

## Update on: Examining the Quality of Life in Families of Children with ASD: Targeting Hard-to-Reach Groups in BC

Master's student Madelaine Ressel has developed relationships with Aboriginal communities. Community leader Rona Sterling-Colins, MSW, has facilitated this work. We have partnered with the The Nzen'man' Child and Family Development Centre Society, They provide an array of services and programs designed to enhance the health, well-being, and resilience of Nlaka'pamux children and their families.

The majority of their programs are delivered on an outreach basis through weekly home visits with parents and other family and extended family members.

The Lytton Centre currently works with approximately 110 families within the 12 First Nations Communities in the Fraser Canyon. The Merritt Centre works with approximately 40 families with the four First Nations in the Nicola Valley (also part of the Nlaka'pmaux Nation) as well as off-reserve Aboriginal families.

The Nlaka'pamux Nation is comprised of twenty First Nations in the Fraser Canyon to the Merritt area. Sixteen of these Bands receive services from Nzen'man' Child & Family Development Centre for their children and families.

In October and November 2018 we *co-organized two knowledge-gathering events*: with Ms. Sterling-Collins as Community Lead. These events allow us to facilitate knowledge sharing among participants including parents, practitioners and Nlaka'pamux Nation community leaders to determine their values and perspectives on child-rearing, parent and family support and services when a child is showing signs of developmental delay. We used participatory research methodologies (e.g., mapping different perspectives) to share knowledge from parents and other caregivers who care for the child, practitioners who work with the child and family, and community leaders who hold cultural and historical knowledge about the community. ***We are now in the process of follow up with qualitative individual interviews*** with parents (N=5) practitioners (N=5) and community leaders (N=5) to more specifically elaborate on the main points identified in the knowledge gathering event. The goal is to identify key values and perspectives from event participants on the supports needed to parent and support a child when there are signs of developmental risk and possible ASD. Interviews will be transcribed verbatim, and qualitative data will be analyzed using a grounded theory approach, in which themes and codes will be identified inductively and allowed to emerge from the data. A constant comparative approach is utilized, in which all the data from emergent themes will be pulled together and compared. Principles of trustworthiness will be adhered to in order to ensure the credibility.

Our work with communities will lead directly to knowledge translation activities, including a webinar, summary reports and other published material for knowledge users who attended the event as well as more broadly in BC and Canada for others who are also wanting to reach out to Aboriginal communities in their province. For example, recently the Director of the Autism Research Centre in Saskatchewan emailed us about our project to find out how they might improve services for their Aboriginal families of children with ASD.

Doctoral student Vanessa Fong is working with Asian communities. She was recently awarded a Graduate Student Fellowship from the BC Support Unit: Advancing Patient Oriented Research Fraser Centre. ***She has engaged two community leaders John Tsang (Chinese Community advocate) and Bosang Lee (Korean Community advocate) who will help her recruit families caring for children with ASD. Data collection will begin in March 2019.***

Studies have revealed that formal and informal support is linked to improved well-being and psychological adjustment for caregivers of children with disabilities. However, these factors in relation to the entire family unit have not yet been examined in families of children with ASD in underrepresented minority populations. Specifically in Chinese and Korean families, these factors may be particularly relevant given the cultural norms that discourage seeking formal support and traditional societal pressures that value conformity rather than individual differences. We are beginning to identify specific characteristics of both formal and informal support that buffer the effects of increased demands and stress on family functioning in underserved and at-risk populations is urgently needed.

*Phase 1*, will involve collecting demographic information and questionnaire responses. Family quality of life (FQOL) will be measured using the *Beach Centre FQOL Scale*<sup>11</sup>. Informal social support will be examined using the *Multidimensional Scale of Perceived Social Support* which assesses perceived social support from three sources: 1) a special person in the respondent's life, 2) friends, and 3) family. Formal support services will be evaluated using the *Services Checklist* developed by Warfield and Gulley which includes a list of 16 services and respondents indicate whether they had received a particular service within the last 12 months.

*Phase 2*, will consist of a qualitative component that addresses the second research question. A small group of parents raising children with ASD will be invited to participate in an interview to explore families' perceptions of FQOL and how their needs are (or are not) addressed within service delivery. The interview format will be semi-structured in order to encourage an open dialogue to explore participant digression. This type of open-ended approach was used to facilitate sharing their experiences regarding FQOL and areas of strength and resilience. Findings will help identify priorities for supports and services and factors which most significantly impact their FQOL. Results will enhance our understanding of inconsistencies and gaps between families' identified needs and the existing services and social supports available. Additionally, this will also shed light on a long unanswered question of why a disproportionate number of Asians with disability and mental illness experience a substantial delay in help-seeking compared to other ethnic groups.