Possible educational implications of the underdiagnosis of autism spectrum disorders, ASDs, among aboriginal children in British Columbia, Canada

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Abstract
Within the aboriginal population in British Columbia, Canada, there are few cases of diagnosed autism spectrum disorder, ASD, among children and researchers have difficulty gaining access to the field. The aim of this paper presentation is to discuss and obtain other researchers views and comments on a review of publications on the prevalence of autism within other aboriginal populations and possibly contribute with insights that can be useful in understanding the situation in BC. The review reveals that aboriginal children in BC, Canada are underdiagnosed and underrepresented in research context. Possible reasons can be diagnostic substitution, cultural, area of residence, ethnical, symptoms being recognized as schizophrenia, ethnic bias in diagnostic decisions and the impact of historical oppression and discrimination. If aboriginal children in fact are underdiagnosed with autism, the educational implications may be severe, individually, but also as a minority group. They are also missing the opportunity to get funding provided by the B.C Ministry of Children and Family Development (2013) for families to purchase treatment and intervention for children up to 18 years of age.

Introduction
The theme of the NERA conference 2013 is “Disruptions and eruptions as opportunities for transforming education”. Seen in the context of education for students with diagnoses within the autism spectrum this theme is relevant as the need for sameness often causes eruptions due to disruptions in the daily school setting. Autism spectrum disorders are complex and characterized by a triad of impairments in social interaction, communication and repetitive activities/imagination (Wing & Gould, 1979). Positive effects on social and classroom behavior have been seen in research regarding music interventions for children with ASDs but music as an educational/special educational tool for inclusion has yet to be investigated. Furthermore there is no research on aboriginal children diagnosed with ASD. My ongoing PhD studies on the meaning of music for aboriginal children in BC diagnosed with ASD
address both these issues. Possibly accurate assessment of ASDs within the aboriginal community and learning about the use and qualities of indigenous music within this population can give us the opportunity to transform educational practice and facilitate inclusion.

**Aim**

The aim of this paper presentation is to discuss and obtain other researchers' views and comments on a review of publications on the prevalence of autism within other aboriginal populations and possibly contribute with insights that can be useful in understanding the situation in BC.

**Study design and method**

Using the searchword autism in various combinations with prevalence, British Columbia, Canada, aboriginal, culture, ethnicity and indigenous, thousands of publications appeared. Out of these I selected 16 articles and 1 dissertation as relevant for this review. The chosen publications are from Canada, the USA, Australia, The Netherlands, Nicaragua, Korea and Ghana.

**Results**

**North American context**

The only publication that specifically relates to aboriginal people in North America is an article by Kapp (2011) who describes the Navajo nations’ philosophy on wellness as beneficial for full inclusion due to the acceptance of diversity. Their parenting style of being a positive role model is compatible with the learning styles of children with autism. Societys’ discrimination of both Navajo and other aboriginal nations, and people with autism, is discussed and issues of stereotyping and segregation raised. Tincani et al. (2009) also state historical oppression and discrimination as contributing to late diagnosis of autism among the aboriginal populations.

Due to changes in diagnostic criteria it is not possible to compare current studies with previous (Matson & Kozlowski, 2011). In recent reports from Center for Disease Control and Prevention (2012) and National Epidemiologic Database for the Study of Autism in Canada (2012) ethnicity is taken into account but not mentioned in the results. Burstyn, Sithole and Zwaigenbaum (2010) found lower rates of ASDs and later diagnosis among children of
aboriginal mothers in Alberta, when examining provincial delivery records from 1998-2004 and ASD follow-ups found in physician billings until March 31, 2008. Oulette-Kuntz, Coo, Yu, Chudley, Noonan, Breitheback, Ramji, Prosic, Bedard and Holden (2006) found a significant underrepresentation of autism among aboriginal children in a study on the prevalence of pervasive developmental disorders, including ASDs, in Manitoba and Prince Edward Island, Canada. In British Columbia, Canada, Coo, Oulette-Kuntz, Lloyd, Kasmara, Holden and Lewis (2008) found that diagnostic substitution, a child being changed from one special needs category to the autism category, was the reason for the rise in prevalence of children with autism in schools.

Differences in genetic vulnerability within populations (Burstyn et al. 2010), aboriginal parents not seeking help (Oulette-Kuntz et al. 2006; Bernier, Mao and Yen, 2010; Tincani, Travers and Boutot, 2010) may be possible reasons for underdiagnosis within aboriginal populations. Diagnostic tools lack in cultural sensitivity (Ouellette-Kuntz et al. 2006; Bernier et al. 2010) which needs to be taken into account by researchers and clinicians seeing as culture may affect the presentation of ASD (Mandell & Novak, 2005; Bernier et al. 2010). Tincani et al. (2009) and Bernier et al. (2010) say that labels such as autism or other disabilities may not exist in certain cultures. According to Burstyn et al. (2010) and Tincani et al. (2009) living in a remote area may influence access to diagnostic and treatment facilities as influential on autism prevalence among aboriginal populations. Bernier et al. (2010) mention that clinicians should examine their cultural biases on the representation and treatment of autism. The diagnosis of intellectual disability may cause professionals not to investigate possible autism among certain ethnic groups (Mandell, Wiggins, Carpenter, Daniels, DiGuiseppi et al. 2009).

International context
Cultural and language are possible obstacles underlying underdiagnosis of aboriginal children in Australia (Roy & Balaratnasingam, 2010), Nicaragua (Kim, 2012) and Ghana (Anthony, 2009). The aboriginal population in Australia reside in rural areas which affects their access to diagnostic and treatment facilities (Leonard, Glasson, Nassar, Whitehouse & Bebbington et al. 2011). In Ghana avoiding eye contact as an expression of autism is not considered problematic (Anthony, 2009). The label autism can be shameful and a stigma for the mother in some cultures (Kim, 2012; Anthony, 2009). Stereotypical views on autism need to be investigated in the Netherlands according to Begeer, Bouk, Boussaid, Terwogt and Koot.
(2009). Roy and Balaratnasingam (2010) found that symptoms expressed by adult aboriginal patients diagnosed with schizophrenia in Australia were symptoms of autism that had been misinterpreted and Leonard et al. (2011) found that aboriginal children in Australia may be more readily diagnosed with intellectual disability than ASD. Wilson and Watson (2011) mention that Australia has a funding program for children with autism but that the impact of colonialism and oppression discourages the aboriginal population from requesting government services.

**Discussion and Conclusions**

There is little academic work published regarding aboriginal populations and autism. By reviewing publications about the North American context and using international publications to cast new light on the situation patterns are discernible. Ethnical and cultural factors may affect the extent in which aboriginal children are diagnosed with ASDs. Diagnostic substitution or symptoms of autism being interpreted as something else are other factors. Ethic bias and the impact of historical oppression and discrimination is still present for many aboriginal people in their everyday life. Lindblom (submitted) discusses the impact of Canadian indian residential schools on the aboriginal people in British Columbia in relation to autism.

It is clear that further research on the under-detection of autism among aboriginal children is needed. The educational implications if they in fact are under-diagnosed may be severe and lead to lifelong discrimination. Families may also be missing funding opportunities that could make the daily lives of the children with autism more meaningful. In this context music as a tool for inclusion may be of importance which implicates that further research is needed in this field also. My ongoing fieldstudies with First Nations children diagnosed with autism addresses both the under-detection of autism but also the use of music as a tool for inclusion for these children. Possibly accurate assessment of ASDs within the aboriginal community and learning about the use and qualities of indigenous music within this population can give us the opportunity to transform educational practice and facilitate inclusion. Discussions with the audience at the conference gave useful insights regarding research ethics and autism as a social or cultural construct.

**References**


Beeger, S., Bouk, S.E., Boussaid, W., Terwogt, M.M., Koot, H.M. (2009). Underdiagnosis and Referal Bias of


