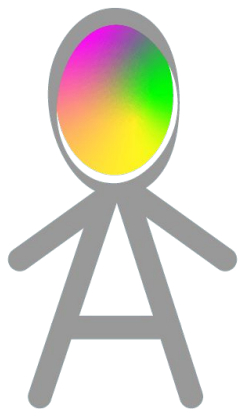




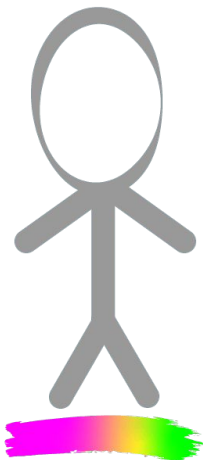
Welcoming Youth and Young Adults with Autism and Complex Care Needs in your Practice

Liliane Savard
Jennifer Lagro

Autism and language: some people prefer...



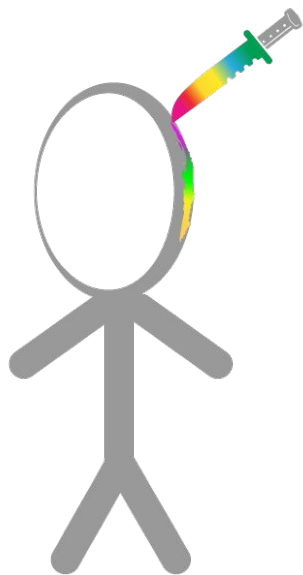
Identity-first:
"Autistic person"



Person-first:
"Person on the spectrum"

Ask how a
person
chooses to
identify.

Avoid Disorder-Based Language



Autism Spectrum Disorder (ASD)

Suffering from autism

At risk for autism

In the UK: Autism Spectrum Condition

The Three Functional Levels of Autism

ASD Level 1 Requiring Support



difficulty initiating social interactions

organization and planning problems can hamper independence

ASD Level 2 Requiring Substantial Support



social interactions limited to narrow special interests

frequent restricted/repetitive behaviors

ASD Level 3 Requiring Very Substantial Support



severe deficits in verbal and nonverbal social communication skills

great distress/difficulty changing actions or focus

Working with patients to improve care

- Opportunity to connect: antidote to burnout
- Safe space for healthcare providers to learn

Goals for today

- 1) Identify ways of obtaining the necessary information you need to facilitate a smooth visit and support your patient's health.
- 2) Define what a successful visit with a new patient on the autism spectrum with complex care needs looks like for families.
- 3) Identify some resources and next steps for your practice.

Our plan

- **Jen's experience with the transition to healthcare for adults (challenges and helpful tips)**

Discussion

- **Supports received from other service providers that can be involved with the transition process (Eco Map)**

Discussion

- **Tools for providers**

Discussion

Pediatrics to Adult Transition Timeline

Age (years)

14

16

18

22

25, 26.....

Legal



School



Vocational



Healthcare



Independent living



Medicaid



Tips and tricks

Preparing for the visit

- Call, email, message: Identify communication, environmental and scheduling considerations
 - [Autism Friendly Questionnaire](#)
- Obtain an EcoMap to identify collaborators
 - [InnerHive](#)
- Make it easy to come to visit the clinic

On the day of the visit:

- Limit the time in the waiting room
- Autistic youth may need to move around in the exam room and explore.
 - Put exam tools and materials in cupboards.
- Offer some control on the environment:
 - Natural lighting if possible.
 - Give choice (exam in regular chair, stay in own clothes,...)
 - Things to do (TV screen, sensory tools, rocking chair,...)
 - Procedure modification: BP cuff over clothes, no contact thermometer...

Communication

- Make sure to include the youth in conversation
- Age appropriate, direct and plain language
- Give processing time: pause to let them answer
- Explain **what** you are doing and **why**, demonstrate on supporter/parent

During challenging situation: Step back and slow down

- Ask the youth
- Ask the parent/guardian
- Ask yourself: can this procedure be postponed, done differently

Take home message

You are not alone

There is a network of support: parents, school, designated agency, VCHIP, OR team

Adjust your expectations for what is a “good” visit:

Being able to see you is better than no healthcare at all.

Other Resources

[All Brains Belong VT](#)

[Timberlane Dental](#)

[HCT project resource page \(Resource for providers\)](#)

[Care consultation and Health system at CHSN](#)

School team and IEP transition plan

[Coordinated Service Plan Act 264 \(link to fillable form\)](#)

[Blueprint for Health Care Management Release Form](#)

[Vermont System of Care Plan 2023-2025](#)

[A National Road Map for Disability-Inclusive Healthcare](#)

References

1. Saqr, Y., Braun, E., Porter, K., Barnette, D., & Hanks, C. (2017) [Addressing medical needs of adolescents and adults with autism spectrum disorders in a primary care setting.](https://doi.org/10.1177/1362361317709970) *Autism*, 22(1), 51–61. <https://doi.org/10.1177/1362361317709970> (Free full text)
2. Hart, L. C., Saha, H., Lawrence, S., Friedman, S., Irwin, P., & Hanks, C. (2022) [Implementation and Evolution of a Primary Care-Based Program for Adolescents and Young Adults on the Autism Spectrum.](https://doi.org/10.1007/s10803-021-05171-w) *J Autism Dev Disord*, 52(7), 2924-2933. doi:10.1007/s10803-021-05171-w (Free full text)

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