

Guest editorial

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Children and adults on the autism spectrum, with and without co-occurring diagnoses of intellectual disability (ID), experience unmet health care needs despite emerging evidence that they display higher rates of physical and mental health disorders compared to people without disabilities. A recent large population-based epidemiological study in Sweden found that autism spectrum disorder was associated with a 2.5-fold increase in mortality rates and life expectancies that were lowered by 16 years (Hirvikoski *et al.*, 2016, BJP). In persons with co-occurring ID, the increased risk for premature death was even higher (sixfold) and related to physical disorders, especially diseases of the nervous system and epilepsy, whereas persons without co-occurring ID displayed a significantly higher risk of premature death from suicide. Ensuring equal access to the health care system is a pivotal step in providing appropriate diagnostics and treatment to children and adults with autism; yet obtaining adequate care remains challenging and many health care providers report limited training experiences and knowledge about working with autistic individuals (Nicolaidis *et al.*, 2013).

Due to the many social, financial and mental and physical health-related challenges that persons with disabilities experience, it is critical that barriers to the health care system be identified and ameliorated to improve the use and quality of health care services. However, current research on improving access to health care services for people with autism spectrum disorder is scarce (Johnson and Levine, 2014).

The aim of this special issue is to stimulate discussion and new research on the health and health care of people with autism spectrum disorder. In a co-productive approach, we give people on the autism spectrum, their families and health care providers a voice to open an exchange between professionals and people with lived experience.

Christine Preißmann, a Physician on the autistic spectrum, shares insightful recommendations for improving health care for patients with autism spectrum disorder in "Autism and healthcare." This eloquent paper is enhanced by her unique perspectives as a health care provider and her experiences as an autistic individual. Michael Seidel provides a view from affected families in his article "Quality of health and health services in people with fragile X syndrome: perspective of their parents." Family members report on the health status, health care access and satisfaction with health care services for their loved ones with fragile X syndrome. Possible options to improve the transition from childhood to adult health care are outlined in the article by Erickson *et al.*: "Transition Tools and Access to Adult Primary Care." Herein, primary care providers evaluate open access transition tools in terms of their ease of use and effectiveness. With his article "Systemic-attachment formulation for families of children with autism," Mark Hudson highlights the importance of the family context in research, services and health care for autism spectrum disorder and presents an integrative formulation approach, incorporating aspects of family systems theory and attachment theory. From this perspective, he outlines a model that has the potential to elucidate the nature of autism spectrum disorder and co-occurring mental health conditions, in order to provide more effective treatment. On the topic of improving the quality of health care for patients with autism spectrum disorder, Riosa Burnham *et al.* provide an excellent example of a training module for hospital staff to improve knowledge about autism spectrum disorder and needed supports during a hospital stay: "An online ASD learning module for pediatric health care professionals." In his comprehensive review, Peter Martin outlines "Peculiarities in pain processing and expression, liability to pain causing disorders and diseases, and specific aspects of pain assessment" in people with Rett Syndrome. This article delineates the challenges associated with appropriate assessment and treatment of pain in individuals with Rett Syndrome and

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it offers specific recommendations to address these issues, which have broader implications for all individuals with autism spectrum disorder.

In this issue, we highlight current knowledge of and challenges to accessing quality health care for people with autism spectrum disorder. We emphasize solutions to overcoming these obstacles from various perspectives (e.g. people on the autism spectrum, family members and health care providers) and propose specific techniques to address these issues, such as standardized instruments, an online learning module, and an integrative approach in clinical practice. We hope to inspire stakeholders in the fields of autism spectrum disorder and health care to further improve the diagnosis and treatment of mental and physical conditions, and thereby, the health status and wellbeing of autistic people.

References

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