

Autism diagnosis 101:

a guide to communicating with autistic people and their families

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These texts are further contextualised using short stories from autistic children, teenagers and adults.



An assessment clinic with diverse needs

Each year, over 300 families visit the ASD assessment clinic at Rivière-des-Prairies Hospital. This is our second article on autism diagnosis, and addresses the practices surrounding the disclosure of an autism diagnosis. Indeed, when a diagnosis of autism is confirmed in children and adolescents, the assessment team not only provides personalised guidance on intervention services (support, stimulation, rehabilitation, psychiatry etc...) but helps those involved to better understand their situation, and come up with ways it can be improved.

Parents most frequently report a need for information that is both general and personalised, as well as support services in the form of guidance and counselling. It is also vital to provide information to autistic children and adolescents. For this reason, special attention is paid to communicating clear and valid information to the person being assessed, their loved ones and their intervention team. Due to the high stakes at play during this brief interaction, our team has elected to develop a guide book which will provide information, support and facilitate communication during these appointments.

A Communication Tool

"Rencontre avec l'autisme : pour comprendre et agir" is the guide book we have developed, based on our current understanding of autism, best practice guidelines and our own clinical experience with disclosing the diagnosis to autistic people and their families. This collaborative work¹ is illustrated by Laura Charrette (graphic designer, recipient of two student awards from the 2018 Grafika contest- see ref.² for more information). The guide consists of brief texts which explain autism, provide guidance on interpreting an autism diagnosis, recommend interventions, and outline the service network in Quebec. These texts are further contextualised using short stories from autistic children, teenagers and adults. Vignettes help to make commonly available information clearer and more accessible, by illustrating how situations may play out in everyday life. In addition, worksheet-style exercises allow families to personalise the guide book to better fit their experiences. These exercises also aim to encourage dialogue between service users and professionals.

Constantly Improving Clinical Practice

A "working version" of this tool was recently incorporated into our clinical practice, to allow clinicians to familiarise themselves with its contents and service users to provide feedback prior to publishing a final version. In this way, we are measuring the tool's *acceptability* in the context of our assessment clinic.

What could be the *impact* of this new tool on our practice? We are presently evaluating the extent to which it may improve the experiences of service users with respect to care provided, and thus their overall satisfaction. By facilitating access to a relevant body of information, we hope that this guide book will improve the understanding of autism in health-service users, and represent a significant first step in their subsequent journey. 🌻

References:

¹ Forgeot d'Arc B, Thermidor G, Chrétien M, Lajeunesse S, Laporte L. Rencontre avec l'autisme: pour comprendre et agir. Illustrations: Charrette L. 2018, 94 pages. ISBN: 978-2-550-80235-8.

² www.lauracharette.com

Note: Encountering Autism: towards understanding and action" is not yet available to the public nor professionals. The purpose of this article is to describe a process by which diagnosis disclosure practices may be improved, and not to advocate a particular approach. Our procedure is still under development, and results will be communicated shortly. Follow "Sur le spectre" for updates! For any queries concerning validation, contact b.forgeot@gmail.com.