

Understanding Autistic Well-being

This video series was produced from the Autism Mental Health Literacy Guide by the Autism Mental Health Literacy Project (AM-HeLP) Group.

This video is one of six in the series about different aspects of autism mental health literacy. For this video, we will talk about: “Understanding Autistic Well-being”

We briefly explore what well-being means, what it looks like and how we can support it. You can learn more about this topic in the AM-HeLP Guide.

Well-being is broad and different for each person, especially day to day. Many factors can influence it. Well-being is based on how people feel and on their contexts.

For example, there are outside factors, like social connections or accessibility, and internal factors, like a how a person copes, their optimism, or their self-esteem.

There are several aspects of well-being:

- Psychological
- Emotional
- Physical
- Social
- Spiritual

Autistic people have fulfilling lives and experience well-being.

Testimonial – “Autistic folks do have fun, we do build coping skills, we do have enjoyable things that make our lives worthwhile. Our lives are treated by society as being the worst-case scenario – like my birth was nothing to be celebrated. But that’s not true. I have fun; I have favourite toys/games, I like to draw and read, I look forward to comic book conventions, I love Christmas and Halloween...I have a full life. Not a tragedy” – Elsbeth Dodman, Adviser

Self-care and community-care are both important things to consider when it comes to Autistic well-being.

Self-care is the many ways people can attend to their own needs, keep themselves feeling as well as possible, and have positive mental health. It’s about taking care of yourself, but this can also include other people helping you take care of yourself.

Self-care looks different for everyone and is not something that is always done by itself. For some, self-care may mean connecting with others, getting, and giving support. For others, it may mean taking a break from connecting with others.

Testimonial – “I choose to find value in crafting, sewing, gardening and home improvements, all activities that are home based and I only shop locally, a short walk from home...I prioritize family and friends, and have people over for tea in the garden or BBQs in good weather. Music and art, reading and learning are all positive activities that can be fulfilled over the internet. I enjoy teaching and offer sewing and crafting on a one-on-one basis. My life is balanced and fulfilling” – Written by an AM-HeLP Adviser, read by Patricia George, Adviser

You can engage in short and long-term self-care strategies. Short-term strategies can be done to immediately boost well-being. For example: you can go to a quiet room, eat your favourite food, or talk to a trusted person.

Testimonial – “I have a self-care shoe box where I put in a few small candy bars, some video games and movies, fidget toys and the like. Or at times I say to myself ‘how can I relax today’ and make a list of activities I would find enjoyable and pick a few from the list.” – Elsbeth Dodman, Adviser

Long-term strategies are strategies that can be done over time and can maintain your well-being. For example:

- Being informed about your mental health – Learning about your mental health and how to support it.

Testimonial – “Diagnosis is kind of a double-edged sword. On the one hand that gives clarity and understanding of who you are and what you need, but at the same time it gives you something to point at and say I'm less than. There's a lot of internalized ableism that comes with it, but on the flipside withholding diagnostic information can result in a lot of confusion and even self-hatred that you just can't explain. With a diagnosis, you're actually able to work through whatever it is you're going through and able to speak to someone about it using the right terminology.” – Alex Echakowitz, Adviser

- Building social support

French Testimonial – «Lorsque j'ai reçu mon diagnostic pour la première fois, il n'y avait aucun groupe d'adultes autistes dans ma communauté. Bien que j'ai trouvé cela décourageant au début, j'ai créé mon propre petit cercle de soutien en créant d'abord un tel groupe localement qui était de nature sociale et récréative. Ensuite, j'ai créé un groupe de soutien dirigé par des Autistes qui se réunit tous les mois. Ces possibilités ont fourni à d'autres comme moi un

«endroit doux pour atterrir» pour les nouveaux diagnostiqués. Pour les adultes autistes de ma communauté, cela a permis de créer un lieu pour relier et valider nos expériences et pour favoriser la fierté autiste.» – Louise Tardif, Conseiller

English Testimonial – “When I first got my diagnosis, there wasn’t any group for Autistic adults in my community. While I found this to be discouraging at first, I created my own little circle of support by first creating such a group locally that was social and recreational in nature. Then, I created a support group that is Autistic-led that meets monthly. These opportunities provided others like me a “soft place to land” for the newly diagnosed. For the Autistic adults in my community, it allowed for a place to connect and validate our experiences and to foster Autistic pride.” – Louise Tardif, Adviser

- Practicing Autistic pride – Being proud to be Autistic and celebrating how Autistic people communicate, experience, and understand the world around them.

Testimonial – “I think pride is something that one practices, not just experiences. Pride wasn’t given to me from the sky. I had to work on it like a skill. If I don’t practice it regularly, it is hard to stay proud. Especially when the whole world is constantly gearing up to tell me I am not worthy of pride.” -
Written by an AM-HeLP Adviser, read by: Patricia George, Adviser

When we talk about self-care, we can’t assume that everyone has the ability to do it and to access support on their own. This is also why it is important to talk about community care when we talk about well-being.

Testimonial – “One of my biggest and most successful self-care strategies is asking for help. I pose questions to similarly affected individuals and I ask for advice on how they’ve solved the same problems I’m dealing with. Hearing from other people who are like me and who have shared lived experience is one of the most hopeful and helpful parts of self-care that I do for myself. It makes me feel like I’m not alone. It also helps me to organize to remove these problems and barriers for others, and that helps me to cope.” – Anonymous Adviser

Community care is choosing to take care of each other, including oneself and others in the community. Examples of community care are peer groups or neighbourhood groups, sometimes called “spoon shares” or “pods” that connect people needing short- or long-term support because of injury, illness, or other life challenges.

Mutual aid is when we provide social support or resources to each other, like running errands for someone in need or food to people when they cannot afford it. These groups work to meet each other’s needs to survive.

Some resources that can be given or asked for in community care include: Practical help like household chores, travel assistance, sharing experiences and more.

Offering, asking, receiving, or declining help may not come easily to an Autistic person, especially if they have mental health challenges. However, community care works based on support and understanding, and you don't have to get it right the first time.

Testimonial – “Community care improves well-being just as much if not more than self-care. Overemphasis on self-care is one of the ways society fails at securing the well-being of disabled people.” – Anonymous Adviser

It is not up to the Autistic person alone. To feel capable and successful, Autistic adults may need some support at home, school, work, and more.

One of the ways society can change is to make things more universally accessible. This means creating and designing products and environments that allow everyone with all levels of ability to access, understand, use, and participate in society. For example, providing gender neutral and wheelchair accessible washrooms, providing Augmentative and Alternative Communication tools, or flexible work hours.

Thriving often takes a combination of understanding autism, knowing what self-care works for each person, and having Autistic adults, service providers and family members - the community - working together.

Knowing more, helps more.

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More information can be found in **Sections 6** of the Mental Health Literacy Guide for Autism.

To learn more about AM-HeLP and to read the Mental Health Literacy Guide for Autism visit: <https://www.yorku.ca/health/lab/ddmh/am-help/>

Watch the animated video: https://youtu.be/Bux_ZZ1oeZY

Credits

Video Produced by: [Spectrum Productions](#)

Voiceovers by: Riley Goldsmith and members of the AM-HeLP Group

Script written by: Paula Tablon Modica, Dr. Yona Lunsky, and Dr. Jonathan Weiss

Contact

For more information on the guide and AM-HeLP, contact Dr. Jonathan Weiss, Department of Psychology, York University at jonweiss@yorku.ca