

AIFRIS 2022  
Oral presentation proposal

**Title:** What are the autonomy support needs of children with neurodevelopmental disorders? A reflection, a dialogue and a fusion of knowledges

**Authors**

**Aline Bogossian** is an assistant professor at the School of Social Work, Université de Montréal and a social worker. Her research focuses on the ethical and social issues affecting children with chronic illnesses or developmental disabilities, their families and health and social service professionals. In practice, teaching and research, she favours a collaborative, participatory and reflective approach that is in line with the impact of the social environment on well-being.

**Delphine Gaudin-Drouelle** is a medical researcher at the University of Western Brittany in the field of innovation in paediatric rehabilitation as a facilitator of child and family participation in research. In her role as a paediatrician, she is also the project leader of the Maison du RIRE (Ressource Innovation Répit pour l'Enfant et la Famille), an experimental participatory community health project dedicated to children and families, aiming to promote children's health in a fully inclusive dimension. She is also a parent of a child with a neurodevelopmental disorder.

**Commentator**

Berna Elias holds a post-graduate degree (DEA) in social psychology and is currently a doctoral candidate at the School of Social Work of the University of Montreal. Ms. Elias has over ten years of experience as a social worker in an international multicultural context. She is interested in supporting people with neurodiversity, their families and practitioners. Her research interests include the child-parent-practitioner partnership in intervention, the cross-cultural context and participatory partnership research. Berna Elias' work is rooted in clinical sociology and in reflective, comprehensive, critical and interdisciplinary approaches.

**Axis 2: Interrogating the logics of action and recognition of users' experience, at the intersection of intervention, research and training**

The transition from paediatric to adult health care is defined as "the planned and deliberate move of chronically ill adolescents from child-centred to adult-centred health care" [1]. The transition from childhood to adulthood is a period in which a young person is expected to 'become self-reliant', increase independence, separate from parents and accept responsibility for complex decisions. However, normative definitions of autonomy only include those who are likely to be able to exercise their full civil responsibility at the time of coming of age and exclude those who are unable to exercise their civil, legal and moral responsibilities, such as people with disabilities, who cannot exercise their responsibility due to lack of accessibility of public services and infrastructures. Normative definitions of autonomy influence the way services are designed and delivered, thus producing situations of social exclusion and reducing the possibility of self-

determination for young people living with neurodevelopmental disorders (i.e. cerebral palsy, epilepsy, autism, learning disabilities) [2]. However, the World Health Organisation's International Classification of Functioning, Disability and Health (ICF) definition recognises social participation as a primary social determinant of health. Thus, limitations to social participation may be induced by definitional problems and have consequences for the development of an inclusive society.

Services to support the transition from paediatric to adult health care are based on the notion of "transition readiness" and are based on values related to the independence of young people. Thus, independence is an important goal in transition programmes and services. However, for many young people, this normative vision of autonomy is neither meaningful nor desirable [3] and does not respond to their contextual and relational realities [4]. Moreover, despite the high value placed on the notion of autonomy, the question of "to be autonomous or not" often rests on the shoulders of individuals and is not considered as a societal issue, of social inclusion or exclusion. How can the environment be adapted to recognise autonomy support needs?

In this presentation, we outline a new research project that draws on pragmatist philosophies and the concept of contextualised autonomy [5,6]. The latter recognises autonomy as a capacity composed of various dimensions, which can be supported, strengthened and implemented to achieve fulfilment and well-being [7,8]. In this sense, autonomy could be considered as a need, just like the need to develop a skill or the need to belong.

In Axis 2 of the conference, we propose to examine the concept of contextualised autonomy using a case vignette [9] and clinical illustrations to explore its definitional, structural, emotional and societal possibilities and challenges. Our aim is to identify the strengths and weaknesses of this concept as a guiding tool for social work practice and other practitioners working with children and their families. In our aim to engage in a dialogue that seeks to represent the perspectives of researchers, practitioners, and concerned individuals, our discussion takes place between a researcher who is a social worker, a pediatrician who is a mother of a child with a neurodevelopmental disorder.

## References:

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