JAE
CANADIAN JOURNAL
OF AUTISM EQUITY
REVUE CANADIENNE DE L'ÉQUITÉ
EN MATIÈRE D'AUTISME

April 2024 Volume 4 Issue 1

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&
Maddy Dever

Stephen Bedard

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&
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&
Baudouin
Forgeot D'arc

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Cover painting
Hiraeth

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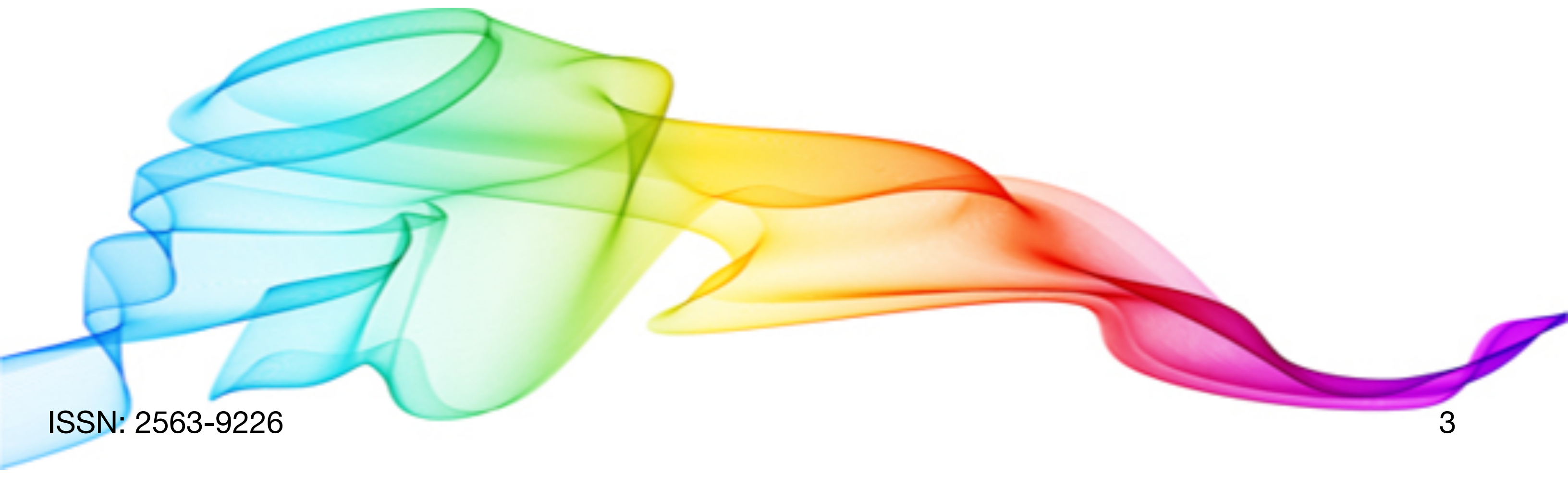

Land Acknowledgement

As Equity-minded members of the Constitutional Democracy of Canada among a Commonwealth of Free Nations, symbolized by honorary monarch, geographically co-situated with the Indigenous Peoples of Northern Turtle Island; we gratefully acknowledge and respect the ancestral relationship between Indigenous Peoples (including 634 First Nations, Inuit First Peoples, and Aboriginal Métis Peoples) and their Traditional Lands, their Truth of self-narrative, and their Cultural Properties.

Language Statement

At the Canadian Journal of Autism Equity (CJAE), our goal is amplifying autistic voices and getting them to the attention of researchers, academics, and other policy makers. To that end, we do not impose or enforce a specific language standard on people writing about their experiences. We realize that many in the autistic community may have a preference for certain types of referential language, like identity-first language ('autistic' person) compared to person-first language (person with autism), and that there is also controversy within the autistic community around use of certain terms relating to older diagnostic terms that have been adopted by some in the autistic community ('aspie'). We also understand that there are different beliefs within the autistic community as to which language standards are 'correct'. We feel that to try and impose a language standard upon other peoples' experience and how they refer to themselves would undermine their autonomy and their self-determination. Therefore, we do not prescribe any particular language standard regarding referential language as it relates to submissions wherein autistic authors are referring to their own experiences as we want to amplify their voices, not replace their voices with the voices of others.

Cover art by Samantha Toh

Hiraeth

2023, Acrylic on canvas

Photograph
by
Samantha Toh

My name is Samantha Toh and I represent myself and others as an advocate dedicated to promoting autism awareness and understanding.

I have an Honours BA in Second Language Teaching and I am working towards the completion of my MA in Bilingualism Studies. In my current role as a Graduate Teaching Assistant, I work to foster an inclusive environment for all students.

Often, I get remarks from others suggesting that I don't fit their perception of autism considering my accomplishments; indicating that they don't see the ways in which autism affects me. This was the inspiration for Hiraeth, an acrylic painting on canvas.

Though my art has yet to reach the public eye, this painting holds much significance to me as it embodies my personal experiences while highlighting that autism is distinct and different for each person.

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Foreword

Tanya McLeod, MHA, CHE

President, The Sinneave Family Foundation

In November 2017, the federal government launched Canada's first-ever National Housing Strategy – *A Place to Call Home* – to ensure everyone in Canada has access to affordable housing that meets their needs. In 2019, the government passed the National Housing Strategy Act, which requires that the National Housing Strategy apply human rights principles to housing, including non-discrimination, inclusion, participation, and accountability. The principles of inclusion and participation specifically seek to include the input of various stakeholders, such as local communities, real estate developers, and people who have experienced housing insecurity first-hand. This fourth edition of the Canadian Journal of Autism Equity aims to offer a platform to amplify these voices by sharing a compelling collection of research and powerful stories we hope to help inform the development of social policy relevant to meeting the housing needs of Autistic Canadians.

Research findings related to housing solutions for Autistic people repeatedly highlight that having access to needed supports is foundational to success. Allison Annesley and Maddy Dever's submission explores the promising role that a Community Connector can have in facilitating access to needed support, particularly during housing transitions. Their research project found that a social impact bond could be a novel way of increasing access to Community Connectors, which can have a positive impact on the quality of life for the people they support and contribute to housing success and stability.

The affordability of both housing and supports are critical elements to address in any housing solution. Access to funding and/or sustainable income are therefore important considerations when planning for current and future housing needs. Elliot Gustafason's submission analyzes autism funding policies in British Columbia, drawing attention to the importance of providing opportunities for children to develop the skills and abilities they will need to live as independently as possible. He also identifies the need for more nuanced and specific autism data to support policy revisions that are informed by the experiences of Autistic Canadians. To complement this, Eric Samtleben's submission explores autistic perspectives on what appear to be key factors for the maintenance of stable income through long-term employment, specifically how managers and organizations can encourage disclosure and accommodations in the workplace.

Two submissions provide powerful insights from personal experiences related to housing transitions. James Townend shares his experience relocating to a new city for a new job and the complexities of his transition, particularly the impact of living apart from his family. His stories illuminate his journey to self-discovery after receiving an autism diagnosis later in life, and how his diagnosis helped him to understand himself and take action in his life. Stephen Bedard shares his experiences with the process of placing two of his children in group homes and the challenges both he and his family faced. His stories underscore the need for a simpler process to access disability funding and the need for more group homes with appropriately trained support staff that can help Autistic people to live their best lives.

Nader, LaSalle, St-Jean, and Huxley submitted an inspiring snapshot of an innovative residential project in Quebec with the objective of developing and building housing adapted to the needs of Autistic adults, made possible by the Véro & Louis Foundation. The project is supported by a research-community partnership model aimed at fostering the generation of scientific, practical, and experiential knowledge about what contributes to inclusive living environments that meet the needs and expectations of Autistic people. Their submission illustrates the important role of community-engaged research in establishing a learning system that continuously contributes to improved housing solutions.

Courcy, Jeanneret, and Forgeot d'Arc explored the perspectives of Autistic people regarding what they want with respect to housing, with a particular focus on the social make-up of residential projects. This submission underscored the importance of involving the autistic community in research and decision-making in order to move towards more inclusive and responsive residential solutions.

The collection of narratives and insights that make up this edition of the journal emphasizes the importance of understanding the diverse perspectives and lived experiences of Autistic people and their families as we seek to advance housing solutions for Autistic people in Canada. These stories highlight a pressing need for change and reinforce my commitment to the *Neuroinclusivity in Housing* initiative (www.nihouse.ca). This initiative was initially motivated by learnings from the *Housing through an Autism lens Solutions Lab* that gathered micro-stories related to housing and Autistic adults to inform the development of a blueprint; a guide for developing inclusive and robust policies, public priorities, and practices when thinking about housing for Autistic Canadians. The objective of *Neuroinclusivity in Housing* is to facilitate knowledge exchange and carry out applied research to move neuroinclusive housing forward. I urge readers to get involved, share their knowledge, and connect to a growing National Housing Network powered by The Sinneave Family Foundation. Through this network, the goal is to create an online space for people to learn, connect, collaborate, and generate momentum that influences positive change in housing.

I wish to acknowledge and thank the contributors to this journal for lending their voices, perspectives, and experiences to the important discussion of housing for Autistic Canadians, and hope that your respective submissions will inspire others to share their stories and perspectivesIn conclusion, I wish to thank the editorial board for granting me the honour and privilege of being the foreword for the third edition of the Canadian Journal of Autism Equity.

Avant-propos

Tanya McLeod, MHA, CHE

Présidente, Fondation de la famille Sinneave

En novembre 2017, le gouvernement fédéral a lancé la toute première Stratégie nationale sur le logement du Canada — Un chez soi d'abord — afin de s'assurer que l'ensemble des Canadien·nes ont accès à un logement abordable qui répond à leurs besoins. En 2019, le gouvernement a adopté la Loi sur la stratégie nationale du logement, qui exige que la stratégie nationale du logement applique les principes des droits de la personne au logement, notamment la non-discrimination, l'inclusion, la participation et la responsabilité. Les principes d'inclusion et de participation visent spécifiquement à inclure la contribution de diverses parties prenantes, telles que les communautés locales, les promoteurs immobiliers et les personnes qui ont fait l'expérience directe de l'insécurité en matière de logement. Cette quatrième édition de la Revue canadienne de l'équité en matière d'autisme vise à offrir une plateforme pour amplifier ces voix en partageant une collection convaincante de recherches et d'histoires marquantes qui, nous l'espérons, aideront à guider le développement des politiques sociales qui répondront aux besoins de logement des Canadien·nes autistes.

Les résultats des recherches sur les solutions de logement pour les personnes autistes soulignent presque constamment le fait que l'accès aux soutiens est un élément essentiel à la réussite. La soumission d'Allison Annesley et Maddy Dever explore le rôle prometteur qu'un connecteur communautaire peut jouer en facilitant l'accès aux soutiens nécessaires, en particulier pendant les transitions de logement. Leur projet de recherche a révélé qu'une obligation à impact social pourrait être un moyen novateur d'accroître l'accès aux connecteurs communautaires, qui peuvent avoir un effet positif sur la qualité de vie des personnes qu'ils soutiennent et contribuer à la réussite et à la stabilité du logement.

Le caractère abordable du logement et des soutiens est également crucial pour toute solution de logement. L'accès au financement et à un revenu durable est donc un élément important à prendre en compte lors de la planification des besoins actuels et futurs en matière de logement. La soumission d'Elliot Gustafason analyse les politiques de financement de l'autisme en Colombie-Britannique, en attirant l'attention sur l'importance d'offrir aux enfants des possibilités de développer les compétences et les capacités dont ils et elles auront besoin pour vivre de la manière la plus indépendante possible. Il souligne également la nécessité de disposer de données plus nuancées et plus précises sur l'autisme afin de pouvoir réviser les politiques en tenant compte de l'expérience des Canadien·nes autistes. En complément, la soumission d'Eric Samtleben explore les perspectives des autistes sur ce qui semble être des facteurs clés pour le maintien d'un revenu stable grâce à un emploi à long terme, en particulier la façon dont les gestionnaires et les organisations peuvent encourager la divulgation du diagnostic et les mesures d'accommodement dans le milieu de travail.

Deux contributions apportent un éclairage puissant sur des expériences personnelles liées aux transitions en matière de logement. James Townend aborde son expérience de déménagement dans une nouvelle ville pour un nouvel emploi et les complexités de sa transition, en particulier l'impact de sa séparation avec sa famille. Ses récits éclairent son parcours de découverte de soi après avoir reçu un diagnostic d'autisme plus tard dans sa vie, et la manière dont ce diagnostic l'a aidé à se comprendre lui-même et à prendre les rênes de sa vie. Stephen Bedard raconte quant à lui son expérience de placement de deux de ses enfants dans des foyers de groupe et les défis auxquels lui et sa famille ont dû faire face. Son histoire souligne la nécessité de simplifier le processus d'accès au financement pour les personnes en situation de handicap et d'augmenter le nombre de foyers de groupe dotés d'un personnel de soutien dûment formé, capable d'aider les personnes autistes à vivre au mieux de leurs capacités.

Nader, LaSalle, St-Jean et Huxley ont soumis un aperçu inspirant d'un projet résidentiel innovant au Québec, dont l'objectif est de développer et de construire des logements adaptés aux besoins des adultes autistes, grâce à la Fondation Véro & Louis. Le projet est soutenu par un modèle de partenariat recherche-communauté visant à favoriser la production de connaissances scientifiques, pratiques et expérientielles sur ce qui contribue à créer des environnements de vie inclusifs qui répondent aux besoins et aux attentes des personnes autistes. Leur contribution illustre le rôle important de la recherche communautaire dans l'établissement d'un système d'apprentissage qui contribue continuellement à l'amélioration des solutions de logement.

Courcy, Jeanneret et Forgeot d'Arc ont exploré le point de vue des personnes autistes quant à ce qu'elles souhaitent en matière de logement, en mettant l'accent sur la composition sociale des projets résidentiels. Cette soumission souligne l'importance d'impliquer la communauté autiste dans la recherche et la prise de décision afin d'évoluer vers des solutions résidentielles plus inclusives et plus réactives.

La collection de récits et de points de vue qui composent cette édition de la Revue souligne l'importance de comprendre les diverses perspectives et expériences vécues par les personnes autistes et leurs familles alors que nous cherchons à faire progresser les solutions de logement pour les personnes autistes au Canada. Ces récits mettent en évidence un besoin urgent de changement et renforcent mon engagement envers l'initiative Neuroinclusivité dans le secteur du logement (https://nihouse.ca/fr/). Cette initiative a été initialement motivée par les enseignements tirés du laboratoire de solutions « Le logement dans l'optique de l'autisme », qui a recueilli des microrécits liés au logement et aux adultes autistes afin d'éclairer l'élaboration d'un plan directeur pour l'élaboration de politiques, de priorités publiques et de pratiques inclusives et solides en matière de logement pour les Canadien·nes autistes. L'objectif de Neuroinclusivité dans le secteur du logement est de faciliter l'échange de connaissances et de mener des recherches appliquées pour faire progresser le logement neuroinclusif. J'encourage vivement les lecteurs et lectrices à s'impliquer, à partager leurs connaissances et à se connecter à un réseau national du logement en pleine expansion, alimenté par la Fondation de la famille Sinneave. Grâce à ce réseau, nous espérons créer un espace en ligne permettant aux gens d'apprendre, de tisser des liens, de collaborer et de générer un élan qui stimulera des changements positifs dans le secteur du logement.

Je tiens à remercier les personnes qui ont contribué à cette Revue d'avoir prêté leur voix, leur point de vue et leur expérience pour participer à l'important débat sur le logement pour les Canadien·nes autistes, et j'espère que leurs contributions respectives inciteront d'autres personnes à partager leurs histoires et leurs points de vue.

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REVUE CANADIENNE DE L'ÉQUITÉ
EN MATIÈRE D'AUTISME

Fostering Inclusion Around Housing Transitions

Favoriser l'inclusion dans le cadre des transitions en matière de logement

Allison Annesley[1], Maddy Dever[2]

Abstract

This qualitative research project was designed to determine how Community Connectors can best support neurodiverse residents when they move into new housing. The research team also sought to generate greater awareness of the Connector role and support for a pilot. Team members collected and analyzed a range of perspectives, including lived experience, by running focus groups, conducting key informant interviews, and consulting with a diverse advisory panel. A Community Connector assisting neurodiverse residents as they transition to more independent housing can have an outsized impact, on housing success, housing stability, and quality of life. The Social Finance for Social Inclusion Solutions Lab has developed an outcomes-based pilot model to increase access to Community Connectors.

Connectors help residents form relationships and over time, develop a new network of support. Housing providers may also be more willing to welcome these tenants, knowing they have adequate support. Connectors can also facilitate volunteer or employment opportunities, further integrating residents as full and valued members of the community. We found a social impact bond could be a novel way of increasing access to Community Connectors. Both impact investors and government funders are interested in the outcomes a pilot would likely achieve. Social impact bonds are just one idea though. Any funding model that could pay for an outcomes-based pilot with independent evaluation, would generate the evidence required to scale and increase access to this important resource.

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Résumé

Ce projet de recherche qualitatif a été conçu pour déterminer comment les connecteurs communautaires peuvent mieux supporter les résidents neurodivers quand ils déménagent dans un nouveau logement. L'équipe de recherche cherchait aussi à générer une meilleure conscience du rôle du connecteur, ainsi que du support pour un projet pilote. Les membres de l'équipe ont recueilli et analysé un éventail de points de vue, y compris l'expérience vécue, en organisant des groupes de discussion, en menant des entretiens avec des informateurs clés et en consultant un groupe consultatif diversifié. Un connecteur communautaire qui aide les résidents neurodivers à faire la transition vers un logement plus indépendant peut avoir un impact considérable sur la réussite et la stabilité du logement, ainsi que sur la qualité de vie. Le Social Finance for Social Inclusion Solutions Lab a développé un modèle pilote basé sur les résultats afin d'accroître l'accès aux connecteurs communautaires.

Les connecteurs aident les résidents à créer des relations sociales et, avec le temps, à développer un nouveau réseau de support. Les fournisseurs de logement peuvent aussi être plus enclins d'accueillir ces locataires, sachant qu'ils bénéficient d'un soutien adéquat. Les connecteurs peuvent aussi faciliter les opportunités de bénévolat ou d'emploi, ce qui permet d'intégrer davantage les résidents comme des membres à part entière et appréciés de la communauté. Nous avons trouvé qu'une obligation à impact social pourrait être une façon novatrice d'accroître l'accès aux connecteurs communautaires. Autant les investisseurs d'impacts que les bailleurs de fonds publics s'intéressent aux résultats qu'un projet pilote est susceptible d'apporter. Les obligations à impact social sont seulement une idée, cependant. Tout modèle de financement qui pourrait financer un projet pilote axé sur les résultats et assorti d'une évaluation indépendante produirait les données nécessaires pour étendre et accroître l'accès à cette ressource importante.

Keywords
Inclusive Housing, community connectors, autism support programs, community inclusion, outcomes-based service delivery
Mots-clés
Logement inclusif, connecteurs communautaires, programmes de support à l'autisme, inclusion communautaire, prestation de services axée sur les résultats

Background

In Canada, over one hundred thousand people diagnosed with autism (autism spectrum disorder/condition) and other developmental disabilities aspire to transition to more independent housing; however, they face many barriers due to a lack of sufficient resources and support (Inclusion Canada, 2018). Autism is classified as a neurodevelopmental disorder (ASA, 2013) often co-occurring with an intellectual disability, as many people diagnosed with autism also have some level of intellectual disability. The reverse is also true (Mefford et al, 2012; Newshaffer et al., 2007; Wilkins and Matson, 2009) and both groups benefit from inclusive housing that provides support tailored to individual needs. The lack of truly inclusive housing is a glaring equity gap, undermining a basic human right (CPRD 2005, & NHSA 2019) for this large group of vulnerable citizens in a country that aims to lead, not lag.

Overview

In 2022, the Canada Mortgage and Housing Corporation (CMHC) funded a Solutions Lab research project designed to explore how this gap can be addressed. The project team sought to find an innovative way to pay for a Community Connector pilot program to demonstrate how this important role improves housing outcomes and quality of life.

Community Connectors help integrate residents into their new communities when they move, fostering inclusion and the development of an informal support network. This one-on-one tailored support helps improve housing success and stability, along with a range of other outcomes valued by our society. In addition, it also provides government stakeholders with the means to scale Connector support across the country.

The project team for this Solutions Lab included the parent of a young adult on the autism spectrum (article co-author Allison Annesley) and the project advisory included an Autistic advocate who is also the parent of four Autistic children (co-author Maddy Dever).

Not surprisingly, we found housing providers are more likely to welcome neurodiverse residents who have Connector support. This is important, given these tenants are frequently screened out in the rental process. Without support, they are more likely to face communication challenges with landlords and neighbours.

Background Research

Our lab research began by trying to identify where and how Community Connector services are currently offered. We also explored the impact Connectors can have on the quality of life for the people they work with. We examined what success looks like and what kinds of funding models are currently used to pay for Community Connector service.

A research scan revealed Connector programs are rare in Canada and where the service does exist (mainly in British Columbia and New Brunswick), Connectors are often provided primarily to support employment goals. We learned that one-on-one Connector service is tailored to the needs of the person being supported, usually on an hourly basis. Funding is typically provided indirectly by government ministries, though in some cases families pay directly for the service. Cost can be a barrier though as most Canadians with disabilities live on low or very low incomes (ESDC, 2016; IRIS, 2013).

Consultation

The Lab team conducted a series of consultations that included focus groups and key informant interviews with people from a variety of backgrounds to gather their insights and perspectives. This included autistics as well as people with other developmental disabilities, family members with lived experience, support agencies, housing providers, policymakers, and subject matter experts who specialize in housing and social finance. Through these consultations, the Lab team found Community Connectors can have a tremendously positive impact on the quality of life for the people they support, particularly with respect to inclusion. We also found meaningful inclusion contributes to housing success and stability. We heard from all groups consulted, including funders, that housing transitions are a time of great need, and that Connector support has or would improve outcomes. Additionally, people making housing transitions may be seeking support for employment or volunteer goals and Connectors can help with both.

The Proposed Solution

Further research was conducted to explore innovative funding options to pay for the Connector service, which is difficult to find or access in most of Canada. Based on the results of this research, a conceptual model for a “social impact bond” or SIB was developed. SIBs are bonds that invite impact investors to provide the capital required for a social program. These investors will often accept a lower return or profit on their investment if the outcomes achieved align with their values. With a SIB, impact investors receive their money back, along with a pre-determined return from outcomes payers, usually government agencies or philanthropic partners. These “outcomes payments” occur after an independent evaluation has confirmed the program the bond was designed to support has achieved its intended outcomes.

In this case, the proposed bond would provide Connector service to neurodivergent adults leading up to and including their transition to more independent housing and continue until they are well settled. The proposed structure would fund service for 1-200 people for 2-3 years with 6 months reserved at the start and end of the program for preparation and evaluation respectively, for a total bond term of 3-4 years.

Metrics to measure success would be based on desired outcomes in three categories: 1 – housing success and stability, 2 – quality of life and well-being, and 3 – social inclusion. The investment required would range from between $1.5 million to $3.5 million, depending on pilot size or the number of residents being supported. The funds would be used to pay for the Connector service, independent evaluation, and general administration, with a proposed rate of return for investors of between 5 and 7%.

The conceptual SIB structure was presented to potential impact investors nationwide in a series of consultations. There was a very high level of interest and support for the Connector service and investors were curious to learn more about how a pilot would work. Potential investors understood the need to generate evidence proving the Connector service can achieve important outcomes. Since a successful pilot could lead to the expansion of the program across the country, there were many questions about how specific metrics could be determined and properly measured to gauge success. Some believed the rate of return could be lower, recognizing the need for this service is great, alongside the need for more affordable housing.

Key Lab Findings

Potential government partners were interested in the idea of funding an outcomes-based pilot but not necessarily with a social impact bond. The proposal to develop meaningful metrics to measure pilot success was very well received. Third-party evaluation would be a novel approach to provide outcomes payers (government partners) greater confidence that their financial support can achieve the outcomes all parties have a shared interest in.

Housing providers, support providers, and other key stakeholders agree the long-term outcomes of a pilot would demonstrate significantly improved housing success and stability. Tenants would thus be able to retain their housing with fewer landlord and property manager disputes and less unit turnover. Tenants would enjoy greater inclusion, leading to the development of personal support networks that, over time, could augment and replace family support, as family members age.

As more developers and property managers observe the success of inclusive housing pilots where Community Connector support is provided, there will be a diminished perception of risk associated with welcoming these tenants. We heard in our engagement with existing landlords that these residents make great tenants. Greater exposure to this kind of positive landlord experience will encourage new partnerships among the various stakeholders required to make more inclusive housing possible.

We anticipate local businesses will also be more welcoming to these residents as they are more visibly active in the community, regardless of the level of support they require. Additionally, tenants with developmental disabilities tend to shop locally, which business owners and staff appreciate and value.

When more neurodivergent residents have housing stability and inclusion, we can expect fewer negative outcomes, along with improved physical and mental health. We found that there was a correlation between housing challenges and higher use of the healthcare system, social services, and the criminal justice system. Whereas truly inclusive housing offering support to tenants based on their individual needs, reduces shelter use and homelessness as some of the most precariously housed people retain their housing.

Providing Connector service on a broad scale has the potential to facilitate deep and wide-ranging social and economic inclusion, as neurodiverse residents participate more fully in their community. In some cases, this can include new or increased employment. The increased independence of these residents can also free up family members and other loved ones to participate more fully in their own social and economic activities. In addition, stigma and discrimination in housing will decrease as examples of successful integration become more common. The longer-term impacts of our project will be felt as Community Connectors are funded more broadly, and inclusive housing projects become more accessible to people in need, as programs are scaled.

Next Steps

At this point, some federal and provincial stakeholders have expressed interest in providing Community Connector support for housing transitions, but further work is needed. The project team's focus on innovative funding has switched to developing a more specific structure for an outcomes-based pilot to demonstrate impact and generate the evidence required to scale. The Lab team is neutral on how a pilot is funded but some groups may still find the Social Impact Bond a useful tool where other funding is not available. We see greater awareness of the many benefits that inclusion can provide as the main takeaway for many stakeholders.

Both federal and provincial funders have expressed interest in what Connector support can achieve. This is an important first step toward unlocking government financial support for broader Connector services. Our team plans to pursue funding to develop a turnkey pilot structure. This includes developing meaningful indicators for desired outcomes based on key stakeholder consultation, especially people with lived experience. Designing a robust pilot evaluation framework is another important element. We are continuing to increase awareness of the

Community Connector role and its potential to improve housing and quality of life outcomes. Based on what we heard from the range of people we spoke to throughout this project, we believe the potential for program uptake is high.

Neurodivergent residents have a right to housing that meets their individual needs and respects their agency. We believe Community Connectors can be a crucial way to help this happen.

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April 2024

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Autistic Children and Group Homes: A Personal Testimony

Les enfants autistes et les foyers de groupe : Un témoignage personnel

Stephen Bedard

Abstract

There is no guaranteed outcome for an autistic person when it comes to housing. It can range from complete independent living to living with family to being placed in a group home. In this personal account, the story of one family with two autistic children with high needs is shared. Placing a child in a group home is difficult for any parent. The emotional cost is great enough but there are additional challenges that can add to the pain of the situation. What is shared is not meant to generalize to the experience of all autistic people, not even all autistic people who are placed in group homes. This account is a snapshot of one family's experience that may highlight some of the problems with the system and potentially point to areas for improvement.

Resumé

Il n'y a pas de résultat garanti pour une personne autiste en matière de logement. Il peut s'agir d'une vie totalement indépendante, d'une vie en famille ou d'un placement dans un foyer de groupe. Dans ce récit personnel, l'histoire d'une famille ayant deux enfants autistes qui ont des besoins importants est partagée. Placer un enfant dans un foyer est difficile pour n'importe quel parent. Le coût émotionnel est déjà assez important, mais il y a d'autres défis qui peuvent ajouter à la douleur de la situation. Ce qui est partagé n'a pas pour but de généraliser l'expérience de toutes les personnes autistes, ni même de toutes les personnes autistes qui sont placées dans des foyers de groupe. Ce récit est un instantané de l'expérience d'une famille qui peut mettre en lumière certains problèmes du système et qui indique éventuellement des domaines à améliorer.

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Keywords
Autism Spectrum, group Homes, housing Policy, parenting
Mots-clés
Spectre de l'autisme, foyers de groupe, politique du logement, être parent

Introduction

When parents have children, there is a moment when possible, futures flash before their eyes. This includes everything from teaching them to drive to what major they will choose in university to where they might raise their own families. Part of this includes the experience of how long children will live at home.

Ideally, parents are not longing to become "empty nesters" the day their first child is born, but there is at least an unspoken expectation of what things will be like. Many parents assume the child will remain in their home for the teen years and then move away from home either to begin postsecondary education or when they begin working. There are not too many variations on this theme.

But what happens when autism enters the picture?

Autism exists on a spectrum, meaning some people may require different levels of individualized support ranging from minimal to significant. As a result, outcomes relating to education, careers, and housing can vary widely. Some autistic people may be comparable to or slightly later than their peers in moving out, while others may never be able to move away from their parents. There is no single autistic experience when it comes to decisions about moving away from parents.

What I intend to do in this essay is to describe what our experience has been with two of our autistic children finding sustainable housing. This is not a statement about what all parents can expect, although based on anecdotal evidence, our experience is not unique.

To provide a balance to what will be shared below, the two autistic children I focus on are only half the autistic members of our family. I was diagnosed when I was in my forties. While I was a quirky child with some strongly held interests, I hit many of the milestones of my peers, although often a few years after them. I moved out of my parent's house in my late twenties and was married in my early thirties. Our youngest daughter was diagnosed with autism in her teens and continues to live with us. While she will likely require some support when she moves out, we do not anticipate a housing solution comparable to our two oldest children.

A Diagnosis Arrives

When our two oldest children were diagnosed with autism, we did not know what to expect, including future living arrangements. At first, we hoped that they would be mildly affected by autism and that after some therapy they would have a life typical of others their age. This would include post-secondary education, moving out, finding a career, and starting a family.

It was not long before we discovered that they were significantly impacted by autism and that they would not experience some of the milestones of their peers. We then began to prepare ourselves to be long-term caregivers. Long after our younger children would move out, we expected our older autistic children would still be with us. We eventually found out that our second assumption was as incorrect as the first.

I have written elsewhere on the emotional cost of sending our children to live in group homes. (Bedard, 2023) Rather than focusing on how we were able to reconcile this decision with our role as parents, I will focus on the process of placing our children in group homes and the challenges that we faced.

Our Daughter's Story

Our daughter, who was seven at the time, was a wonderful little girl but her behaviours were difficult to manage. She would destroy our possessions, damage the interior of our house, and most seriously, would injure our younger children. This is not necessarily typical of autistic people. Of our immediate family of seven people, four have been diagnosed with autism and our oldest daughter was the only family member who was aggressive. We tried numerous interventions, including sending her for residential treatment to get her medications regulated, but nothing worked. Life in our house became more and more difficult.

We met with a group representing many of the agencies that worked with disabled children to express the crisis that our family was facing. They listened intently to our concerns and agreed that something needed to happen. Unfortunately, they had nothing to offer. They explained that there were no beds available and that even if there were, there was no funding to pay for that bed. They had nothing to offer us but advice.

The chairperson of that group told us that there was only one option if we truly believed that our ability to care for our daughter at home was at an end. We were advised to call Family and Child Services and inform them that we were abandoning our daughter. While I know people who have been forced to take that option, we were not prepared to go that way yet.

Remarkably, an hour after that meeting, we received a phone call from that chairperson telling us that both a bed and the funding had become available and that our daughter could move into a group home early the next week. It was what we had hoped for, although not without an emotional cost. On one hand, our daily routine became much easier but on the other, we struggled with feelings of abandoning our daughter. Even the newfound calmness of our home made us feel guilty. It is something that we are still coming to terms with.

Moving our daughter into the building was not the end of our challenges. The group home was a school that had been renovated into dorms. None of the other residents had the traditional diagnoses that are considered a disability, and they were mostly children that had been taken in by Family and Children's Services. Caring for a child with autism resulted in a steep learning curve for the staff.

Less than a year after our daughter's placement, we were informed that the government was reluctant to continue the funding. The cost of keeping a child in a group home with all that entails is significant and it will always be economically beneficial for the government if the child is raised at home with the parents. It required many phone calls and much advocacy on our part to confirm that our daughter could not return home and that the funding was justified.

Once the funding was settled, there was more change. The large institutional settings had fallen out of favour and the school building was closed. Thankfully, the agency still owned a house in which they could keep four residents, including our daughter. They also chose to focus on children with intellectual disabilities rather than the population they had previously cared for. It ended up being a good fit for the most part and the agency was willing to work with us.

Ultimately, this decision, as painful as it was, improved our relationship with our daughter significantly. We were able to focus on just enjoying our visits with her instead of being weighed down by the challenges of her behaviour. She seemed to save up all her best behaviour for her visits with us. She also enjoyed her new home so much that she would insist on going back after a day even if we had planned a weekend visit. We are thankful that we were able to make this housing arrangement.

Our Son's Story

We knew that our daughter had high support needs, and while we did not expect her to move from our home at such a young age, we knew it would happen eventually. The housing outcome for our son was much more uncertain. While at a similar end of the spectrum, our son was less a danger to others and more to himself. Our son had the tendency to run away, and being nonverbal and lacking basic safety awareness, this was a problem. We literally would pile up boxes in front of the front door so that he would not leave the house during the night.

At around the age of thirteen, his behaviours began to shift toward harming other family members. While not as consistent in his aggressions as our daughter, the lack of predictability made things difficult. He was also at that age when his body was growing rapidly, and he could harm even an adult if he tried. We looked into having him placed in a group home and once again were pointed to Family and Children's Services.

While abandoning our son was offered as an option, as we had previously encountered with our daughter, we were thankfully given other options. We did not have to surrender all our parental rights. It was suggested that we enter into a temporary care agreement in which Family and Children's Services would take custody of our son, while we retained our parental rights. This would provide a respite and having him in their system would open doors for longer-term care.

This option was attractive but not without concerns. There were some within the agency who wanted to discourage us from seeking a placement. One worker, who was involved in the intake, informed us that they were not prepared to offer the assurance of safety that we required given his elopement risk. The worker explicitly stated that if we continued the process of seeking a placement, that we were putting our son's life in jeopardy. Looking to have our son move into a group home was already making us question our parenting ability; this was taking it to the next level.

Since the situation at home had developed to the point that we knew a placement would be necessary, we went ahead and entered into a temporary care agreement and our son was placed in a house with several other boys. We soon found out that the worker's warnings about our son's safety were not idle.

We received a phone call mid-morning from the group home, telling us that our son had been missing for approximately 1.5 hours. Despite knowing that there was a flight risk for our son, they left him alone outside to wait for the school bus. By the time the bus arrived, our son was gone. We arrived at the group home to find many police cars, a K-9 unit, and a media truck. Over the next hour, we were convinced that our son had died, especially as the group home was in a high-traffic area and he had demonstrated no safety skills. We eventually discovered that our son had walked almost 10 km to his school in the next city, having memorized the route from the bus rides, and assuming that the bus was not coming for him. His abilities in terms of memorization and safety skills far surpassed our assumptions.

Our son was later placed in a home with a different agency and things have become much better. He has outgrown the need to elope and settled into a comfortable routine. He enjoys visits with us and is treated very well by the staff that work with him.

The Problem is Bigger

While we faced many challenges along the journey of having our children placed in group homes, we are one of the fortunate families. Both our children were eventually moved into a group home that was run by an agency that understood how to meet their needs. They were able to finish off their childhood living in the same house and enjoying each other's company. While they were originally placed because of challenging behaviours, they have both developed into wonderful young adults who are loved by their family and the staff at the homes. Once they reached adulthood, they moved to separate houses operated by the same agency. The people who work with our children take care of their needs and seek for them to have fulfilling lives. They still experience meltdowns and other difficult behaviours, although less frequently than in their childhood. We have had to come to terms with the fact that other people were better equipped to care for our children than us. Once we let go of what we considered the expected parental roles, we were able to transition into a new and healthier relationship with our children.

Sadly, this is not every family's story. We know of families who have had to take the step that we were spared from. They were forced to abandon their children and surrender all parental rights. Others have been able to keep their children into adulthood and by the time they become aggressive, there are few opportunities available for them to be placed. Even if the children do not get aggressive, and most do not, some parents find it difficult to care for adult autistic children and may feel that it is beyond their ability. The waiting lists for people to be placed in group homes can run into the decades. (Viau, 2019)

Conclusion

What has been described here is not the experience of everyone with autism. It was not my experience as an autistic person who moved away from my parents in my late twenties or of our other daughter, who is a teenager with autism and who still lives with us. But this is the experience of some families with autism.

There are some significant needs when it comes to housing autistic people, children, and adults, who require a group home setting. There is a need for more group homes, large enough to house up to four residents. There is a need for a simpler and more accessible process for disability funding. There is a need for better trained staff, who not only will keep residents safe but will also help autistic people to live their best lives. Each of these areas have their own sets of challenges and we hope that sharing our story will help influence movement in the right direction.

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REVUE CANADIENNE DE L'ÉQUITÉ
EN MATIÈRE D'AUTISME

La cohabitation en mixité sociale : qu'en pensent des personnes autistes ?

Housing Projects in Social Mix Cohabitation: What do Autistic People Think About it?

Isabelle Courcy[1],Nuria Jeanneret[2], Baudouin Forgeot D'Arc[3]

Resumé

L'inclusion des personnes autistes dans la communauté est un élément essentiel à considérer dans le développement de projets résidentiels qui leur sont destinés. La cohabitation en mixité sociale est une approche intéressante pour favoriser cette inclusion dans la communauté. Toutefois, peu de recherches ont été menées à ce jour sur ce que souhaitent les personnes autistes en matière de logement et d'habitation. Encore plus rares sont celles qui abordent la question sous l'angle de la cohabitation en mixité sociale. Qu'en disent les personnes autistes ? Sont-elles intéressées à cohabiter avec des familles, des personnes de différentes générations ou des personnes étudiantes? En collaboration avec un organisme communautaire en autisme, un sondage a été réalisé (n = 370). Les résultats indiquent qu'environ 4 personnes sur 5 sont intéressées à cohabiter dans un projet résidentiel en mixité sociale composée de personnes autistes et de personnes non autistes. Cet intérêt varie peu selon les caractéristiques sociodémographiques et les besoins de soutien ou d'accompagnement à la vie autonome. L'analyse qualitative des commentaires offre des pistes pour mieux comprendre les raisons pour lesquelles les personnes sont intéressées (ou non) à cohabiter en mixité sociale. Les résultats montrent que la cohabitation en mixité sociale est un modèle qui pourrait convenir à plusieurs, mais que des défis sont craints en raison du manque de connaissance perçu de la population générale à l'égard des différentes réalités de l'autisme.

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Abstract

Many autistic adults wish to find a stable, long-term living environment where they can live into the community. However, little research has been conducted on what autistic people want regarding housing, and even fewer are those who address the issue from the perspective of cohabitation in social diversity. What do autistic people say about cohabiting in a social mix setting? Are they interested in cohabiting with families, people of different age generations, or students? This article presents the results of an exploratory research conducted in collaboration with a non-profit organization whose mission is to support and promote inclusion for Autistics. A questionnaire was developed in collaboration with the community organization and autistic individuals and relatives. The voluntary sample consists of 370 people: 179 autistic participants (who completed the questionnaire either independently or with assistance) and 191 people who responded on behalf of their autistic relatives. The results show that around 4 out of 5 people are interested in living together in a social mixed residential project made up of autistic and non-autistic people. The interest in living together in a social mixed residential project varies little based on socio-demographic characteristics and independent living support or accompaniment needs. The analysis of comments offers insights into the reasons why people are interested (or not) in living together in a social mixed residential project. Considerations include the potential for mutual assistance, socializing and sharing interests, personal space, peace and quiet environment, compatibility of interests and lifestyles with roommates and neighbors, as well as the openness and knowledge of others regarding autism.

Mots-clés
Habitation, logement, hébergement, Québec
Keywords
Housing, home, lodging, Quebec

La cohabitation en mixité sociale : qu'en pensent des personnes autistes ?

L'accès à un logement adéquat est « essentiel au sentiment de dignité, de sécurité et d'inclusion d'une personne » (Lonsberry et al., 2022, p. 3). Bon nombre de personnes autistes souhaitent trouver un milieu de vie stable où ils et elles pourront vivre dans la communauté. Depuis les dernières années, différents projets résidentiels voient le jour. Les caractéristiques architecturales du bâtiment (Kinnaer et al., 2016), son financement tout comme son emplacement et son offre de services sont des éléments qui sont réfléchis et planifiés (Académie canadienne des sciences de la santé, 2022). L'inclusion des personnes résidentes dans la communauté où prennent place ces projets est un autre élément essentiel à considérer.

La mixité sociale réfère à la cohabitation de personnes provenant de différents horizons socio-économiques, culturels ou ethniques au sein d'une même communauté, d'un même quartier, d'une même ville ou d'une même société (par exemple, des individus de différentes classes sociales, origines ethniques, religions, niveaux d'éducation, professions, âges, genres, orientations sexuelles) (Schnapper, 2005.) Cette perspective s'étend également pour englober l'inclusion de personnes présentant des conditions de santé variées ou des besoins en termes d'accessibilité. L'approche de la cohabitation en mixité sociale est axée sur la création d'environnements inclusifs permettant aux individus de s'engager avec d'autres résidents et de profiter des avantages de la diversité sociale tout en respectant leurs particularités. Pour être réussie, la mixité sociale ne doit pas être imposée artificiellement, par exemple dans le cadre de logements attribués par des programmes sociaux (Dansereau et al., 2002). Cette mise en garde revêt une signification particulière pour les personnes autistes dont l'histoire est marquée par l'institutionnalisation ou leur ségrégation dans des lieux excentrés des communautés et de leurs proches (Nadesan, 2013 ; Wright, 2015). Cette perspective met également en évidence la nécessité de considérer les préférences et les besoins spécifiques de la population autiste lors de la planification des projets de cohabitation en mixité sociale. Toutefois, peu de recherches ont été menées à ce jour sur ce que souhaitent ces personnes en matière de logement et d'habitation. Encore plus rares sont celles qui abordent la question sous l'angle de la cohabitation en mixité sociale. Que disent les personnes autistes de la cohabitation en mixité sociale ? Sont-elles intéressées à cohabiter avec des familles, des personnes de différentes générations ou des personnes étudiantes ?

Cet article présente les résultats d'une recherche exploratoire menée en collaboration avec un organisme communautaire en autisme. En 2020, lors d'une table de concertation, des acteurs communautaires, de la recherche, du secteur philanthropique, des personnes autistes et des proches ont déploré le manque de connaissances sur les préférences et besoins des adultes autistes en ce qui concerne le logement et l'hébergement au Québec. La recherche entamée découle de cette préoccupation. Un comité mixte[1] (autistes et non autistes) a été formé pour guider la mise en œuvre du projet à toutes ses étapes. La recherche a reçu l'approbation d'un comité d'éthique universitaire. Nous présenterons dans les prochaines sections la méthode utilisée suivie des principaux résultats obtenus et de leur discussion.

Méthode par questionnaire en ligne

Le questionnaire a été élaboré avec l'organisme communautaire et une dizaine de personnes autistes et de proches. Leurs suggestions ont permis d'améliorer la formulation des questions et des options de réponse. Le questionnaire comportait une trentaine de questions à choix multiples et huit questions ouvertes[2]. Différents thèmes étaient abordés : situation d'habitation souhaitée, préférences en matière de logement et d'hébergement, besoins de soutien, etc. Une section portait sur un projet de cohabitation en mixité sociale : « Un projet est en cours de développement : il regroupe des logements où vivent des adultes autistes et des logements où vivent des adultes non autistes (par exemple des étudiants, des personnes retraitées, des familles) ». Deux questions étaient posées. La première était : « Seriez-vous à l'aise de vivre en cohabitation avec des personnes non autistes ? » Les options de réponse étaient : « oui », « non », « ça dépend » et « je ne sais pas ». La deuxième question était plus spécifique : « Plus précisément, seriez-vous à l'aise de cohabiter avec des étudiants universitaires, des familles et des personnes retraitées. Les personnes pouvaient sélectionner un ou plusieurs groupes et étaient ensuite invitées à expliquer leurs réponses[3].

Afin de rejoindre une diversité de réalités et de contextes de vie, plusieurs options étaient proposées pour remplir le questionnaire : il était disponible en français et en anglais, pouvait être interrompu puis terminer plus tard et être rempli avec l'assistance d'un proche ou d'un membre de l'équipe de recherche (en présence ou par téléphone). Il pouvait également être rempli par une personne majeure agissant comme répondante (par exemple un proche, membre de la famille, intervenant·e). Il était alors demandé à la personne de répondre aux questions en se mettant à la place de la personne autiste pour qui elle répondait (et non pas en donnant son avis en tant que proche). Nous avons deux groupes : 1) les participants autistes ayant répondu au questionnaire, avec ou sans assistance et 2) les participants pour lesquels un parent ou un proche a agi comme répondant·e.

La collecte de données a eu lieu entre octobre 2021 et mai 2022. L'appel à participation a été diffusé sur le site web de l'organisme partenaire, dans les réseaux des chercheurs et sur les médias sociaux. Il était accompagné d'une capsule vidéo bilingue présentant le projet et le témoignage d'une personne autiste sur sa situation et ses aspirations en matière de logement (plus de 32 000 visionnements)[4]. La plupart des organismes communautaires en autisme au Québec et plusieurs écoles ont été contactés; 149 d'entre eux se sont engagés à transmettre l'appel de participation à leurs membres. Des membres de l'équipe se sont également rendus dans des centres d'éducation pour adultes et des organismes communautaires pour offrir leur soutien aux personnes intéressées à remplir le questionnaire.

Les questionnaires incomplets, les doublons et ceux des personnes résidant hors du Québec ont été exclus. Les fréquences statistiques ont été réalisées grâce au logiciel SPSS 28. Les réponses aux questions ouvertes et aux demandes de précisions ont fait l'objet d'une analyse qualitative de contenu (Bardin, 2013). L'échantillon volontaire se compose de 370 personnes : 179 participants autistes (ayant rempli le questionnaire seules ou avec l'assistance d'un tiers) et 191 répondants qui ont répondu pour leur proche autiste.

Résultats

1. Profil sociodémographique et soutien ou accompagnement à la vie autonome

Une bonne part des participant·e·s se compose de jeunes adultes âgé·e·s de 18 à 35 ans (66,5 %). La moyenne d'âge est de 32,7 ans. Les personnes avec répondant·e étaient en moyenne plus jeunes, avec une moyenne d'âge de 23,7 ans. Les participant·e·s se sont identifiés comme femmes (44,3 %) ou hommes (40,8 %) dans des proportions similaires et 14,9 % se sont identifié·e·s comme non-binaires, fluides ou en dehors des catégories de genre traditionnelles. Parmi les personnes avec répondant·e, les hommes étaient beaucoup plus nombreux (78,5 %). Dans notre échantillon, 15,5 % des participant·e·s sont racisé·e·s ou Autochtones, tout comme 8,6 % des personnes avec répondant·e. Près de deux tiers (63,9 %) des participant·e·s détiennent un diplôme postsecondaire. C'est moins souvent le cas parmi celles avec répondant·e (12,2 %). Parmi ces dernières, 58 % n'ont pas complété de diplôme au-delà du cursus primaire. En ce qui a trait à l'occupation, 45,3 % des participant·e·s ont indiqué être en emploi (comparativement à 14,1 % du deuxième groupe). Près d'un tiers des participant·e·s (29,5 %) ont indiqué être en couple. Un peu plus de la moitié (52,4 %) des participant·e·s habitaient dans la grande région de Montréal alors que près des trois quarts (72,5 %) des personnes avec répondant·e résidaient dans une autre région du Québec. De ces dernières, plus des trois quarts (77,5 %) résidaient avec leur famille, ce qui a été moins souvent le cas pour les participant·e·s du premier groupe (44,7 %). En effet, iels sont en plus nombreuses à partager leur domicile avec un colocataire ou un partenaire ou à vivre seule avec ou sans soutien (33 % des participant·e·s et 8,4 % des personnes avec répondant·e). En contrepartie, les personnes avec répondant·e sont plus nombreuses à vivre dans une résidence adaptée ou une maison d'accueil (13,1 % comparativement à 2,8 % des participant·e·s). Le tableau 1 présente ces résultats :

Tableau 1. Profil sociodémographique

Variables	Participant·e·s		Répondant·e·s	
	n	*M (ÉT)*	*n*	*M (ÉT)*
Âge	179	32,7 (11,2)	191	23,7 (6,9)
		% (*n*)		% (*n*)
16-35 ans 36-49 ans 50 ans et +	179	67,0 (120) 22,9 (41) 10,1 (18)	191	92,7 (177) 6,3 (12) 1,0 (2)
Genre	174		191	
Femme Homme Non binaire, fluide		44,3 (77) 40,8 (71) 14,9 (26)		19,9 (38) 78,5 (150) 1,6 (3)
Personnes racisées ou Autochtones	174		186	
		15,5 (27)		8,6 (16)
Scolarité	169		188	
Primaire ou moins Secondaire ou Préparation à l'emploi Études professionnelles ou collégiales Universitaire		4,7 (8) 31,4 (53) 34,3 (58) 29,6 (50)		58,0 (109) 29,8 (56) 10,1 (19) 2,1 (4)
	179		191	
En emploi		45,3 (81)		14,1 (27)
Aux études ou en stage		36,9 (66)		36,1 (69)
Région de résidence	164		182	
Montréal Reste du Québec		52,4 (86) 47,6 (78)		27,5 (50) 72,5 (132)
En couple	173		168	
		29,5 (51)		3,0 (5)
Habite actuellement	179		191	
Seul·e		33,0 (59)		8,4 (16)
Avec sa famille		44,7 (80)		77,5 (148)
Avec un colocataire ou partenaire		20,7 (37)		1,0 (2)
En résidence adaptée ou maison d'accueil		2,8 (5)		13,1 (25)

ÉT : Écart-type

Les besoins de soutien et d'accompagnement à la vie autonome varient entre les participants autistes et celles avec un·e proche répondant·e. Des écarts sont remarqués entre ces deux groupes, notamment pour le soutien dans les activités quotidiennes comme le ménage, la cuisine et l'épicerie (90,6 % des proches et 63,7 % des participants autistes). Un autre écart important est aussi remarqué pour la socialisation et les loisirs : ce type de soutien est rapporté par près des trois quarts (73,8 %) des personnes avec répondant·e comparativement à 42,5 % des participant·e·s autistes. De plus, environ la moitié ont signifié des besoins de soutien à la communication (respectivement 53,9 % et 40,2 %). Dans une moindre mesure, des personnes ont aussi sélectionné le soutien moteur ou sensoriel (respectivement 19,9 % et 14,0 %). Le soutien en santé mentale a été le choix le plus fréquent dans le groupe formé des personnes autistes (68,2 % contre 54,5 %). Dans l'ensemble, soulignons que les besoins de soutien et d'accompagnement à la vie autonome sont prégnants. En effet, seulement 5,4 % des personnes de l'échantillon rapportent n'avoir besoin d'aucun de ces cinq soutiens dans leur vie de tous les jours (respectivement 2,6 % et 8,4 %).

En somme, les personnes autistes qui ont répondu par elles-mêmes (avec ou sans soutien) et celles avec répondant·e se distinguent sur la plupart des variables sociodémographiques et de soutien ou d'accompagnement à la vie autonome mesurées.

2. Intérêt à cohabiter en mixité sociale

De manière générale, on constate un intérêt en faveur de la cohabitation en mixité sociale, soit 81,2 % pour les personnes autistes et 86,7 % pour les personnes avec répondant·e (tableau 2). De manière plus détaillée, environ la moitié ont coché « oui » (51,5 % des personnes autistes et 57,8 % des personnes avec répondant·e) et plus d'un quart ont coché « ça dépend », signifiant, comme nous verrons dans la section suivante, une ouverture sous certaines conditions (respectivement 30,3 % et 28,9 %). Enfin, 18,2 % des participant·e·s autistes et 13,3 % des répondant·e·s ont coché « non ». Les personnes étaient ensuite interrogées sur leur intérêt à cohabiter avec différents groupes sociaux (personnes retraitées, personnes étudiantes et familles). Près de la moitié (42 %) des répondant·e·s ont indiqué ne pas être en mesure (« ne savaient pas ») de répondre à la question (comparativement à 21,5 % des participants). Pour les personnes avec répondant·e, l'intérêt à cohabiter est relativement similaire pour les trois catégories de groupes proposés (respectivement 33,1 %, 34,3 % et 34,9 %). Des variations plus marquées se dessinent dans les réponses des participants autistes. Plus de la moitié (54,4 %) ont exprimé un intérêt pour la cohabitation avec des étudiant·e·s, un peu moins avec des personnes retraitées 40,9 % et encore moins avec des familles – autre que la leur (30,2 %).

En somme, bien qu'il y ait un intérêt général à cohabiter en mixité sociale, des préférences sont remarquées. De toutes les combinaisons possibles, le choix le plus populaire est celui formé des trois catégories « étudiant·e·s, famille et personnes retraitées » (17,2 % pour les répondant·e·s et 18,8 % pour les participant·e·s), à égalité avec la catégorie des « étudiant·e·s seulement » chez les participantes autistes (18,8 %).

Tableau 2 : Intérêt à cohabiter

		Participants		Répondants
Intérêt à cohabiter	n	%	n	%
	165		166	
Non		18,2		13,3
Ça dépend (ouvert)		30,3		28,9
Oui		51,5		57,8
Avec	149		169	
Ne sait pas		21,5		42,0
Retraité·e·s		40,9		33,1
Étudiant·e·s		54,4		34,3
Famille		30,2		34,9

Compte tenu des différences soulevées entre les deux groupes dans la section précédente quant au profil sociodémographique et aux besoins de soutien des personnes participantes, nous voulions voir si ces différences pouvaient s'accompagner de variations dans l'intérêt à cohabiter en mixité sociale. Les résultats présentés dans le tableau 3 indiquent certains écarts à l'intérieur des deux groupes. Dans le groupe des participant·e·s autistes, on remarque que les proportions de personnes intéressées à cohabiter en mixité sociale augmentent avec la diminution par paliers d'âge. Les plus jeunes sont plus nombreux à avoir indiqué leur intérêt. En ce qui a trait aux besoins de soutien ou d'accompagnement à la vie autonome, on remarque que les participant·e·s autistes qui présentent des besoins de soutien pour la communication et de support moteur ou sensoriel sont moins nombreux à se dire intéressés à la cohabitation en mixité sociale que les personnes pour qui un proche à répondu (tableau 4). Toutefois, certains écarts doivent être interprétés avec grande précaution en raison du très petit nombre dans certaines catégories. C'est notamment le cas pour le genre, l'âge, la scolarité et le fait d'être en couple pour les personnes avec répondant·e.

Des distinctions entre les deux groupes sont également remarquées. Par exemple, les participant·e·s autistes en couple sont proportionnellement moins nombreux à être intéressés par la cohabitation en mixité sociale (nous verrons que cela s'explique par le fait que ces personnes habitent déjà avec leur partenaire ou le souhaiteraient). Cependant, c'est le contraire dans le groupe avec répondant·e : les cinq personnes en couple vivent chez leurs parents et souhaitent en partir. Dans les deux groupes, les personnes sans emploi, ainsi que celles aux études ou en stage sont proportionnellement plus nombreuses à être intéressées à cohabiter en mixité sociale. Le fait de vivre à Montréal ou dans une autre région du Québec ne semble pas avoir d'influence.

Tableau 3 : Intérêt pour la cohabitation selon le profil sociodémographique

	Participants			Répondants		
		Oui	Non		Oui	Non
	n	%	%	*n*	%	%
Genre						
Femmes	71	80,3	19,7	31	83,9	16,1
Hommes	65	83,1	16,9	132	87,1	12,9
Non binaire, fluide	25	80,0	20,0	3	100	0
Âge						
16-35 ans	112	85,7	14,3	154	88,3	11,7
36-49 ans	36	75,0	25,0	10	60,0	40,0
50 ans et +	17	70,6	29,4	2	100	0
Situation						
Pas en couple	112	84,8	15,2	141	88,7	11,3
En couple	47	74,5	25,5	5	100	0
Scolarité						
Primaire ou moins	7	85,7	14,3	92	88,0	12,0
Secondaire ou FPT	46	84,8	15,2	50	88,0	12,0
Études professionnelles ou collégiales	56	82,1	17,9	17	82,4	17,6
Universitaire	46	87,3	21,7	4	75,0	25,0
Emploi						
Oui	76	76,3	23,7	23	78,3	21,7
Non	89	86,5	13,5	143	88,1	11,9
Aux études ou en stage						
Oui	62	88,7	11,3	57	89,5	10,5
Non	103	77,7	22,3	109	85,3	14,7
Montréal	81	80,2	19,8	46	87,0	13,0
Reste du Québec	71	81,7	18,3	113	88,5	11,5

Tableau 4 : Intérêt pour la cohabitation selon le soutien ou l'accompagnement à la vie autonome

	Participants			Répondants		
		Oui	Non		Oui	Non
	n	%	%	*n*	%	%
Besoin de soutien						
Organisation de la vie quotidienne	105	81,9	18,1	150	86,7	12,5
Santé mentale	110	80,0	20,0	93	88,2	11,8
Socialisation et les loisirs	69	82,6	17,4	126	88,1	11,9
Communication	66	75,8	24,2	90	84,4	15,6
Support moteur ou sensoriel	24	79,2	20,8	34	88,2	11,8

3. Raisons en faveurs (ou en défaveur) de cohabiter en mixité sociale

Nous avons vu que la plupart des personnes sondées ont rapporté un intérêt à cohabiter en mixité sociale. D'autres se sont montrées ouvertes à l'idée, mais sous certaines conditions. De façon plus spécifique, des personnes ont envisagé la cohabitation dans une optique de voisinage, d'autres dans un contexte de colocation. Trois principaux arguments en faveur ont été soulevés : apprendre de part et d'autre, s'entraider, socialiser et partager des intérêts :

> Ce serait formidable de rencontrer des gens de mon âge qui ne sont pas autistes, de vivre tous ensemble et d'apprendre les uns des autres[5] (Participant·e)
>
> Avoir un coloc pourrait […] l'aider dans sa routine quotidienne et prise de médicaments (Proche)
>
> Je veux habiter avec des personnes […] qui peuvent m'aider à devenir plus indépendante, mais pas mes parents (Participante)
>
> Il serait très heureux car il est très sociable. Il aime discuter d'affaires publiques ou fréquenter les musées et les cinémas (Proche)

Des personnes ont mentionné l'importance du calme et de la tranquillité des lieux. Une personne exprime à cet effet : « Si c'est insonorisé pour que je puisse faire une stimulation vocale (l'environnement [pourrait] devenir bruyant pour moi-même ou les voisins)[6]. Des personnes ont dit avoir des réticences à cohabiter avec des familles de jeunes enfants : « J'ai des besoins sensoriels au niveau du son. Je ne peux pas supporter les jeunes enfants et les bruits ». À contrario, les personnes aînées étaient perçues comme « plus calmes » et « agréables à côtoyer ». Une autre condition portait sur l'importance d'avoir un espace à soi. La compatibilité des intérêts et des modes de vie avec les personnes colocataires ou le voisinage a également été mentionnée. Plusieurs ont écrit à ce sujet :

> Il ne s'agit pas tellement de qui ils sont, mais de savoir s'ils s'entendent bien avec une personne (est-ce qu'ils se comprennent, etc.). L'âge, le statut, etc. sont sans importance[7] (Participant)
>
> Je serais plus à l'aise de vivre avec des gens de mon âge que ce soient des étudiants ou des gens sur le marché du travail (Participante)

En ce qui a trait aux arguments en défaveur, des personnes ont dit vouloir vivre seul·e ou seulement avec leur partenaire: « Je préfère mon isolement. C'est un choix personnel » et « Je ne pourrais pas habiter avec une personne qui n'est pas un·e partenaire ». D'entre elles, plusieurs redoutaient le bruit, les interactions sociales imposées ou conflictuelles et la perturbation de leur routine quotidienne. Un participant raconte :

> Leurs routines et habitudes causeraient des problèmes avec ma routine. J'ai eu de mauvaises expériences lorsque je vivais avec des étrangers qui fumaient ou étaient négligents avec leur ménage. J'ai dû faire face à des conflits et c'était douloureux, stressant et m'a conduit à la dépression[8] (Participant)

Comme cette participante, certains étaient intéressée à cohabiter, mais avec des personnes autistes seulement :

> Les personnes autistes se comprennent mutuellement et s'entendent mieux[9] (Participante)
>
> Demeurer avec ou près de personnes tellement différentes ou loin de notre réalité peut causer plus de stress qu'autre chose (Participante)

Plusieurs ont confié craindre, expériences malheureuses à l'appui, de ne pas être acceptée, comprises, d'être jugées ou de déranger. Une participante confie : « Je ne suis pas sûre que les personnes non autistes seraient capables d'accepter ce qu'elles considèrent comme un comportement "étrange" de la part des personnes autistes[10] ». En lien avec cette préoccupation, l'importance de l'ouverture d'esprit et des connaissances à l'égard de l'autisme de la part des personnes colocataires et du voisinage était mentionnée. Une participante a écrit à ce sujet :

> Tant que les personnes autistes ne sont pas stigmatisées… peut-être en obligeant les autres locataires à assister à une formation ou à un café-rencontre par une personne autiste et un·e intervenant·e (Participante)

Enfin, des proches ont précisé qu'une ressource d'hébergement avec supervision et encadrement soutenus serait plus adaptée pour leur proche. La cohabitation était donc considérée, mais dans ce contexte de non-mixité, comme le souligne ce parent : « Mon fils doit avoir une surveillance constante, il ne peut être laissé seul. Dans son cas, seule une résidence spécialisée peut devenir un lieu sécuritaire et stimulant pour lui ».

Discussion

Les résultats indiquent qu'environ 4 personnes sur 5 sont intéressées à cohabiter dans un projet résidentiel en mixité sociale composé de personnes autistes et non autistes. Ce résultat contredit le stéréotype encore trop souvent entendu selon lequel les personnes autistes ne veulent pas développer de lien avec les autres (Brownlow et al., 2015 ; Milton, 2012 ; Nicolaidis et al., 2019). Des personnes ont également signifié leur préférence à vivre avec d'autres personnes autistes. En fait, plusieurs commentaires témoignaient de situation de stigmatisation sociale et de discrimination vécues ou d'expériences de cohabitation qui s'étaient mal déroulées (Botha et Frost, 2020). Des proches ont également précisé qu'un projet résidentiel qui n'offre pas de supervision constante de la personne ne pourrait assurer sa sécurité. Compte tenu de la taille de l'échantillon et de sa composition sur une base volontaire, nous avons limité l'usage de tests d'association statistiques reposant sur la prémisse probabiliste. Toutefois, et avec grande prudence, certaines caractéristiques semblent plus souvent associées à l'intérêt de cohabiter en mixité sociale au sein de notre échantillon. Il s'agit des personnes plus jeunes, celles qui sont en stage, aux études et celles qui ne sont pas en emploi. Bien que ces associations doivent faire l'objet de plus ample validation, l'analyse qualitative des commentaires nous offre des pistes pour mieux comprendre ces tendances. En effet, plusieurs personnes ont soulevé l'idée que la cohabitation offre des opportunités d'échanges, de soutien récréatif et pour l'organisation de la vie quotidienne. En contrepartie, les participants plus âgés avaient plus de chance d'être dans une situation d'habitation qui leur convenait (avec leur partenaire par exemple) ou d'avoir vécu des expériences négatives de cohabitation dans le passé qui freinaient ou modéraient leur intérêt pour le projet résidentiel proposé.

Un autre résultat saillant est la prégnance et la diversité des besoins de soutien à la vie autonome rapportés dans les deux groupes composant l'échantillon. Ces éléments doivent être pris en compte pour assurer une cohabitation réussie. Par exemple, les besoins en termes de support moteur ou sensoriel soulèvent l'importance de concevoir des espaces accessibles et adaptés sur le plan sensoriel en intégrant des éléments tels que : des sources de lumières naturelle, des espaces insonorisés, des rampes d'accès et des ascenseurs. La proximité géographique avec des services en santé mentale, non seulement accessibles mais aussi sensibles aux réalités de l'autisme et de la neurodivergence, constitue un autre élément que pointent nos résultats afin d'assurer le bien-être et le maintien de la personne dans la communauté. Les liens entre le logement, la santé mentale et la qualité de vie ont déjà été étudiés auprès d'autres populations non autistes vivant avec une problématique de santé mentale (Kyle et Dunn, 2008). Vivre dans un logement inadapté peut avoir des répercussions négatives sur la qualité de vie perçue (Baker et Douglas, 1990) alors qu'être dans un logement adapté (Billstedt, 2011, Lawson et al., 2020 ; Scheeren et al., 2022) et avoir le sentiment de pouvoir choix de son lieu de vie y est positivement associé (McGlauglin et al., 2004 ; Nelson et al., 2007). Les liens d'entraide, pouvant varier dans leur intensité, sont en étroite cohérence avec la perspective de la cohabitation en mixité sociale (Dehan, 2007). Ceci peut prendre la forme d'échanges de services ou d'aide dans la réalisation des tâches domestiques (ex. aller nourrir le chat, chercher le courrier, répondre aux livreurs, maintenance des aires communes, covoiturage, travail au potager communautaire). Les liens qui se créent et le soutien informel qui peut être échangé peuvent contribuer à un sentiment plus fort d'appartenance et de sécurité au sein de la communauté. Établir un réseau de relations amicales, bienveillantes et fiables pourrait à contribuer à réduire l'isolement social et à améliorer la qualité de vie (Scheeren et al., 2022). Bien que l'entraide entre voisins et résidents ne remplace pas les services professionnels médicaux et psychosociaux, ils peuvent tout de même constituer un filet de sécurité à considérer (Scheeren et al., 2022), le soutien social étant étroitement lié au bien-être et à la qualité de vie (Camm-Crosbie et al., 2019).

Ces éléments mettent également en évidence l'importance d'investir dans la création de liens et de réseaux entre les personnes autistes et non autistes qui seront amenées à se côtoyer. Les arguments en faveur ou en défaveur de la cohabitation en mixité sociale, de même que les conditions sous lesquelles elle peut être envisagée partagent la nécessité de créer des environnements où chacun se sent écouté, respecté et soutenu. La préservation de l'intimité (notamment par une isolation acoustique adéquate) et une délimitation claire des espaces communs sont également des éléments rapportés dans d'autres études (Crompton et al., 2020 ;

Kinnaer et al., 2014; Leloup et Séraphin, 2009 ; Nagib et Williams, 2017 ; Nguyen et al., 2020).

L'entraide entre voisins requiert une planification et une préparation minutieuses. Par exemple, des discussions ouvertes et transparentes entre les résident·e·s, les propriétaires et les personnes travaillant dans les entreprises locales à proximité sont essentielles afin de définir les attentes, les limites et les responsabilités de chacun. Il est également important de mettre en place des mesures visant à prévenir les conflits potentiels et à encourager une communication ouverte. Des personnes organisatrices communautaires pourraient soutenir ces initiatives résidentielles et citoyennes (Dansereau et al., 2002). La cohabitation en mixité sociale, surtout lorsqu'elle est intentionnellement planifiée, doit prendre en compte les composantes sociales favorables à l'inclusion des individus, la configuration des espaces et le choix des matériaux. Elle doit également être encouragée par des incitatifs et des politiques sociales, tout en étant soutenue par l'action d'organismes du tiers secteur. Enfin, une cohabitation en mixité sociale réussie nécessite une acceptation et une ouverture à l'autre, soulignant ainsi l'importance de poursuivre les efforts de sensibilisation de la population canadienne aux réalités de l'autisme et de la neurodiversité.

Il est important de noter que l'échantillon utilisé dans cette recherche ne prétend pas représenter la population autiste dans son ensemble. De plus, les réponses fournies par les répondant·e·s ne reflètent pas nécessairement à tous égards la pensée et les souhaits des personnes pour lesquelles elles et ils ont répondu. Cependant, les différences observées en ce qui concerne le profil sociodémographique et les besoins en soutien à la vie autonome soulignent l'importance de recueillir des informations à partir de diverses sources lors de la consultation des personnes autistes. Il serait intéressant de refaire cette recherche auprès de la population non autiste, notamment des personnes retraitées ou étudiantes et des familles. En plus de mesurer l'intérêt à cohabiter avec des personnes autistes, cela pourrait permettre d'identifier d'éventuels obstacles et de proposer des solutions pour les surmonter.

En terminant, rappelons l'importance d'impliquer la communauté autiste dans la recherche et la prise de décision. En incluant leurs perspectives dans la planification de projets, nous pouvons progresser vers des solutions résidentielles plus inclusives et adaptées, créant ainsi un environnement où toutes les personnes, qu'elles soient autistes ou non, peuvent s'épanouir et vivre pleinement. Se sentir chez soi, respecté et en sécurité constitue le point de départ vers plus d'équité et l'exercice d'une « pleine citoyenneté » (Dorvil et al., 2005).

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Annexe 1

Quels énoncés correspondent le mieux à votre situation ?

o J'ai reçu un diagnostic d'autisme
o Je m'identifie comme une personne autiste, mais je n'ai pas reçu de diagnostic
o Je suis en attente pour une évaluation diagnostique
o Je suis le parent ou le proche d'une personne qui a reçu un diagnostic d'autisme et qui est âgée de 16 ans et plus
o Je suis le parent ou le proche d'une personne qui n'a pas reçu de diagnostic d'autisme, mais qui s'identifie comme une personne autiste et qui est âgée de 16 ans et plus
o Je suis le parent ou le proche d'une personne qui est en attente pour une évaluation diagnostique et qui est âgée de 16 ans et plus
o Je n'ai pas reçu de diagnostic d'autisme, je ne m'identifie pas comme une personne autiste et je ne suis pas le parent ou le proche d'une personne autiste

Pour qui souhaitez-vous répondre au questionnaire ?

o Pour moi-même

- Pour mon enfant/proche

Quel âge avez-vous ? / Quel âge a la personne pour qui vous répondez ?

Comment remplissez-vous ce formulaire ?

- Seul-e
- Avec notre soutien au téléphone
- Avec l'aide d'ami-es ou de proches Quelle est votre situation d'hébergement actuelle ?
- Seul-e sans soutien comme locataire ou propriétaire
- Seul-e avec soutien comme locataire ou propriétaire
- Avec un-e colocataire (ami-es ou connaissance) ou un-e conjoint-e (locataire ou propriétaire)
- Avec un ou des proches (mère, père, frère, sœur, oncle, tante, etc.)
- Dans un logement multigénérationnel
- Dans une résidence adaptée
- En maison ou foyer d'accueil
- « Couchsurfing » et autres modes d'habitation temporaires
- Sans domicile fixe
- Autre. *Veuillez préciser :*

De quels services de soutien et d'accompagnement avez-vous besoin ?

- Soutien pour l'organisation de la vie quotidienne
- Soutien à la planification (à moyen et long terme)
- Aide à la communication
- Support moteur et/ou sensoriel
- Autorégulation et/ou soutien émotionnel
- Aide à la cuisine et/ou à l'épicerie
- Soutien à l'emploi et/ou aux études
- Soutien à la socialisation et/ou aux loisirs
- Aucun
- Autre. *Veuillez préciser* :

Nous aimerions connaître vos besoins en matière de services de santé et d'éducation. *Cochez si vous avez besoin de ces services. Peu importe si vous les recevez ou non.*

- Soutien en santé mentale
- Soutien individuel (par exemple intervenant communautaire, personne accompagnante, éducateur spécialisé)
- Soutien à la coordination (par exemple travailleur social, intervenant pivot)
- Orientation et formation professionnelle. Accompagnement en emploi
- Planification de la transition à la vie adulte
- Assistance à l'Aide sociale (par exemple accompagnement au bureau de l'Aide sociale, aide avec les formulaires)

Est-ce qu'il y a d'autres services que vous recevez ou dont vous avez besoin et qui ne sont pas mentionnés dans le tableau précédent ? *Précisez s'il-vous-plaît* : Un projet est en cours de développement : il regroupe des logements où vivent des adultes autistes et des logements où vivent des adultes non autistes (par exemple des étudiants universitaires, des personnes retraitées, des familles). Seriez-vous à l'aise de vivre en cohabitation avec des personnes non autistes ?

- Oui
- Non
- Je ne sais pas
- Cela dépend. Veuillez préciser :

Plus précisément, vous seriez à l'aise de cohabiter avec... (Plusieurs réponses possibles)

- des étudiant-es universitaires
- des familles
- des personnes retraitées
- Je ne sais pas
- Je préfère ne pas répondre

Vous résidez...

- au Québec, Canada
- hors du Québec mais au Canada
- hors du Canada

À quel genre vous identifiez-vous ?

- Femme
- Homme
- Non-binaire
- Je préfère ne pas répondre
- Autre. *Veuillez préciser :*

Quel est le niveau d'études le plus élevé que vous avez complété ?

- École primaire ou moins
- Secondaire
- Études professionnelles
- Études collégiales (par exemple Cegep)
- Études universitaires:
- Autre. *Veuillez préciser :*

Quel est votre état civil ?

- Marié-e
- Divorcé-e
- Célibataire
- En couple
- Ne s'applique pas
- Autre. *Veuillez préciser :*

Vivez-vous avec votre partenaire ?

- Oui
- Non
- Ne s'applique pas

- Autre. *Veuillez préciser :*

Quelle est votre occupation ? (*Plusieurs réponses possibles*)

- Emploi à temps plein
- Emploi à temps partiel o Travail autonome
- Stage
- Études à temps partiel
- Études à temps plein
- Retraité-e
- Bénévolat
- Parent à la maison
- Proche aidant
- Sans emploi
- Autre. *Veuillez préciser :*

Dans le souci de mieux comprendre vos besoins d'hébergement, *veuillez inscrire s'il- vous-plaît les trois (3) premiers caractères de votre code postal.*

[1] *Ève-Marie Beaudoin, Kenza Deschênes-Kherchi, Lucila Guerrero, Dylan Hervé, Gabriela Ovalle*

[2] Pour plus de détails sur le questionnaire et la méthodologie, voir https://www.researchgate.net/publication/371503068_Un_chez-soi_dans_la_communaute_Les_besoins_attentes_et_preferences_d'adultes_autistes_en_matiere_d'hebergement_et_de_logement_au_Quebec

[3] Pour les questions dont il est mention dans cet article, voir Annexe 1.

[4] https://fb.watch/pOl0Hbh_v8/ (français) ou https://fb.watch/pOk-0VZex8/ (anglais)

[5] « It would be great to meet people my age who aren't autistic, and all live together and learn from each other and such »

[6] « If it is soundproof so I can vocally stim (the environment [could] get loud either for myself or neighbors) »

[7] « It's not so much about who they are but whether he clicks with an individual (do they get each other, etc.). Age, status, etc. are irrelevant »

[8] « Their routines and habits would cause issues with my routine. l have had bad experiences since l was living with strangers who were smoking or were messy with their cleaning. Had to deal with conflicts and it was painful, stressful and drove me to depression »

[9] « Autistic people understand each other and get along better »

[10] « I'm not sure if non-autistic people would be able to accept what they consider "weird" behaviour from autistic people »

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British Columbia's Autism Funding Policies: Benefits and Gaps

Politiques de financement de l'autisme en Colombie-Britannique : les avantages et les lacunes

Elliot Gustafson

Abstract

Autism Spectrum Disorder (ASD) affects one out of 100 children worldwide (World Health Organization, 2023). In Canada, public debates about policies related to autism funding have been ongoing. This research paper provides an analysis of the autism funding policies in British Columbia from inception to present day. Using an economic, social, and educational lens, this paper will examine the progress that has been made to support children living with ASD over two decades and the issues that exist within current autism funding policies that require addressing to improve access and quality of care, support services, and education for those with ASD.

Resumé

Les troubles du spectre de l'autisme (TSA) affectent 1 enfant sur 100 dans le monde (Organisation mondiale de la santé, 2023). Au Canada, les débats publiques sur les politiques liées au financement de l'autisme se poursuivent. Cet article de recherche fournisse une analyse des politiques de financement de l'autisme en Colombie-Britannique de leurs débuts jusqu'à aujourd'hui. Dans une optique économique, social et éducative, cet article examinera les progrès accomplis pour soutenir les enfants vivant avec un TSA au cours des deux dernières décennies, ainsi que des problèmes que posent les politiques actuelles de financement de l'autisme et qui doivent être résolus pour améliorer l'accès et la qualité des soins, des services de soutien et de l'éducation pour les gens avec un TSA.

Keywords
Autism; autism policy; early intensive behavioural intervention (EIBI); Canada; British Columbia (BC)
Mots-clés
Autisme, politique de l'autisme, intervention comportementale intensive précoce (ICIP), Canada, Colombie-Britannique (CB)

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Introduction

The purpose of this study is to conduct a policy analysis and evaluation of the British Columbia (BC) Autism Funding Policy. Specifically, this paper explores the progression of the Autism Funding Policy in BC, how the policy has changed and developed over the years, and what gaps exist in the funding policy. I will also explore the impacts of this policy at a community level and provide potential recommendations and/or revisions to the current Autism Funding Policy.

To begin, it is important to define Autism Spectrum Disorder (ASD). ASD is a complex condition, which can manifest itself differently for individuals. ASD is classified as a pervasive neurodevelopment disorder that affects verbal and nonverbal communication, social interaction, and life skills development (Whitman, 2004). The Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-V) issued by the American Psychiatric Association (APA) offers a lengthy and clinical definition of ASD. Although, the definition has changed over the years, it has consistently referenced impairments in communication and social interactions, as well as repetitive, stereotypical behaviours and limited interests, and sensory processing difficulties. Clearly a deficit framed definition of a neurodevelopment condition focused on examining the impairments.

In 2013, the DSM-V, merged autism, Asperger's syndrome, childhood disintegrative disorder (CDD) and pervasive development disorder – not otherwise specified (PDD-NOS) into autism spectrum disorder. However, it is again important to note that autism presents differently from person to person. In BC, to assess for ASD, two main standardized tools are used including the Autism Diagnostic Observation Schedule-Second Edition (ADOS-2) and Autism Diagnostic Interview Revised (ADI-R) (Dua, 2003). Both tools cover the autistic behavioural features presented in the DSM-V and rely on observations using a quantitative checklist and self-reporting of parents/guardians through an interview and survey (Dua, 2003).

In recent years, the prevalence of ASD has increased significantly relative to other developmental conditions (Centers for Disease Control and Prevention, 2020). The World Health Organization estimates the prevalence at 1%, affecting 1 in every 100 children (World Health Organization, 2023). Although, there is no clear evidence as to what causes ASD and how to treat it, there are a multitude of treatment approaches. There are on-going debates on which “treatment” is the best, yet there is no effective “one size fits all” treatment approach for people living with ASD. Over the decades, the predominant approach to supporting children with ASD is early autism intervention, also called Early Intensive Behavioural Intervention (EIBI) (Kent, 2000). Intervention is meant to help minimize disruptive behaviours while offering an educational approach to teaching life skills, improving communication abilities to allow someone with ASD to live a more independent life (National Research Council, 2001).

EIBI dates to the 1960s and was developed by Ole Ivar Lovaas at the University of California. EIBI is rooted in Applied Behaviour Analysis (ABA) developed by B.F. Skinner in the 1930s. The strategies of ABA include the use of functional analysis of behaviour, followed by reinforcement, prompting, correcting, and shaping the behaviour to what is expected (Wong et al, 2015). EIBI programs are individualized to the needs of the child. Some children with ASD may need a combination of speech therapy, occupational therapy, physiotherapy, and autism behaviour modification, while others may not.

Supporters of EIBI by Lovaas claim it is the only effective method for treating ASD (Kent, 2000).

For EIBI to be successful, it must be implemented between two and six years of age and for a minimum of 20 hours a week (Lovass et al, 1973; Klintwall & Eikeseth, 2014). The Lovaas EIBI method becomes a critical player in the creation of the BC Autism Funding policy and will be discussed further in this paper.

Situating Myself in this Research

I was diagnosed with ASD in 2005 at age two. Little was known about ASD at that time, leaving a void that was filled by a few troubling social touchpoints. One standout includes the character Raymond Babbitt, an autistic savant played by Dustin Hoffman in the movie "Rain Man." Hoffman's portrayal has been polarizing (Ikalyuk & Kuzmyn, 2015; MacLeod, Lewis, & Robertson, 2013) with some feeling that the movie helped to portray autism from a perspective of being gifted, while others felt the movie perpetuated a stereotype of people on the spectrum having gifts with patterns and numbers, but being plagued by fits of hysteria (Ikalyuk & Kuzmyn, 2015). Another standout is Jenny McCarthy's "educational" campaign which, in direct opposition to the medical community, claimed that early childhood vaccines led to cognitive delays in children resulting in ASD (Yochim & Silva, 2013).

This was the social context at the time of my diagnosis. Soon after, I was enrolled in the autism funding policy offered by the Ministry of Children and Family Development (MCFD). My family opted not to receive the funding directly but rather work with the multi-disciplinary, integrated early intervention autism program at Queen Alexandra Hospital in Victoria, BC. From the age of three to six, when I aged out of the program, I attended the EIBI programs, for four hours a day, five days a week. When I started kindergarten at age five, I attended half-day kindergarten in the mornings and autism intervention in the afternoons, which meant I was in some form of formal education/training from 8:30 to 5:00, Monday to Friday. Once I turned six, my family received $6000 a year in support, which included ongoing educational psychology assessments, speech therapy, and social group programming with an occupational therapist.

As someone who has received funding for ASD, I have a personal interest in the topic of autism funding policy. I have been curious about how this funding came about, how it supports children with ASD and their families, and what are the limitations of this funding policy. I am also interested in this topic from the perspective of an undergraduate student in economics.

Program/Policy History

In 2002, MCFD became responsible for providing autism funding to parents and guardians with children diagnosed with ASD. To support an analysis of the Autism Funding Policy in BC, below is a brief historical overview of the policy. Although individual funding was sent to families as early as 2001, there was limited support available in terms of behaviour intervention, speech therapy, occupational therapy, and physical therapy. The genesis of the current Autism Funding Program was precedent-setting litigation known as "The *Auton* Decision" (MCFD-funded services for Children with ASD, 2013). This decision resulted from a small group of families, coordinated by Families for Early Autism Treatment of BC (FEAT), who collectively launched a lawsuit against the provincial government. The litigation took place from 1998 to 2004. The families involved were seeking funding for the Applied Behaviour Analysis (ABA) treatment program for their children (Manfredi & Maioni, 2005, p.111). The FEAT group of families argued that the Lovaas EIBI method was the only proven treatment for autism. However, families for EIBI were individually paying up to $70,000 a year for the intensive therapy (Kent, 2000). Up until the litigation, funding requests for treatment were denied. In the court proceedings, the families argued that by denying funding for ABA, provincial authorities had violated the constitutional rights of citizens to treatment for autism within its public healthcare system. Using a rights-based litigation approach towards healthcare policy reform, arguing that if the province paid for the cost of early intervention, it would mean less draw on healthcare in the future. In 2004, the Supreme Court of BC ruled in favour of the families for ABA (MCFD-funded services for Children with ASD, 13).

Under the Christy Clarke government, in 2009, significant changes were made to the services for children and youth diagnosed with ASD and their families to equalize access and improve service levels. In a CBC article *BC cut back autism funding* posted on September 16, 2009. Mary Polak of MCFD claimed the province wanted to offer treatment to more children than the current policy allows. Polak references that the "creation of the BC early intensive therapy program was partly in response to a court battle, but that the time had come for more equality in allocating support" (CBC, 2009).

According to to a September 16th, 2009 News Release by the BC Government, the following changes were made:

- An increase to under-age-six funding from $20,000 to $22,000 per year.
- Funding discontinuation for the province's Early Intensive Behavioural Intervention (EIBI) programs.
- Budget reallocation for the creation of a new provincial outreach program for young children with ASD to improve access to professional services, particularly in rural and remote communities (Ministry of Children and Family Development, 2009).

Methods

For this paper, I employed a qualitative research approach to examine the effectiveness of the Autism Funding Policy and Eligibility Policy in BC, and to identify potential policy gaps and challenges. In my analysis, I also use a content approach, descriptive approach, and evaluation approach (Delaney, 2017) to examine how effective these policies are in creating an efficient yet inclusive society. From here, I will look at the policy frames and discourses that are evident among the policy makers in the making of said policy. Finally, using a critical policy lens (Delaney, 2017) I will analyse and determine who benefits from the policy as well as who should benefit.

To accomplish this study, I analyzed relevant literature found through library databases, web searches, and policies made available through MCFD staff. I also conducted a library database search, utilizing archive.org, the Legislative Library of British Columbia, and Government Archives. The search terms included autism, autism department, autism spectrum disorder (ASD), autism policy, autism funding, and autism intervention and yielded 147 articles. From there I reduced the articles to the 24 most relevant to my study. I mainly focused on articles in relation to BC but did also compare articles and research papers about autism policies in other provinces.

Most of the articles found related to ASD and education in public school, ASD and counselling, and intervention approaches. Although these articles related to my topic, they were not specific to issues regarding funding policies and were thus excluded from my review. I also conducted a web search for non-academic materials that would also provide additional relevant context such as ministry reports, articles related to the *Auton* litigation and the *Anderson* class action. This includes news releases from local papers, op-ed pieces, government news releases, and parent blogs. Lastly, relevant data was supported through correspondence with the Ministry of Children and Family Development (MCFD) staff.

Policy bias – from Disease to Disability

The *Auton* litigation began in 1999 with the filing of a writ of summons (a legal document that requires someone to attend court), then a statement of claim and an application for certification of the action (Class Proceedings Act, R.S.B.C. 1996, c.50). The litigation sought a declaration that the denial of funding for Lovaas treatment discriminated based on mental disability against those who had been diagnosed with autism and any other neurological condition (Anderson et al. v. Attorney General of British Columbia, 2003 BCSC 1299). However, once the *Auton* litigation reached the Supreme Court of Canada in 2004, the ruling was made that the government of British Columbia did not infringe on the petitioners' s.7 rights of the charter of rights and freedoms (Auton et al v. Attorney General of British Columbia, 2001 BCSC 220).

Legal scholars and academics looking back on the decision say that the "Auton [ruling] is no longer good law, and there is nothing precluding 'social assistance' being a 'service' subject to the protections afforded by the Act and in accordance with principles of substantive equality" (Disability Rights Coalition v. Nova Scotia (Attorney General), 2021 NSCA 70). From this ruling, the Anderson class action focused on arguing that the lack of government funding towards autism intervention services was a violation of their s.15 rights in the Charter of Rights and Freedoms (Anderson et al. v. Attorney General of British Columbia, 2003 BCSC 1299). As stated by the council for the petitioners, "they have failed in their attempts to obtain public funding for intensive behavioural autism treatment based on the Lovaas Autism Treatment method. The petitioners now seek relief under s.24(1) of the charter in respect of a breach of their s.15 equality rights" (Anderson et al. v. Attorney General of British Columbia, 2003 BCSC 1299, p.2/12). By September 9th, 2003, The Honourable Justice Pitfield, ruled that the crown had violated the infant petitioners' rights under s.15 of the Charter of Rights and Freedoms (Anderson et al. v. Attorney General of British Columbia, 2003 BCSC 1299).

From here, the Canadian government had to treat autism as a disability and not a disease, which demanded a redesign of provincial and federal autism policies – access to funding for autism treatment had become a human right.

Autism Diagnosis, Autism Treatment, and Funding Models

Many provinces had their finance departments do internal audits on how to refinance themselves to make the changes that were now being required of them. All provinces including British Columbia found three main things that they need to make sure are addressed in the redesigning of the policy: (1) family capacity (2) program expectations (3) use of funds. In summary, most provinces in their internal audits had discovered that ministries across the country and specifically in BC were not prepared or able to meet these demands given the available resources. The recommendations were as follows:

> "We recommend that the ministry consider a range of strategies to improve the program's ability to manage these risks, including: structured orientation and training program's for parents; additional supports and resources for parents such as a central call centre;

> additional programming choices for families who are unable or unwilling to participate in individualized funding; better communication of program expectations, possibly in additional languages; more appropriate resourcing for program administration, such as a centralized resource for monitoring parents' expenditure reporting; and specific procedures for following up questionable use of funds, and for dealing with parents who have misused funding." (MacPhail et al, 2004, p.2).

Provinces now were given clear details from their internal audits of what needed to be addressed, on top of the federal requirements of allowing parents to secure funding for autism treatments such as EIBI.

Autism related policies in BC are divided into two types: eligibility and funding, both of which fall under the order of the "Supply Act" and court ruling of the Anderson class action. The Ministry of Children and Family Development (MCFD) was now required to provide autism programs for eligible children and their families. The purpose of the policies and accompanying standards was to provide clarification regarding the criteria and process used to determine eligibility for the autism funding under age six and autism funding between ages six and 18. Families of children with ASD under the age of six could receive up to $22,000 per year for purchasing eligible autism intervention services, based on the best practices, that promote their child's communication, social-emotional, pre-academic and functional life skills development. Autism funding for ages six to 18 program provides up to $6,000 per year to assist with the cost of out-of-school autism intervention services that will promote their child's communication, social-emotional, academic, and functional life skills development.

To provide each eligible child access to the funding for these services, the BC government developed a behavioural plan of intervention (BPI). According to the government website, the BPI "is an individualized plan of intervention designed for a specific child or youth that focuses on identifying areas where intervention is needed. The BPI should have a multidisciplinary focus that emphasizes academics, communication, social/play skills, emotional/self regulation, motor/sensory functioning, [and] independence/life skills" (Government of BC, 2015). With the BPI, governments and parents can measure the success of autism intervention programs/services for their children's lives in relation to social expectations.

Looking at the anecdotal research done by both government internal audits and researchers contracted to review the supports, its seems that early intervention is critical for children with autism and ASD. Beginning in 2001, the University of British Columbia conducted research funded by the province over a three-year period on 70 children under six who were receiving autism intervention. The research found that parents, on average, saw significant improvements in their children and were satisfied with the effects of the services. The research also found no significant outcome differences between direct-funded, government-run intervention and contracted intervention services. However, there is no empirical evidence to indicate which children are most likely to benefit from intervention or to benefit from intervention at all. There is also no evidence to indicate whether additional intervention hours would benefit the children (Government of BC, 2015).

Researchers in the academy continue to conduct research projects related to the benefits of early intervention (Bottema-Beutel et.al, 2021; Tarbox et.al, 2014; Hunter, 2023). Autism intervention services, although not perfect, seem to have a positive effect on kids according to their parents. Parents recorded in multiple interviews assert that their kids' lives have improved with intervention services.

However, most parents still struggle with their kids' challenges in the school system, including a lack of staff with the training and experience to support students with autism (Sheppard and Waddell, 2015). One parent stated that "the school system is probably the most regressive and unaccountable system that we have left in the province" (Sheppard and Waddell, 2015). Many parents also reported that social experiences such as bullying, and loneliness were particularly difficult for children with autism (Sheppard and Waddell, 2015).

Literature Review

I began the literature review with the goal of finding studies that focused on the effectiveness of autism/ASD policies in BC and Canada. It is clear given in the background section up above, that there is a need for more analysis of autism policies in BC as well as in Canada generally.

I have also identified four key findings related to autism supports and services and associated funding and eligibility policies. One, there is a clear conflict in the definition of autism. The research literature describes autism is a neuro-disorder and a disability. Two, the policies are structured as gatekeepers to limit the amount of money allocated to those on the spectrum while satisfying the federal standard. Three, there is a lack of empirical evidence to measure the effectiveness of the policies as well as the EIBI services that the policies are designed to support. Lastly, there is a woeful lack of literature analysing the progress and gaps of autism policies in general.

Results and Analysis

The original autism funding policy in BC grew out of contentious litigation. Families with children on the spectrum made the case that receiving funding to treat autism as a human right much like receiving medical attention for a disease or other medical condition. This litigation was heavily influenced by the only research done on autism treatment at the time, the Lovaas treatment method, that required intensive daily treatment of speech therapy, occupational therapy, physiotherapy, and autism behaviour modification. Although the litigation started in the late 1990s, the litigators were relying on original research done on the Lovaas method from 1987 (Kent, 2000). Accordingly, the BC Office of Health Technology's assessment of the research on Lovaas therapy is lacking. Dr. Bassett stated "In his program, Lovaas provides a detailed manual, but the extent to which it was followed in his own studies is unknown. You can't even tell whether what is going on now is similar to what went on in the original study." (As quoted in Kent, 2000, p. 1181).

A systematic review by Bassett, Green, and Kazanjian (2000) indicated that there was only one controlled clinical trial regarding autism treatment through the Lovaas method (p. ix). They also point out the study involved only 19 children in the treatment group with little information about the children beyond the diagnosis of ASD. Furthermore, they mention that there has been little corroboration through independent studies regarding the Lovaas method (p. ix). The research done by Lovaas is therefore problematic. The lack of follow up, the lack of a control group, and a lack of empirical evidence on how well this treatment correlated with the success of autistic children integrating into society is concerning. That's why, as part of this paper, I examined key statistics highlighting the progress of autistic people. For example, I looked at the employment rates and labour force participation rate for autistics before EIBI/Lovaas treatment and after, as well as for those living independently or on welfare/assisted living. I believe that looking at the empirical evidence will help determine the success of the policies made by the BC government.

Table 1: *Peoples with disability in* employment vs on welfare (Statistics Canada 2023)

Year	% of employed	# on welfare	Total population	% on welfare
1995	25	19,902	3,700,000	0.54
2015	65	82,987	4,600,000	0.02
2022	69	103,513	5,400,000	0.02

Unfortunately, the province does not collect statistics specially related to experiences of ASD individuals. Statistics that would help the claims made earlier in the litigation against the province listed better employment rates resulting from autism funding. However, I have examined more general statistics related to disabilities. According to the statistics collected by the Ministry of Social Development, in 1995, the number of citizens in British Columbia living on social welfare was 19,902 out of 3.7 million (0.54% of the population) (Stat Can, 2023) (Government of BC, 2023). In 2015, the number of citizens in British Columbia living on social welfare was 82,987 out of 4.6 million (0.02% of the population) (Stat Can, 2023) (Government of BC, 2023). In 2022, the number of citizens living in British Columbia living on social welfare was 103,513 out of 5.4 million (0.02% of the population) (Stat Can, 2023) (Government of BC, 2023). Looking at employment rates from the Ministry of Labour, in 1995, 25% of those with a disability were employed for at least a year, whether part time or full time (Government of BC, 2023). In 2015, 65% of those with a disability were employed for at least a year (Government of BC, 2023). In 2022, 69% of those with a disability were employed for at least a year (Government of BC, 2023). It is difficult to determine the number of individuals who may be on the spectrum out of the 69% identifying as disabled. However, in general employment numbers for peoples living with a disability have improved.

Discussions

This paper has provided a detailed historical and contemporary look at autism policies in BC. In this section, I revisit several important ideas revealed through this study. These include three important themes: the need to develop more effective research and policy evaluation strategies, the need to work with agencies and government to move away from deficit thinking to inclusive forms of thinking about people with ASD, and the need to develop principles of inclusion to guide how funding is provided. These key themes are important to explore as part of developing policy that helps integrate those with ASD, such that they may thrive in their communities. More effective research is needed. I found few sources for my analysis, and parameters are lacking in both academia and government to measure the effectiveness of policies. Therefore, I developed a way to measure policy goals through employment rates and labour force participation rates for autistics and those living independently or on welfare/assisted living. The government does not track these statistics, so one could infer that the government does not want to know the long-term impacts of the policy, which might indicate why funding and supports are inadequate. Instead, they group in autism and all other mental and physical impairments into one category: disabled. This makes it much harder to measure the effectiveness of the policy as there aren't any targeted areas to help improve the lives of those with ASD or to help them access the workforce.

With humans in general, there is a tendency to measure progress that emphasizes deficit and scarcity thinking over sustainability and integration. This comes from our innate understanding of resources and life being finite. This pattern of thinking leads us into a negative spiral and thus inevitably into a negative view of life as a competition for finite resources. Thus, it makes sense that humans, when coming up with solving any problem, will come up to the plate with a deficit mindset. Since it is possible to create and maintain a sustainable society where everyone's needs to survive are met, it should come with a mentality of accessibility for all.

Developing a model to calculate how much a policy needs to be funded year after year is quite difficult. It makes sense that governments revise annual budgets to try and provide services to the best of their abilities. That's why funding for projects and models are kept to whole numbers and are quite vague and limited for scarcity. That is a key theme and a prevalent situation for families with autistic children trying to attain or afford the services their child needs. This causes distrust and a disconnect from those in government in relation to the individual in the system.

Recommendations

Based on the research for this paper and analysis of the BC Autism Funding policy, three clear recommendations come to mind.

1) To better serve children and families, autism funding policy needs to be revised considering the current and relevant literature about ASD. Earlier ASD research has primarily been done by researchers not on the spectrum. There are more researchers now who are on the spectrum studying the spectrum and their research needs to be considered. As the Lovaas research is quite dated and has significant concerns regarding the methodology used in the original study.

2) The collection of more nuanced statistics is needed. Statistics specifically related to people on the spectrum including high school graduation rates, post-secondary degree completion rates, employment access, income levels, and access to independent living should be collected to measure the integration of people with autism in society. This data would help to establish new funding priorities and inspire new research on intervention and other forms of treatment.

3) Overall, more research needs to be conducted on the benefits of intervention programs to include more methodologies beyond EIBI. The current funding policy relates to only one intervention method and, considering ASD is a spectrum condition, more models are needed that are grounded in research to support people on the spectrum.

Conclusion

The BC autism funding policy is meant to support children on the spectrum to receive autism intervention, speech, and life skills. The origins of the funding policy came from litigation. However, there are many issues regarding the funding and the foundational bases for the policy creation. It is important to recognize that checks and balances are needed for all programs designed to provide services effectively to those who need it. Without proper parameters and measurements, there is no empirical evidence that the policies are working. As presented in the recommendations section, to better serve families with autistic children, the autism funding and eligibility policy needs to be revised with the current and relevant literature about ASD, what is

ASD, and what interventions and supports work. Earlier ASD research has primarily been done by researchers not on the spectrum or not specialized in neurodevelopmental disorders. Today more researchers are on the spectrum studying the spectrum as well as being specialized in neurodevelopmental disorders. Their research needs to be considered. The Lovaas research and Dr. Strain's research are now out of date and there is criticism regarding the methods used in the original study by Lovaas.

In addition, to support any policy revisions, a collection of more nuanced and specific statistics is needed. Statistics specifically related to people on the spectrum including high school graduation rates, postsecondary degree completion rates, employment access, income levels, and access to independent living would be helpful to see the level of integration of people with autism in society. Overall, more research needs to be conducted on the benefits of intervention programs to include more methodologies beyond EIBI. The current funding policy relates to only one intervention method and considering ASD is a spectrum condition, additional models are needed that are grounded in research to support people on the spectrum and any development of policies that are meant to support people with ASD.

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REVUE CANADIENNE DE L'ÉQUITÉ
EN MATIÈRE D'AUTISME

Une maison de groupe fondée sur la recherche, inspirée par les personnes autistes : un exemple de partenariat recherche-communauté

A research-based group home inspired by autistic people: an example of a research-community partnership

Anne-Marie Nader[1], Virginie LaSalle[2], Estellane St-Jean[3], Sarah Huxley[4]

Resumé

Le développement d'habitation adaptées et valorisantes pour les personnes autistes répond à la volonté d'œuvrer en vue d'une meilleure justice sociale en créant des milieux de vie inclusifs en accord avec les besoins et les attentes des personnes autistes. Le présent projet vise à décrire un exemple de partenariat recherche-communauté qui a mené à la conception d'un milieu de vie de groupe conçu en fonction des préférences des personnes autistes.

Abstract

The development of adapted housing for autistic adults responds to the desire to work towards greater social justice by developing inclusive living environments in agreement with the needs and expectations of autistic individuals. The aim of this project is to describe an example of a research-community partnership that led to the design of a group living environment based on the preferences of autistic adults.

Mots-clés

Autisme, habitation, milieu communautaire, architecture, bien-être

Keywords

Autism, housing, community environment, wellbeing

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Introduction

Le droit au logement est un droit fondamental et reconnu dans la déclaration universelle des droits de l'homme (Organisation des Nations Unies, 1949). L'accès à un milieu de vie est donc une question de justice sociale, exacerbée depuis quelques années par le contexte de la crise du logement. D'ailleurs, l'Organisation mondiale de la santé (2011) fait valoir que les facteurs environnementaux et contextuels constituent l'un des principaux éléments contributifs à la qualité de vie. En conséquent, le milieu de vie a un impact important sur le bien-être, tout comme le sont d'autres facteurs comme la possibilité d'exercer différents rôles sociaux (ex. : l'accès à l'emploi) ou de développer des relations sociales (Guite et al., 2006; Mahdi et al., 2018). Mais qu'en est-il de l'accès à un logement où l'on se sent chez soi pour les personnes autistes qui présentent un besoin de soutien à l'âge adulte ?

L'objectif du présent propos est (1) de brosser un bref portrait des enjeux d'habitation communautaire pour les personnes autistes; (2) de présenter un projet résidentiel novateur au Canada qui est conçu en fonction des meilleurs pratiques répertoriées (Maison Véro & Louis); et (3) de décrire un modèle de partenariat recherche-communauté dont le but est de créer un espace de cocréation qui met de l'avant les différents savoirs scientifiques, pratiques, expérientiels. Le développement d'habitations adaptées et valorisantes pour les personnes autistes répond à la volonté d'œuvrer pour une meilleure justice sociale en développant des milieux de vie inclusifs qui répondent aux besoins et aux attentes des personnes autistes.

Contexte actuel de l'habitation communautaire pour les personnes autistes

Le trouble du spectre de l'autisme [ci-après « l'autisme »] est une condition neurodéveloppementale marquée par (1) la présence de particularités sur le plan de la communication et des interactions sociales et (2) des comportements et des champs d'intérêts dits restreints et répétitifs (Association américaine de psychiatrie, 2013). Les manifestations de l'autisme sont diverses, tout comme les trajectoires développementales. La présence de conditions associées est fréquente en autisme, que ce soient des troubles du développement (ex. : déficience intellectuelle, troubles du langage; trouble déficitaire de l'attention) ou de santé mentale (ex. : anxiété, dépression) (Al-Beltagi, 2021; Buck et al., 2014; Hollocks et al., 2019; Lai et al., 2019).

À l'âge adulte, une part importante de personnes autistes nécessitent une forme de soutien pour composer avec différentes facettes de la vie quotidienne (Matthews et al., 2015; Farley et al., 2018; Gray et al., 2014; Poon & Sidhu, 2017; Thompson et al., 2018). Au Québec et ailleurs dans le monde, la plupart des adultes autistes vivent à la maison avec les membres de leur famille (Fortuna et al., 2016; Magiati et al., 2014; Poon & Sidhu, 2017; Sosnowy et al., 2018) ou dans des ressources communautaires (Anderson et al., 2014; Steele & Ahrentzen, 2015). Par exemple, deux études longitudinales, l'une menée auprès d'une cohorte de 89 enfants suivis jusqu'à l'âge adulte en Australie et l'autre auprès de 1 860 participants aux États-Unis, ont démontré que seule une faible proportion d'adultes autistes réside de manière indépendante (9 % dans Gray et al., 2014; 16,6 % dans Anderson et al., 2014). Par ailleurs, le taux d'employabilité demeure faible chez les adultes autistes (van Asselt-Goverts et al., 2015; Wei et al., 2015) ce qui constitue un obstacle supplémentaire pour l'accès au chez-soi (Ghanouni et al., 2021; Mason et al., 2023).

Pourtant, de nombreux adultes autistes souhaitent avoir accès à une forme de chez-soi et, ainsi, acquérir une forme d'autonomie résidentielle (Arsenault et al., 2016; Sosnowy et al., 2018). Les parents d'adultes autistes souhaitent également que leurs enfants grandissent et vieillissent dans un environnement qui répond à leurs besoins et qui soutient leur participation sociale au sein de la communauté (Ghanouni et al., 2021). La notion de « chez-soi », qui est utilisée dans ce texte, réfère à l'idée d'un endroit à la fois physique et social marqué par une relation émotionnelle qui se construit entre la personne et son environnement (Vassart, 2006). Pour certains adultes, l'accès au chez-soi se traduit par la disponibilité d'un milieu de vie communautaire qui apporte le soutien nécessaire à la personne autiste pour s'épanouir. Cependant, les ressources offrant un soutien sont limitées et, dans un contexte où les besoins sont nombreux, cela génère de longues listes d'attente (Ghanouni et al., 2021; Schott et al., 2021). Par conséquent, la transition vers l'âge adulte est souvent une source de stress autant pour la personne autiste que pour sa famille, car cette transition est généralement suivie d'une cessation ou d'une baisse significative des services (Anderson & Butt, 2018; Dudley et al., 2019; Laxman et al., 2019; Schott et al., 2021).

Au Québec, le système public propose principalement deux formes d'hébergement : les ressources de type familiales (RTF ou familles d'accueil) et les ressources de type intermédiaires (RI) qui se veulent être complémentaires au milieu naturel ou institutionnel (Gatien et Leroux, 2017; Lauzon, 2019). Les RTF et les RI accueillent des personnes ayant un besoin de soutien au niveau de l'autonomie, de l'intégration et de la participation sociale et qui leur sont confiées par les établissements publics (ministère de la Santé et des Services sociaux, 2018). Elles s'inscrivent donc dans la trajectoire des services de santé et des services sociaux. Les RI, qui regroupent des appartements supervisés, des maisons de chambres, des maisons d'accueil et des résidences communautaires, sont des milieux opérés de façon privée, alors que les RTF sont opérées par des responsables qui accueillent des résidents dans leur propre domicile. Bien que le mandat des RTF et des RI soit d'offrir des services individualisés en milieu communautaire afin de soutenir l'intégration communautaire et la participation sociale de la personne, ces ressources résidentielles ne parviennent pas nécessairement à répondre aux besoins des personnes autistes (Lauzon, 2019). Ces ressources résidentielles souffrent de manques financiers, de personnel ayant l'expertise nécessaire, ainsi que du jumelage de résidents ayant des profils de fonctionnement et des besoins bien différents. Les services individualisés sont également variables d'un milieu à l'autre (Lauzon, 2019).

Plusieurs personnes autistes entretiennent une relation particulière avec leur environnement, notamment en raison de leurs particularités avec le traitement de l'information sensorielle qui peuvent générer des inconforts, voire pour certaines personnes, de la détresse dans certaines situations (ex. : réactivité dans un environnement riche en stimulation; intolérance face à certains bruits; ou importance accordée aux détails) (Ben-Sasson et al., 2019; Chung & Son, 2020; Robertson & Baron-Cohen, 2017). L'anxiété est répertoriée chez de nombreux adultes autistes et elle peut aussi être associée à l'inconfort face au changement, au besoin de prévisibilité, aux difficultés de compréhension dans certains contextes ou aux situations sociales (Boulter et al., 2014; Hwang et al., 2020; Jenkinson et al., 2020). Diverses adaptations au milieu de vie permettent de soutenir le bien-être et le fonctionnement de la personne autiste, notamment le choix des matériaux pour réduire la surcharge sensorielle (ex. : type de lumière, insonorisation des murs); l'aménagement de l'espace (ex. : zone de transition entre les pièces; conception d'espaces offrant différents modes de socialisation); ainsi que l'accès à des soutiens visuels (Denne et al., 2018; Miller, 2016; Rutherford et al., 2020) ou à la technologie (Hedges et al., 2018; Ribu & Patel, 2016).

Les options résidentielles actuelles pour les personnes autistes demeurent limitées et correspondent rarement à la pluralité des besoins et aux préférences variées des personnes autistes (Courcy & Jeanneret, 2023; Ghanouni et al., 2021). Par exemple, dans le rapport du projet « Un

Chez-soi dans la Communauté », dans lequel 179 personnes autistes ont été interrogés, plus de la moitié ont rapporté un manque de logement ou de ressources d'hébergements adaptés à leurs besoins et 76 % d'entre elles ont répondu que leur situation d'habitation actuelle ne correspondait pas à leurs besoins (Courcy & Jeanneret, 2023).

Au Québec, comme ailleurs dans le monde, les structures d'hébergement conçues spécifiquement pour répondre aux besoins et aux préférences des adultes autistes (parfois libellées comme *autism-friendly environments*) sont encore rares et difficiles d'accès (ministère de la Santé et des Services sociaux du Québec, 2017). Par exemple, peu de structures sont adaptées aux caractéristiques sensorielles des personnes autistes (Ghanouni et al., 2021). De plus, l'approche clinique n'a pas toujours été penser en fonction de leurs besoins, notamment, la formation du personnel adaptée aux réalités diverses de l'autisme. Un milieu de vie inadapté peut alors conduire à fragiliser la qualité de vie et la santé mentale, ainsi qu'au développement de problématiques comportementales chez les adultes autistes, entraînant pour certains une hausse du recours à la médication ou des déménagements répétés (Im, 2021; Lauzon, 2019).

Ces dernières années, des projets de maisons qui sont spécifiquement conçues pour répondre aux besoins des personnes autistes ont vu le jour. Ces projets se caractérisent par une architecture et un design adapté, un personnel formé et des activités personnalisées. Cependant, la littérature scientifique sur la portée de ces projets est presque inexistante, ou du moins, elle est peu disponible dans la littérature scientifique, de sorte que les connaissances sur les facteurs contributifs au bien-être et l'impact de ces initiatives sont très limitées, voire presqu'inexistantes (cf. revue systématique sur les environnements de vie de Nader et al., 2022).

Un exemple de projet résidentiel novateur : La Maison Véro & Louis

Considérant le besoin pour des milieux de vie de qualité, qui sont fondés sur les meilleures pratiques tant au niveau de l'environnement bâti et de l'environnement social que de l'approche clinique, le développement d'un milieu de vie intégrant la recherche dès sa conception s'est avéré essentiel. C'est dans cette optique qu'en 2016, la Fondation Véro & Louis (FVL) s'est donné l'objectif de développer et de construire des résidences adaptées aux besoins des adultes autistes.

En s'associant à des équipes de chercheurs provenant de différentes universités et de différents domaines, la FVL a développé un modèle de milieu de vie novateur offrant des espaces physiques architecturalement pensés pour répondre aux particularités sensorielles et comportementales des personnes autistes, tout en offrant une approche clinique qui permet de soutenir la qualité de vie, l'autonomie et la participation sociale de sa clientèle.

Avec l'ouverture de leur première maison en 2021, la FVL dessert à présent des services résidentiels et éducatifs à 16 résidents, en plus d'y offrir une programmation éducative de jour qui peuvent être accessibles à cinq participants externes. Afin de constituer le premier groupe de résidents ayant la chance d'habiter ce milieu de vie novateur, la FVL a fait appel au Centre intégré de santé et de services sociaux de la Montérégie-Ouest (CISSS MO), l'établissement public du territoire qui œuvre en santé et en services sociaux. Les résidents ont été référés en fonction de leur inscription sur la liste d'attente pour un hébergement et de leur profil de besoins, avec une réflexion particulière portant sur le pairage avec les autres résidents.

L'environnement bâti

Le développement, la conception et la construction de la première maison Véro & Louis (MVL) se sont échelonnés sur cinq ans (Fondation Véro & Louis, 2023). Ce temps était nécessaire à la collecte de fonds pour la construction du milieu, ainsi que pour la conception de la programmation, de la structure clinique et administrative, ainsi que des projets de recherche. La pandémie COVID-19 a mis un frein à la construction pendant quelques mois en 2020, ce qui a reporté l'ouverture de la MVL au printemps 2021.

En 2018, la FVL a fait appel à une équipe de chercheurs multidisciplinaires (design d'intérieur, architecture et architecture de paysage) de la Faculté de l'aménagement de l'Université de Montréal dans le but d'effectuer une étude préparatoire faisant état des meilleures pratiques nationales et internationales en termes de conception des milieux dédiés à cette population (LaSalle et al., 2018). Les résultats de cette étude, transmis aux professionnels de l'Atelier TAG qui a été mandaté pour la conception architecturale de la première Maison Véro & Louis, formulent des principes destinés à alimenter une conception de l'environnement bâti qui est centrée sur le bien-être et les besoins particuliers des adultes autistes.

Le rapport de l'étude préparatoire adopte une forme distincte qui s'appuie sur 13 études de cas qui incluent des projets de design d'intérieur, d'architecture et/ou d'architecture de paysage jugés de grande qualité. Les cas répertoriés et analysés proviennent de plusieurs pays différents; les critères de sélection étant l'exemplarité de l'environnement bâti de haute qualité, ainsi que l'accès aux informations et documents sur les projets. C'est à partir de ces projets que huit principes de conception ont été formulés : (1) la mise en sécurité architecturale; (2) le confort et la cohérence des ambiances sensorielles; (3) le développement d'un système de communication spatio-architectural adapté; (4) l'adaptabilité des aménagements, des ambiances et des usages; (5) le pouvoir de choisir les modalités de la relation sociale; (6) la pérennité du lieu et de ses qualités d'occupation; (7) le style de vie et la culture de l'établissement; et (8) la gestion des espaces intermédiaires. Chacun de ces principes a d'abord été introduit et contextualisé en lien avec son importance pour l'expérience de la personne autiste dans l'environnement bâti. Les principes ont ensuite été expliqués au moyen de stratégies théoriques qui en expliquent la logique. Puis, ces mêmes stratégies ont été reprises dans une version appliquée et exemplifiée à l'aide des cas d'étude. La méthodologie de l'étude, ainsi que le format non-prescriptif de sa communication, ont eu pour objectif d'inspirer et d'accompagner les concepteurs de l'environnement bâti de la première MVL.

L'étude préparatoire produite par les chercheurs de l'Université de Montréal a amené à créer un environnement physique adapté aux besoins sensoriels et sociaux des résidents. Afin de répondre à ces besoins, l'architecture et l'aménagement de la maison ont été pensés pour offrir des espaces communs et individuels, ainsi que du mobilier adapté. Spécifiquement, la maison est construite sur deux étages. Au premier niveau se trouvent les espaces communs où les résidents peuvent participer à différentes activités de groupe (ex. : repas, soirée cinéma, activité physique). Au second niveau se trouvent les maisonnées. Ces maisonnées comportent toutes quatre chambres et un salon commun où les résidents peuvent se rassembler et faire des activités individuelles ou communes en plus petits groupes.

Les données issues de l'étude préparatoire ont permis de mettre en œuvre un environnement bâti sécuritaire, dont les ambiances physiques, qui sont notamment de nature lumineuse et acoustique, sont contrôlées. C'est aussi un lieu qui offre de multiples choix à ceux qui y habitent, par exemple, par rapport aux manières d'être en relation avec les autres résidents et occupants, ainsi qu'en lien aux ambiances proposées. Par exemple, la salle à manger prend la forme de deux pièces distinctes, qui encadrent l'espace cuisine. La première pièce se confond avec l'espace de circulation principal qui longe les fenêtres qui sont en plain pied sur la cour, offrant une ambiance lumineuse et stimulante par la présence du passage des gens. Une seconde pièce se situe derrière la cuisine. On y accède par un court passage qui marque un retrait des aires de vie les plus animées, ainsi qu'un éloignement des sources sonores. La lumière naturelle y est atténuée, contrôlée par des fenêtres moins nombreuses et plus étroites. Ces deux pièces, pensées en complément, donnent un exemple d'alternatives offertes aux résidents de la maison, selon leurs besoins particuliers, leurs préférences du moment, l'activité en cours et les côtoiements possibles.

Le personnel

Sur place, des éducateurs formés dans différentes disciplines de la relation d'aide (ex. : éducation spécialisée, travail social, psychoéducation) sont présents en tout temps le jour et le soir pour un ratio de 1:4. Une responsable de la programmation et des activités cliniques soutient les éducateurs dans l'offre d'une programmation éducative en créant des liens avec des acteurs de la communauté, ainsi qu'en suivant l'évolution des résidents. En plus du personnel éducateur, des préposées aux bénéficiaires sont présentes dans un ratio de 1:8 pour soutenir les résidents dans leurs activités de la vie quotidienne. La nuit, deux surveillants assurent l'entretien ménager des aires communes et répondent aux besoins des résidents. Du personnel de soutien (ex. : cuisinier, gestion, administration) est également présent afin d'assurer le bon déroulement et la sécurité de la Maison. Un programme de formation continue est offert au personnel pour encourager le développement de leurs compétences.

L'approche clinique

L'approche clinique proposée à la MVL s'inscrit dans l'objectif de promouvoir l'autodétermination, la qualité de vie et le développement de l'autonomie des résidents. En tant qu'adultes, les résidents ont des outils et des stratégies de communication qui leur sont propres, de même que des préférences occupationnelles qui correspondent à leurs valeurs et qui soutiennent leur bien-être. En complément, la Maison Véro & Louis a implanté un courant d'intervention basé sur le soutien au comportement positif (Bissonnette et al., 2020), afin d'offrir une structure de base et une cohérence à son équipe et aux résidents. Cette approche mise sur les forces des adultes autistes, ainsi que sur la cohérence des interventions en fonction des valeurs du milieu pour promouvoir une meilleure qualité de vie.

De manière plus spécifique, ce modèle d'intervention, qui se base sur des données probantes, propose de mettre en place un système de renforcement préventif et proactif des comportements positifs (on peut aussi dire « attentes comportementales ») (Bissonnette et al., 2020). Concrètement, il s'agit de déterminer les attentes comportementales qui sont applicables tant pour les résidents que pour le personnel en fonction des valeurs du milieu. Ensuite, les éducateurs soutiennent les résidents dans l'apprentissage des comportements déterminés. Ces apprentissages favorisent un vivre-ensemble plus harmonieux, tout en permettant l'autodétermination et la naissance d'un sentiment d'appartenance à la maison. En effet, une attention particulière est portée aux opportunités présentées aux résidents, afin qu'ils puissent prendre des décisions et faire des choix sur les aspects de leur vie qui leur sont importants, que ce soit au niveau de l'alimentation, des activités, des déplacements ou de la façon de structurer leur temps. Le personnel éducateur et le personnel de soutien reçoivent de la formation sur les de besoins des personnes autistes et ils sont également formés à cette approche afin de la partager avec les résidents d'une manière adéquate et cohérente. Cette approche permet une bonne utilisation des stratégies d'accompagnement déjà en place, tout en permettant aux résidents de faire les apprentissages nécessaires pour mieux vivre ensemble.

La communauté est aussi partie prenante de l'approche clinique de la Maison Véro & Louis, tant dans son implication dans la maison que dans l'intégration des résidents au sein de leur communauté. Différents professionnels s'impliquent bénévolement ou offrent leurs services au sein de la Maison, que ce soit pour des soins de base (ex. : coiffure, soins de pieds) ou pour des activités enrichissantes (ex. : zoothérapie, danse-thérapie). Les résidents sont aussi invités à participer aux activités de leur communauté, entre autres, en fréquentant la bibliothèque de la Ville ou en faisant des courses pour leur Maison.

Les services

Le personnel apporte un soutien aux résidents dans le développement et le maintien de leurs habiletés, ainsi que dans leurs activités de la vie quotidienne grâce à une programmation clinique riche, variée et adaptée. La programmation clinique a, entre autres, pour but de favoriser l'autodétermination et la participation sociale des adultes autistes pour soutenir le développement de leur potentiel à l'âge adulte

En partenariat avec le CISSS de la Montérégie-Ouest, la MVL offre une programmation éducative et socioprofessionnelle aux résidents, ainsi qu'à une clientèle externe de 21 ans et plus qui sont autistes et qui n'ont pas accès à des activités de jour. L'objectif de ce service est de promouvoir la participation sociale avec l'aide d'un accompagnement quotidien, individualisé et éducatif adapté aux besoins de la personne. Jusqu'à quatre jours par semaine, cinq jeunes adultes autistes viennent participer aux activités offertes à la Maison Véro & Louis en compagnie des résidents et de l'équipe sur place.

Une maison issue de la recherche et des recherches ancrées dans le vécu

Depuis les débuts de son projet, la Fondation Véro & Louis (FVL) fait équipe avec différents groupes de chercheurs afin d'offrir des milieux de vie qui répondent le plus adéquatement possible aux besoins des adultes autistes en s'inspirant de l'état actuel des connaissances dans le domaine. Par conséquent, avant même l'ouverture de la MVL, la recherche a joué un rôle essentiel dans la vie des résidents et du personnel. D'abord, la recherche a permis de concevoir et de construire une maison qui est un milieu de vie favorable aux adultes autistes au moyen de données probantes. Ensuite, la recherche a mis en lumière le point de vue des personnes autistes et de leurs proches lors de la transition au sein de ce nouveau milieu de vie.

Après plus de deux ans d'ouverture, l'arrimage avec la recherche se poursuit. Les équipes de recherche de différentes universités québécoises qui sont partenaires de la FVL suivent les résidents sur des périodes variables afin de rassembler des données sur diverses thématiques, notamment (1) sur le fonctionnement de la maison; (2) sur le bien-être et la qualité de vie des résidents; (3) sur l'implantation de l'approche de soutien aux comportements positifs; (4) sur la formation du personnel; (5) sur les technologies de soutien au développement de l'autonomie; et (6) sur l'impact de l'environnement bâti dans le quotidien des résidents. Les universités participantes incluent l'Université de Montréal, l'Université de Sherbrooke et l'Université du Québec à Trois-Rivières. Les devis de recherche visent à mettre de l'avant la complémentarité des savoirs expérientiels, lesquels incluent non seulement les proches et le personnel, mais également les personnes autistes elles-mêmes. En effet, les attentes et les préférences des personnes autistes ont été recueillies, ce qui a appelé les équipes de recherche à concevoir une méthodologie et des outils universels qui sont adaptés aux modes de communication diversifiés des résidents, que ces derniers soient verbaux ou non verbaux (Nader et al., 2022).

La recherche qui se poursuit à la MVL a pour objectif d'évaluer et de documenter les aspects de cette première maison du point de vue de l'environnement bâti, social et occupationnel, car ces aspects sont contributifs au bien-être et à l'optimisation du potentiel des personnes autistes. De plus, on vise par ces démarches à établir un système apprenant où les résultats de la recherche nourrissent les réflexions et les ajustements qu'il faudra apporter, le cas échéant. Ce système permet, entre autres, de bonifier l'offre de service, d'améliorer les infrastructures et de s'assurer de l'apport positif à la qualité de vie des résidents pour continuer à perfectionner le modèle développé au sein de la Maison Véro & Louis, afin que ce modèle d'infrastructure puisse être reproduit partout au Québec.

Conclusion

Le droit à un logement convenable est reconnu comme partie intégrante du « droit à un niveau de vie suffisant » dans l'article 25 de la Déclaration universelle des droits de l'homme de l'Organisation des Nations Unies (Organisation des Nations Unis, 1948). Ce droit couvre certaines libertés, notamment un accès égal et sans discrimination à un logement convenable. L'arrêt des services à l'âge adulte, l'épuisement des familles et le désir des adultes autistes à vivre de manière indépendante favorise la recherche d'une solution résidentielle pérenne. Malgré ces enjeux de justice sociale, les ressources d'habitation de type communautaire qui sont adaptées aux besoins des personnes autistes se font rares, et les ressources existantes ont rarement fait l'objet d'études qui permettent d'évaluer leurs services.

C'est donc dans cette perspective que la Fondation Véro & Louis (FVL) s'est intéressée à développer et à établir un réseau de résidences adaptées aux besoins des personnes autistes. Avec une première maison déjà établie, la FVL est sur le point de lancer deux nouveaux projets de résidence dans différentes régions québécoises. Ces nouvelles maisons permettront de bonifier les données déjà recueillies à la première Maison Véro & Louis afin de perfectionner l'offre de service. Avec la poursuite du partenariat recherche-communauté dans ces prochaines maisons, il sera possible d'approfondir les résultats qui sont rattachés à la première maison et, ainsi, faire progresser les connaissances scientifiques en matière d'habitation pour les personnes autistes.

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REVUE CANADIENNE DE L'ÉQUITÉ
EN MATIÈRE D'AUTISME

An Autistic Perspective on Workplace Disclosure and Accommodation

Une perspective autiste sur la divulgation de la condition et les accommodements en milieux de travail

Eric Samtleben

Abstract

The negative stereotypes associated with autism have created many barriers to employment. As a result, the autistic population has some of the lowest workforce participation rates among all types of disability; with about only one-quarter of the working age population actively participating. These low unemployment rates persist despite many autistic people expressing the desire to work and being more than capable to do so. Among successfully employed autistic people, disclosure and effective accommodations appear to be key factors for the maintenance of long-term employment. Thus, the present study aimed to provide a qualitative exploration of autistic perspectives on how managers/organizations can encourage disclosure and accommodation requests. In addition, this project sought to explore how managers and/or organizations can best support their autistic employees following an accommodation request. Results from the thematic analysis revealed four primary themes (i.e., authentic culture of caring and inclusivity; strengths approach; individualization and collaboration; and clear and consistent structure/communication) stratified by two categories (i.e., encouraging disclosure and accommodation requests; and supporting autistic employees). The results from this study provide managers/organizations with a practical framework for encouraging disclosure and informing the accommodation process.

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Resumé

Les stéréotypes négatifs associés à l'autisme ont créé de nombreuses barrières à l'emploi. En conséquence, la population autiste a l'un des taux de participation les plus faibles sur le marché du travail parmi tous les types de handicaps avec seulement un quart de la population qui est en âge de travailler qui participe activement. Ces faibles taux de chômage persistent, bien que plusieurs personnes autistes expriment le désir de travailler et qu'ils soient plus que capable de le faire. Parmi les personnes autistes qui ont du succès dans leur emploi, la divulgation de leur condition et des accommodements efficaces semblent être des facteurs clés pour le maintien d'un emploi à long terme. Ainsi, la présente étude visait à fournir une exploration qualitative des perspectives autistes sur la façon dont les directeurs d'entreprise/les organisations peuvent encourager la divulgation de la condition et les demandes d'accommodements. De plus, ce projet cherchait à explorer comment les directeurs d'entreprise et/ou les organisations pouvaient mieux supporter leurs employés autistes après une demande d'accommodement. Les résultats de l'analyse thématique ont révélé quatre thèmes principaux (c'est-à-dire, une culture authentique du bien-être et de l'inclusivité; une approche basée sur les forces; l'individualisation et la collaboration; et une structure et une communication claires et cohérentes) stratifiés en deux catégories (c'est-à-dire, encourager la divulgation de la condition et des demandes d'accommodements; et supporter les employés autistes). Les résultats de cette étude fournissent aux directeurs d'entreprise/aux organisations un cadre pratique pour encourager la divulgation de la condition, ainsi pour informer sur le processus d'accommodement.

Keywords
Autism, ADHD, accommodation, disclosure, employment
Mots-clés
Autisme, TDAH, accommodement, divulgation de la condition, emploi

An Autistic Perspective on Workplace Disclosure and Accommodation

Introduction

Autism Spectrum Disorder (ASD) is a collection of neurodevelopmental disorders that can range from severe to mild and are commonly characterized by social deficits in establishing/maintaining relationships and verbal/nonverbal communication, as well as by repetitive restrictive patterns of behaviour, interests, or activities (Attwood, 2006). Currently, the autistic population is growing with an estimated 1/88 to 1/66 children meeting the criteria for ASD (Johnson & Joshi, 2016; Parr & Hunter, 2014). Within this growing community, unemployment is a pressing issue as estimates indicate the current unemployment rate among autistic adults ranges from 50% to 80% with an estimated >500 thousand autistic youth entering the workforce in the next 5 years (Government of Canada, 2018; Khalifa et al., 2020; Zwickey et al., 2017).

Current workforce participation rates among the autistic are notoriously low ranging from 22% to 34% among ASD adults compared to 54% among adults with other disabilities (e.g., visual impairments, hearing impairments, learning disabilities, chronic pain, mental and psychological deficits) and 80% to 83% among adults with no disabilities (Cope & Remmington, 2020; Khalifa et al., 2020; Statistics Canada, 2017). One could easily assume this is indicative of a lack of capability. However, this appears to not be the case as the majority of autistic adults have average to above-average intelligence and can often possess strengths in one of many areas (e.g., memory, visuospatial awareness, reading, drawing, computation; Bury et al., 2020; Mottron et al., 2006; Scott et al., 2019; Wong et al., 2018). Alternatively, a lack of motivation and/or desire to work but are unable to find and/or maintain employment (Cope & Remmington, 2020). When autistic individuals do manage to find employment, they often work below their qualifications and struggle to maintain this employment long-term as many work environments are not suited to support the unique challenges associated with autism (Harvery et al., 2021; Scott et al., 2019). Collectively, the above research highlights the need to better support employment among autistic adults.

Past research examining successful employment among autistic adults has demonstrated that those who disclose their diagnosis are three times more likely to get hired (Lindsay et al., 2021), and those who received workplace accommodations focused on utilizing personal strengths and interests, identifying person-job fit, and providing long term support demonstrated an 89% job retention rate after one year (Keel et al., 1997). However, the effectiveness of workplace accommodations can be negated from the perspective of the autistic employee when managers and co-workers lack the necessary confidence and ASD awareness to implement accommodations properly (Lindsay et al., 2021; Romualdez et al., 2021b).Despite the potential benefits of disclosure and workplace support for the successful employment of adult autistics disclosure rates can vary from 25% to 69% with an average of 52%. Among those who disclose, accommodation request rates range from 50% to 85% (Romualdez et al., 2021b). Commonly reported barriers to disclosure and accommodation requests within the workplace include fear of discrimination, fear of bullying, fear of repercussions, lack of perceived organizational support, and the mentality that disclosure is not beneficial (Thompson-Hodgetts et al., 2021; Romualdez et al., 2021b). Further complicating the issue of successfully accommodating ASD employees is the nature of the disability itself as it exists on a spectrum meaning there are great variations in its presentation and therefore in the necessary accommodations (Vogeley et al., 2013).

In light of this research, the present paper aims to examine autistic perspectives on how managers/organizations can encourage disclosure and accommodation requests. In addition, this project sought to explore how managers and/or organizations can best support their autistic employees following an accommodation request. Results, from this study, can help organizations and managers better understand and integrate autistic employees into the workplace by providing a practical framework for encouraging disclosure and informing the accommodation process.

Methods

Procedure and Ethics

The sample consisted of 6 participants all diagnosed or self-identified as ASD and/or ADHD; also included, was the author himself who has a diagnosis of ASD+ADHD for a total of 7 participants (N = 7). 7 participants were deemed sufficient for the qualitative study as this is the commonly recommended sample size for qualitative research (Howitt, 2010). The author was included as he met all the inclusion criteria (i.e., low support needs, sustained employment for greater than 3 years, and diagnosed or self-identified ASD and/or ADHD). Furthermore, steadily employed low support need autistic adults are a relatively niche population which can be difficult to access. Regarding possible bias, his inclusion would not have biased the data and resulting analysis anymore than if he would not have participated as the data was collected independently and all participants had the same level of knowledge regarding the study objectives. Thus, given his wealth of work experience across multiple fields his exclusion would risk missing valuable insights (Wong et al., 2018). Both ASD and/or ADHD participants were included in the present study because insights from the ASD population may benefit those with ADHD and vice versa due to the high degree of overlap between the two conditions (Antshel & Russo, 2019; Craig et al., 2015; May et al., 2018). All procedures and materials used in the present study were approved by

Trent University's Research Ethics Board.

Recruitment was done via routine social interactions such as text messages and workplace socialization. Those who expressed interest in sharing their perspective had any questions answered and were sent an email containing a link to a Qualtrics questionnaire. After providing consent participants were redirected to five study items assessing age, work history, and workplace disclosure and accommodations. Example items include: 'I*n your past/current experiences what reasonable accommodations could your employer have provided to improve your overall experience?'* and '*In your past/current experiences what reasonable actions could your employer take to make you feel comfortable disclosing your autism?'*.

Data Analysis

Participants' text responses were transcribed into an excel sheet for thematic analysis. After a familiarization period, the author assigned initial codes to each participant's transcript (Braun & Clarke, 2006; Clarke & Braun, 2013). From the coded data an initial set of 7 themes were identified. After reviewing these themes for overlap a final set of 4 themes was developed. Each theme was then defined in terms of the general actions managers can take and/or changes they can make to encourage disclosure and better support their autistic employees.

Results

Participant	Age	Years of Work Experience	Occupational History
1	44	20	IT/Web developer
2	31	14	Salesperson; sales manager; wedding photographer; warehouse manager
3	30	14	Salesperson; warehouse worker
4	30	14	Psychotherapist; unspecified
5	27	5	University student services; research assistant; teaching assistant
6	45	22	Behaviour services
7	28	12	Coaching; landscaping; recycling person; salesperson; tutor; teaching assistant

Note. *This table contains participants' age, work experience in years, and occupational history*.

The average age of the sample was 33.57 years ranging from 27 to 45 with 14.42 average years of work experience ranging from 5 to 22. Participants held a wide range of jobs over their working lives including positions in technology, sales, labour, health services, and teaching/higher education (see Table 1). Overall, these demographics indicate that the perspectives included were from individuals who have ample experience in the workforce and a diverse background of employment history; meaning they are likely to have valuable insight into the successful employment of autistic individuals. The results of the thematic analysis are presented in detail below and summarized in Table 2.

Encouraging Disclosure and Accommodation Requests

Theme 1: Authentic Culture of Inclusivity and Caring

For autistic workers to be properly supported they first must disclose their diagnosis and feel comfortable enough to request accommodations. To encourage these behaviours participants' indicated that an *authentic culture of inclusivity and caring* within the organization would be effective. The desire for authenticity is not surprising given that autistic individuals tend to be very loyal and care deeply about those they are involved with (Russell et al., 2019; Scott et al., 2019; Wong et al., 2018). Furthermore, they expect these qualities in return meaning the autistic employee will feel less comfortable disclosing their diagnosis and requesting accommodations if the organization is perceived as having a faux culture of inclusivity and caring (Parr & Hunter, 2014; Romualdez et al., 2021a). The desire for authenticity was best reflected in a quote from Participant 1 who stated:

> *Personally, I'm always pretty open about things I go through, but it feels like people don't really care. It would be nice if you felt like an employer actually cared about you, rather than treated you like a cog in a big machine*.

When assessing the authenticity of an organization's approach to neurodiversity three main characteristics emerged from the participants' responses. Participants expressed a desire to see organizational efforts aimed at increasing awareness of general mental health and ASD (e.g., workshops, and wellness policies) to foster an open environment where these subjects are not viewed as taboo. This was best reflected in responses from Participant 4 who stated that "*In my experience a lack of understanding often leads to fear of disclosure*" and further recommended that organizations adopt, "*An inclusivity acknowledgment and commitment to continued education in the workplace. In my experience education leads to understanding, which leads to acceptance*".

Furthermore, participants expressed a desire to see organizations adopting a person-environment fit for all employees. A person-environment fit approach is when organizations identify employees' strengths and match them to a work role/environment to which they are best suited (Van Vianen, 2018). This desire was best reflected in a quote from Participant 2 who indicated "*I feel that if an employer strived to provide an environment where all employees were able to work to their fullest potential it would make me feel more comfortable disclosing my autism*".

Lastly, participants indicated a desire to see neurodivergent employees in senior positions as this sends a message that neurodivergence is valued. This can be infrequent though as senior management positions tend to held by older individuals who if neurodivergent are more likely to have gone undiagnosed due to historical trends in autism diagnostic procedures (Lewis 2018; Pellicano et al., 2022). However, when these role models are present and open about their experiences it helps individuals feel more comfortable discussing their own experiences as a neurodivergent or with mental health in general. This desire was best reflected in a quote from Participant 5 who stated:

> *In terms of comfort disclosing my diagnosis, I think the open culture of my current workspace has made me feel comfortable to disclose my diagnosis and to talk about my experiences with it. Part of that probably comes from my supervisor and other senior colleagues modeling this behaviour by being comfortable sharing their own neurodivergent experiences or struggles with learning disabilities.*

In summary, to encourage disclosure and accommodation requests from autistic employees' organizations and managers should strive to create a genuine culture of caring and inclusivity. They can achieve this through the primary strategies: First, by implementing wellness policies that consider the needs of all their employees. Second, the use of a person-environment fit strategy when assigning work roles. Lastly, ensuring there are autistic or neurodivergent role models in senior positions.

Supporting Autistic Employees'

Theme 2: Strengths Approach

To effectively support autistic employees, participants stressed employers needed to adopt a strengths-based over a deficits-based approach to supporting autistic workers. This is not surprising given that in recent times the neurodivergent community and its advocates have been calling for an approach to workplace support that recognizes and attempts to maximize the potential of neurodivergent workers while minimizing their deficits (Waisman-Nitzan et al., 2021). Within the workplace autistic employees commonly display various strengths including enhanced focus and perception, superior attention to detail, and strong logical thinking that result in average to above-average performance ratings from their employers (Cope & Remington, 2022; Khalifa et al., 2020). Thus, autistic employees do possess strengths employers can focus on and the desire for employers to do this was best reflected in a quote from Participant 6:

The biggest part is employers understanding the value that neurodiversity brings to a workplace. Much like adding racial and/or gender diversity to a team adding diverse abilities and neurotypes strengthens a team.

To achieve a strength-based approach participants' responses were reflective of two defining characteristics. First, participants expressed the desire for employers to identify their unique strengths through open and honest communication which is not surprising given that autistic individuals have an affinity for honesty and a preference for direct/open communication (Parr & Hunter, 2014; Russell et al., 2019). Furthermore, participants desired for their strengths to be matched with their work role, although no specific strategies were recommended on how this could be achieved. Previous research has highlighted 'try it out' roles as promising; these roles involve a trial experience in a specific position to determine its suitability to an employee's strengths and are effective for finding the ideal person-environment fit (Hagner & Cooney, 2005).

Second, participants felt that to help create a better person-environment fit employers should aim to create teams that integrate neurodivergent individuals with neurotypicals in a complementary fashion meaning each individual's strengths should complement the other's weaknesses. This is best reflected in a quote from Participant 6 who stated "*a disorganized ASD/*

ADHD employee that understands their co-worker can help them to organize a project and allow the ASD/ADHD employee to explore many perspectives to avoid challenges and pitfalls". Lastly, participants felt that adopting a complimentary team-building approach would feedback into open and honest communication at the employer-to-employee and employee-to-employee levels.

In sum, organizations and managers can best support their autistic employees by adopting a strength-based over deficit-based approach. A strengths-based approach tends to focus on maximizing the individual's strengths and exploring their interests; while a deficits-based approach tends to solely focus on minimizing dysfunctional or unwanted behaviours (Urbanowicz et al., 2019; Wong et al., 2022). A deficits-based approach can be detrimental to the autistic employees as it can leave their potential unrecognized and contribute to a negative self-image (Wong et al., 2022). Concerning autistic employees, managers can achieve a strengths-based approach through a collaborative process characterized by open and honest communication and 'try it out' roles. Additionally, creating integrated teams where neurodivergent strengths/weaknesses complement neurotypical strengths/weaknesses can be an effective strategy.

Theme 3: Individualization and Collaboration

Building off the strengths-based approach, participants also stressed the need for individualization of their accommodations and collaboration with managers when determining their nature. There is little wonder why this theme emerged when we consider the great variety in how autism can present itself (Attwood, 2006). Common examples of individual differences include social impairments (e.g., interpreting verbal/non-verbal communication), and behavioural impairments (e.g., emotional meltdowns/shutdowns, partial or full Tourette's, selective mutism) ranging from severe to mild; there are large variations in hypo/hyper sensory reactivity; and some show special isolated skills in areas such as memory, reading, visuospatial awareness/intelligence, music, art, and mathematics/computation (Attwood, 2006; Bury et al., 2020; Russel et al., 2019; Scott et al., 2019; Wong et al., 2018). Based on the great variation in strengths and deficits it follows that autistic employees may require a variety of accommodations and be best suited to differing roles. Accordingly, it would benefit managers to work with their autistic employees at the one-on-one level to successfully integrate them.

Participants' responses revealed three key characteristics that can help guide managers in collaborating with their autistic employees to develop personalized accommodations. The first was to ensure the appropriate structure of the work environment which included adjusting elements such as lighting, introducing personalized organization systems, providing control of background stimuli (e.g., listening to one's music, noise-canceling headphones), and adjusting environmental rewards (e.g., social praise, fidget toys). The desire for the individualized structure was best exemplified by the following two quotes: Participant 7 stated "*When working, I need absolute silence to focus or I become easily distracted*". In contrast, participant 3 stated:

> *Being able to listen to my own music. I have a hard time focusing on the task at hand with music I don't like playing in the background. I find being able to sing/listen along with the music while I'm working will keep me on track because I am less likely to be distracted if I'm concentrating on something not important in the back of my mind.*

Second, participants expressed a desire for the ability to self-manage their workflow in a manner that as one participant put it "*was focused on task completion, not hours put in*" as they often expressed maintaining a rigid 9 to 5 schedule frequently contributed to greater autistic burnout which occurs when the individual's self-regulatory resources are depleted resulting in the exacerbation of any ASD impairments (e.g., increased frequency of emotional meltdowns, increased self-harm or suicidal ideation; Raymaker et al., 2020). This effect was best demonstrated by the following quote from participant 1:

> *At work, we're generally forced to put in hours, regardless of how we're feeling. On a good day, I can cope with being at work, and I might even find that things aren't moving fast enough for me. But then I'll inevitably need to crash a bit, and be a little less productive. It's on those days when it's so hard to be at work just putting in my time.*

The logic behind the need for atypical flexibility is not to avoid work but rather to take a different route to completion and was best reflected in a quote from Participant 1:

> *Also, I think having more flexibility around hours is a big thing, but not in the way people think. I've always felt pretty comfortable in post-secondary education because I know what I have to get done and can pace myself accordingly. So, on bad days, I might not do anything. Then on a good day, I might get LOTS of work done. It always evens out and I get my work done.*

Finally, participants desired the option to adjust their level and type of social interactions as necessary. This is because for the majority of autistic individuals keeping up appearances for the sake of neurotypicals – also known as masking – is extremely exhausting to engage in regularly and contributes to further autistic burnout (Miller et al., 2021; Raymaker et al., 2020). The benefits of the option to remote work on challenging days are best illustrated by Participant 2 who stated:

> *Working from home also allowed me to forgo the preparation and energy required to work in a regular office environment, such as appearing and dressing professionally, preparing lunches, and social exchanges. I also had a lot of control over the mediums in which I interacted with people, for example suggesting phone calls over video calls or in-person meetings.*

Taken together, the results presented above indicate that managers and organizations must be willing to engage in a collaborative process to individualize their autistic employees' accommodations. This process was characterized by three features: individualization regarding the structure of the work environment, self-management of workflow, and the level of social interaction.

Theme 4: Clear and Consistent Structure/Communication

It is no secret that autistic individuals communicate and perceive the world differently from neurotypicals as autistics tend to process information locally (i.e., details) vs globally (i.e., big picture or gestalts) and are more aware of lower level or automatic cognitive processes (Mottron et al., 2006). What this means is that autistic individuals tend to process information in 'bits' while neurotypicals tend to process information as a whole. Furthermore, autistics' increased awareness of automatic cognitive processes (e.g., sight, hearing) allows them to discern more detail but also increases their sensitivity to stimuli impairing their focus (Mottron et al., 2006). The atypical processing observed in autistics results in deficits in communication characterized by an inability to adapt and respond to unfamiliar or unstructured social stimuli (Johnson & Joshi et al., 2014; Mottron et al., 2006; O'Connor, 2012). Thus, it is not surprising the final theme that emerged was *clear and consistent structure/communication* which participants stressed as vital to workplace success.

To achieve this, two defining characteristics were identified from the participants' responses. The first was to provide consistent delivery of job tasks prioritized in order of importance with clear deadlines to meet so they were able to "*pace themselves appropriately*" as Participant 1 stated.

The need for a job structure such as this was best exemplified by Participant 3 who indicated:

> *Having a specific to-do list geared towards my tasks that need to be done for the day. I*

> *will often start something, forget about it and start something else and come back to the first task wishing I had done it earlier because it might be time-sensitive or something.*

Second, participants reported a desire to have the big picture communicated to them so they can better understand how their role fits into it because as Participant 7 indicated, “If I don’t know why I am doing it I probably won’t do it”. This is not surprising given the atypical processing of autistic individuals as they often need to understand how the pieces fit together to understand the function of their role which helps create motivation (Mottron et al., 2006; Stewart, 1996). Thus, managers must provide clear consistent communication to their autistic employees or they risk them becoming unmotivated.

In sum, it appears managers should be cognisant of their communication style when interacting with their autistic employees due to differences in information processing. Specifically, managers should aim to be consistent in how they deliver job tasks or expect tasks to be completed. They should be sure to emphasize which tasks are time sensitive and should be completed first. Lastly, managers should be sure to communicate the ‘big picture’ to their autistic employees to help them understand the importance of their role.

Table 2. ASD Disclosure and Support Framework

Encouraging Disclosure and Accommodation Requests	**Supporting Autistic Employees**		
Authentic Culture of Inclusivity and Caring	**Strengths Approach**	**Individualization and Collaboration**	**Clear and Consistent Structure/ Communication**
Provide psychoeducation to increase and encourage ASD awareness as well as open discussion of mental health	Identify the employees strengths and roles to match these strengths through open, honest communication	Appropriate structure of the work environment (e.g., lighting, personalized organization, background stimuli - music/media, rewards)	Consistent delivery of job instructions/tasks/requirements prioritized in order of importance with clear deadlines
Person-environment fit approach toward all employees to maximize everyone’s strengths	Identify how ASD strengths can be complimented by neurotypical strengths for integration of their role into the big picture	Degree of autonomy to self-manage their work environment (e.g., location, stimuli) plus work rate and schedule/ hours	Communication of the big picture and how the pieces fit into it, in other words why are they performing their role?
When possible have neurodivergent role models in senior positions		Adjusting the level of/type of/medium of social interactions as necessary	

Note. *This table contains four primary themes stratified into 2 main categories encouraging disclosure and accommodation requests and supporting autistic employees. The four primary themes include Authentic Culture of Inclusivity and Caring, Strengths Approach, Individualization and Collaboration, and Clear and Consistent Structure/Communication. Finally, it contains the defining characteristics that correspond to each primary theme.*

Discussion

According to the framework presented in Table 2, the first step to supporting autistic employees is to encourage disclosure and accommodation requests. To do this, autistic employees wish to see an authentic culture of inclusivity and caring defined by ASD/mental health awareness, a person-environment fit approach, and neurodivergent role models. To create a genuinely authentic culture it is recommended that managers aim to be authentic in their actions meaning that they consider all perspectives, adhere to high moral standards, create relational transparency (i.e., open display of thoughts/feelings to share true self), and demonstrate knowledge of their own as well as their employees' strengths/weaknesses (Parr & Hunter, 2014).

The next step is for employers to adopt a strengths-based approach defined by implementing a person-environment fit strategy when assigning work roles and team members (Van Vianen, 2018). This approach to management has been shown to increase job productivity and satisfaction across several contexts and populations (Andela & van der Doef, 2019; Khalifa et al., 2020; Lai et al., 2020; Peng & Mao, 2015). However, employers need to adopt this approach with their autistic employees; as a deficit-based approach may leave their unique strengths unrecognized and actively suppress them to the point of extinction (Russel et al., 2019; Schall, 2010; Wong et al., 2018).

Individualization and collaboration throughout the accommodation process will help employers to adopt a strength-based approach as it will allow employers to co-learn and bond with their autistic employee(s) as they work together to determine the ideal role and supports (Bowman et al., 2020; Hagner & Cooney, 2005; Nicholas et al., 2018). The need for individualization has been emphasized in previous research demonstrating that a blanket approach to accommodation reduces the efficacy of these efforts (Lindsay et al., 2021; Romualdez et al., 2021b). In comparison, research on individualized/collaborative accommodations has demonstrated they produce more positive employment outcomes such as job satisfaction, engagement, organizational commitment, and well-being (Johnson & Joshi, 2016; Khalifa et al., 2020; Nicholas et al., 2018, 2019).

Lastly, due to perceptual differences, employers must be clear when communicating with their autistic employees (e.g., direct/open, how they fit into big-picture goals; Mottron et al., 2006). In addition, they must be consistent in how they structure their work roles (e.g., routine procedures, or schedule; Nicholas et al., 2018, 2019). Research on communication with autistic employees has demonstrated that when managers adjust their communication style to better suit them, autistic employees' job performance increases, and there is less friction within the relationship (Bowman et al., 2020; Parr & Hunter 2014; Russel et al., 2019). While the present results are promising several limitations must be noted and will be discussed

Limitations

The framework proposed in the present study suffers from generalizability issues as the relatively mild nature of the participants' autism and/or ADHD may limit the application of the results to this specific subpopulation. This is because it is often recommended that in instances of more severe ASD and/or ADHD more support will be required (Antshel & Russo, 2019; Attwood, 2006; Taurines et al., 2012). Further limiting the generalizability is the qualitative nature of the data and the small sample size. However, smaller sample sizes are recommended for qualitative studies as the goal is to capture and explain individual experiences, not necessarily establish generalizability to a larger population (Howwit, 2010). Thus, the present study achieved its goal of exploring the experiences of successfully employed adult autistics with low support needs. Future research should seek to conduct a more in-depth examination of workplace accommodations among autistic adults using a larger number of perspectives that are more representative of the diversity among autistics to update this framework; this can be done via focus groups. Once refined, qualitative frameworks can be implemented to have their effectiveness measured quantitatively where results can be generalized to larger populations.

Finally, the interviewing was non-exhaustive and done via email, meaning there were a limited number of questions and no chance for a follow-up to ask for any clarification on participants' responses. To address this future research should compile a more exhaustive list of questions before conducting in-person semi-structured interviews or focus groups that will allow for a better exploration of this topic. Despite these limitations, the present framework is lent strength in that it was informed by an autistic perspective at the level of the researcher and participants and provides a practical framework.

Conclusion

In conclusion, the present paper provides a glimpse into the autistic perspective on how to improve employment outcomes among this population. The current framework can help employers to encourage disclosure and accommodation requests from autistic employees by providing a map to the cultivation of a culture of authentic inclusivity and caring. Furthermore, the present framework will help employers and organizations provide more effective support for autistic employees. It achieves this by providing a simple general framework managers can adopt and apply to individual cases. This is of great importance due to the high unemployment rates among the rapidly growing and competent autistic population.

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Hiding in Plain Sight

Se cacher à la vue de tous

James Townend

Abstract

Receiving an autism diagnosis later in life led the author to contextualize a lifetime of struggles and accomplishments, sparking profound reflection on the meaning of success, happiness, and interpersonal relationships. These two stories share the author's lived experience with intimate detail. In the first story, the author shares his mental model that likens living with autism to 'hiding in plain sight', uncovering the intensive emotional toll it takes. In the second story, titled 'All the Best With Your Future Endeavours,' the author delves into the realm of work in our world, and the relentless pursuit of societal definitions of success. As the author grapples with his late diagnosis, the need to understand his past from a new lens becomes a journey towards self-discovery. What emerges from this is a moving account of a life molded by a desire to conform to societal roles, a norm shown through such mastery that it hides the true self. This narrative explores the challenges of understanding and embracing one's identity, particularly within a world that often fails to recognize and accept differences. Together, these narratives illuminate the struggle of navigating life with autism and the simultaneous joy that can come from discovering one's unique personal power.

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Resumé

La réception du diagnostic d'autisme à un âge avancé a amené l'auteur à contextualiser une vie de luttes et d'accomplissements qui ont allumé une profonde réflexion sur la signification du succès, du bonheur et des relations interpersonnelles. Ces deux histoires partagent l'expérience vécue par l'auteur avec des détails intimes. Dans la première histoire, l'auteur partage son modèle mental qui compare la vie avec l'autisme à « se cacher à la vue de tous », dévoilant le lourd tribut émotionnel que ça suppose. Dans la deuxième histoire, appelée « Tous mes vœux de réussite pour vos projets futurs », l'auteur se penche sur la question du travail dans notre monde et de la poursuite incessante des définitions sociales du succès. Alors que l'auteur se débat avec son diagnostic tardif, le besoin de comprendre son passé sous un nouvel angle devient un voyage vers la découverte de soi. Ce qui en émerge est un récit poignant d'une vie moulée par un désir de se conformer aux rôles sociaux, une norme montrée avec une telle maîtrise que ça cache le vrai soi. Ce narratif explore les défis de comprendre et d'embrasser son identité, particulièrement dans un monde qui manque souvent de reconnaître et d'accepter les différences. Ensemble, ces narratifs éclaircissent la lutte de naviguer dans la vie avec l'autisme, ainsi que la joie simultanée qui peut découler de la découverte de son pouvoir personnel unique.

Keywords
Autism, lived experience, late diagnosis
Mots-clés
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I was talking to my therapist today about my values. I recalled a scene from the movie *Ocean's 11,* where Matt Damon's character was playing a Liquor and Gaming agent. In the scene, he was told, by Brad Pitt's character, to be liked, but also forgotten as soon as he left. That is a role I have been playing my entire life. When I worked at the bank people told me I looked like a banker; average looking, a little overweight, quiet, and, as I looked the part, I even landed the gig of being Santa for the kid's photos.

I worked long hours, and everyone thought I was a nice guy. I was well-liked, existed safely in my space, was comfortable in my knowledge of how to act, and knew how to control things around me. I was always friendly but never revealed too much. My customers liked me; I was good at small talk and getting to know others, while only having to reveal what I wanted known about me. I could exist in this world without ever having to escape my safety net. I was playing a part.

On rare occasions, I would actually connect with a client or a co-worker, but all my energy would be spent playing my part, leaving me by the end of the day with nothing left emotionally. I was tired, both mentally and physically, but I thought I was doing what a good father, husband, friend, and employee was supposed to be doing. I was a people pleaser who believed that if I kept people happy, there would be no conflict, no stress, and I could make it through my days. This left nothing for those who were expecting me to be more connected.

I don't recall ever fighting with any of my friends or co-workers, yet at home, the fighting and the stress never stopped. I didn't understand it, I was doing what I was supposed to be doing. I was providing financially, kept a safe home, put food on the table, and never missed a soccer practice, dance recital, birthday, or Christmas. Ever. We looked happy, but there was no real happiness.

I have learned how to act in most situations in my life by being quiet, observing, agreeing, and blending in. I got so good at it that I no longer even know who I am and what my values, dreams or desires really are. I spent so much time trying to fit into a role that I never really discovered who I was as a person. This explained a lot of decisions that I had made in my life, and I felt I knew myself better and understood why I had made those decisions.

The only role I never really learned was how to be in an intimate relationship because I never saw how that was done. I want that, I want to feel, I want to have that. Most days I get through by knowing what to say and what not to say, the only time I don't is when I get overwhelmed with emotion or get into a situation that I haven't incurred before. My mind feels cloudy, and I figure out a way to escape as soon as I can. I used my body to hide, carrying a little extra weight, wearing clothes that weren't too "loud", and so on. Some of my friends refer to me as "beige," and tell me I need to add some colour. I am working towards becoming me, whoever that may be.

My diagnosis helped me understand a lot of things and take action in my own life. Looking back now makes sense to me why any real relationships I had were unsuccessful. I had no clue what I was doing. I still don't, but I want to. I want to have that meaning and that feeling in my life. I am tired of hiding and blending in. I want to be me, but I am not sure who that is. Mental illness hasn't always been socially accepted and is still not understood. To this day, I tell people I am on the autism spectrum, but they have no idea really what that means. I get told I look "normal"; and "I never would have guessed", I think to myself that's because I have spent my entire life learning how to hide in plain sight. I want to come out of the shadows and into the light which scares me because it's not something I have ever done.

I am still trying to figure out what "autistic" is or isn't, but it is who I am, not a role I am playing. This is my life and I want it to be mine, not some other version of what others or society thinks it should be.

I don't want to be labeled and stuck in a box anymore, but I also don't want to bust out of it completely. I want to learn to be me, it is something I struggle with every day, and the toughest part is trying to do it in a world that doesn't understand and always accepts something or someone that is different, that's why I will continue to hide until I figure it out. I hope I can stop hiding soon.

The best example of what I go through daily and what it cost me is the experience I had when I got a new job in Calgary and my family, and I decided to move. The whole experience ending up costing me my family and my career.

All The Best With Your Future Endeavours

We were living in Regina – more like existing. My wife and I had talked about moving back to Calgary, we thought it would be better, and more exciting to be there. I took this and ran with it because I really wanted to get back there. I worked for one of Canada's big banks. At work, you could put your name on a list for job opportunities and job locations, I set mine for Calgary as a Senior Financial Advisor. That's the job I had always wanted and had been working toward all my life. The very day I hit send on my application, I got a call from a Senior Manager in Calgary. She said she wanted me in Calgary as soon as possible. Without hesitation, I accepted it because this is what we wanted as a family. At least we thought it was what we wanted as a family. It was easy. I was going to stay with my friend in Calgary while we waited for our house to sell — it shouldn't take more than a couple of months, right? I went home to tell my wife and didn't think anything of what us living apart from one another was going to do to us. She went along with it and said supportive things. "How long would it be?" she asked, I told her "only a couple of short months." Boy, was I ever wrong. It took sixteen months for our house to sell and for us to be reunited. I didn't really notice anything as time went on. My visits home were less frequent as work was busy. I was doing well, making good money, and taking care of what I was supposed to. I was providing for my family.

I didn't know what this was really costing me. I was going to hockey games, going out, and doing things, I thought I was parenting. I thought I was being a good husband. But in reality, I was absent from the life I had created. But, in hindsight, was it really the life I wanted or was happy in?

As the months went by, the stress increased and took an emotional toll on my wife and daughter. They were saying all the right things but they felt I wasn't there for them which I didn't understand. I was working. What did they want me to do? Sit in Calgary and not do anything? When I was home at Christmas I bought A LOT of presents for my daughter. I got her everything on her Christmas list. I thought that was what Christmas was about. I wasn't there to put up the tree. I was so exhausted from work and writing my qualification exams that I slept the first three days of my two-week Christmas vacation.

This is how life went for sixteen months. Me working hard but growing further apart from my family. I was unaware as I was caught up in doing what I believed I was supposed to do, what I mirrored back when I looked at others. Work hard. Become successful. Make enough money so I could take care of my family. After sixteen long months, the house in Regina had finally sold. We found a house in Airdrie and were reunited. But things weren't the same for any of us. The move had created a chasm between us. We were very different. They had learned to live without me and I had learned to live without them – I had redefined success by success at work.

Four months after my family arrived, and four days before my birthday, I was brought into a meeting with corporate security. I have replayed and retold this foundational event in my life many times. Steve, from corporate security, questioned me about reimbursing service fees to my clients. He mentioned sums of money and different client situations. I answered easily and honestly. I had nothing to hide. I was working within the parameters of my job and my boss had signed off on all the reports and transactions that I had submitted so I didn't think anything was wrong.

The last question he asked me was, in my opinion, what was more important, the bank's needs or my customer's needs? I naturally answered my customers' needs because without my customers we don't have a business. It was the truthful answer. It was easy to answer. Without question or hesitation, it was the right answer.

Those were the last words I said as an employee of the bank. Less than an hour later my manager, Sherry, the same manager who had recruited me to the branch; the same manager for whom I had been a top performer, handed me a letter stating that we were parting ways. She thanked me for my service and said "all the best with your future endeavours."

"All the best with your future endeavours."

"All the best with your future endeavours????" Just like that? Without emotion? Without any connection?

The assistant branch manager, Pat, was in tears because I think she knew this was wrong and she saw the look on my face and saw my heart breaking. I wasn't upset for me but all I thought of was my daughter. How would this impact her? I decided to move back to Calgary for this job and now it was gone.

As I was escorted out of the building after collecting my things, my phone started to buzz and ring non-stop. I had twenty-one text messages asking what was going on. I sat in my car in disbelief; crying; in a daze; wondering how this happened. I hadn't done anything wrong. I was a top-ranked Senior Financial Advisor in Alberta, I did what was right for my clients and the bank, I worked long hours, I put together charity events, and I had the top sales and customer reviews. It took me over an hour to leave as I couldn't compose myself. I had to go home and had to tell my family what had happened without really understanding why. They cried and were upset but they saw what this meant to me and hugged me and said we would make it through. I could see on their face how they hurt, but they also had words and actions that I could never feel or express.

I went for a walk that night around my neighbourhood and looked at all the houses and stopped in front of mine. All the houses looked the same. My house and my life looked like it should. Nice house. Family. Two cars in the garage. But I didn't feel happy. Is this what I was working for? All this stuff? My family wasn't happy. We were struggling. But no one could ever tell because I put on a happy face every day. I told everyone how great things were and that we were working hard to pull through. Everyone showed concern and empathy over how we had been separated and the stress of being apart and trying to sell a home.

Behind closed doors, my wife would often ask me if I was being a jerk or if there was something wrong with me. She and my daughter wanted "work" [redacted), not the [redacted] I was when I got home. I didn't get her point, I was working hard and providing the things that were expected of a husband and a father, I never missed dance recitals, soccer games, parent-teacher interviews, etc. I did my work around the house. When we broke up, my wife told me that they knew I loved them but I wasn't emotionally present. There would be times when she or my daughter would be upset and crying and I would be sitting there anxiously waiting for her to finish what she was saying so I could solve the problem. I didn't cry or get upset. I didn't realize that anything was wrong. When my wife suggested there was in fact something wrong I didn't believe her. Everyone else thought I was a nice guy and was doing everything I could.

I was diagnosed in October 2017. It was right before we split up. I was 45-years-old. My autism diagnosis made a lot of my behaviours and emotional disconnection make sense. When I started therapy it took me 6 months to stop saying I needed to be fixed. Through my sessions, I realized that what was happening was normal for someone with ASD. When I'm highly anxious or stressed I act as though everything is OK. I pretend everything is OK. I'd laugh at jokes I didn't understand. This behaviour is known as masking. I masked to get through my day, always saying yes to things and never wanting to cause any conflict. But that behaviour led to longer days and autistic burnout. By the time I got home to my family, I had nothing left, I was emotionally and mentally drained so I just went through the motions when I got home, I was physically present but had no emotional energy or support.

I thought I was providing enough but I wasn't. When I was working in Calgary and my wife and daughter were living in Regina, it was easy for me. I could hyper-focus on work all day, have a short call with them, and then have time to decompress alone. When they finally moved out here, I found myself needing more time alone and eventually, the space between us was too much. We were just going through the motions. When we split I didn't cry and wasn't angry. It felt inevitable and with my diagnosis, it made sense to me. Looking back, I so badly wish I'd been diagnosed earlier in life. I was so hyper-focused on what I thought I should be doing, I missed out on what was truly meaningful – knowing myself and my family. After all that time and effort I put into my career, mirroring what I thought I was supposed to do, it was gone in a flash. The ramifications of my autistic actions still follow me to this day.

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