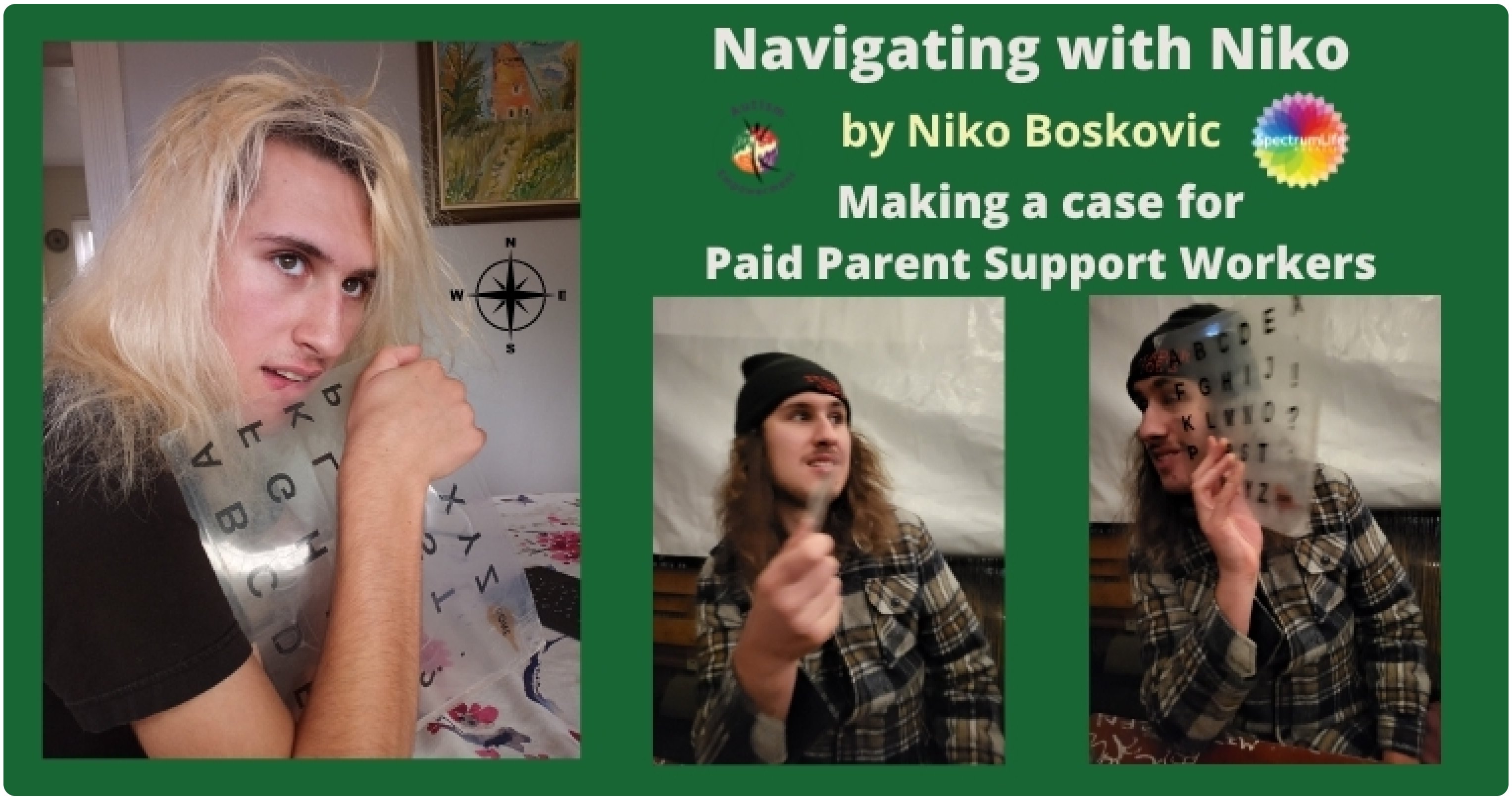
Posted By Spectrum Life Editor on 01/07/2023 in Advocacy

Navigating with Niko - A Case for Paid Parent Caregivers



There will always be a need for quality caregiving. -

By Niko Boskovic -

I recently heard a news story about the situation facing many families that have someone who relies on someone else for support whether that's at work, at school, in the community, or at home.

Being someone who relies on others in all these places, it is really interesting to get another perspective on this work. I know issues can always arise with individual workers, but the biggest challenge facing families right now is having **no** pool of available support workers in the first place. I'm sure a lot of people are also looking for providers who can support their child's unique needs, especially in the autism community, and that makes the pool of available people even smaller.

In my opinion, nothing would make more sense than if parents could be paid to be their child's care provider. I speak from experience: when I was little, my parents both worked. They had to because the therapy I was getting at home wasn't covered by insurance, and I was getting a LOT of therapy!

But somehow, my mom managed to find a part-time job that she could do from home. It meant that in her spare time, she could oversee the people they had hired to do Applied Behavioral Analysis (ABA) with me. This overlapped with her work time, and when you consider that my sister had just been born, it made my mom incredibly stressed out. And frankly, if we consider that she was also new to the world of disability and had a huge learning curve, she was having a lot of trouble managing it all.

Fast forward to my 18th birthday, and suddenly I was an adult. I transitioned to adult Developmental Disability (DD) services and became a consumer of the adult system. I'm not sure why there's a distinction, because in all ways, my days looked the same.

The only thing that changed was that now my mom was able to be paid to spend time with me. This meant that she could free up her week a little bit to be free from the work emails, and we got to spend time doing fun things. Her demeanor changed in that she seemed way less stressed out, and we enjoyed each other's company more. In all ways, it has become so much calmer in our household.

Perhaps there are critics who don't agree with the idea of paying parents to support their children, and that this is somehow the beginning of a new social entitlement program. Yet the state of Oregon made this a reality for some families of young disabled children, so at some point during the covid pandemic, it realized some families were really struggling and made this employment program temporarily available.

In any case, it doesn't seem like families have any choice but to do what they can to make ends meet while caring for someone with high support needs. **Paying them a fair wage for supporting their family members is good for business because it creates a pool of potential support workers who might eventually move into the professional healthcare field, special education, and policy work.** Nursing homes are also potential sites for such folks.

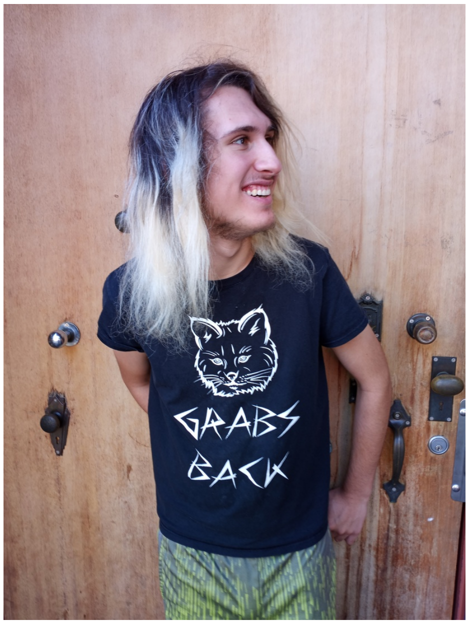
Having paid parent support workers could also be a great way to bring in disability rights and advocacy training which could include all sorts of opportunities to change the way disability is incorporated into daily life; speakers who are disabled to lead workshops; and the consideration of ableism and how it impacts families depending on their life experiences.

There are many varieties of disability, but caregiving will always be one-on-one. And as people age, their level of support may become more specialized, so there will always be a need for care professionals.

By that point, it's an added bonus to be able to pull from a pool of people who have been brought up in believing that **disability is a natural by-product of being human**. I do believe that we could have a huge impact on the way we live as disabled Oregonians by paying parents to be support workers for their young children.

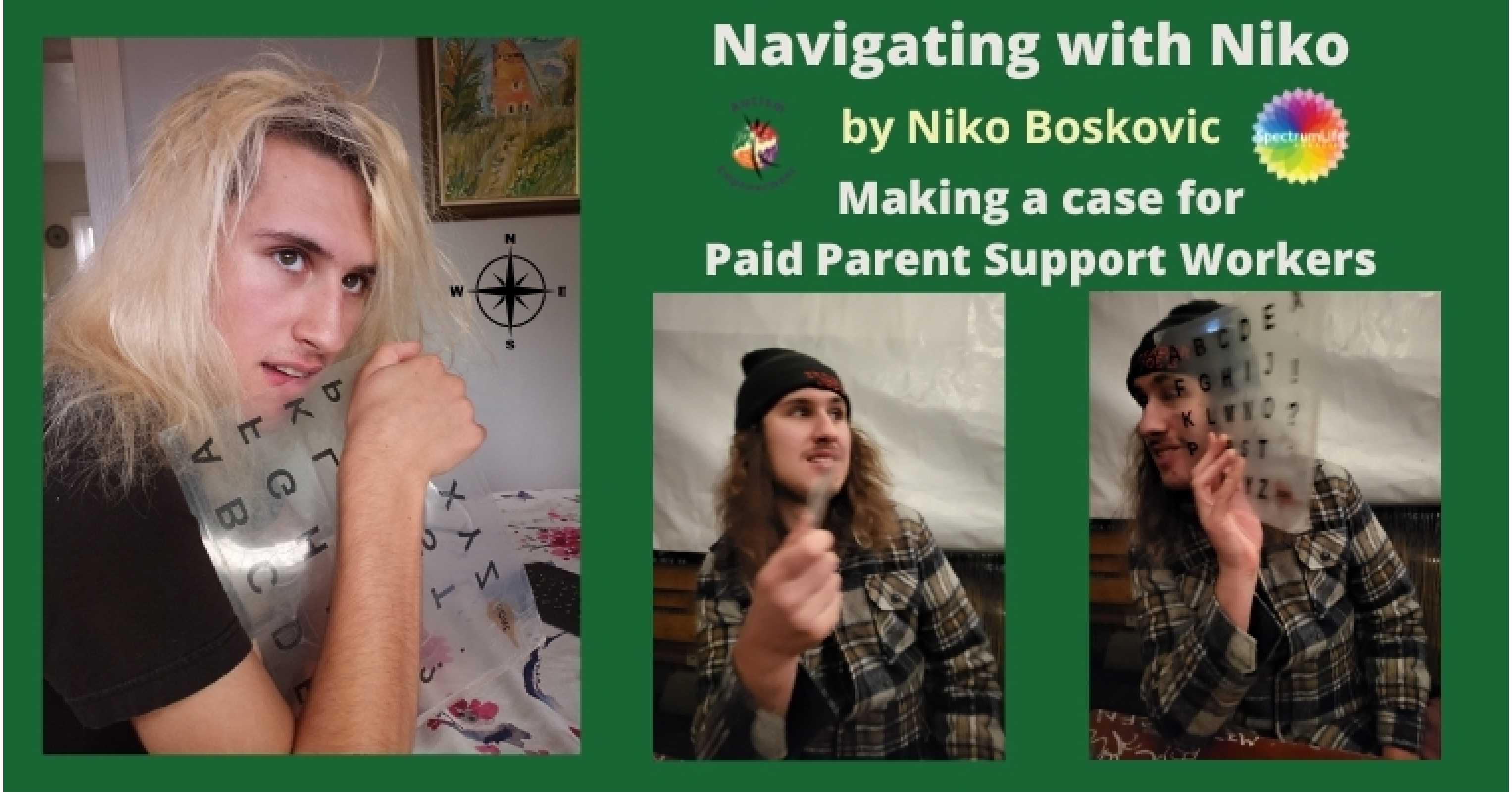
Editor's note: Unfortunately most states do not currently have a paid family caregiver policy for parents of disabled children under 18 but advocates and lawmakers in many states including Oregon are working on making a change. To learn more about currently proposed legislation in Oregon, see:
https://stateofreform.com/featured/2022/12/proposed-legislation-would-pay-oregon-parents-to-care-for-their-disabled-kids/

This blog is part of a continuing regular series at Autism Empowerment and *Spectrum Life Magazine* by Niko Boskovic. To read past articles and get connected with autistic community members, visit **www.spectrumlife.org/nikoboskovic**.



Niko Boskovic is a 21-year-old autistic adult from North Portland, Oregon who uses a letterboard to communicate, advocate and share his passions and ideas. He graduated in 2019 with an Oregon high school diploma and currently takes classes at Portland Community College in writing and history.

Niko is passionate about poetry, nature, family, and disability justice and is very pleased to be able to share his thoughts and experiences with youth, adults and families in autism communities through his monthly blog at Autism Empowerment and Spectrum Life, *Navigating with Niko*. Connect with Niko on Facebook: **NikoBoskovicPDX**



Photos courtesy of Loreta Boskovic.

Niko Boskovic Navigating with Niko Nonspeaking Advocacy Caregiving Support Workers

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