be autonomous. We learned of several skill areas that Autistic people with ID could develop to also benefit autonomy. Relationships are critical. It takes a community to support Autistic adults with ID to be autonomous, ultimately enhancing self-determination and quality of life. It also points to the need for more Autistic-centred and inclusive research, across geographic and cultural borders. We hope that this work inspires others to consider how they can best support Autistic people with ID.

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APPENDICES

Appendix 1 – Research 101 Recruitment Email

Subject line: Research 101 “Effective Collaborator” Training Study

Body of Email:

We would like to invite you to take part in our research project evaluating the Research 101 “Effective Collaborator” Training to improve the training and resources for future attendees. You have been invited to participate because you recently attended the Training as part of your role as an Autistic Community Partner for the [Autonomy Study or Campus Ready Study].

Before you decide whether to participate, we would like you to understand why the research is being conducted and what it would involve for you. Attached is a Participant Information Letter and Consent Form. Please ask us questions if anything is unclear.

The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta (Pro00119538).

If you decide to participate, please sign, and return the Consent Form to me at jgryan@ualberta.ca. You may electronically sign the Consent Form, or you may print the Consent Form, sign it, scan it, and return it to me via email, or you may print the Consent Form, sign it, and return it via mail to:

Jackie Ryan
Room 3-78, Corbett Hall
University of Alberta
8205 114 St NW
Edmonton, AB T6G 2G4

Sincerely,

Jackie Ryan
PhD Candidate, Rehabilitation Science

Appendix 2 – Research 101 Information Letter and Consent Form

INFORMATION LETTER and CONSENT FORM

Study Title: Research 101 “Effective Collaborator” Training Development

Ethics ID#: Pro00119538

Principal Investigator:

Jackie Ryan, PhD Candidate
Faculty of Rehabilitation Medicine
3-78 Corbett Hall
8205 114 St NW
Edmonton, AB T6G 2G4
jqryan@ualberta.ca

Supervisor:

Dr. Sandy Thompson-Hodgetts
Department of Occupational Therapy
3-20 Corbett Hall
8205 114 St NW
Edmonton, AB T6G 2G4
sandra.hodgetts@ualberta.ca
780 -492-8216

Background

You are being asked to be in this study because you recently attended the Research 101 “Effective Collaborator” Training as part of your role as an Autistic Community Partner for the [Autonomy Study or Campus Ready Study]. The results of this study will be used in support of my thesis and is partially funded by Social Sciences and Humanities Research Council of Canada. Before you decide, one of the researchers will go over this form with you. You are encouraged to ask questions if you feel anything needs to be made clearer. You will be given a copy of this form for your records.

Purpose

To create an open access training package to increase autistic adults’ knowledge of the research process and skills for collaboration. This research will help us to improve the training package.

What will happen during this study?

You will take part in an interview over Zoom that will take about 30 minutes. You may choose to have your camera off. The interview will be audio recorded and transcribed, without using your name. After transcription, the audio recording will be deleted. The information you provide will be used to improve the Research 101 “Effective Collaborator” Training materials.

What are the benefits of this study?

You will help us to improve the Research 101 “Effective Collaborator” training for future attendees.

What are the risks of this study?

We do not expect that you will experience any harm if you participate in this study. You may experience fatigue during the interview. You can request a break. You can stop taking part at any time.

Will I be paid to be in this research?

You will receive a gift card for participating in the interview. If you withdraw from the study after the interview, you will still receive a gift card.

Voluntary participation

You do not have to take part in this study. This will have no impact on your right to attend the Research 101 “Effective Collaborator” Training sessions. Even if you agree to be in the study, you can change your mind and withdraw at any time. If you withdraw after we have completed data analysis, we cannot remove your data, but we will not use any direct quotes from you. You may choose to not answer specific questions during the interview.

Will my privacy be protected?

The data collected from you will be shared with the research team. Members of the research team have signed confidentiality agreements that require them to keep all the information in any form confidential and secure while in their possession. Data will not identify you by name. A pseudonym that is only known to the researchers will be used. We intend to publish the research (for example, in scholarly publications) and make public presentations based on the research findings. If the results of the study are published and / or presented your identity will remain confidential. We will not identify you by name. The information that you share with the research team will be kept for at least five years after the study is done. All information will be kept in a secure and locked filing cabinet or on an encrypted computer that can only be entered through a password. Zoom recordings and transcriptions may be uploaded to a server outside Canada and subject to the privacy laws of that jurisdiction. The anonymised transcriptions will be shared with the Research 101 team and analysed to improve future workshops but will not be shared with anyone else or used for any other purpose.

Questions/concerns:

Please contact Jackie Ryan via email jgryan@ualberta.ca.

The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. For question regarding participant rights and ethical conduct of research, contact the Research Ethics Office at reoffice@ualberta.ca (and reference Ethics ID Pro00119538). This office is independent of the researchers.

How do I indicate my agreement to be in this study?

By signing below, you understand:

- That you have read the above information and have had anything that you do not understand explained to you to your satisfaction.
- That you will be taking part in a research study.
- That you may freely leave the research study at any time.
- That you do not waive your legal rights by being in the study
- That the legal and professional obligations of the investigators and involved institutions are not changed by your taking part in this study.

SIGNATURE OF STUDY PARTICIPANT

Name of Participant

Signature of Participant

Date

SIGNATURE OF PERSON OBTAINING CONSENT

Name of Person Obtaining Consent

Contact Number

A copy of this consent form has been given to you to keep for your records and reference.

Appendix 3 – Participant Information Letter – Bristol, UK

Participant Information Sheet

Project title: Research 101: Evaluation

Invitation paragraph

We would like to invite you to take part in our research project evaluating the Research 101 Workshop. Before you decide whether or not to participate, we would like you to understand why the research is being conducted and what it would involve for you. Talk to others about the study if you wish. Please ask us questions if anything is unclear.

What is the purpose of the project?

This project seeks to evaluate the Research 101 Training workshop, to improve the training and resources for future attendees.

Why have I been invited to participate?

You have been invited to participate because you have signed up to attend the training workshop. Please note that the research project is completely separate to the workshop, and you can choose to attend the workshop without taking part in the research project. Your experience of the workshop will not be affected by whether or not you choose to participate in this project.

Do I have to take part?

It is up to you whether you decide to take part in this research project. You can take some time to read through this information sheet and ask us any questions you might have, and you can discuss this with other people. If you decide not to take part you can still attend the workshop. You are free to withdraw from the study at any point before the interview takes place, without giving a reason. If you withdraw from the study this will not impact your attendance at the workshop.

You can also withdraw from the study after the interview takes place. However, your answers will be transcribed and anonymised approximately two weeks after the interview takes place, and any recordings will be deleted. After this time it will not be possible to remove your answers from the study as we will not be able to identify them.

What will happen to me if I take part and what will I have to do?

If you take part, we would like you to take part in an interview to share your feedback on the training workshop, approximately 2-6 weeks after the last workshop session. You can choose whether this is a private meeting with just you and the researcher, or a focus group where several people answer the questions at the same time. The interview will take place online, using Zoom, and will take approximately 30 minutes for a one-to-one meeting, or around 1.5 hours for a focus group.

You will be sent the questions before the interview, and you can choose not to answer any question if you do not wish to. The questions will focus on the content of the workshop and ask is anything that could be done differently to improve your experience of the workshop.

You can choose whether to have your video on or off, and whether you would like to speak your answers or type them in the chat. The interview will be recorded so that we can make a note of

your answers later on. Any personal information will be removed from the transcripts so that they will be completely anonymised, and nobody will be able to tell that you took part. We will delete the recording once the transcript has been produced.

What are the possible disadvantages and risks involved in taking part in the project?

We do not anticipate any risks, discomfort, or inconvenience as a result of taking part.

What are the possible benefits of taking part?

There are no direct benefits to you for taking part, although you will help us improve the Research 101 workshop for future attendees. You will also receive a £50 voucher as thanks for your time.

Will my participation in this project be kept confidential?

All your answers to the questions will be kept confidential. If you take part in a focus group to give feedback, all members of the focus group will be reminded that everything said during the focus group should remain confidential.

Your data will be collected through video recordings on Zoom, which will be stored on the secure University of Bristol server. The recordings will be transcribed, with any personally identifying information removed, so that no one will be able to tell from the transcriptions that you took part. The recordings will be deleted two weeks after the interview, once the transcriptions have been produced. The anonymised transcriptions will be shared with the Research 101 team and analysed to improve future workshops, but will not be shared with anyone else or used for any other purpose.

What will happen to the results of the research project?

We will use your feedback to improve the Research 101 training workshop and resources. We will make changes based on your comments, and try out the updated version of the workshop in other settings. The workshop may go through several more tests before the final version is developed. Once we have produced the final version of resources, we will share these with you if you would like. The workshop slides and other resources will be made freely available on an open website for anyone to download and use.

Who is organising and funding the research?

The research is being organised by Laura Hull (Bristol Medical School, University of Bristol), Jackie Ryan (University of Alberta) and Sue Fletcher-Watson (University of Edinburgh). It is funded by the Elizabeth Blackwell Institute at the University of Bristol, from the Participatory Research Fund.

Who has reviewed the study?

This study has been reviewed by the Faculty of Health Sciences Research Ethics Committee at the University of Bristol.

Further information and contact details

If you would like any further information about this study, or have any questions before you decide whether to take part, please contact Laura Hull: laura.hull@bristol.ac.uk.

If you have any concerns related to your participation in this study, please contact the Faculty of Health Science Research Ethics Committee, via the Research Governance Team, research-governance@bristol.ac.uk.

Appendix 4 – Consent Form – Bristol, UK

CONSENT FORM

Title of Project: **Research 101: Evaluation**

Name of Researcher: **Laura Hull**

Please initial all boxes

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time up until two weeks after the interview/focus group, without giving a reason. I understand that after this time my responses will be anonymised and so my data cannot be withdrawn.

3. I understand and consent to the use of the recording by University of Bristol. I understand that the information and recording is for research and training purposes only, and will only be shared with members of the research team, and that the recording will be deleted after transcripts have been produced.

4. I agree to being audio recorded during the interview/focus group.

5. I agree to take part in the above study.

Appendix 5 - Guiding Questions for Research 101 Interviews

1. Before the training, did you have any experience of autism research?
 - a. This could be as a participant in research studies, as a collaborator or researcher, or by reading or discussing autism research with other people.
2. Why did you decide to attend the Research 101 Training?
 - a. Was there any particular goal or skill that you wanted to achieve through attending?
3. Overall, what was your experience of the Research 101 Training?
 - a. What was your experience of being in a group of Autistic people?
4. What is your main takeaway from the training?
 - a. Will this make a difference to your life? If yes, how?
5. What was the best part of the training?
6. What was the worst part of the training?
7. Was the workshop material relevant and easy to understand?
 - a. Introduction
 - b. Being a Collaborator
 - c. Research Process 1: Getting to the Question
 - d. Research Process 2: Answering the Research Question
 - e. Research Process 3: Practical Questions
 - f. Outcomes, Publications, and Implementation
 - g. Next Steps
 - h. What would you change if anything?
8. Did the support content (visual materials, videos, group activities, etc.) help you to learn?
 - a. What would you change if anything?
 - b. What would you like more of?
 - c. What would you like less of?
9. What did you think of the design of the slides?
 - a. Were the colours and contrast appropriate?
 - b. Were the slides too busy or boring?

- c. How could they be improved?
10. Was the length of each session appropriate?
 - a. Were you too tired by the end?
 - b. Could you have continued learning for longer?
 11. Was the pace of each session appropriate?
 - a. Did the trainers spend too much time on any areas?
 - b. Did the trainers spend too little time on any areas?
 12. Was there enough time allocated for questions?
 13. Was the proportion of time spent on lecture, interactive and group work satisfactory?
 14. Do you feel that you are prepared to work with researchers as an equal and empowered partner?
 - a. If not, what knowledge and/or skills do you need to acquire?

Appendix 6 – Invitation to Parent Information Session (ASP Participants)

INVITATION TO INFORMATION SESSION ABOUT STUDY (PARENTS/GUARDIANS)

Learning from and with autistic adults about making their own choices.

Ethics ID#: Pro00103146

Research Investigator: Jackie Ryan, MA, PhD Candidate

Supervisor: Dr. Sandy Thompson-Hodgetts

When

Monday, August 16, 2021 at 6:30 pm

Where

Zoom:

Zoom link

Who

Parents and/or guardians of ASP participants

What

An information session about research to learn from and with autistic adults about autonomy. Autonomy is the freedom to make one's own choices; to act according to one's preferences, interests, and abilities.

Why

Autonomy is important to quality of life.

Most researchers have not taken the time to listen to autistic people who have trouble expressing their inner thoughts and ideas. We know of several promising methods to learn from these autistic adults. Methods include arts-based approaches, photovoice, and Deep Assessment. We will describe these methods in detail at the information session.

Appendix 7 – Parent/Guardian Consent Form

Study Title:

Learning from and with autistic adults about making their own choices

Ethics ID#: Pro00103146

Principal Investigator:

Jackie Ryan, PhD Candidate
Faculty of Rehabilitation Medicine
University of Alberta
jqryan@ualberta.ca

Supervisor:

Dr. Sandy Thompson-Hodgetts
Department of Occupational Therapy
University of Alberta
780-492-8416
sandra.hodgetts@ualberta.ca

Background and Purpose:

- Being self-determined enhances quality of life.
- Autistic people are less self-determined than their peers, including peers with developmental disabilities.
- Autonomy is an important factor for self-determination.
- There is little research with autistic people who have non-traditional communication preferences or have difficulty describing their inner thoughts and ideas.
- We want to understand what autonomy and choice means to autistic people.
- We want to understand what supports autonomy and choice for autistic people.

Why is this research important?

- So we know when and how to support autonomy and choice for autistic people.

Who can join this study?

- ASP participants.
- ASP participants' parents/guardians (Deep Assessment only, separate information & consent form)
- ASP program facilitators.

What will happen during this study?

- We will ask you to assist your son/daughter to fill out some paperwork that will include demographics, information about their autonomy, quality of life, and anxiety; and how autonomy-supportive the ASP environment is.
- Your son/daughter will take part in their choice of activity to help us understand what autonomy means to them and what supports their autonomy. The options are:
 - Interview
 - Photovoice or other art
 - Written diary
 - Deep assessment (Separate Consent Form)
- Activities will take place during ASP sessions at the Shammy or the Centre. These sessions will be led by the research team. Participants may be supported by the program facilitators and/or parents/guardians.
- Activities will be video and/or audio recorded and being part of the study requires that recordings will be made.

What are the benefits of this study?

- What we learn will help us to design better supports for autistic adults. What we learn will help us to make ASP more fun for your son/daughter.
- Your son/daughter will receive a small gift-card for his or her participation.

What are the risks of this study?

- We do not expect that your son/daughter will experience any harm if he or she participates in this study.
- If you decide you do not want to take part in this study, it will not affect your son/daughter's participation in ASP.
- Your son/daughter may experience fatigue when doing the activities. They can request a break. They can stop taking part at any time.

Will my privacy be protected?

- The data collected about your son/daughter will be shared with the research team.
- Members of the research team have signed confidentiality agreements that require them to keep all the information in any form confidential and secure while in their possession.
- Data will not identify your son/daughter by name. A pseudonym that is only known to the researchers will be used.
- We intend to publish the research (for example, in scholarly publications) and make public presentations based on the research findings. If the results of the study are published and / or presented your son/daughter's identity will remain confidential.
- Any report published because of this research will not identify your son/daughter by name.
- You and your son/daughter may choose to have their name attached to their artwork that may be displayed as part of a presentation. If you and your son/daughter choose this, then we will honour your request and credit their artwork. If either of you or your son/daughter do not choose to have their name attached to their artwork, we will not attach their name.
- The information that you share with the research team will be kept for at least five years after the study is done. All information will be kept in a secure and locked filing cabinet or in an encrypted computer that can only be entered through a password.
- Zoom recordings and Otter transcriptions may be uploaded to a server outside Canada and subject to the privacy laws of that jurisdiction.

Can I withdraw from the study?

- You are free to withdraw your consent to take part in this study at any time. Withdrawing your consent does not change your ability to participate in the ASP program.

Questions/concerns:

- Please contact Jackie via email at jgryan@ualberta.ca or via phone at 780-XXX-XXXX.
- The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. For question regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.

CONSENT FORM

Project Title: Learning from and with autistic adults about making their own choices	Tel: (780) XXX-XXXX
Locally Responsible Investigator: Jackie Ryan	

	<u>Yes</u>	<u>No</u>
Do you understand that your son/daughter has been asked to be in a research study?	<input type="checkbox"/>	<input type="checkbox"/>
Have you read and received a copy of the attached Information Sheet?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand the benefits and risks involved in your son/daughter taking part in this research study?	<input type="checkbox"/>	<input type="checkbox"/>
Have you had an opportunity to ask questions and discuss this study?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand that your son/daughter is free to withdraw from the study at any time without having to give a reason and without affecting your son/daughter's participation in ASP?	<input type="checkbox"/>	<input type="checkbox"/>
Has the issue of confidentiality been explained to you?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand who will have access to the records?	<input type="checkbox"/>	<input type="checkbox"/>
Who explained this study to you? _____		

I agree for my son/daughter to participate in the research activities	YES	<input type="checkbox"/>	NO	<input type="checkbox"/>
I would like my son/daughter's contact information added to a recruitment list for future research	YES	<input type="checkbox"/>	NO	<input type="checkbox"/>
Signature of Parent/Guardian: _____				
(Printed Name): _____				
Date: _____				
I believe that the person signing this form understands what is involved in the study and voluntarily agrees to take part.				
Signature of Investigator or Designee _____ Date _____				

Appendix 8 – Autistic Adults with ID Assent Form

Study Title:

Learning from and with autistic adults about making their own choices

Ethics ID#: Pro00103146

Principal Investigator:

Jackie Ryan, PhD Candidate
Faculty of Rehabilitation Medicine
University of Alberta
jqryan@ualberta.ca

Supervisor:

Dr. Sandy Thompson-Hodgetts
Department of Occupational Therapy
University of Alberta
780-492-8416
sandra.hodgetts@ualberta.ca

Background and Purpose:

- Being self-determined enhances quality of life.
- Autonomy and choice are important factors for self-determination.
- Self-determination means you are in charge of your life.
- We want to understand what autonomy and choice means to autistic people.
- Autonomy means that you choose to do things that you like and want to do.
- We want to understand what supports autonomy and choice for autistic people.



Why is this research important?

- So we know when and how to support autonomy and choice for autistic people.

Who can join this study?

- ASP participants.
- ASP participants' parents/guardians.
- ASP program facilitators.

What will happen during this study?

- We will ask you to fill out some paperwork that will include information about you and your autonomy, quality of life, and anxiety; and how much choice you get in ASP. Your parents/guardians can help you.
- You will take part in your choice of activity to help us understand what autonomy and choice means to you and what helps you to make choices. The choices are:
 - Interview
 - Photography or other art
 - Keeping a diary
 - Deep assessment
- Activities will take place during ASP sessions at the Shabby or the Centre. These sessions will be led by the research team. You may be supported by the program facilitators and/or your parents/guardians.
- You will be video recorded during the activities. We will use software called Otter to write down what you say.



What are the benefits of this study?

- What we learn will help us to design better supports for autistic people. What we learn will help us to make ASP more fun for you.

- You will receive a small gift-card for your participation.

What are the risks of this study?

- We do not expect that you will experience any harm if you participate in this study.
- If you decide you do not want to take part in this study, it will not affect your ability to take part in ASP.
- You may experience fatigue when doing the activities. You can ask for a break. You can stop taking part at any time.

Will my privacy be protected?



- The data collected about you will be shared with the research team.
- Members of the research team have signed confidentiality agreements that require them to keep all the information in any form confidential and secure while in their possession.
- Data will not identify you by name. A pseudonym that is only known to the researchers will be used. A pseudonym is a fake name. You can choose your pseudonym.
- We intend to publish the research (for example, in research publications) and make public presentations based on the research findings. If the results of the study are published and / or presented your identity will remain confidential.
- Any report published because of this research will not identify you by name.
- You may choose to have your name attached to your artwork that may be displayed as part of a presentation. If you choose this, then we will put your name on your artwork.
- The information that you share with the research team will be kept for at least five years after the study is done. All information will be kept in a secure and locked filing cabinet or in an encrypted computer that can only be entered through a password.
- Zoom recordings and Otter transcriptions may be uploaded to a server outside of Canada and subject to the privacy laws of that location.



Can I withdraw from the study?

- You are free to withdraw your consent to take part in this study at any time. Withdrawing your consent does not change your ability to take part in ASP.

Questions/concerns:

- Please contact Jackie via email at jgryan@ualberta.ca or via phone at 780-XXX-XXXX.
- The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. For questions about participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.

ASSENT FORM

Project Title: Learning from and with autistic adults about making their own choices Locally Responsible Investigator: Jackie Ryan	Tel: (780) XXX-XXXX
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	<u>Yes</u>	<u>No</u>
Do you understand that you have been asked to be in a research study?	<input type="checkbox"/>	<input type="checkbox"/>
Have you read and received a copy of the attached Information Sheet?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand the benefits and risks involved in taking part in this research study?	<input type="checkbox"/>	<input type="checkbox"/>
Have you had an opportunity to ask questions and discuss this study?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand that you are free to withdraw from the study at any time without having to give a reason and without affecting your participation ASP?	<input type="checkbox"/>	<input type="checkbox"/>
Has the issue of confidentiality been explained to you?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand who will have access to the records?	<input type="checkbox"/>	<input type="checkbox"/>
Who explained this study to you? _____		

I agree to take part in the research activities	YES	<input type="checkbox"/>	NO	<input type="checkbox"/>
I would like my contact information added to a recruitment list for future research	YES	<input type="checkbox"/>	NO	<input type="checkbox"/>
Signature of Participant: _____				
(Printed Name): _____				
Date: _____				
I believe that the person signing this form understands what is involved in the study and voluntarily agrees to take part.				
Signature of Investigator or Designee _____ Date _____				

Appendix 9 – Program Staff Consent Form

Study Title:

Learning from and with autistic adults about making their own choices

Ethics ID#: Pro00103146

Principal Investigator:

Jackie Ryan, PhD Candidate
Faculty of Rehabilitation Medicine
University of Alberta
jqryan@ualberta.ca

Supervisor:

Dr. Sandy Thompson-Hodgetts
Department of Occupational Therapy
University of Alberta
780-492-8416
sandra.hodgetts@ualberta.ca

Background and Purpose:

- Being self-determined enhances quality of life.
- Autistic people are less self-determined than their peers, including peers with developmental disabilities.
- Autonomy is an important factor for self-determination.
- There is little research with autistic people who communicate in non-traditional ways or have difficulty describing their inner thoughts and ideas.
- We want to understand what autonomy and choice means to autistic people.
- We want to understand what supports autonomy and choice for autistic people.

Why is this research important?

- So we know when and how to support autonomy and choice for autistic people.

Who can join this study?

- ASP participants.
- ASP participants' parents/guardians (Deep Assessment only, separate information & consent form)
- ASP program facilitators.

What will happen during this study?

- You will take part in a focus group to help us understand autonomy and making choices from your perspective and to learn about autonomy-supportive strategies used in ASP or that could be used in ASP.
- You may assist ASP participants to take part in their choice of activity to help us understand what autonomy means to them and what supports their autonomy. The options are:
 - Interview
 - Photovoice or other art
 - Written diary
 - Deep assessment (Separate Consent Form)
- All activities will be video recorded.

What are the benefits of this study?

- What we learn will help us to design better supports for autistic adults. What we learn will help us to make ASP more fun and interesting.
- You will receive a small gift-card for your participation.

What are the risks of this study?

- We do not expect that you will experience any harm if you participate in this study.
- If you decide you do not want to take part in this study, it will not affect your employment in ASP.
- You may experience fatigue when doing the activities. You can request a break. You can stop taking part at any time.

Will my privacy be protected?

- The data collected about you will be shared with the research team.
- Members of the research team have signed confidentiality agreements that require them to keep all the information in any form confidential and secure while in their possession.
- Data will not identify you by name. A pseudonym that is only known to the researchers will be used.
- We intend to publish the research (for example, in scholarly publications) and make public presentations based on the research findings. If the results of the study are published and / or presented your identity will remain confidential.
- Any report published because of this research will not identify you by name.
- The information that you share with the research team will be kept for at least five years after the study is done. All information will be kept in a secure and locked filing cabinet or in an encrypted computer that can only be entered through a password.
- Zoom recordings and Otter transcriptions may be uploaded to a server outside Canada and subject to the privacy laws of that jurisdiction.

Can I withdraw from the study?

- You are free to withdraw your consent to take part in this study at any time. Withdrawing your consent does not change your employment in the ASP program.

Questions/concerns:

- Please contact Jackie via email at jgryan@ualberta.ca or via phone at 780-XXX-XXXX.
- The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.

CONSENT FORM

Project Title: Learning from and with autistic adults about making their own choices Locally Responsible Investigator: Jackie Ryan	Tel: (780) XXX-XXXX
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	<u>Yes</u>	<u>No</u>
Do you understand that you have been asked to be in a research study?	<input type="checkbox"/>	<input type="checkbox"/>
Have you read and received a copy of the attached Information Sheet?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand the benefits and risks involved in taking part in this research study?	<input type="checkbox"/>	<input type="checkbox"/>
Have you had an opportunity to ask questions and discuss this study?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand that you are free to withdraw from the study at any time without having to give a reason and without affecting your employment in ASP?	<input type="checkbox"/>	<input type="checkbox"/>
Has the issue of confidentiality been explained to you?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand who will have access to the records?	<input type="checkbox"/>	<input type="checkbox"/>
Who explained this study to you? _____		
I agree to be participate in the research activities	YES <input type="checkbox"/>	NO <input type="checkbox"/>
Signature of Participant: _____		
(Printed Name): _____		
Date: _____		
I believe that the person signing this form understands what is involved in the study and voluntarily agrees to take part.		
Signature of Investigator or Designee _____		Date _____

Appendix 10 – Guiding Questions for Focus Group (staff)

This first group of questions can be applied to any context in your life:

1. Tell me about why you decided to participate in this study.
 - a. How did you make that choice?
 - b. Was anyone else involved in that decision?
2. What kind of choices are important to you?
 - a. Tell me more about these choices.
 - b. Why are these important choices?
 - c. Tell me about how making these choices influence your wellbeing.
3. Tell me about times when having a choice is not important to you.
 - a. What are some examples of choices that are not important to you?

The context for this second group of questions is the ASP program:

4. How do you currently help program participants to be autonomous and make their own choices?
5. What are the current facilitators to supporting autonomy and choice in the program?
6. What are the current barriers to supporting autonomy and choice in the program?
7. What are some specific strategies that would help enable autonomy and choice for program participants?
8. How do you think we could implement strategies for autonomy support?
9. What resources might be needed?
10. What skills do you need?
11. What skills do you think program participants need?