

Autism All Grown Up

The Autism Nexus of Oregon

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Mission

The mission of Autism All Grown Up (AAGU) is to empower autistic adults in Oregon by serving as a nexus that provides accessible information, resources, and services tailored to their unique needs. By bridging gaps in the existing infrastructure, we connect and interconnect the adult autistic community and their supporters, facilitate information exchange, and promote collaboration. This ensures that autistic individuals can access the support and opportunities they need to thrive, enhancing their well-being and independence throughout the state.

Executive Summary

Background

Dr. Ariel Balter, an experienced scientist and data analyst, was diagnosed with ADHD and ASD later in life and is raising a teenager with both diagnoses. His desire to understand these challenges led him to study the scientific and social aspects of neurodiversity. Recent changes driven by autistic self-advocates and researchers have reshaped our understanding of autism, revealing significant gaps in support for autistic adults. These changes have led to controversies and arguments that are still unfolding, emphasizing the evolving nature of the understanding of autism.

Through his personal journey and interactions with the local autistic community, Dr. Balter identified significant gaps in services, support, and understanding for autistic adults without intellectual disabilities. He was struck by the level of unmet need he heard from his peers—people with skills, education, and abilities but struggling for reasons related to autism. These personal experiences led Dr. Balter to found Autism All Grown Up (AAGU) to address these gaps.

Goals

Autism All Grown Up has four key objectives:

1. Facilitate connections and collaboration within the adult autistic community
2. Identify the unmet needs of autistic adults and report on the causes
3. Provide accurate, accessible content *for* autistic adults that we will continuously review and update as knowledge evolves
4. Provide accurate, accessible content *about* autism and *about* the autistic community that we will continuously review and update as knowledge evolves

Autism All Grown Up

Autism is all grown up now, and it isn't always pretty. The phrase "All Grown Up" captures the bittersweet realization that often occurs when one encounters an individual they knew as

a child, only to find that their preconceived notions no longer fit the adult standing before them.

For decades, autism was seen as a challenge that primarily affected children. Outdated notions of what constitutes genuine autism have caused adults to be overlooked by key stakeholders. Because so little research has acknowledged the lives of adults with autism, we know close to nothing about what successful adult development looks like. Some existing research suggests that autistic adults face reduced life expectancy, increased risk for physical disability, and an earlier onset of age-related cognitive concerns^{?,?}. Late-identified and never-identified autistic adults face unique challenges with respect to aging, and most of these “lost generations”^{?-?} have not yet even been identified, accounted for, or documented.

The Nexus Approach

Rather than working on advocacy, Dr. Balter feels he can more directly serve the autistic community in Oregon by solving problems on the ground. Systemic and societal problems can only be addressed through advocacy. But many of the real-world problems can be solved without waiting for systemic changes by increasing the connectivity and information flow within existing infrastructure. Rather than being a hub that consumes resources and provides services, AAGU will catalyze and strengthen relationships around it to form a *nexus*.

Autism in 2024

The New World of Autism

Recent advancements in the understanding of autism, largely driven by autistic self-advocates and researchers, have highlighted the need for a paradigm shift in understanding, coexisting with, and when necessary, supporting autistic individuals. <something about shift from behavioral description to internal>

Key findings include^{?,?}: <move these citations to where they belong>

- **Lifelong Condition:**

Autism is developmental. Autistic people carry their neurological and physiological differences through their entire lives. While society has been hyper-focused on autism in children, autism is not new to the human race. There are four times as many adults as children, so there are four times as many autistic adults as there are autistic children. <citations> <something else about focus on children>

- **The Autism Spectrum is not Linear**

Autistic people aren't "more" or "less" autistic so much as they are autistic in different ways.

- **Misconceptions:**

New research has refuted many harmful misconceptions about autism. Some autistic people do have accompanying conditions that can result in problems with body awareness, identifying their emotional state, or using speech. However, autistic people do not intrinsically lack feelings, empathy, social skills, or the ability to communicate. <citations>

Also, by the most current estimates, less than 1/3 of autistic people have intellectual or cognitive difficulties. Many autistic people who are unable to speak (for one or more reasons) do have language skills and can be competent writers and speakers with assistive technology. <citations>

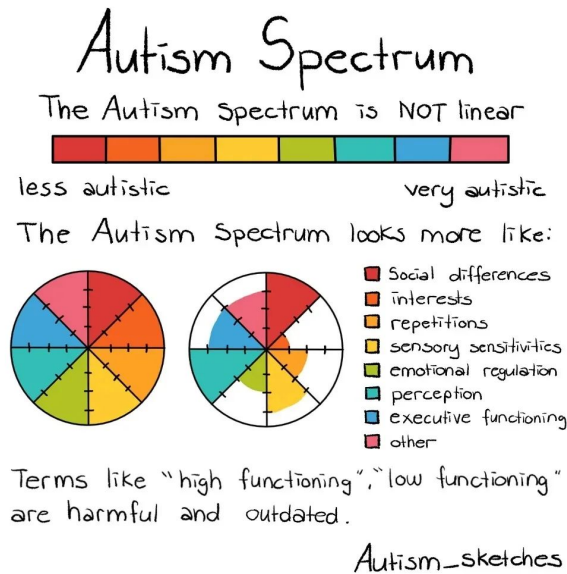


Figure 1: Figure 1. What the autism spectrum means.

- **Disability can be Contextual:**

Most autistic individuals are not intellectually or physically disabled but face substantial challenges navigating a neurotypical world. It can feel like being a left-handed person using right-handed scissors: difficult and unwieldy at best. <something about not wanting to be cured just have life easier> <citations>

- **Not Just in the Brain:**

Autism frequently comes with physiological differences that are just beginning to be understood and studied. Autistic people may experience higher or lower risk for certain diseases and conditions as well as different levels of physical abilities like flexibility. Many autistic people experience pain and other sensations differently. <citations> Few doctors are aware of these issues, and most are poorly trained in most aspects of supporting autistic patients. <citations>

- **Double Empathy:**

<Describe double empathy with citations>

- **The True Challenges:**

Many autistic people will tell you that the hardest part about being autistic isn't being autistic but navigating a neurotypical world that includes unconscious bias and ableism^{?,?}. Research backs this up, indicating that discrimination, not autism, is a significant barrier in society[?], especially in the workplace^{?,?}.

- **Neurodiversity & Neurodivergence:**

The *neurodiversity paradigm* recognizes autism as a natural variation in human neurology. Individuals with significantly atypical neurotypes are *neurodivergent*, and sometimes need different things than *neurotypical* people do.

Lost Generations of Autistic Adults

Research and services have predominantly focused on children and neglected the needs of adults, especially those of us without profound disabilities. Society has failed, and continues to fail, to adequately study autistic life after high school when children lose many supports. <citation>

Despite these challenges, many autistic adults possess valuable skills, talents, and perspectives that society misses out on by not acknowledging their needs, hearing their voices, and making room for them at the table. <citation>

Unmet Needs

Autistic adults who are impacted more profoundly or who have accompanying intellectual or cognitive challenges are generally able to find support through systems of support designed for people with disabilities. However, autistic adults without intellectual disabilities often lack access to appropriate healthcare and support services, if they even exist. <citation>

Autistic adults perceived as having lower support needs face a conundrum. While we rarely qualify for existing systems of support, most face significant challenges that are often overlooked, dismissed, or disbelieved. <citation>

Autism All Grown Up (AAGU): A Nexus for Change

Origin

AAGU was born out of Dr. Balter's desire to use his personal experiences and analytical skills to help his newfound community. By conducting root cause analyses and working with local organizations, he identified key areas where AAGU could make an immediate impact, such as:

- Creating accessible guides for obtaining adult autism diagnoses through Oregon's Medicaid and Vocational Rehabilitation systems
- Establishing *The Uncommons*, autism-friendly co-working and community spaces
- Improving online resources for autistic adults and providing consulting services to others to do the same
- Participating in data analysis and research efforts to better understand the needs of autistic adults in Oregon

What We Have Started

AAGU has already made strides in achieving its objectives through initiatives such as:

- Partnering with Health Share Oregon to create guides for accessing autism assessments through Medicaid and developing a template Letter of Medical Necessity to facilitate evaluations through I/DD and Vocational Rehab programs
- Securing temporary spaces for *The Uncommons*, autism-friendly co-working and community spaces
- Consulting with the Autism Society of Oregon to improve their online resources
- Participating in the Oregon Commission on Autism Spectrum Disorder's data working group
- Planning a State-wide conference to *****

Goals

Autism All Grown Up (AAGU) seeks to activate and empower the autistic community in Oregon by improving communication channels and information resources. Our immediate actions include:

- Establishing *The Uncommons*, a meeting and coworking space for autistic adults
- Creating comprehensive guides on navigating healthcare, employment, and social services
- Building partnerships with local organizations to enhance service delivery
- Participating in data analysis and research to inform policy and advocacy efforts

Our growth plan consists of three phases:

1. Seed (Weeks 1-8): Set up organizational structure, solicit initial funds, establish community presence, and build initial partnerships
2. Sprout (Weeks 9-26): Continue building community connections, develop *The Uncommons*, create informational materials, and identify large funding opportunities
3. Grow (Beyond Week 26): Expand *The Uncommons*, apply for large grants, build information and communication infrastructure, and establish a sustainable model for ongoing operations

Growth Plan

Our growth plan consists of three phases:

1. Seed (Weeks 1-8 approx)

- **Budget:** \$2,310/week, approx \$18,480 total
- **Effort:** 1.5 FTE
- **Actions:**
 - Set up organizational structure
 - Solicit initial funds
 - Establish community presence
 - Build initial partnerships

2. Sprout (Weeks 9-26)

- **Budget:** sprout_per_week/week, \$38,720 total
- **Effort:** 2.75 FTE
- **Actions:**
 - Continue building community connections
 - Develop *The Uncommons*

- Create informational materials
- Identify large funding opportunities

3. Grow (Beyond Week 26)

- **Budget:** \$4,840/week, \$87,120 total
- **Effort:** 4.25 FTE
- **Actions:**
 - Expand *The Uncommons*
 - Apply for large grants
 - Build information and communication infrastructure
 - Establish a sustainable model for ongoing operations

By establishing a comprehensive support system for autistic adults, AAGU aims to improve their quality of life, promote independence, and foster a sense of community and belonging. Through a phased growth plan, AAGU will continue to expand its reach and impact, with a strong emphasis on hiring autistic individuals and providing them with meaningful employment opportunities. By leveraging the strengths and talents of the autistic community, AAGU is uniquely positioned to create lasting, positive change for autistic adults in Oregon.

Funding

We are poised to launch a GoFundMe crowdsource campaign as soon as we have our nonprofit status confirmed by ARRO. We hope to raise seed money of \$2k-\$3k per week to jump start formal operations ***** next \$34k for our 8-week Sprout phase. We hope to launch the Sprout phase within our first month.

A key element of our first 8 weeks of formal operation (Sprout) will be to create a calendar of funding deadlines and communicate with funders to prioritize our initial grant-writing efforts. It will also be crucial that we complete the initial projects we have started during the Sprout phase to demonstrate our effectiveness to potential supporters. At the end of the Sprout phase, we will report to our umbrella organizations and all funders/sponsors.

We are on the verge of launching a GoFundMe crowdsource campaign, a crucial step that hinges on our nonprofit status being confirmed by ARRO. The urgency is palpable as we aim to raise a substantial seed fund of \$2k-\$3k per week, a total of \$34k, to kickstart our formal operations. This will pave the way for our 8-week Sprout phase, which we plan to initiate within our first month.

Our initial 8 weeks of formal operation, known as the Sprout phase, are meticulously planned. We will create a comprehensive calendar of funding deadlines and proactively communicate with funders to prioritize our grant-writing efforts. Equally important is the completion of our initial projects during this phase, which will serve as tangible proof of our effectiveness to potential supporters. At the end of the Sprout phase, we will provide a detailed report to our umbrella organizations and all funders/sponsors.

We have already identified almost 100 grants and sponsorships (see Appendix ??) for which we meet the basic requirements. These include grants from the State of Oregon (e.g. Oregon Health Authority), Oregon healthcare companies (Legacy, Pacific Source, Cambia, etc.), and a mixture of private and public foundations and trusts. We have missed the 2024 funding cycle for some of these, but many have multiple cycles per year or do not run in cycles. Some of these are small pots of money, and others regularly award hundreds of thousands of dollars. We will also collect sliding-scale fees for using *The Uncommons* co-working spaces.

During our Grow phase, we hope to show that we can collect, analyze, and disseminate information for and about the adult autistic community with a very high level of capacity and efficiency. We hope this expertise will enable us to secure outside contracts as subject matter experts, analysts, and report writers, providing another avenue for revenue. We will complete the Grow phase with a report to our umbrella organization and our financial supporters.