Families Raising Neuro-diverse Children in British Columbia: Socioeconomic Barriers Preventing Access to Supports and Services

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Where people live, work, and grow, along with the conditions in their surroundings that shape the context of life, are referred to as the Social Determinants of Health (Robinson et al., 2022). Raising a family has many challenges, but those raising a family with a child or children on the autism spectrum face more complex problems in accessing quality healthcare. Difficulty accessing interventional healthcare services directly impacts the severity of an autistic child's disability (Raouafi et al., 2018). Stressors such as poverty, financial challenges, inadequate education, and lack of access have a large impact on families raising autistic children (Menezes et al., 2024). Resiliency comes from adversity and grows into advocacy (Coelho et al., 2020; Smith-Young et al., 2022; Menezes et al., 2024). This paper explores how socioeconomic status is a barrier to accessing support and resources for families raising autistic children in British Columbia (B.C.) and the impact of resiliency toward advocacy. I will share some ideas that can perpetuate change while still promoting inclusion within this community to educate and foster change within all communities.

Community Health Assessment (Health Promotion Problem)

Healthcare focuses on a patient-centered approach, but how that is implemented varies amongst communities. In the autistic community, assessing the dynamic that neighbourhoods have on the resilience of these families as a whole also creates a more accessible community with regard to resources (Menezes et al., 2024). The Canadian Community as Partner Model (CCAP) identifies that the subsystem in which individuals live, in this case, the neighbourhood, both affects and influences individual families within it (Vollman and Jackson, 2021). Stressors within the autistic community that limit access to early intervention are rooted in circumstances stemming from poverty, including lack of finances, reduced education impacting ability to navigate the system and inability to find adequate government resources (Hidalgo et al. 2015; Smith-Young et al., 2023).

Social Determinants of Health and their impact on families

Socioeconomic status encompasses education, income and employment and is rated based on a scale from low to high (National Cancer Institute, n.d.). Key social determinants of health categorized under the umbrella term of socioeconomic status include income and social status, education and literacy, and social supports and coping skills (Government of Canada, 2024). Considering the overall socioeconomic status of neuro-diverse families, location (urban/rural), financial assistance towards the cost of therapy, overall family income, and housing conditions affect access to services (Raouafi et al., 2018). Families in Atlantic Canada indicate that it is challenging to find what supports and services are available to support their children (Smith-Young et al., 2022). They indicate there are breadcrumbs of information available if they search for it, but state there is a need for those breadcrumbs to be compiled and accessible in one website or location that all families can access.

Data from across Canada indicates that families with lower socioeconomic status who must manage with a lack of family assistance and increased out-of-pocket expenses experience additional barriers to service, which impacts the overall severity of their child's disability diagnosis (Raouafi et al., 2018). Research by Wallace-Watkin et al. (2023) found that families lack knowledge regarding available resources, what autism is, and overall child development experience barriers to accessing services. Furthermore, immigrant populations encounter challenges related to differing perspectives of their understanding of autism, including believing it doesn't exist and that it is temporary and will go away. They preferred to accept advice from their ethnic community to use more traditional or alternative treatment methods, delaying access to services (Wallace-Watkin et al., 2022).

Resilience of the Community

When faced with challenging adversities and overcoming them people build a strength called resilience (American Psychology Association, n.d.). Menezes et al. (2024) conducted a qualitative study researching the impacts of community on families with autistic children. They found that those who felt a strong sense of community also felt that they were a better cohesive family unit, which also indicated resilience to their adverse situation. “Family resilience is the ability of the family to cope with adversity and to overcome life challenges” (Coelho et al., 2022 p. 208).

Appendix 1 shows that, when families converge with their community, they help each other with child care and other activities if needed, and share where they go for help and support. This helps build resiliency in each family by working through problems together, giving each family a sense of strength that they can draw from, and getting help through difficult situations (Menezes et al. 2024). As families build resilience, they are simultaneously building advocacy skills. Advocacy requires a parent to be educated in all social, economic and political realms. Understanding how components of the social world work regarding budgets, legislation and how providers deliver services is instrumental in advocacy (Smith-Young et al., 2022). Appendix 2 shows that as advocacy skills develop barriers get removed and the ability to express concerns, seek help, access services, and raise awareness increases.

Analysis of the Community

Analyzing common trends within this community helps determine applied solutions and must involve autistic families as a unit (Vollman and Jackson, 2021). Research shows that early intervention helps children with autism have better outcomes than those who receive interventions later in life (Hidaldo et al., 2015; Mendez et al., 2024; Gerlach et al., 2022). It is important to recognize that there are inequities within the autistic population that predispose families to disparities, irrespective of their child’s diagnosis. For example, in Canada Indigenous families are predisposed to inequalities. In the United States families with existing problems accessing public funding through Employment Insurance (EI) also experience additional barriers to accessing funding provided through EI that is specifically meant for their disabled children (Gerlach et al., 2022; Mendez et al., 2024).

In terms of socioeconomic status, the lack of finances to provide additional support for the child is the hardest to manage for those already struggling with basic needs. The government of B.C. allocates $22,000 a year to children under the age of six diagnosed with Autism Spectrum Disorder and $6,000 a year for children over the age of six (Government of British Columbia., n.d.). The provincial government allocated an additional $26 million dollars towards families managing children with complex needs and disabilities in the 2024/25 budget. Inclusion BC (a non-profit organization advocating for all disabled people in B.C.) indicates that although this sounds like a lot of money, it will only cover the increasing demand for services as more youth are diagnosed, instead of funding increased treatment and support for families (Inclusion BC., n.d.).

Recognizing that this community problem lies within the lack of access, knowledge, and disparity of available services, determining prevention and intervention is imperative. CCAP identifies five levels of prevention: primordial, primary, secondary, tertiary and quaternary (Vollman and Jackson, 2023). Prevention cannot be done at the primordial level because research about the cause(s) of autism is still developing. Recent research indicates that Autism is one of the most heritable disorders, with many contributory factors relating to its origin (Thapar et al., 2021) and primary prevention is hard to focus on if Autism has a genetic component. The focus for prevention is therefore on secondary and tertiary levels (Vollman and Jackson, 2023). At the secondary level of prevention, this would include early interventional therapies aimed at minimizing the disability. At the tertiary level, the focus is to prevent long-term effects of the disability, with interventional therapies (Vollman and Jackson, 2023).

Diagnosing the Community

A community health diagnosis aims to synthesize the data obtained in the assessment phase and provide reason and data for action to be taken (Vollman and Jackson, 2021). I have identified interventions for three community health diagnoses for the autistic community in B.C.

1. Increase family income for families raising neuro-diverse children, related to inadequate government funding, and increased inflation as manifested by the current 2024/25 budget inadequately addressing the needs of currently diagnosed children and families struggling to give their children needed interventions.
2. Increase community engagement for families with autistic children related to building resiliency and advocacy as manifested by collaborative help and strengths built from this support and collaboration of the community.
3. Improve the knowledge of immigrant families with neuro-diverse children related to their hesitancy to follow Western methods and interventional therapies as manifested by the delay in accessing services beneficial to their children.

Evaluating the Community

Imploring the evaluation process of the CCAP model focuses on working with the community as a partner in action (Vollman and Jackson, 2021). When it comes to the socioeconomic status of families raising neuro-diverse children in B.C., it would be beneficial to use the collaborative action evaluation method outlined by these authors. As mentioned above, families raising neuro-diverse children face socioeconomic barriers such as lack of education, low income, inadequate housing, lack of access to services, and community disempowerment (National Cancer Institute, n.d; Raouafi et al., 2018). Many factors exacerbate these barriers. The more government agencies are responsible for providing programs, services, and funding and use evaluative methods such as the collaborative action approach, the more the voices of the families are heard. When the affected community is the voice to drive change, the result is a more positive and stronger community. Autism BC reported that in 2021, 2.6% of children aged 0-18 had active autism diagnoses and accessed funds provided by the Autism Funding Program. This is an increase of 0.6% since 2019 and an increase of 11% between the years of 2013-2019.

New strategic plan

The review of the research indicated that more neuro-diverse research surrounding access barriers to service is needed. More comprehensive data are needed, focusing on the medical, environmental, and societal factors correlating to disability so that improvements can be made to the quality of interventions provided (Raoufi et al., 2018). Menezes et al. indicate that future studies would benefit from a community approach, where the focus is on how impactful community support is with resilience but excluding any additional support measures (2024). This would isolate the impact that the community has on resilience. Further examination of the referral process is needed to pick out factors contributing to disparities within the application process and receipt of services prior to diagnosis (Mendez et al., 2024).

Research aside, I propose future planning and research in B.C. must consider changing the funding model to support children over the age of six. Currently, children over the age of six require more support than can be provided with $6,000 a year. As a parent of two autistic children, I spent all $6,000 over three months to support my six-year-old with toilet training. This was with one support therapist and the school assisting during daytime hours. It will still be several months until he is using the toilet independently and asking or indicating to an adult that he is doing so. The school board receives $15,000 for every child diagnosed with autism over the age of six, but that money is distributed throughout all schools to help fund speech therapists, occupational therapists, and education assistants (Inclusion BC, n.d.). There is no guarantee that every child requiring services will get them while attending school. Essentially, the only guaranteed money families get is $6,000. Appendix 3 shows that over two million people in B.C. are at or below the median income level after taxes. People are struggling financially even without having a disabled child who requires additional services that will be an out-of-pocket cost. Additional funding and guaranteed services will also positively contribute to the Sustainable Development Goal of reducing poverty.

As a parent who is a part of the online autistic community in B.C., I believe that the current education system's level of support is not working. I have heard many times from families who are contacted daily to take their children home because school staff cannot handle their behaviours. The child who needs extra support is given no support and no way of acquiring an education in this situation. The School Board and Government of B.C. need to collaborate with specialists and families to come up with a better solution where children are supported to have a basic education. This is a fundamental human right and another Sustainable Development Goal that our country is trying to reach by 2030 (Vollman and Jackson, 2021).

The Strongstart program in B.C. was developed out of the recognition that some neighbourhood children were not ready to start kindergarten. This program was developed to provide families with somewhere their children can meet other children and work on early childhood developmental milestones through play, similar to how a preschool would be structured but with parent/caregiver participation (Government of B.C., n.d.). If the government, School Board, families, and therapists could come up with a similar in-school program that could support disabled children, this would help alleviate some of the problems. If every school had dedicated therapy staff with a dedicated therapy area that included necessary equipment, every student requiring services would have support. Students would receive therapy as many times a week as necessary for their growth and development relating to where they are on their spectrum or as needed based on their disability. This would only take them out of their classroom with all the other kids for as long as necessary to support their growth. This program could provide instructional support to teachers and educational assistants on professional development days to give them tools to help all students thrive regardless of their diagnosis. This is another way to achieve the educational aspect of the Sustainable Development Goals, as adults also benefit from additional education.

Rajotte et al. (2022), conducted a study which found that both students and teachers benefitted from occupational therapy support in schools. Although further research is needed in this area, this study identified positive outcomes for having occupational support in schools, benefitting teachers to reduce stress and autistic children to be in a more inclusive environment amongst their peers where they are actively involved in activities. Many theorists have indicated the importance of communication and speech in children’s development into adulthood. Speech Language Pathologists also help autistic children with communication and social skills in a variety of settings (The American Speech Language and Hearing Association. n.d.)

Secondary to a program designed within the school system, a program designed within the community is important to strengthen acceptance, resilience, and advocacy for families with children with disabilities. Menezes et al. (2024) indicate that families build resilience through informal support networks such as the community in which they live. As a parent of two neuro-diverse children, I rarely see the close friends I have had for years, so a neighbourhood program in which I would gain friends and allow for increased acceptance and understanding of my unique children would benefit everyone. This could be as simple as a weekly meeting at a park or community center and could grow into larger community events. This would also be a way to achieve the Sustainable Development Goal of good health and well-being.

My final suggestion is that all support, services, and resources be contained within one location or website accessible to all, as was indicated in the study by Smith-Young et al. (2022). Any required legislation should be developed to ensure transparency and ease of access to families. Currently, some groups are completely transparent and list all the organizations they partner with, such as the BC Disability Collaborative. Others, such as the Children’s Autism Federation of BC, don’t list any organization they are partnered with. The internet is already a confusing resource with some great and some not so great information so families must get easy-to-find, sound information and resources to support their family. All families of children with autism diagnoses are directed to the My Family Services website through the Ministry of Children and Family Development. This could facilitate all of the links to websites that are responsible for listing available supports and services, creating a localized and easy place for families to access this valuable information. It should be implemented on all other disability websites as well so that everyone has equal access.

Conclusion

Families with neuro-diverse children in B.C. are faced with disparities stemming from socioeconomic factors affecting their access to services. Close to half of approximately 5.6 million people in B.C. don't make the median income level (Government of Canada., n.d.). Families already struggling with basic needs experience even more strain financially and emotionally with the added complexity of raising a child who is neuro-diverse. Some families have trouble finding resources, and others face challenges about acceptance and management of their autistic children's support and treatment from a cultural perspective. Meeting Sustainable Development Goals as a country is a priority. I believe that if this doesn't start with communities that face the most disparities, then the goals will not be reached. Social Determinants of Health prevent many families from accessing suitable and equitable health care. Through increased community engagement, families with neuro-diverse children gain a greater feeling of acceptance while also building their resilience and ability to advocate for their families.

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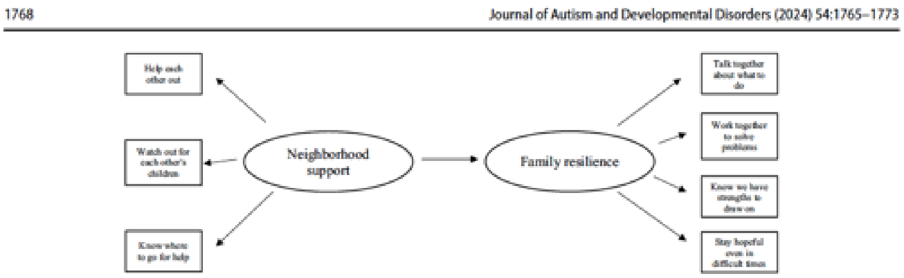
Appendices

Appendix 1

Figure 1

Journal of Autism and Developmental Disorders, 2024



Menezes et al. 2024., p.1768

“Note: Structural equation model for association between neighbourhood support and family resilience in households with autistic children. Model covariates and residuals are not depicted for parsimony. *Child age, sex, child race, autism symptom severity, co-occurring ID, co-occurring conduct problems, single parent households, and family household income were included as covariates in the prediction of family resilience.” (Menezes et al., 2024. P. 1768)

Appendix 2

Pathway in parents' advocacy journey with children and youth *diagnosed with ASD*

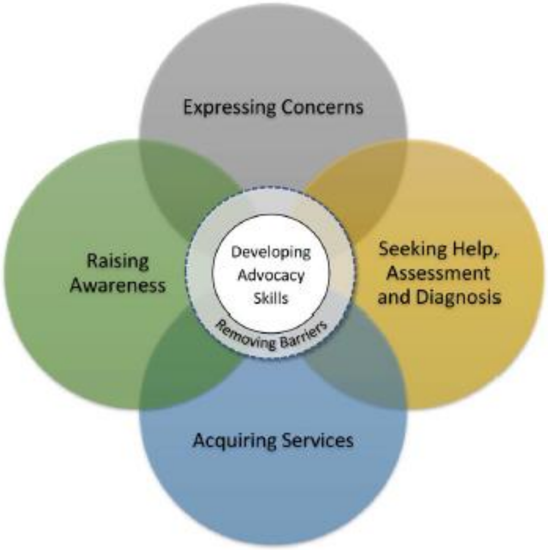
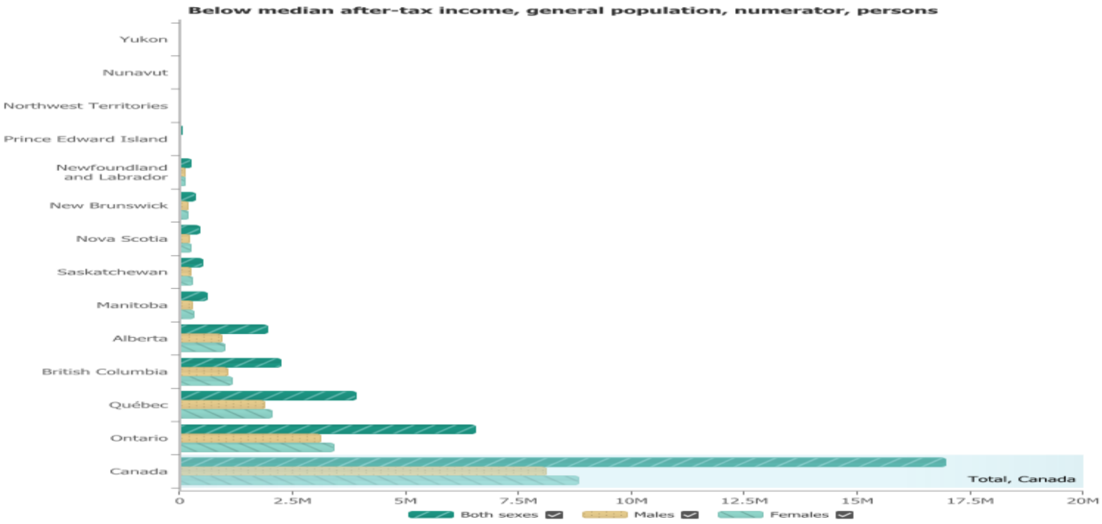


Figure 1. Pathway in parents' advocacy journey with children and youth diagnosed with ASD.

Smith-Young et. al., 2022.

Appendix 3



Source: Census 2016

Government of Canada (n.d.)