

Autism All Grown Up

The Autism Nexus of Oregon

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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.

3 Executive Summary

3.1 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.

3.2 Goals

The organization 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, and up-to-date information and resources *for* autistic adults
4. Provide accurate, accessible, and up-to-date information and resources *about* autism and *about* the autistic community

3.3 Autism All Grown Up

Autism is all grown up, and it isn't 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 developmental challenge that primarily affected children. Outdated notions of what constitutes genuine autism have caused adults to be overlooked by many people. 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 (Mason et al. (2022)). Late-identified and never-identified autistic adults face unique challenges with respect to aging, and most of these “lost generations” (Wright 2015) have not yet even been counted.

3.4 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 faced by supporting existing infrastructure by increasing the connectivity and information flow. Rather than being a hub that consumes resources and provides services, AAGU will catalyze and strengthen relationships around it to form a *nexus*.

4 Autism in 2024

4.1 The New World of Autism

Recent advancements in our understanding of autism, largely driven by autistic self-advocates and researchers, have highlighted the need for a paradigm shift in understanding and supporting autistic individuals. Key findings include Weiss (2023):

- **The Autism Spectrum is not Linear**

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

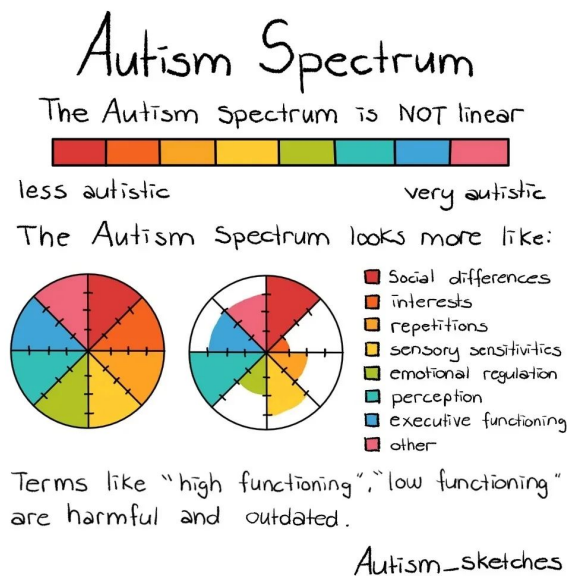


Figure 4.1: Figure 1. What the autism spectrum means.

- **Disability can be Contextual:**

Most autistic individuals are not intellectually or physically disabled but face substantial challenges navigating society. Navigating society feels like being a left-handed person using right-handed scissors: difficult and unwieldy at best.

- **Misconceptions:**

Science has refuted many harmful misconceptions about autism. Some autistic people have different 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.

- **Lifelong Condition:**

Autism is a lifelong neurological difference, not a disorder to be cured. There are roughly the same percentage of autistic adults as children, but there are four times as many adults as children.

- **Neurodiversity & Neurodivergence:**

The *neurodiversity paradigm* recognizes autism as a natural variation in human neurology. Individual people with cognitive styles that are significantly atypical are *neurodivergent*, and many have unmet needs.

4.2 Lost Generations of Autistic Adults

Autistic adults face unique challenges that are often overlooked, such as navigating social and employment environments not designed for neurodivergent individuals. Autistic adults without intellectual disabilities often face a lack of access to appropriate healthcare and support services.

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. Research backs this up, indicating that discrimination, not autism, is a significant barrier in the workplace.

Autistic adults face unique challenges that are often overlooked, such as navigating social and employment environments not designed for neurodivergent individuals. Key issues include:

- **Focus Gaps:** Research and services have predominantly focused on children leaving out adults, especially those without profound disabilities. We have failed, and continue to fail, to adequately study autistic life after high school when children lose many supports.

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.

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

5.1 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

5.2 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 *****

5.3 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

5.4 Growth Plan

Our growth plan consists of three phases:

1. Seed (Weeks 1-8)

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

2. Sprout (Weeks 9-26)

- **Budget:** \$4,620/week
- **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:** \$6,468/week
- **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.

6 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-potential-funders?**)) 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.

7 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-representative-salaries?**)). We project a budget of approximately \$150,000 for the first six months (26 weeks) of operation.

7.1 Seed

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	

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	

7.2

7.3

7.4 Sprout

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.
Web Development	0.50	Design and build website.
Total	2.75	

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	

7.5 Grow

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.

Responsibility	FTE	Description
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	

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
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	

8

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A Special Issues and Concerns

A.1 The Services Cliff

- Services Cliff: Young autistic adults also face significant challenges transitioning out of high school, often referred to as the “services cliff.” This sudden drop-off in support can lead to difficulties in finding meaningful work, pursuing higher education, and living independently. [<https://drexel.edu/autismoutcomes/blog/overview/2015/August/falling-off-the-services-cliff/>].

Transition to Adulthood This problem does not just affect existing 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?

A.2 Access to Medical Care

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.

A.3 Medical Training

Lack of training for healthcare providers

A.4 Autism Research Funding Priorities

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.

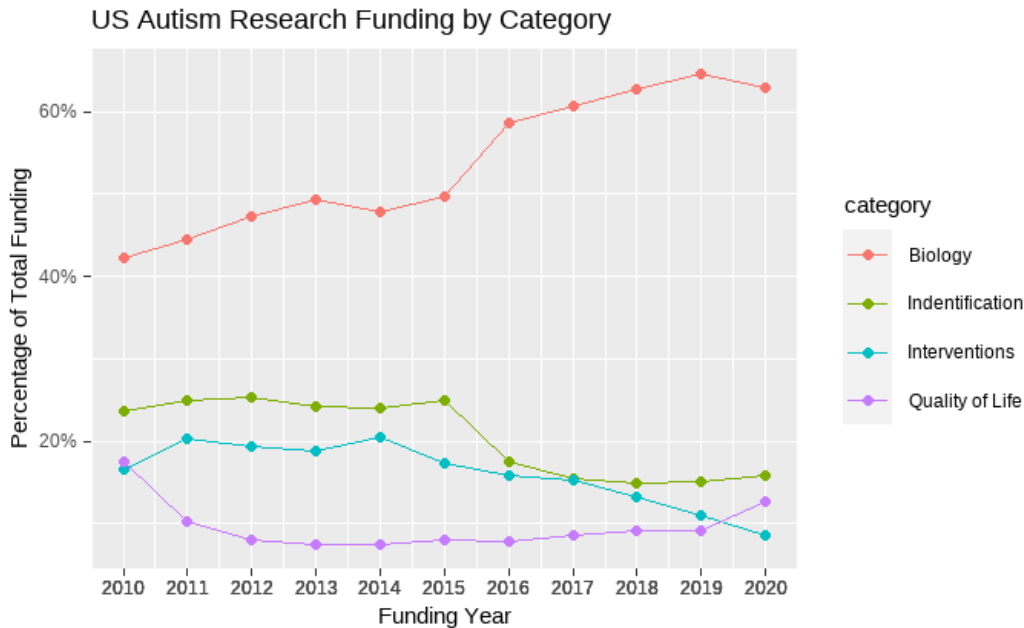


Figure A.1: Figure 2. Data from [Interagency Autism Coordination Committee](<https://iacc.hhs.gov/funding/data/>)

A.5 Intersectionally Marginalized Groups

All of these problems compound for members of intersectional populations who may already be marginalized along other dimensions. Many researchers believe that autism is (Fombonne and Zuckerman 2022), particularly in Black communities (Angell, Empey, and Zuckerman 2018), as well as for (D’Mello et al. 2022). Meanwhile, fluidity in gender and sexual orientation Rita George and Stokes (2018) is more highly represented among autistic people. Little research has been done to assess how autism uniquely affects people in these different subgroups.

A.6 Physical and Mental Health

- Health and Well-being: Autistic adults experience higher rates of mental health issues, physical health disparities, and substantially elevated suicide risk [<https://www.nature.com/articles/s41583-021-00463-7>, <https://pubmed.ncbi.nlm.nih.gov/33407027/>].
- Social Isolation: Negative social experiences can lead to self-isolation, exacerbating feelings of loneliness and exclusion (Loomes, Hull, and Mandy 2017)

Across a variety of health domains, autistic people fare worse Lodi-Smith, Rodgers, et al. (2021). Additionally, we are exposed to risks that are not of primary concern for most people (Muskens, Velders, and Staal 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.

A.7 Unemployment

- Employment: Many autistic adults face difficulties finding and maintaining employment due to biases and lack of accommodations. In a study of 254 autistic adults, 77% reported difficulties applying for jobs, and only 16% are in full-time paid work [<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5215190/>, <https://www.frontiersin.org/articles/10.3389/fpsyg.2021.719827/full>].

A.8 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).

A.9 Suicide

As a group, their suicide risk may be two to seven times higher than the risk for youth and adults who do not have autism. When researchers took into account psychiatric conditions that increase suicide risk, such as depression, anxiety, and substance abuse disorders, autistic people still had a higher risk than the comparison group [autism2022]. The International Society for Autism Research says “Suicide in autism is a hidden crisis, overlooked by policymakers, clinicians and researchers worldwide.” and highlights three barriers: a lack of evidence-based assessment tools and interventions to identify and treat suicidal thoughts and behaviors; a lack of access to mental health services¹⁰ and exclusion from conversations about policies and guidelines that affect autistic people.” (Cassidy et al. 2021)

B Glossary

Term	Definition
ADLs	When a person applies for Medicaid long-term care services in Oregon, we look
Alexithymia	Alexithymia is the inability for someone to recognize, identify, and describe feel
Asperger’s Syndrome	Asperger’s syndrome (sometimes called high-functioning autism) is part of a wi
Co-Occurring Conditions	The preferred term in the autistic community as a replacement for “comorbid”
Double Empathy	Double empathy refers to how: 1. It is easier to understand the mindset of people
Dyslexia	Dyslexia is a specific learning difficulty which primarily affects reading and writ
Dyspraxia	Dyspraxia is a term that refers to lifelong trouble with movement and coordinat
fMRI	Functional MRI is a type of MRI scan that can show which areas of your brain
Gender identity	One’s innermost concept of self as male, female, a blend of both or neither – ho
Genome	The genome is the entire set of DNA instructions found in a cell. In humans, th
Health Share Oregon	One of Oregon’s Community Care Organizations (CCO) for OHP. https://www
I/DD	Oregon Department of Human Services: Intellectual and Developmental Disabil
Letter of Medical Necessity	A Letter of Medical Necessity (LMN) is the written explanation from the treati
Neurodivergent	See Appendix 4: Neurodiversity and Neurodivergence
Neurodiversity	See Appendix 4: Neurodiversity and Neurodivergence
Non-Speaking	When an autistic person doesn’t speak, it’s known as nonspeaking autism. You
OCD	Obsessive-compulsive disorder (OCD) is a disorder in which people have recurri
ODDS	Oregon Office of Developmental Disabilities Services
OHP	Oregon Health Plan: Oregon Medicaid
Services Cliff	Many high school students on the autism spectrum get help through special edu
Sexual orientation	An inherent or immutable enduring emotional, romantic or sexual attraction to
Synesthesia	Synesthesia is when your brain routes sensory information through multiple un
Theory of Mind	In psychology, theory of mind refers to the capacity to understand other people

C Representative Salaries

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

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		\$7,910.00	\$1,825.00	\$46.00
	\$94,915.00			
75th Percentile		\$6,808.00	\$1,571.00	\$39.00
	\$81,700.00			
Average		\$5,982.00	\$1,380.00	\$35.00
	\$71,781.00			
25th Percentile		\$4,817.00	\$1,112.00	\$28.00
	\$57,800.00			
Senior Manager				
	Annual Salary	Monthly Pay	Weekly Pay	Hourly Wage
Top Earners	\$ 178,695.00		\$3,436.00	\$86.00
		\$14,891.00		
75th Percentile	\$ 144,800.00		\$2,784.00	\$70.00
		\$12,066.00		
Average		\$7,812.00	\$1,802.00	\$45.00
	\$93,748.00			
25th Percentile		\$4,333.00	\$1,000.00	\$25.00
	\$52,000.00			
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		\$7,067.00	\$1,631.00	\$41.00
	\$84,800.00			
Average		\$6,436.00	\$1,485.00	\$37.00
	\$77,227.00			
25th Percentile		\$4,725.00	\$1,090.00	\$27.00
	\$56,700.00			
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		\$7,091.00	\$1,636.00	\$41.00
	\$85,087.00			
25th Percentile		\$5,608.00	\$1,294.00	\$32.00
	\$67,300.00			

D

E Potential Funders

E.1 Seed jobs

Responsibility	FTE	Description
Organizing and Directing	0.75	Implement business systems—payrol, formal job descriptions, insurance, et
Coworking space manager	0.25	Research how coworking spaces run. Create a budget and game plan for i
Research support	0.25	Collect and organize information. Writing.
Web Development	0.25	Design and build website.
Total	1.50	NA

E.2 Seed budget

Table E.2: Seed budget

Responsibility	FTE	Rate	Weekly Total	Overhead (10%)
Organizing and Directing	0.75	40	1200	120
Coworking space manager	0.25	30	300	30
Research support	0.25	30	300	30
Web Development	0.25	30	300	30
Subtotal per week	NA	NA	2100	210
Total per week	NA	NA	2310	NA

E.3 Sprout jobs

Responsibility	FTE	Description
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Organizing and Directing	0.75	Complete current information product projects. Investigate access gaps. I
Data engineering	0.50	Create databases. Research portal design.
Coworking space manager	0.50	Research how coworking spaces run. Solicit community feedback. Run tra
Research support	0.50	Collect and organize information. Writing.
Web Development	0.50	Design and build website.
Total	2.75	NA

E.4 Sprout budget

Table E.4: Sprout budget

Responsibility	FTE	Rate	Weekly Total	Overhead (10%)
Organizing and Directing	0.75	50	1500	150
Data engineering	0.50	45	900	90
Coworking space manager	0.50	30	600	60
Research support	0.50	30	600	60
Web Development	0.50	30	600	60
Subtotal per week	NA	NA	4200	420
Total per week	NA	NA	4620	NA
Total for 8 weeks	NA	NA	33600	NA

E.5 Grow Jobs

Table E.5:

Responsibility	FTE	Description
Organizing and Directing	1.00	Seek out partners and funding opportunities. Work with stakeholders to
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 re
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 p
Coworking space attendant	0.50	Oversee operation.
Total	4.25	NA

E.6 Grow budget

Table E.6: Grow budget

Responsibility	FTE	Rate	Weekly Total	Overhead (10%)
Organizing and Directing	0.75	65	1950	195
Data engineering	0.30	50	600	60
Jr. Data management	0.20	30	240	24
Research and analysis	0.50	45	900	90
Research support (Jr.)	0.50	30	600	60
Web Development	0.25	45	450	45
Coworking space manager	0.75	40	1200	120
Coworking space attendant	0.50	25	500	50
Subtotal per week	NA	NA	5940	594
Total per week	NA	NA	6534	NA
Total for 18 weeks	NA	NA	117612	NA

E.7 Salaries

Table E.7: Salaries

Data Analyst	...2	...3	...4	...5
NA	Annual Salary	Monthly Pay	Weekly Pay	Hourly Wage
Top Earners	127790	10649	2458	61
75th Percentile	102900	8575	1979	49
Average	87640	7303	1685	42
25th Percentile	66300	5525	1275	32
NA	NULL	NULL	NULL	NULL
Data Engineer	NULL	NULL	NULL	NULL
NA	Annual Salary	Monthly Pay	Weekly Pay	Hourly Wage
Top Earners	171801	14316	3303	83
75th Percentile	145800	12150	2803	70
Average	138279	11523	2659	66
25th Percentile	121400	10116	2334	58
NA	NULL	NULL	NULL	NULL
Database Administrator	NULL	NULL	NULL	NULL
NA	Annual Salary	Monthly Pay	Weekly Pay	Hourly Wage

Top Earners	150061	12505	2886	72
75th Percentile	130400	10867	2508	63
Average	108448	9037	2086	52
25th Percentile	84800	7067	1631	41
NA	NULL	NULL	NULL	NULL
Director of Operations	NULL	NULL	NULL	NULL
NA	Annual Salary	Monthly Pay	Weekly Pay	Hourly Wage
Top Earners	171801	14316	3303	83
75th Percentile	143700	11975	2763	69
Average	102922	8576	1979	49
25th Percentile	80100	6675	1540	39
NA	NULL	NULL	NULL	NULL
Grant Writer	NULL	NULL	NULL	NULL
NA	Annual Salary	Monthly Pay	Weekly Pay	Hourly Wage
Top Earners	91733	7644	1764	44
75th Percentile	77900	6492	1498	37
Average	70107	5842	1348	34
25th Percentile	55100	4592	1060	26
NA	NULL	NULL	NULL	NULL
Director of Operations	NULL	NULL	NULL	NULL
NA	Annual Salary	Monthly Pay	Weekly Pay	Hourly Wage
Top Earners	171801	14316	3303	83
75th Percentile	143700	11975	2763	69
Average	102922	8576	1979	49
25th Percentile	80100	6675	1540	39
NA	NULL	NULL	NULL	NULL
Operations Manager	NULL	NULL	NULL	NULL
NA	Annual Salary	Monthly Pay	Weekly Pay	Hourly Wage
Top Earners	115064	9588	2212	55
75th Percentile	82200	6850	1580	40
Average	68498	5708	1317	33
25th Percentile	43500	3625	836	21
NA	NULL	NULL	NULL	NULL
Policy Analyst	NULL	NULL	NULL	NULL
NA	Annual Salary	Monthly Pay	Weekly Pay	Hourly Wage
Top Earners	123548	10295	2375	59
75th Percentile	123500	10291	2375	59
Average	97464	8122	1874	47
25th Percentile	88000	7333	1692	42
NA	NULL	NULL	NULL	NULL

Research Associate	NULL	NULL	NULL	NULL
NA	Annual Salary	Monthly Pay	Weekly Pay	Hourly Wage
Top Earners	94915	7910	1825	46
75th Percentile	81700	6808	1571	39
Average	71781	5982	1380	35
25th Percentile	57800	4817	1112	28
NA	NULL	NULL	NULL	NULL
Senior Manager	NULL	NULL	NULL	NULL
NA	Annual Salary	Monthly Pay	Weekly Pay	Hourly Wage
Top Earners	178695	14891	3436	86
75th Percentile	144800	12066	2784	70
Average	93748	7812	1802	45
25th Percentile	52000	4333	1000	25
NA	NULL	NULL	NULL	NULL
Website Designer	NULL	NULL	NULL	NULL
NA	Annual Salary	Monthly Pay	Weekly Pay	Hourly Wage
Top Earners	109232	9103	2101	53
75th Percentile	84800	7067	1631	41
Average	77227	6436	1485	37
25th Percentile	56700	4725	1090	27
NA	NULL	NULL	NULL	NULL
Website Programmer	NULL	NULL	NULL	NULL
NA	Annual Salary	Monthly Pay	Weekly Pay	Hourly Wage
Top Earners	119306	9942	2294	57
75th Percentile	100700	8392	1937	48
Average	85087	7091	1636	41
25th Percentile	67300	5608	1294	32

E.8 Glossary

Term	Definition
ADLs	When a person applies for Medicaid long-term care services in Oregon, we look
Alexithymia	Alexithymia is the inability for someone to recognize, identify, and describe feel
Asperger's Syndrome	Asperger's syndrome (sometimes called high-functioning autism) is part of a wi
Co-Occurring Conditions	The preferred term in the autistic community as a replacement for "comorbid"
Double Empathy	Double empathy refers to how: 1. It is easier to understand the mindset of peop

Dyslexia	Dyslexia is a specific learning difficulty which primarily affects reading and writing
Dyspraxia	Dyspraxia is a term that refers to lifelong trouble with movement and coordination
fMRI	Functional MRI is a type of MRI scan that can show which areas of your brain are active
Gender identity	One's innermost concept of self as male, female, a blend of both or neither – how one experiences their gender
Genome	The genome is the entire set of DNA instructions found in a cell. In humans, the genome consists of 23 pairs of chromosomes, found in the nucleus, with thousands of genes
Health Share Oregon	One of Oregon's Community Care Organizations (CCO) for OHP. https://www.healthshare.org
I/DD	Oregon Department of Human Services: Intellectual and Developmental Disabilities
Letter of Medical Necessity	A Letter of Medical Necessity (LMN) is the written explanation from the treating provider that a service is medically necessary
Neurodivergent	See Appendix 4: Neurodiversity and Neurodivergence
Neurodiversity	See Appendix 4: Neurodiversity and Neurodivergence
Non-Speaking	When an autistic person doesn't speak, it's known as nonspeaking autism. You can communicate in many other ways
OCD	Obsessive-compulsive disorder (OCD) is a disorder in which people have recurring thoughts or images that cause them anxiety
ODDS	Oregon Office of Developmental Disabilities Services
OHP	Oregon Health Plan: Oregon Medicaid
Services Cliff	Many high school students on the autism spectrum get help through special education services
Sexual orientation	An inherent or immutable enduring emotional, romantic or sexual attraction to other people
Synesthesia	Synesthesia is when your brain routes sensory information through multiple unconnected senses
Theory of Mind	In psychology, theory of mind refers to the capacity to understand other people's behavior from their perspective

E.9 Sheet3

Table E.9: Sheet3

Category	Number
Adults Receiving I/DD Service	22984
Autistic Adults Receiving I/DD Service	6435
Autistic Adults	77616
Max Autistic Adults	95318
Min Autistic Adults	62297

F 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](#):

F.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.

F.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.

F.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.

F.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.

F.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.

F.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.

References

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