



**Perspectives of students with autistic spectrum conditions and their parents concerning their inclusion in high school: a France - Quebec comparison.**

**Presented by:**

**Morgane Aubineau, doctor in neurodevelopmental psychopathology**

This PhD abstract for use by the members of the expert national network in autistic spectrum disorders (RNETSA). The partial or complete reproduction of this document for personal, teaching or non-commercial purposes is allowed if the source is mentioned. Any modification or adaptation on the content is forbidden without the explicit authorization of the author. The RNETSA is grateful to Dr. Aubineau for her contribution to expertise and development of knowledge in this field.

If citing this document, please use the following:

AUBINEAU, Morgane. « *Vécu de l'inclusion scolaire au secondaire des élèves ayant un trouble du spectre de l'autisme : regards croisés des adolescents et de leurs parents, en France et au Québec* », Québec, février 2018, Réseau national d'expertise en trouble du spectre de l'autisme, disponible en ligne au [http://www.rnetsa.ca/theses-et-memoires/resumes-de-theses]

**February 2018**

## **Perspectives of students with autistic spectrum conditions and their parents concerning their inclusion in high school: a France - Quebec comparison.**

---

### **Background and objective**

For the last ten years, an increasing number of students diagnosed with high functioning autistic spectrum disorders (HFASD) have been able to attend mainstream high schools in both France and Quebec (French government, 2016; Ministry of Health and Social Services, 2017; Poirier & Cappe, 2016). Despite international studies and governmental recommendations to directly involve youth with HFASD in research (Humphrey & Lewis 2008; Tobias, 2009), their own perspective is rarely taken into account in francophone research settings (Godeau, Sentenac, Pacoricona Alfaro, & Ehlinger, 2015). Yet, their singular perception of the world and their difficulties with social understanding can be obstacles for their academic and social fulfillment, especially during adolescence (Fortuna, 2014; McLaughlin & Rafferty, 2014; Saggars, 2015). Grounded in an ecological and collaborative approach in which participants are acknowledged as experts and knowledge co-producers, our work aims to understand how they cope with mainstream education in high schools.

### **Methods**

Twenty-six teenagers with HFASD (ages 13-17) and their parents collaborated in this research, in both France (n=17) and Quebec (n=9). Both youth and parents took part in semi-structured in-depth interviews and completed questionnaires (Adolescents: Friendship Qualities Scale (FQS) and Self-Perception Profile for Adolescents (SPPA); Parents: Strengths and Difficulties Questionnaire (SDQ) and personal information sheet) (Bukowski, Hoza & Boivin, 1994; Goodman, 2001; Harter, 1988).

### **Results and discussion**

**Questionnaire analysis.** Cluster analysis identified three adolescent profiles for friendship representations, mainly distinguished regarding two dimensions: companionship and help/aid from the friend. Three dimensions (social acceptance, close friends and physical appearance) differentiate self-perception into a 4-group typology (SPPA). Moreover, the presence of a teaching assistant in class and the social skills training support (individual or group sessions) are correlated positively with self and friendship representations. Despite moderate to high

scores of impact and parental burden (SDQ), results indicate that satisfying parental representations are positively correlated with adolescent' prosocial behaviors, full-time job for mothers and diagnosis of ASD in parents.

***Thematic analysis of teenagers' interviews.*** Managing school sensory aspects, perceived immature behaviors from their peers and tiredness resulting from a heavy workload are the main obstacles to their wellbeing in high school. However, being included in an intensive or international academic program, being driven by a passion or a clear objective and having a friend in the school environment appear to be important enablers for inclusion success. Although strongly dependent on peers' representations, the autistic identity is generally well experienced and accepted, especially outside of high school.

### Prospects for success

Transition from adolescence to adulthood will constitute one of the major challenges for youth with HFASD in the next few years and being prepared is key. Preparation would allow the adolescents to gain autonomy and practical skills to understand their needs and strengths and be able to speak for themselves in a postsecondary or professional environment. Finally, our work highlights the importance of moving from a deficit-led approach to a neurodiversity paradigm, promoting empowerment of individuals and considering ASD as a valuable contribution to human diversity.

### Recommendations for practice

Based on our research, we propose the following recommendations for those involved in the academic and social inclusion of teenagers with HFASD in order to support them with their transition into adulthood.

***1. Input from the students is critical.*** Every decision regarding the teenagers has to be made in consultation with them, whether about education, academic and vocational guidance, leisure or support services. In particular:

- ✚ Teens have to be involved in the drafting and (re-)evaluation of their individualized intervention plans. Their opinion is just as valuable as the adults: they are key members of the school staff;

- ✚ If the student prefers not to disclose a diagnosis to the school members (teachers, peers, etc.), this choice should be respected. Disclosing the diagnosis of a student without full consent would likely be counter-productive;
- ✚ In the teens' testimonies, tiredness appears as one of the most recurrent and invalidating obstacles for a successful inclusion. Thus, it is imperative to respect the need for decompression and relaxation. This could be accomplished by a (temporary or not) cessation of support services, participation in (non-therapeutic) leisure activities, more time spending in one's room, etc.;
- ✚ Similarly, at some point, teens may decide to stop participating in social skills training. Even if the encourage considers this training necessary or beneficial, it is critically important to take their choices into consideration and be vigilant about the risk of normalization and over-adaptation;
- ✚ Leisure activities with typical peers are highly valuable by allowing the establishment of relationships outside of the school environment and generalization of certain social skills. In many testimonies, these activities appear as levers for social inclusion, among typical peers.

**II. Provide “just enough” to promote autonomy.** Being autonomous does not mean the lack of support but rather being able to ask for the help one's need. Thus, within a perspective of evolving empowerment, the student, his parents and the staff would benefit greatly by organizing “just enough” support for teenagers to be able to function and progress in their environment. This “just enough” depends on every student and should be regularly re-evaluated with the teen's input.

**III. Evaluate.** Given the diversity of ways in which people express autism,, support options should be done on a case-by-case basis, after a rigorous, regular and individualized evaluation of the student' strengths and needs. Particular attention must be paid to the frequent comorbidities that are often found in the ASD population, such as ADHD3, anxiety or learning disabilities.

**IV. Invest in the students' strengths.** Passions and strengths constitute one of the key enablers for inclusion. Consequently, it is critical for staff and parents to take time to get to know their passions and strengths consider them and add value to them, in the student academic process setting. In this perspective, some international education programs with a

focus on music or sports can be excellent options for students strongly motivated and academically capable.

*V. Help teens to have a deep understanding of their diagnosis.* An in-depth and early understanding of their condition allows students to develop empowerment, communicate needs and strengths to the people in charge, and be able to advocate for themselves. This process must be set up as soon as possible, with the support of parents, staff and professional caregivers.

*VI. Promote neurodiversity.* For all the stakeholders, promoting awareness about the particularities of individuals with HFASD is essential so that they can access the same opportunities in education, work, and social life. To this end, the use of certain words are important, such as progressively moving from “ASD” to “ASC” (for “autistic spectrum conditions”) promotes honouring everyone’s capacities and adds value to neurodiversity.

## Conclusion

The transition into adulthood constitutes a decisive step for students and their parents and should be anticipated early on. Two key steps in order to do this are 1) promoting early empowerment by enabling youth to gain an in-depth understanding of their diagnosis (strengths and needs); and 2) encouraging them to speak for themselves. In addition, a step-by-step increase in autonomy also has positive consequences for the whole family, by relieving parents (and siblings) of the need to manage the numerous burdensome administrative requirements (school, health, service support, etc.). Finally, and perhaps most importantly, look for the voices of the teenagers who are, above all, “the most expert, most capable of telling what it is like to be them” (Speraw, 2009, p.736).

**Keywords:** autistic spectrum conditions; adolescent’ identity formation; academic and social inclusion; student’ perspective; friendship and self-representations; social cognition; France – Quebec comparison.

### Bibliographical references

Bukowski, W. M., Hoza, B., & Boivin, M. (1994). Measuring friendship quality during pre- and early adolescence: The development and psychometric properties of the Friendship Qualities Scale. *Journal of social and Personal Relationships*, 11(3), p. 471-484.

Fortuna, R. (2014). The social and emotional functioning of students with an autistic spectrum disorder during the transition between primary and secondary schools. *Support for Learning*, 29(2), 177-191.

Godeau, E., Sentenac, M., Pacoricona Alfaro, D. L., & Ehlinger, V. (2015). Élèves handicapés ou porteurs de maladies chroniques. Perception de leur vie et de leur bien-être au collège. *Éducation et formations* (88-89), 145-161.

Goodman, R. (2001). Psychometric properties of the Strengths and Difficulties Questionnaire (SDQ). *Journal of the American Academy of Child and Adolescent Psychiatry*, 40, p. 1337-1345.

Gouvernement français (2016). École inclusive : création de 32 000 contrats d'accompagnants des élèves en situation de handicap. Document téléaccessible à l'adresse <<http://www.gouvernement.fr/argumentaire/ecole-inclusive-creation-de-32-000-contrats-d-accompagnants-des-eleves-en-situation-de-4931>>. Consulté le 4 septembre 2017.

Harter, S. (1988). *Manual for the Self-Perception Profile for Adolescents*. Denver, CO: University of Denver.

Hill, L. (2014). Some of it I haven't told anybody else': Using photo elicitation to explore the experiences of secondary school education from the perspective of young people with a diagnosis of Autistic Spectrum Disorder. *Educational and Child Psychology*, 31(1), 79-89.

Humphrey, N., & Lewis, S. (2008). Make me normal 'The views and experiences of pupils on the autistic spectrum in mainstream secondary schools. *Autism*, 12(1), 23-46.

McLaughlin, S. & Rafferty, H. (2014). Me and 'It': Seven young people given a diagnosis of Asperger's Syndrome. *Educational & Child Psychology*, 31(1), 63-78.

Ministère de la Santé et des Services sociaux (2017). *Des actions structurantes pour les personnes et leur famille. Plan d'action sur le trouble du spectre de l'autisme 2017-2022*. Québec : gouvernement du Québec.

Poirier, N., & Cappe, É. (2016). Les dispositifs scolaires québécois et français offerts aux élèves ayant un trouble du spectre de l'autisme. *Bulletin de psychologie*, (4), 267-278.

Saggers, B. (2015). Student perceptions: Improving the educational experiences of high school students on the autism spectrum. *Improving Schools*, p. 1-11.

Speraw, S. (2009). "Talk to Me - I'm Human": The Story of a Girl, Her Personhood, and the Failures of Health Care. *Qualitative Health Research*, 19(6), 732-743.

Tobias, A. (2009). Supporting students with autistic spectrum disorder (ASD) at secondary school: a parent and student perspective. *Educational Psychology in Practice*, 25(2), 151-165.