

Autism All Grown Up

The Autism Nexus of Oregon

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5/26/24

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2 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 of Oregon.

3 Executive summary

3.1 Background

Dr. Ariel Balter, an experienced scientist and data analyst, was diagnosed with ADHD and ASD very late in life and is also raising a teenager with both of these diagnoses. Dr. Balter's desire to use this new framework to help understand his life and career challenges led him to study the scientific literature on autism as well as non-scientific essays about neurodiversity. He found that both our scientific and social understanding of autism and other types of neurodivergence were going through rapid, seismic changes. Much of the change in the past decade came from autistic self-advocates, and especially autistic researchers putting themselves into the research process. These changes have led to controversies and arguments that are still unfolding and will take time to resolve. However, it is indisputable that a number of facts about autism in adulthood have caught society off guard:

1. Most autistic people are [not intellectually disabled](#). But navigating society feels like being a left-handed person using right-handed scissors: difficult and unwieldy at best.
2. Being autistic is how you are born, and you stay that way for your whole life. Therefore, there are roughly the same percentage of autistic adults as children.
3. We know very little about autistic adults who aren't intellectually disabled and how life has impacted them. Almost all research and services have focused on children and intellectually disabled adults.
4. Oregon likely has between 75,000 and 150,000 autistic adults. A small fraction of them receive disability services. A large and unknown fraction are enduring unnecessary negative life experiences.

Because autism presents as a constellation of traits rather than a linear spectrum of abilities, most autistic adults are able to perform the [activities of daily living](#) (ADLs) independently, but often at a great cost to their emotional well-being. The unique challenges we face do not check the boxes in Oregon's Department of Intellectual and Developmental Disabilities (I/DD) assessments. But they are real.

In the Winter of 2023, Dr. Balter started attending local support groups for autistic adults and participating in online communities. He was struck by the level of unmet need he was hearing about from his many peers—people who have skills, education, and abilities but nonetheless are struggling due to common challenges navigating a neurotypical world. Some of these challenges

arise from societal factors that will only change over decades through persistent advocacy work. Others simply reflected breakdowns of existing systems (healthcare, employment, social service) largely due to misinformation or lack of information. He began doing some root cause analysis and founded Autism All Grown Up along with some of the amazing people he met.

3.2 Goals

We are naming the organization Autism All Grown Up (AAGU) in part because of the way people tend to use that phrase when they meet someone whom they had only known as a child and find themselves struck by how different the adult person in front of them is from the picture of the child they had carried around in their head. Calling ourselves a Nexus refers to how we envision our organization integrating into the universe comprised of autistic adults in Oregon and the various organizations, programs, services, and providers they interact with. Most social organizations are hubs, which means they are locations that take in money along some channels and provide services or information outward along other channels. AAGU will activate and empower the autistic community and autism-focused organizations by improving and building channels of communication and bodies of information they need.

This project will combine a long-term strategy with immediate action. There are many things we can do and are doing immediately, such as building relationships, creating information products, and launching *The Uncommons* (reference). Other goals will take time.

Our work is already helping autistic adults find and use the services they need and helping others better understand the needs of autistic adults. We are ready to start autistic-friendly meeting and coworking spaces called *The Uncommons*, where people can safely unmask, mingle, and collaborate authentically. We are working with local organizations to create better information for and about autistic medical needs. We are seeking out programs and organizations that exist but are not widely known about and working to connect these organizations to potential clients and to each other. We have been invited to participate in a data analysis working group sponsored by the Oregon Commission on Autism Spectrum Disorder.

3.3 Growth Plan

We plan to build out our capability in phases through funding and continued in-kind donations, with a low emphasis on volunteer work. Dr. Balter strongly believes that AAGU should be staffed by autistic people earning a market wage. Our current model proposes a 10% overhead for our parent organization to cover certain executive and business services.

Initial Weeks: Seed (Startup phase)

Budget: \$2,310/week, Effort: 1.5 FTE

- Set up organization structure

- Solicit funds for *Sprout* phase (crowdfunding, donations, small grants)
- Establish partnerships and presence in the community

Weeks 1-8: Sprout (Establishing the project)

Budget: \$33,600, Effort: 2.75 FTE

- Continue the work we have been doing:
 - The Uncommons
 - Informational materials
 - Building community and connections
- Define our capabilities
- Identify large funding opportunities
- Build relationships, find partnerships, solicit contracts

Weeks 9-26: Grow (Achieving Maturity)

Budget: \$117,612.00, Effort: 4.25 FTE

- Continue ongoing work
- Market and expand *The Uncommons*
- Apply for large grants and contracts
- Build our information infrastructure
 - Databases
 - Expertise
- Build our communication infrastructure
 - Website
 - Information products
 - Podcasts, talks, lectures

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5 Autism in 2024

5.1 It's a Whole New World

Although Temple Grandin wrote about her experiences as an autistic person in 1983, [autistic self-advocacy](#) and voices really gained momentum in the early 2010s. Autistic adults began describing their own experiences as quite different from the prevailing understanding, which had been primarily based on non-autistic observation of children. A small but active cohort of autistic researchers were entering graduate school and soon set up their own research programs. The double empathy hypothesis (Milton, 2012) was repeatedly validated, and the theory of mind deficit hypothesis (Baron-Cohen, 1985) was repeatedly invalidated. Genetic studies and functional MRI (fMRI) imaging showed that autism is purely developmental, highly heritable, and primarily genetic. The prevailing scientific narratives about autism were just wrong.

This is not a problem for science. This is the process of science functioning as it should. However, for autistic people in the general population, this is a HUGE problem. Because the scientific community and policymakers had mistakenly assumed that we could treat or even prevent autism, we focused almost all of our resources on children with the assumption that if we succeeded in those efforts, we could greatly reduce the impacts on adults. However, the opposite happened. We now know that people are born autistic and will die autistic. And that while autism frequently co-occurs with challenging conditions such as seizures, speech problems, sensory issues, and physical conditions, whether autism inherently imparts limitations or enhanced abilities varies greatly from person to person, from family to family, and from situation to situation.

The use of the term *spectrum syndrome* in the DSM-V has created some confusion, as often happens when those without clinical and scientific training use clinical and scientific terms without fully educating themselves about them first. Most of us are most familiar with the term “spectrum” in reference to the visual spectrum of light, which is a *range* of light frequencies that our eyes are sensitive to. A *spectrum syndrome* actually refers to the concept that the syndrome includes a broad collection of traits as well as a range of presentations among them.

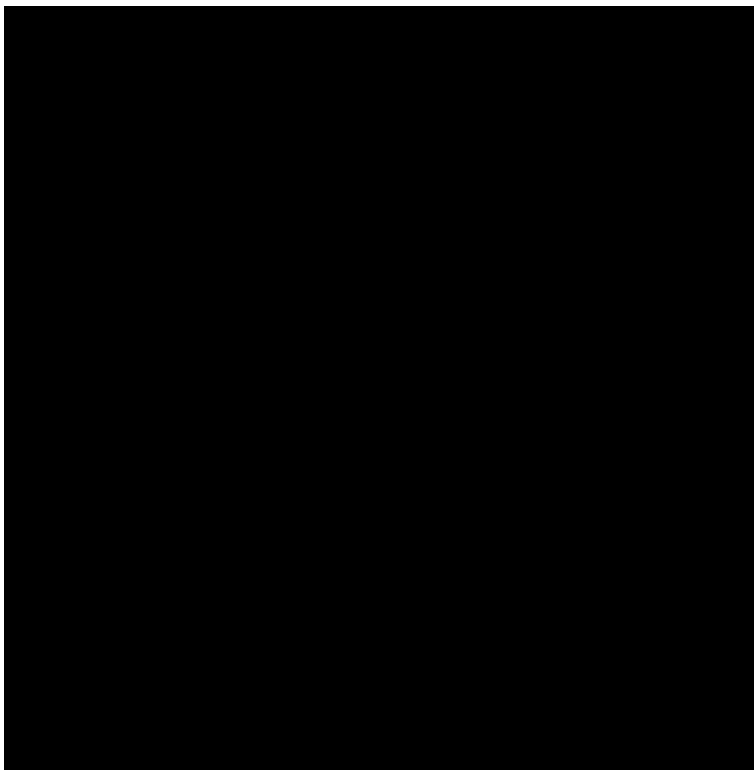


Figure 1: What “spectrum” really means

This revolution in autism science coincided with the growth of the neurodiversity paradigm and resulted in a number of controversies within the autism community. Autism has a high rate of co-occurrence with other areas of neurodiversity. While the term “neurodivergent” does not have a proper scholarly definition, there is a general agreement that it refers to innate aspects of cognition and perception that are based on neurology rather than lived experience. In fact, science has found strong relationships with commonly co-occurring traits, including ADHD, OCD, alexithymia, dyslexia, synesthesia, epilepsy, certain types of cognitive or learning disabilities, and possibly some types of clinical anxiety.

The unique experience of every autistic person involves a different set of experiences, differences in perception and perspective, challenges, and areas of strength. This widely acknowledged variation in how autism appears in our lives is partly explained by co-occurring neurodivergences. Creating community and addressing the needs of autistic adults in a useful way necessitates that we are inclusive with respect to all areas of neurodivergence. The neurodiversity paradigm shift forces us to reconsider previous views of autism, both in academia and in the culture at large.

We have recently learned that many of these co-occurring neurodivergent traits can be diagnosed independently from autism. We have learned that many non-speaking autistic people are actually capable of using language and can be brilliant writers with assistive technology.

We have scientifically confirmed some anecdotes about autistic people in terms of their increased aptitude for problem-solving, pattern matching, cognitive empathy, and certain types of rational and logical thinking. Perhaps most significantly, we have learned through confirmation of the double empathy hypothesis that autistic people are not deficient in either the ability or the desire to socialize. Instead, autistic and non-autistic people have very different socialization styles, learning and sensory needs, limitations, and expectations. All of this is to say that:

- Autistic children inevitably grow up to be equally autistic adults and later autistic elders.
- Any individual autistic person has a unique combination of traits that may or may not be disabling in certain contexts.
- These same traits can be exceptionally enabling, fulfilling, and productive in other contexts.
- The very fact of being autistic in a predominantly non-autistic world presents obstacles, inflicts subtle traumas, and is extremely exhausting, even for individuals with few intrinsic limitations.

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7 The Lost Generation

7.1 Unique Challenges

Autistic adults perceived as having lower support needs face a conundrum. While they rarely qualify for existing systems of support, most face significant challenges that are often overlooked, dismissed, or disbelieved. Most 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 (provide link). As Ludmila N. Praslova writes, [Autism Doesn't Hold People Back at Work. Discrimination Does](#), and research is backing this up. These things exacerbate the problems individuals may already face due to sensory differences, ADHD, anxiety, and other common issues autistic people deal with. Autistic adults experience substantially elevated suicide risk and reduced life expectancy, and even those with college educations routinely lack full employment. Not only are huge numbers of invisible autistic adults suffering, but [society is also missing out](#) on the benefits of their talents and skills.

7.2 Lack of Awareness

For decades, autism was seen as a developmental challenge that primarily affected children. Outdated notions of what constitutes genuine autism are overlooked by many people. Because so little research has even acknowledged the lives of adults with autism, we know close to nothing about what successful adult development looks like. Some have described those who were never identified as a lost generation. Late-identified and never-identified autistic adults face unique challenges with respect to aging. Existing research suggests that we face reduced life expectancy, increased risk for physical disability, and an earlier onset of age-related cognitive concerns, including Alzheimer's and related dementias. There is an immense amount of work to do to help prepare the aging autistic adult community and a poorly informed medical system to successfully face these challenges right now and in the coming decades. Fortunately, there are also many skilled, intelligent, creative, compassionate, and hard-working people in the autistic community who are ready and capable of doing this work. And they are the right people to do it.

7.3 Lack of Research

Research on the unique experiences of autistic adults [has only recently begun in earnest](#), and we are especially behind regarding those referred to in the scientific literature as ‘autistic without intellectual disabilities’ (formerly known as having Asperger’s Syndrome or being “high-functioning”). (find reference for the change in nomenclature) While we know they are out there, no formal surveys have been done to get to know (let alone quantify) the adult autistic population. Consequently, we know very little about who they are, what they want, and what they need. This dearth of knowledge has created huge gaps in available services for these individuals, which adversely impacts them, their families, and their communities in terms of physical health, mental health, and economic well-being. But, ironically, because autism is so misunderstood when they do go looking for help, [the majority of autistic adults are perceived as too capable to be needing assistance](#) and simply fall through the cracks.

Despite the fact that advocates and researchers have been pushing for decades to have autism research funding focus more on quality of life and less on “prevention and cure”, the trend has only gotten worse.

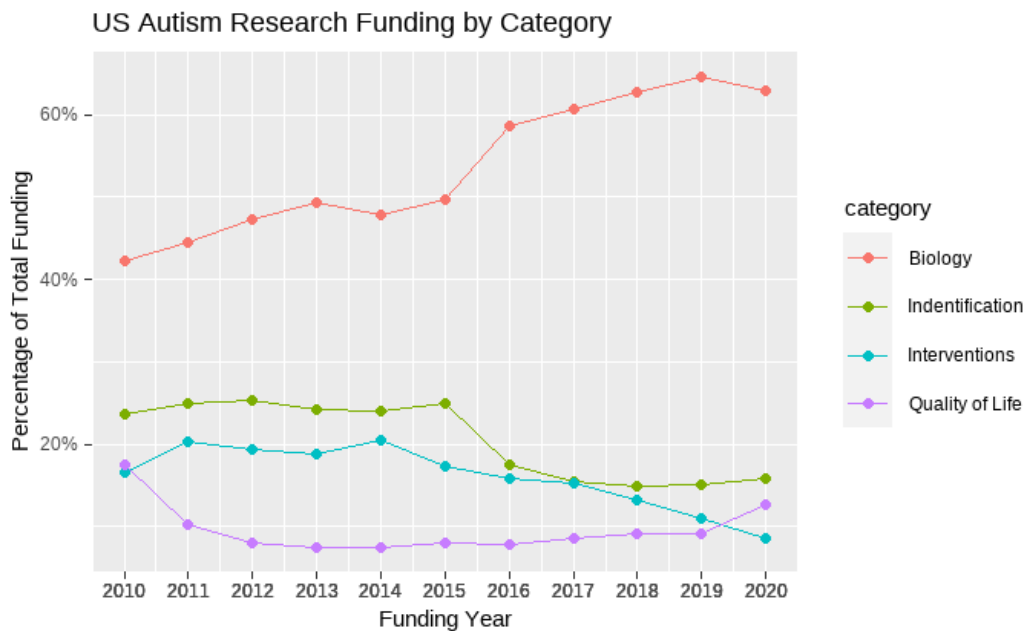


Figure 2. Data from [Interagency Autism Coordination Committee](#)

7.4 Transition to Adulthood

The problems we are discussing don't only affect existing autistic adults. The sudden drop-off of support upon graduating high school has become known as the *services cliff*. One of the biggest worries faced by both parents of autistic people and young autistic people themselves is what will happen after they graduate from high school. Will they be offered meaningful work in tolerant and respectful environments? Will they be able to earn enough to live independently? Will they find open doors in trade schools or colleges and be offered the support they might need?

Fortunately, the transition to adulthood has received some attention from the research community and policymakers. Most institutes of higher learning have programs to support neurodivergent students, and many workplaces have enabled employees to form Employee Resource Groups (ERGs) to provide peer support. However, accessing those supports requires first getting into college or being hired at an organization that has an autism ERG. In other words, there is some help in some circumstances, but one first has to get there.

7.5 Additional Issues

7.5.1 Employment

Autistic adults without intellectual disabilities face significant challenges in finding and maintaining employment. In a study of 254 autistic adults, 77% reported difficulties in applying for jobs, with challenges in communication, social interaction, and sensory sensitivities. Sensory processing differences are reported by 50-70% of autistic people. Executive functioning challenges, affecting skills like organization and time management, are experienced by an estimated 80% of autistic individuals. However, only 58% of autistic employees report receiving any workplace accommodation.

Underemployment is a major issue, with studies finding that 53% of autistic adults work in jobs below their skill level, 51% work part-time despite wanting full-time employment, and only 16% are in full-time paid work. In a survey of 1,201 autistic adults, 51% reported experiencing discrimination in hiring or promotion, and only 14% reported being in full-time employment. The unemployment rate for autistic adults is estimated to be 30-40%, significantly higher than the general population.

These challenges lead to financial instability, with 46% of autistic adults reporting incomes below the poverty level. Workplace accommodations, flexibility, and understanding are crucial to improve employment outcomes, but only 28% of autistic employees report having adequate supports at work. Systemic changes are needed to create more inclusive and accessible workplaces for the estimated 50-75% of autistic adults without intellectual disability.

7.5.2 Marginalized Populations

All of these problems compound for members of intersectional populations who may already be marginalized along other dimensions. Many researchers believe that autism is [underdiagnosed in communities of color](#), particularly in Black communities, as well as for [female-presenting people](#). Meanwhile, fluidity in [gender identity](#) and [sexual orientation](#) is more highly represented among autistic people. Little research has been done to assess how autism uniquely affects people in these different subgroups.

7.5.3 Suicide

Estimates of the life expectancy of autistic adults are typically about seven to fifteen years lower than expected (O’Nions et al., 2023), a disparity due in part to the higher than average risk for suicide (Hirvikoski et al.2016) and accidental deaths (Smith DaWalt et al., 2019). In contrast to allistic people, these are primary sources of mortality, competing with more typical causes of death in the larger population. An autistic person is nearly as likely to die from suicide as they are to die from cardiovascular disease. And yet, public health efforts and autistic support services largely ignore this reality.

Autistic people face high rates of suicidality and overrepresentation in deaths by suicide. Current estimates indicate that autistic individuals account for approximately 3-4% of children and 2-3% of adults. However, researchers conducting psychological autopsies indicate that 10% of deaths by suicide are undiagnosed autistic individuals. The same researchers indicate that up to 40% of people who die by suicide have autistic traits. Among diagnosed autistics, as many as 72% of autistic people experience suicidal ideation, and up to 47% of autistic people attempt to end their own lives. The importance of supporting autistic individuals struggling with suicidality is well-established. However, there is a lack of dedicated crisis support for autistic people. The existing resources are clearly not meeting the needs of autistic people, and we need not accept these deaths as inevitable.

Suicidality in autistic people is not inherent to being autistic. Existing research indicates that autistic suicidality is driven by thwarted belonging and camouflaging autistic traits. Importantly, autistic people communicate suicidality differently than non-autistic people, and the differences between autistic and non-autistic communication leads to misunderstandings. Compounding this, autistic warning signs of suicide differ from neurotypical warning signs. These factors, when combined with the *double empathy problem* (for example, autistic people express suicidality in a unique way) can lead to both traumatic miscommunications and missed opportunities with tragic outcomes.

7.5.4 Physical and Mental Health

Across a variety of health domains, autistic people fare worse (Lodi-Smith 2021). Additionally, we are exposed to risks that are not of primary concern for most people (Muskens et al., 2017). These include autoimmune dysregulation of many kinds, autonomic dysregulation, connective tissue disorders, gastrointestinal disorders, and many other areas of health concerns. A lack of understanding regarding these differences, coupled with communication barriers and false notions about autism all collude to create barriers to accessing health services and care.

7.5.5 Homelessness

Barriers to entry to the workplace as well as challenges and holding jobs due to ableist attitudes or inflexible policies put us at risk of severe financial strain (Ohl et al., 2017). This coupled with the possibility of reduced social support all increase our risk of exposure to homelessness. The few studies that attempted to investigate autism in homeless populations suggest that rates of autism in homeless populations is much higher than that observed in the general public, and may be ten times higher (Churchard et al., 2019). Autistic people additionally face extra barriers in accessing the few services for unhoused people. Environments created with the intention of providing support may be aversive or even harmful for autistic people (Kargas et al., 2019).

8 Adult Autism in Oregon

9 Autism All Grown Up (AAGU)

9.1 Formation

Dr. Ariel Balter, a late diagnosed autistic scientist, conceived of the *autism nexus* idea when he started performing root cause analysis (RCA) to help members of his new community of local autistic adults. He heard about obstacles to getting evaluations in Oregon and a mixture of opinions regarding why. Determined to provide definitive answers, he found himself working with HealthShare Oregon to create new materials on behalf of OHP specifically designed to give members of the adult community a definitive and complete flowchart of options and contacts. Meetings with administrators from Vocational Rehab allowed him to create a similar prescriptive path that would meet their legal requirements for providing evaluations.

On hearing informal discussions of starting occasional co-working meetups at libraries, Dr. Balter found that the community would strongly favor dedicated, autism-friendly coworking spaces. So he explored the minimum requirements to make that happen and found some available options.

In order to find if solutions for some of these problems already exist in the community, Dr. Balter searched for and contacted many local organizations that work with autistic adults – Oregon I/DD, The Autism Society of Oregon (ASO), Autism Community Activity Program (ACAP), Autism Research and Resources of Oregon (ARRO), The Arc of Oregon, We’ve Network, Smart Living, Learning, & Earning with Autism (SSLEA) – and was surprised by how little communication, coordination, and mutual awareness existed between them. Dr. Balter began floating ideas for how to foster these connections.

Most of the organizations that serve the autistic community, both adults and children, create pages on their websites where they list local resources, suggest other organizations, link to useful sources of information, try to answer basic questions and that sort of thing. Providing this information is never the main focus of the organization. Keeping information about autism up-to-date is a job in and of itself. Also, most of these websites are written *for* or *about* autistic people rather than by them. The information on these pages degrades much faster than it can be practically updated without a dedicated mission to do so.

Some of Dr. Balter’s favorite things to do are performing information work, getting to the bottom of difficult problems, and making fortuitous connections between people. Forming an organization that could become the go-to source of information both for and about the adult autistic community seemed like a logical step, and the *autism nexus* concept was born.

By working from within the autistic community, we will build connections between autistic adults, between organizations, and between individuals and organizations. Contrary to outdated misconceptions, autistic people enjoy social connections with and communicate well with people who share their neurology. The talent pool of immensely skilled and capable but underemployed or unemployed autistic adults in Oregon will form the engine that drives our work.

Team

9.2 What We Have Started

These are projects Dr. Balter has started working on but set aside to work on creating AAGU. They are the first things that will be finished when we have enough funding to support a small staff for a couple of months.

9.2.1 The Uncommons

Two organizations have offered us temporary use of high-quality common space for coworking and meetings. The spaces include internet, printers, computers, meeting areas, lounge areas, and kitchen facilities. This will be the start of The Uncommons.

9.2.2 Access to Assessments

Finding a provider to do an autism or ADHD evaluation can be hard, even with private insurance. For those on Medicaid, it can be literally impossible. We have been partnering with Health Share Oregon to create two guides. One, for Medicaid members, explains the Community Care Organization (CCO) system and outlines the processes and requirements of different health plans. Another, for Medicaid doctors, explains why it is important for adults to get evaluations and provides information on writing a successful referral.

9.2.3 Alternate Routes for Assessments

Because some networks are entirely lacking providers at this time, we have communicated with I/DD and Vocational Rehab (VR) and created materials to facilitate accessing evaluations through those programs. We have created a template Letter of Medical Necessity based on the requirements these programs use to determine if they will directly pay for a client's evaluation and the laws about Medicaid/Medicare coverage. This template reduces the burden on providers less familiar with autism in adults, making it easier for them to provide the necessary documentation. A client can have a licensed medical or behavioral practitioner fill out this letter and then present it to I/DD or VR.

9.2.4 Outreach Consulting and Development

We have begun working with the Autism Society of Oregon to help them refine and improve their online resources, which could turn into a consulting contract.

9.2.5 Data Analysis

After discussing the general issues we have described above with the director of the Oregon Commission on Autism Spectrum Disorder (OCASD), Dr. Balter has been invited to represent AAGU in their data working group.

9.2.6 Adult Autism Services Conference

To jump-start collaboration and communication between organizations that work with autistic adults, the AAGU has proposed hosting a state-wide conference at which organizations that work with autistic adults can introduce themselves and learn about each other. So far, a number of organizations have expressed a desire to participate.

9.3 Ongoing Activities

The day-to-day operations at AAGU will evolve and adapt as we form and grow. The following are things we will always be working on to one extent or another, with effort rebalanced based on need and funding:

9.3.1 Community

- Staff and manage *The Uncommons*.
- Build relationships with entities, organizations, businesses, and service providers that work with or for adult autistic people through regular meetings or check-ins. Exchange non-private information that will help us better understand the community.
- Learn about unmet needs in the adult autistic community:
 - Maintain an active presence.
 - Staff chat helpline for general questions that aren't answered on the website.
 - Conduct informal surveys to “feel out” the community.
 - Listen to ideas from the community and from organizations and help connect them to the support they need.

- Report on unmet needs in the community and use Root Cause Analysis to determine if unmet needs result from a lack of existing services, stigma or bias, or inaccurate, out-of-date, or missing information.
- Facilitate peer-support. We need to research best practices.

9.3.2 Information

- Maintain a database of organizations that provide services for or work with autistic adults, including what services they provide, to whom, how to access these services, and pertinent contact information.
- Maintain a database of medical providers for autistic adults with rich information on their training, experience, specialties, and insurance coverage.
- Maintain a database of miscellaneous community-based entities and programs for autistic adults, such as meetups, businesses, clubs, etc.
- Host these databases on our website through a portal that employs the ultimate in user-friendly and intuitive interfaces. Also, provide an application programming interface (API) for information workers.
- Create web pages, pamphlets, documents, guides, etc., written in multiple languages and at multiple levels of detail for a neurodiverse audience with information on local issues affecting autistic adults. Examples:
 - How to decide if you want/need a diagnosis
 - How to get a diagnosis
 - What do public entities like OHP, I/DD, and Vocational Rehab do? What should you expect? How to work with them?
 - Tips for working with medical and mental health providers. For example, advice on how to approach them as an autistic individual.
 - Information to give medical and mental health providers. Most are unaware of differences in our sensory systems, frequency of co-occurring physical conditions, and how to navigate different communication styles.
 - Forms and checklists
 - I just got diagnosed. What do I do now (Oregon-specific)?
- Collect any data we can get our hands on connected to autism in Oregon and look for ways to extract useful information from them.

- Perform data analysis and reporting for other organizations or entities on a contract basis.
- Participate in research studies as subject matter experts and analysts.
- Maintain and update the *autism-facts.org* website with the most current factual information about autism based on current research and thought.
- Regularly circle back to *everything* in our database to ensure our information is accurate and current, and timestamp every update. That way, users will know whether the information is up-to-date.

As you can see, we do not intend to be an advocacy organization or a service organization. Instead we are going to support advocacy, self-advocacy, services, and policy related to autistic adults by providing the community the insights and information assets these other efforts need.

9.4 Future plans

We are also working on a model that will allow us to apply for small research grants and accept contracts for analysis and reporting. Dr. Balter has extensive data science experience, including academic publications, and has the support and interest of other scientists and analysts in the area. The Oregon Research Institute (ORI) has a partner called ORI Community Evaluation Service (ORICES) that is able to leverage resources (such as research review board approval) at ORI to work on smaller projects. We are exploring how to use that model or something similar.

9.5 Growth and Development

Three phases: seed, sprout, grow

Report to umbrella and funders.

9.6 Seed

Responsibility	FTE	Description
Organizing and Directing	0.75	Implement business systems—payrol, formal job descriptions, insurance, etc. Hold regular meetings with select partner organizations and individuals. Solicit and apply for funding for Sprout phase.
Coworking space manager	0.25	Research how coworking spaces run. Create a budget and game plan for initial set-up. Begin planning marketing and promotion.
Research support	0.25	Collect and organize information. Writing.
Web Development	0.25	Design and build website.
Total	1.50	

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9.8 Sprout

Responsibility	FTE	Description
Organizing and Directing	0.75	Complete current information product projects. Investigate access gaps. Locate resources. Continue building relationships. Oversee and participate in research on community resources and funding opportunities.
Data engineering	0.50	Create databases. Research portal design.
Coworking space manager	0.50	Research how coworking spaces run. Solicit community feedback. Run trails.
Research support	0.50	Collect and organize information. Writing.
Web Development	0.50	Design and build website.
Total	2.75	

9.8.1 Grow

9.8.2 Staffing

Res pon- sibility	FTE	Description
Organizing and Directing Data engi- neering	1.00	Seek out partners and funding opportunities. Work with stakeholders to define contract requirements. Direct grant writing. Meet regularly with partner organizations and individuals.
Jr. Data manage- ment	0.30	Maintain databases and portal. Assist with analysis and reporting.
Jr. Data manage- ment	0.20	Collect data. Enter data. Basic reporting.
Research and analysis	0.50	Perform analysis and generate reports. Lead grant-writing efforts. Be responsible for obtaining necessary approvals, meeting all grant requirements, and submitting on time.
Research support (Jr.)	0.50	Locate resources. Collect and organize information. Conduct surveys.
Web De- velopment	0.25	Maintain website.
Coworking space manager	1.00	Determine best practices. Maintain the physical space. Set and enforce policies.
Coworking space attendant	0.50	Oversee operation.
Total	4.25	

10

11 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 so we can 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 have already identified almost 100 grants and sponsorships 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 hundred 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, analyse, 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, which will provide yet another avenue for revenue. We will complete the Grow phase with a report to our umbrella organization and our financial supporters.

12 Budget

Autism All Grown Up will place a strong emphasis on hiring autistic and neurodiverse Oregon adults and paying them a market wage. The wages will be at the low end during the initial Seed and Sprout phases and increase during the later phases. The hourly rates shown represent full compensation on a 1099 and do not include benefits. We will make necessary adjustments when we are able to provide benefits as well.

We have created our budget estimate based on the minimum staffing we believe can meet our performance goals combined with market-rate salary estimates from ZipRecruiter (<https://www.ziprecruiter.com/Salaries>) for approximate job titles in the Portland, OR area (see [Appendix 2: Representative Salaries](#)). We project a budget of approximately \$150,000 for the first six months (26 weeks) of operation.

12.1

12.2 Seed

12.2.1 Staffing

Responsibility	FTE	Description
Organizing and Directing	0.75	Implement business systems—payroll, formal job descriptions, insurance, etc. Hold regular meetings with select partner organizations and individuals. Solicit and apply for funding for Sprout phase.
Coworking space manager	0.25	Research how coworking spaces run. Create a budget and game plan for initial set-up. Begin planning marketing and promotion.
Research support	0.25	Collect and organize information. Writing.
Web Development	0.25	Design and build website.
Total	1.50	

12.2.2 Budget

Responsibility	FTE	Rate	Weekly Total	Overhead (10%)
Organizing and Directing	0.75	\$40.00	\$1,200.00	\$120.00
Coworking space manager	0.25	\$30.00	\$300.00	\$30.00
Research support	0.25	\$30.00	\$300.00	\$30.00
Web Development	0.25	\$30.00	\$300.00	\$30.00
Subtotal per week			\$2,100.00	\$210.00
Total per week			\$ 2,310.00	

12.3

12.4

12.5 Sprout

12.5.1 Staffing

Responsibility	FTE	Description
Organizing and Directing	0.75	Complete current information product projects. Investigate access gaps. Locate resources. Continue building relationships. Oversee and participate in research on community resources and funding opportunities.
Data engineering	0.50	Create databases. Research portal design.
Coworking space manager	0.50	Research how coworking spaces run. Solicit community feedback. Run trails.
Research support	0.50	Collect and organize information. Writing.

Responsibility	FTE	Description
Web Development	0.50	Design and build website.
Total	2.75	

12.5.2 Budget

Responsibility	FTE	Rate	Weekly Total	Overhead (10%)
Organizing and Directing	0.75	\$50.00	\$1,500.00	\$150.00
Data engineering	0.50	\$45.00	\$900.00	\$90.00
Coworking space manager	0.50	\$30.00	\$600.00	\$60.00
Research support	0.50	\$30.00	\$600.00	\$60.00
Web Development	0.50	\$30.00	\$600.00	\$60.00
Subtotal per week			\$4,200.00	\$420.00
Total per week			\$4,620.00	
Total for 8 weeks			\$33,600.00	

12.5.3

12.6 Grow

12.6.1 Staffing

Responsibility	FTE	Description
Organizing and Directing	1.00	Seek out partners and funding opportunities. Work with stakeholders to define contract requirements. Direct grant writing. Meet regularly with partner organizations and individuals.
Data engineering	0.30	Maintain databases and portal. Assist with analysis and reporting.
Jr. Data management	0.20	Collect data. Enter data. Basic reporting.
Research and analysis	0.50	Perform analysis and generate reports. Lead grant-writing efforts. Be responsible for obtaining necessary approvals, meeting all grant requirements, and submitting on time.
Research support (Jr.)	0.50	Locate resources. Collect and organize information. Conduct surveys.
Web Development	0.25	Maintain website.
Coworking space manager	1.00	Determine best practices. Maintain the physical space. Set and enforce policies.
Coworking space attendant	0.50	Oversee operation.
Total	4.25	

12.6.2 Budget

Responsibility	FTE	Rate	Weekly Total	Overhead (10%)
Organizing and Directing	0.75	\$65.00	\$1,950.00	\$195.00
Data engineering	0.30	\$45.00	\$540.00	\$54.00
Jr. Data management	0.20	\$30.00	\$240.00	\$24.00
Research and analysis	0.50	\$45.00	\$900.00	\$90.00
Research support (Jr.)	0.50	\$30.00	\$600.00	\$60.00
Web Development	0.25	\$45.00	\$450.00	\$45.00

Responsibility	FTE	Rate	Weekly Total	Overhead (10%)
Coworking space manager	0.75	\$40.00	\$1,200.00	\$120.00
Coworking space attendant	0.50	\$25.00	\$500.00	\$50.00
Subtotal per week			\$5,880.00	\$588.00
Total per week			\$6,468.00	
Total for 18 weeks			\$11 6,424.00	

13

A Appendix 1: Glossary

TermDefinition

ADLs When a person applies for Medicaid long-term care services in Oregon, we look at how much help they need to perform Activities of Daily Living. Because funding is limited, we use this information (called a service priority level) to decide who is eligible for services. Activities of Daily Living are the basic personal activities all of us need to do that are essential for health and safety. These activities are defined in OAR 411-015-0006 <https://www.oregon.gov/odhs/aging-disability-services/pages/adl.aspx>

- Alexithymia is the inability for someone to recognize, identify, and describe feelings or emotions. It is sometimes referred to as emotional blindness.

<https://www.health.com/alexithymia-8361963>

ithymia**

Asperger's syndrome Asperger's syndrome (sometimes called high-functioning autism) is part of a wide diagnosis called autism spectrum disorder (ASD). Since 2013, Asperger's syndrome is replaced by the broader diagnosis of ASD within the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) revised criteria. <https://my.clevelandclinic.org/health/diseases/6436-asperger-syndrome>

Co-Occurring The preferred term in the autistic community as a replacement for “comorbid” for conditions, traits, and behaviors that are commonly found along with autism.

Con-di-tions

Double Double empathy refers to how:

- Em-** 1. It is easier to understand the mindset of people who are similar to you
- pa-** 2. It is more difficult to understand the mindset of those who are different from you

thy This concept was specifically developed by the autistic autism researcher Damian Milton to explain how autistics and neurotypicals empathize with each other. It explains how allistics (non-autistics) struggle to understand the lived experiences of autistics and autistics struggle to understand the lived experiences of allistics. Likewise, autistics are better at understanding other autistics and allistics are better at understanding other allistics. <https://embrace-autism.com/autism-and-the-double-empathy-problem/>

TermDefinition

Dyslexia Dyslexia is a specific learning difficulty which primarily affects reading and writing skills. However, it does not only affect these skills. Dyslexia is actually about information processing. Dyslexic people may have difficulty processing and remembering information they see and hear, which can affect learning and the acquisition of literacy skills. Dyslexia can also impact on other areas such as organisational skills. It is important to remember that there are positives to thinking differently. Many dyslexic people show strengths in areas such as reasoning and in visual and creative fields. [https :
//www.bdadyslexia.org.uk/dyslexia/about-dyslexia/what-is-dyslexia](https://www.bdadyslexia.org.uk/dyslexia/about-dyslexia/what-is-dyslexia)

Dyspraxia Dyspraxia is a term that refers to lifelong trouble with movement and coordination. It's not a formal diagnosis. But you may still hear people use this term, especially in the U.K. The formal diagnosis is developmental coordination disorder (DCD). <https://www.understood.org/en/articles/understanding-dyspraxia>

fMRI Functional MRI is a type of MRI scan that can show which areas of your brain are most active. Tracking and comparing that activity to what you were doing at the time can help “map” your brain activity. It's most often used for planning surgery or similar procedures in the brain. <https://my.clevelandclinic.org/health/diagnostics/25034-functional-mr-i-fmri>

Gender identity One's innermost concept of self as male, female, a blend of both or neither – how individuals perceive themselves and what they call themselves. One's gender identity can be the same or different from their sex assigned at birth. <https://www.hrc.org/resources/sexual-orientation-and-gender-identity-terminology-and-definitions>

Genome The genome is the entire set of DNA instructions found in a cell. In humans, the genome consists of 23 pairs of chromosomes located in the cell's nucleus, as well as a small chromosome in the cell's mitochondria. A genome contains all the information needed for an individual to develop and function. <https://www.genome.gov/genetics-glossary/Genome>

HealthShare Oregon One of Oregon's Community Care Organizations (CCO) for OHP.

<https://www.healthshareoregon.org/>

Oregon

gon

I/DD [Oregon Department of Human Services: Intellectual and Developmental Disabilities.](#)

Letter of Medical Necessity (LMN) is the written explanation from the treating physician describing the medical need for services, equipment, or supplies to assist the claimant in the treatment, care, or relief of their accepted work-related illness(es).

Medical Outreach [https://www.dol.gov/sites/dolgov/files/OWCP/energy/regs/compliance /
Outreach/Outreach_Presentation/lmn_mba06222022.pdf](https://www.dol.gov/sites/dolgov/files/OWCP/energy/regs/compliance/Outreach/Outreach_Presentation/lmn_mba06222022.pdf)

**Ne-
ces-
sity**

Term	Definition
Neurodivergent	Neurodiversity
Non-speaking	When an autistic person doesn't speak, it's known as nonspeaking autism. You may see it described as nonverbal autism. However, the term nonverbal isn't completely accurate, since it means "without words. Even if an autistic person is nonspeaking, they may still use words in other ways (such as in writing). They may also understand the words that are spoken to them or that they overhear. https://www.healthline.com/health/autism/nonverbal-autism
OCD	Obsessive-compulsive disorder (OCD) is a disorder in which people have recurring, unwanted thoughts, ideas or sensations (obsessions). To get rid of the thoughts, they feel driven to do something repetitively (compulsions). The repetitive behaviors, such as hand washing/cleaning, checking on things, and mental acts like (counting) or other activities, can significantly interfere with a person's daily activities and social interactions. https://www.psychiatry.org/patients-families/obsessive-compulsive-disorder/what-is-obsessive-compulsive-disorder
ODDS	Oregon Office of Developmental Disabilities Services
OHP	Oregon Health Plan: Oregon Medicaid
Services	Many high school students on the autism spectrum get help through special education
Cliff	– most commonly including speech-language therapy, service coordination/case management, behavior management, and special transportation. Each student has a team that works with the student and family to decide which services are needed to prepare him or her for young adulthood, and federal law requires schools to offer the necessary services. Sounds like a good plan for how to help vulnerable youth through a challenging period of life. But then, following the last day of high school, the legal mandate for help suddenly ends. [https://drexel.edu/autismoutcomes/blog/overview/2015/August/falling-off-the-services-cliff/]{.underline}
Sexual orientation	Inherent or immutable enduring emotional, romantic or sexual attraction to other people. Note: an individual's sexual orientation is independent of their gender identity. [http://www.hrc.org/resources/sexual-orientation-and-gender-identity-terminology-and-definitions]{.underline}

TermDefinition

- Synesthesia is when your brain routes sensory information through multiple unrelated senses, causing you to experience more than one sense simultaneously. Some examples include tasting words or linking colors to numbers and letters. It's not a medical condition, and many people find it useful to help them learn and remember information. <https://my.clevelandclinic.org/health/symptoms/24995-synesthesia>

Theory of Mind psychology, theory of mind refers to the capacity to understand other people by ascribing mental states to them. A theory of mind includes the knowledge that others' beliefs, desires, intentions, emotions, and thoughts may be different from one's own.

Possessing a functional theory of mind is crucial for success in everyday human social interactions. People utilize a theory of mind when analyzing, judging, and inferring others' behaviors. The discovery and development of theory of mind primarily came from studies done with animals and infants. Factors including drug and alcohol consumption, language development, cognitive delays, age, and culture can affect a person's capacity to display theory of mind. Having a theory of mind is similar to but not identical with having the capacity for empathy or sympathy.

https://en.wikipedia.org/wiki/Theory_of_mind

B

C Appendix 2: Representative Salaries

Data Analyst				
	Annual Salary	Monthly Pay	Weekly Pay	Hourly Wage
Top Earners	\$ 127,790.00	\$10,649.00	\$2,458.00	\$61.00
75th Percentile	\$ 102,900.00	\$8,575.00	\$1,979.00	\$49.00
Average	\$87,640.00	\$7,303.00	\$1,685.00	\$42.00
25th Percentile	\$66,300.00	\$5,525.00	\$1,275.00	\$32.00
Data Engineer				
	Annual Salary	Monthly Pay	Weekly Pay	Hourly Wage
Top Earners	\$ 171,801.00	\$14,316.00	\$3,303.00	\$83.00
75th Percentile	\$ 145,800.00	\$12,150.00	\$2,803.00	\$70.00
Average	\$ 138,279.00	\$11,523.00	\$2,659.00	\$66.00
25th Percentile	\$ 121,400.00	\$10,116.00	\$2,334.00	\$58.00
Database Administrator				
	Annual Salary	Monthly Pay	Weekly Pay	Hourly Wage
Top Earners	\$ 150,061.00	\$12,505.00	\$2,886.00	\$72.00
75th Percentile	\$ 130,400.00	\$10,867.00	\$2,508.00	\$63.00
Average	\$ 108,448.00	\$9,037.00	\$2,086.00	\$52.00
25th Percentile	\$84,800.00	\$7,067.00	\$1,631.00	\$41.00
Director of Operations				
	Annual Salary	Monthly Pay	Weekly Pay	Hourly Wage
Top Earners	\$ 171,801.00	\$14,316.00	\$3,303.00	\$83.00
75th Percentile	\$ 143,700.00	\$11,975.00	\$2,763.00	\$69.00

Data Analyst				
Average	\$ 102,922.00	\$8,576.00	\$1,979.00	\$49.00
25th Percentile		\$6,675.00	\$1,540.00	\$39.00
	\$80,100.00			
Grant Writer				
	Annual Salary	Monthly Pay	Weekly Pay	Hourly Wage
Top Earners		\$7,644.00	\$1,764.00	\$44.00
	\$91,733.00			
75th Percentile		\$6,492.00	\$1,498.00	\$37.00
	\$77,900.00			
Average		\$5,842.00	\$1,348.00	\$34.00
	\$70,107.00			
25th Percentile		\$4,592.00	\$1,060.00	\$26.00
	\$55,100.00			
Director of Operations				
	Annual Salary	Monthly Pay	Weekly Pay	Hourly Wage
Top Earners	\$ 171,801.00		\$3,303.00	\$83.00
		\$14,316.00		
75th Percentile	\$ 143,700.00		\$2,763.00	\$69.00
		\$11,975.00		
Average	\$ 102,922.00	\$8,576.00	\$1,979.00	\$49.00
25th Percentile		\$6,675.00	\$1,540.00	\$39.00
	\$80,100.00			
Operations Manager				
	Annual Salary	Monthly Pay	Weekly Pay	Hourly Wage
Top Earners	\$ 115,064.00	\$9,588.00	\$2,212.00	\$55.00
75th Percentile		\$6,850.00	\$1,580.00	\$40.00
	\$82,200.00			
Average		\$5,708.00	\$1,317.00	\$33.00
	\$68,498.00			
25th Percentile		\$3,625.00	\$836.00	\$21.00
	\$43,500.00			
Policy Analyst				
	Annual Salary	Monthly Pay	Weekly Pay	Hourly Wage
Top Earners	\$ 123,548.00		\$2,375.00	\$59.00
		\$10,295.00		
75th Percentile	\$ 123,500.00		\$2,375.00	\$59.00
		\$10,291.00		
Average		\$8,122.00	\$1,874.00	\$47.00
	\$97,464.00			
25th Percentile		\$7,333.00	\$1,692.00	\$42.00
	\$88,000.00			

Data Analyst				
Research Associate				
	Annual Salary	Monthly Pay	Weekly Pay	Hourly Wage
Top Earners	\$94,915.00	\$7,910.00	\$1,825.00	\$46.00
75th Percentile	\$81,700.00	\$6,808.00	\$1,571.00	\$39.00
Average	\$71,781.00	\$5,982.00	\$1,380.00	\$35.00
25th Percentile	\$57,800.00	\$4,817.00	\$1,112.00	\$28.00
Senior Manager				
	Annual Salary	Monthly Pay	Weekly Pay	Hourly Wage
Top Earners	\$ 178,695.00	\$14,891.00	\$3,436.00	\$86.00
75th Percentile	\$ 144,800.00	\$12,066.00	\$2,784.00	\$70.00
Average	\$93,748.00	\$7,812.00	\$1,802.00	\$45.00
25th Percentile	\$52,000.00	\$4,333.00	\$1,000.00	\$25.00
Website Designer				
	Annual Salary	Monthly Pay	Weekly Pay	Hourly Wage
Top Earners	\$ 109,232.00	\$9,103.00	\$2,101.00	\$53.00
75th Percentile	\$84,800.00	\$7,067.00	\$1,631.00	\$41.00
Average	\$77,227.00	\$6,436.00	\$1,485.00	\$37.00
25th Percentile	\$56,700.00	\$4,725.00	\$1,090.00	\$27.00
Website Programmer				
	Annual Salary	Monthly Pay	Weekly Pay	Hourly Wage
Top Earners	\$ 119,306.00	\$9,942.00	\$2,294.00	\$57.00
75th Percentile	\$ 100,700.00	\$8,392.00	\$1,937.00	\$48.00
Average	\$85,087.00	\$7,091.00	\$1,636.00	\$41.00
25th Percentile	\$67,300.00	\$5,608.00	\$1,294.00	\$32.00

D

E Appendix 3: Potential Funders

E.1 Healthcare Corporations

Or ganiz ation	Pr oduct	Links
Adve ntist	S ponso rship Re quest	https://hi_paa-submit.jotform.com/221594871753061
Adve ntist	Comm unity Be nefit	https://adventisthealth.org/portland/about-us/community-benefit/
C ambia	He althy and Conn ected Aging	https://www.cambiahealthfoundation.org/focus-areas/healthy-and-connected-aging.html
C ambia	S ponso rship	https://www.cambiahealthfoundation.org/applicant-resources/current-funding-opportunities.html
CareO regon	Comm unity G iving g rants and sp onsor ships	https://www.careoregon.org/community/community-giving-grants-for-nonprofit-organizations
CareO regon	HRSN Ser vices	re_quest.social.determinants@careoregon.org ,
H ealth Share	S ponso rship	https://www.healthshareoregon.org/about/sponsorship
H ealth Share	HRSN Ser vices	https://www.healthshareoregon.org/community-partners/hrsn
H ealth Share	HRSN Ser vices	https://health-share-or.portals.zeninehq.com/program/community-capacity-building/info
K aiser	HRSN Ser vices	Laura.J.Howard@kp.org
K aiser	HRSN Ser vices	https://communityhealth-midatlantic.kaiserpermanente.org/improving-communities/grantmaking/
K aiser	HRSN Ser vices	https://communityhealth-midatlantic.kaiserpermanente.org/wp-content/uploads/2024/02/LOI-Submitter-Help-Document_508.pdf
K aiser	HRSN Ser vices	MedicaidHRSflexfunds@ kp.org
K aiser	Comm unity Be nefit	community.benefit@kp.org

Or ganiz ation	Pr oduct	Links
L egacy	Comm unity H ealth Grant	https://www.legacyhealth.org/Giving-and-Support/community-engagement/Community-Grants
L egacy	L egacy Res earch Inst itute	https://www.legacyhealth.org/For-Health-Professionals/legacy-research-institute/services/grants
L egacy	S ponso rship	https://www.legacyhealth.org/Giving-and-Support/community-engagement/Sponsorships
L egacy Ochin OHSU	HRSN Ser vices	HealthRelatedServices@pacificsource.com
OHSU	Comm unity P artne rship Pr ogram	https://www.ohsu.edu/knight-cancer-institute/community-partnership-program-grants
OHSU	Comm unity P artne rship Pr ogram	https://www.ohsu.edu/knight-cancer-institute/how-apply-community-grant
OHSU	Comm unity P artne rship Pr ogram	https://www.ohsu.edu/sites/default/files/2024-01/CPP_RFP_2024.1_FINAL_lowres_0.pdf
OHSU	T iered G rants	https://www.ohsu.edu/knight-cancer-institute/tiered-grants
OHSU OHSU	HRSN Ser vices Rural Popul ation H ealth Incu bator Pr ogram	https://www.ohsu.edu/health-services { .underline} https://www.ohsu.edu/oregon-office-of-rural-health/rural-population-health-incubator-program { .underline}
Pa cific S ource	Comm unity H ealth Excel lence G rants	https://pacificsource.com/sites/default/files/2023-02/PRV510_0123_CHE%20Flyer.pdf
Pa cific S ource	Comm unity Ca pacit y-Bui lding Fu nding for HRSN ser vices	https://pacificsource.com/article/community-capacity-building-funding-hrsn-services
Pa cific S ource	Comm unity H ealth Excel lence G rants	https://www.ruralhealthinfo.org/funding/5469 { .underline}
Pa cific S ource	All	https://pacificsource.com/sites/default/files/2023-08/CLB1330_0823_PacificSource%20Funding%20Navigation%20Guide.pdf

Organization	Product	Links
Pacific Source	Pacific Source Foundation for Health Improvement	https://pacificsource.com/community/foundation?utm_source=pdf&utm_medium=flier&utm_campaign=FundingGuide&utm_id=CLB1330
Pacific Source	Healthy Communities Program	[http://www.grantinterface.com/Home/Logon]{.underline}
Providence	Community Grants / Donations	https://www.providence.org/locations/wa/providence-regional-medical-center-everett/donate-and-volunteer/community-sponsorships
Providence	Sponsorship	https://webportalapp.com/sp/login/prmce-sponsor-application
Providence Trillium	HRSN Services Community Benefit Initiatives	HRSNBenefit@Providence.org https://www.pnewswire.com/news-releases/trillium-community-health-plan-announces-request-for-applications-for-2023-small-grants-for-community-benefit-initiatives-301845411.html
Trillium	Community Benefit Initiatives	[https://www.trilliumohp.com/supporting-oregon-communities/community-benefit-initiatives.html]{.underline}
Trillium	Community Capacity Building Funding	https://www.trilliumohp.com/supporting-oregon-communities/health-related-social-needs/community-capacity-building-funding.html
Central Oregon Health Council	Standard Grants	[https://cohealthcouncil.org/standard-grants/]{.underline}
	Mini Grants	[https://cohealthcouncil.org/mini-grants/]{.underline}
St Charles Health System	Community Benefit Grants and Sponsorships	[https://www.stcharleshealthcare.org/community-health/community-benefit-grants-and-sponsorships]{.underline}

E.2 State Agencies

Entity	Product	Links
Oregon Health Authority	Block Grants	https://www.oregon.gov/oha/hsd/amhpac/pages/block-grants.aspx
Oregon Health Authority	Community Capacity Building Funds	https://www.oregon.gov/oha/hsd/medicaid-policy/pages/ccbf.aspx
Oregon Health Authority	Community Capacity Building Funds	https://content.govdelivery.com/accounts/ORHA/bulletins/38e15e8
Oregon Health Authority	SHARE Initiative	https://www.oregon.gov/oha/hsd/dsi-tc/pages/share.aspx
Oregon Health Authority	PUBLIC HEALTH EQUITY	https://www.oregon.gov/oha/PH/ABOUT/MODCET%20CBO%20Documents/PH%20Equity%20CBO%20Fiscal%20Guidance%20-%20AY25%20%20DRAFT-%2002.28.24.pdf
Oregon Health Authority	PUBLIC HEALTH EQUITY	https://content.govdelivery.com/accounts/ORHA/bulletins/37611cc
Oregon Health Authority	GRANT	https://www.oregon.gov/oha/ph/healthypeoplefamilies/youth/healthschool/schoolbasedhealthcenters/pages/mh-expansion-grant.aspx
Oregon Health Authority	HTO CHIP Project Grants	https://www.oregon.gov/oha/PH/ABOUT/Documents/HTO%20CHIP%202024%20FAQ.pdf
Oregon State	IMPACTS Grant Program	https://www.oregon.gov/cjc/impacts/Documents/2020_IMPACTSOnePager.pdf

E.3 Foundations and Trusts

Foundation	Product	Links
Carpenter Foundation	Grant	http://carpenter-foundation.org/
Anna May Family Foundation	Grant	http://www.annamay.org/
Gordon Elwood Foundation	Grant	[http://www.gordonelwoodfoundation.org/index]{.underline}

Foun dation	P roduct	Links
Ma ybelle Clark Mac donald Fund	Grant	https://mcmfundgiving.org/grants/
M J M urdock Char itable Trust	STR ATEGIC GRANT	https://murdocktrust.org/grant-application-process/
C ollins Foun dation	Resp onsive Grant	https://www.collinsfoundation.org/responsive-grantmaking-submission-guidelines
C ollins Foun dation	Resp onsive Grant	https://www.collinsfoundation.org/responsive-grantmaking-submission-guidelines/frequently-asked-questions
Benton Com munity Foun dation	Com munity Grants	https://bcfgives.org/wp-content/uploads/2024/02/2023-Full-Grant-History.pdf
Reser Family Foun dation Foster Foun dation	Resp onsive Grant Pr ograms Grant	https://thereserfamilyfoundation.org/apply-for-a-grant/ [ht tp://www.thefosterfoundation.org/Home.htm]{.underl ine}
Doug Flutie Foun dation	Autism Com munity Impact Grant	https://flutiefoundation.org/helping-communities/autism-community-impact-grant/
Doug Flutie Foun dation	Flutie F ellows – Career and Life Goal S upport	[ht tps://flutiefoundation.org/helping-individuals/flutie-fellows-career-and-life-goal-support/]{.underl ine}
Doug Flutie Foun dation	Fin ancial Relief for Fa milies	https://flutiefoundation.org/helping-families/direct-financial-support/
Ch ambers Family Foun dation	Grant	https://www.chambersfamilyfoundation.com/submissions
Meyer Me morial Trust	Grant	https://mmt.org/
Ben B Cheney Foun dation	Grant	[https://www.benbcheneyfoundation.org/]{. underline}
Autzen Foun dation	Grant	[https://www.autzenfoundation.org/deadlines]{.under line}
Oregon Com munity Foun dation	Grant	https://oregoncf.org/grants-and-scholarships/grants/

Foun dation	P roduct	Links
Robert Wood J ohnson Foun dation	Mu ltiple	[https://www.rwjf.org/en/grants.html] {.underline}
Robert Wood J ohnson Foun dation	Mu ltiple	https://www. rwjf.org/en/grants/active-funding-opportunities.ht ml?o=1&us=1
Weyer houser	Giving Fund	ht tps://www.weyerhaeuser.com/company/values/citizens hip/giving-fund/

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G Appendix 4: Neurodiversity and Neurodivergence

Many people find [this article](#) by Dr. Nick Walker to be the definitive overview of these terms and how they are used and misused. We put together the summary below with the help of [chatGPT](#):

G.1 Neurodiversity (concept)

Definition: Neurodiversity is the idea that neurological differences, like autism, ADHD, dyslexia, and others, are natural variations of the human genome. This concept emphasizes that these differences should be recognized and respected as a part of human diversity.

Historical and Social Context: The term “neurodiversity” was coined in the late 1990s by sociologist Judy Singer. It arose from the disability rights movement and the autistic rights movement, which sought to challenge the medical model of disability that views neurological differences as deficits or disorders to be cured. Instead, neurodiversity advocates promote acceptance and understanding, emphasizing the strengths and contributions of neurodivergent individuals.

G.2 Neurodiversity (paradigm)

Definition: The neurodiversity paradigm is a framework that challenges traditional views of neurological differences. It posits that these differences should be seen as normal variations rather than abnormalities or deficits. This paradigm promotes the idea that society should adapt to accommodate these differences rather than forcing individuals to conform to a neurotypical standard.

Historical and Social Context: This paradigm shift gained momentum in the early 2000s, aligning with broader social movements advocating for civil rights and inclusion. It has influenced fields like education, employment, and healthcare, encouraging practices that support diverse ways of thinking and learning.

G.3 Neurodiversity (movement)

Definition: The neurodiversity movement is a social movement that advocates for the rights and inclusion of neurodivergent individuals. It seeks to promote understanding, acceptance, and accommodation of neurological differences. The movement has worked to reframe autism as a minority identity rather than a disorder.

Historical and Social Context: Emerging in the late 20th century, the neurodiversity movement has been driven by self-advocates and allies. It challenges stigmatizing narratives and calls for systemic changes in how neurodivergent individuals are treated in society. This movement has led to increased visibility and advocacy for policies that support neurodiversity in schools, workplaces, and communities.

G.4 Neurodivergence

Definition: Neurodivergence refers to the state of having a brain that functions differently from the typical standards of society. It is an umbrella term that includes various neurological conditions like autism, ADHD, dyslexia, and more.

Historical and Social Context: The term “neurodivergence” gained prominence alongside the neurodiversity movement. It helps to create a more inclusive language that recognizes the spectrum of neurological differences without implying pathology. This shift in terminology supports a more positive and accepting view of diverse cognitive profiles.

G.5 Neurodivergent

Definition: Neurodivergent describes individuals whose neurological development and functioning are atypical. This term is used to identify people who have conditions like autism, ADHD, dyslexia, etc.

Historical and Social Context: The adoption of the term “neurodivergent” reflects a growing acceptance of diversity in neurological functioning. It emphasizes identity and self-advocacy, allowing individuals to claim their differences as part of who they are rather than as something to be fixed or hidden.

G.6 Neurotypical

Definition: Neurotypical refers to individuals whose neurological development and functioning are considered standard or typical by societal norms. It is often used in contrast to neurodivergent.

Historical and Social Context: The term “neurotypical” originated within the neurodiversity community as a way to distinguish between those who conform to societal norms of neurological functioning and those who do not. It highlights that “typical” neurological functioning is not the only valid or acceptable way of being, promoting a more inclusive view of human diversity.

G.6.1 References

1. Singer, J. (1998). **Odd People In: The Birth of Community Amongst People on the ‘Autistic Spectrum’**. Honours Thesis, University of Technology, Sydney.
2. Silberman, S. (2015). **NeuroTribes: The Legacy of Autism and the Future of Neurodiversity**. Avery.
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