

Navigating the Healthcare System as a Neurodivergent Person



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Brought to You By:



**Timotheus "T.J."
Gordon, Jr.**

**Multimedia Artist,
Speaker, Self-Advocate
and Consultant**



Notes

- This was originally a workshop for a local neurodivergent adults group, looking for tools and ways to navigate their health care
- T.J. is not a medical professional, thus he is not giving medical advice nor is authorized to give medical advice. He is providing information based on his personal and advocacy experiences.
- If you would like seek advice about your health care, he advises you to talk with your doctor or medical professional that knows your health more in-depth.
- Some of the images are AI generated.

Summary of Workshop

In this workshop, people will learn about the struggles, barriers, and difficulties that neurodivergent people face in figuring out the best health insurance options, choosing their primary providers and specialists, connecting with mental and behavioral health supports that are neurodivergent AND culturally affirming, and more. They will also learn tools and advocacy strategies for selecting options, resources, and medical team members that are right for them.

Researcher and autistic self-advocate Timotheus “T.J.” Gordon, Jr., will use examples from his experience navigating health care and interactive exercises to help neurodivergent people build their healthcare options and support team.

Workshop Learning Objectives

- To illustrate what it means to navigate the healthcare system and what to consider (e.g., health insurance options, finding neurodivergent community-affirmative care and providers, insurance coverage, what treatment or intervention options are helpful for YOU, etc.)
- To talk through examples of barriers and difficulties that neurodivergent individuals face when deciding the best healthcare options that fit their needs
- To provide tools and tips that can help you navigate and advocate for your right to have adequate health care that is for you and your needs as a neurodivergent person

About T.J.

- UIC Researcher
- Autistic Self-Advocate and Multimedia Artist
- Creator of *The Black Autist*
- Fun Fact: I love American football! Not only I follow the games, but I also love to talk about football transactions, football and culture, football history, strategies, and more. In fact, I once tried to complete a coaching certificate and play football at University of Minnesota



Section #1: What is Healthcare

Word Cloud Example of Healthcare/Healthcare Access

Words and Phrases That Describe Healthcare

slow insurance
difficult confusing
doctors caring debt sad
judgement compassion
science expensive judgmental

Another Word Cloud Example of Healthcare/Healthcare Access



What is Healthcare?

- Overall upkeep or looking-after ALL aspects of your health
 - Physical health
 - Mental health
 - Sexual/reproductive health
 - Neurological/developmental health
- Healthcare includes, but not limited to:
 - Nutrition
 - Holistic approaches to health
 - Therapy
 - Checkups and Follow-Up appointments
 - Emergency Health
 - Medicine

What Does Navigating Healthcare Look Like For Neurodivergent People?

- Seeking care that is tied to your neurodivergent traits/conditions
- Some may see multiple specialists for their overall care
- May need more time and supports in planning your healthcare
 - Written prompts and reminders
 - Finding medical team members that can understand you and be patient with you
 - Planning trips to clinics ahead of time to make sure you're on time
 - Making sure that the communication is clear and direct between medical providers and their neurodivergent clients

Barriers to Navigating Healthcare

- Executive functioning overload with keeping up with information, appointment dates, etc.
- Sensory overload (e.g., hot or cold instruments, bright lights)
- Communication barriers (e.g., vague and technical language that you may not understand)
- Navigating past medical traumas and discriminations

Barriers to Navigating Healthcare

- Finding the medical professionals that are caring, knowledgeable neurodivergent/disability community affirming, culturally-affirming, AND gender-affirming
- Disability/medical condition getting dismissed
 - “Your condition is not real”
 - “Your imagining things”
 - Downplaying your condition/identity or using “inspiration porn”/ “overcoming barriers” language

Section #2: How to Identify and Take Care of Your Health Care Needs

Using Patient Portals and Medical/Health Apps

- You can now access your health information using online patient portals
 - Patient portals, like Epic or MyChart, has past and scheduled visits, medical records, tracking your health (e.g., vitals, weight, test/lab results)
 - You can request to share information between hospitals and clinics that you frequently visited through patient portals, or sign in on multiple accounts using the same sign in information
- Health Apps
 - You can use digital apps to track your exercise routines, mental health, emergency information to share with 911 (Smart 911) or clinics, vitals, medication, and more
 - You can sync information from health apps to other health apps or patient portals

Choosing Your Medical Team

- Finding providers and specialists that are neurodivergent-affirming
- Finding providers and specialists who are affirming to people with intersectional identities (disability, race, gender, etc.)
- Choosing medical professionals that are “in-network” (or within your insurance coverage area) vs “out-of-network” (where you may have to pay out-of-pocket, or ask your insurance permission to cover some or all the costs)
- Are you willing to travel for medical care, go to a local place, or take care of your medical needs remotely through phone or telehealth video calls?

Choosing Your Medical Team

- Finding people or clinics who are willing to provide you the care you need AND want. For instance, you can choose to seek specialists that doesn't use applied behavior analysis or who prefers weight management without surgery.
 - Remember, it is YOUR choice on how you want to address your health and who can do it based on your needs and wants.
 - Consult medical professionals on which options are right for YOU
- Research! Research! Research your clinic and medical team options.
 - It's okay to use AI to research your medical needs and resources. But with anything...ALWAYS double check your sources before using your resources. Some sources might be outdated, incorrect, or not relevant to your needs.

Adding Support People to Your Medical Team

- Support people can help advocate for your needs, support you in crises, be your emergency contact, help you with your care, be powers of attorney in case of emergencies, and more
- They can be people close friends and family members that you can trust, or paid/volunteer care professionals that you can trust

Adding Support People to Your Medical Team

- You do not have to manage challenges alone. Trusted support people can provide encouragement, practical help, and emotional support during difficult times.
- Support people can help recognize early warning signs. Family members, friends, peers, or providers may notice changes in mood, behavior, or stress levels before a situation becomes a crisis.
- A strong support network can provide assistance in a way that respects your wishes, choices, and goals.
- Support people can remind you of coping strategies, appointments, medications, or wellness activities that are important to your recovery.

Choosing Your Insurance

- Monthly cost
- If your providers are “in-network” or “out-of-network”
- What does your insurance cover



Choosing Your Insurance

- How to apply for insurance (including Medicaid, Medicare, ACA/Obamacare, and employer-provided insurance)
- Benefits (gym memberships, rides to the clinic)
- Does your employer offer insurance?



Medicaid Workplace Requirements

- Some adults on Medicaid may have to meet a work requirement to keep their coverage. This generally applies to certain adults ages 19-64 and may not apply to people who qualify for an exemption.
- The requirement is usually 80 hours per month of approved activities. Approved activities can include working, job training, education, or community service.

Medicaid Workplace Requirements

- Many people are exempt. Exemptions may include pregnant individuals, people with disabilities or serious health conditions, certain caregivers, and other groups identified by law.
- People may need to report their activities or exemption status. If required information is not provided or the requirement is not met, Medicaid coverage could be affected.

Visit <https://medicaid.gov/community-engagement> (CMS's Medicaid Community Engagement page) for plain-language information, updates, and state resources

Tools to Prepare Your Medical Visits and Navigate Your Health Care

- Using social stories to help you prepare for doctor visits or guide you with your health care
 - Step-by-Step processes and expectations
 - Example: [Social Story on Going to the Doctor](#)
- Calendar reminders, alarm reminders for when to take your meds
- Pill counters to organize your medicine

Tools to Prepare Your Medical Visits and Navigate Your Health Care

- Keeping files of your medical records
- Writing down allergies, emergency information
- Scripts for what to say or ask during medical visits or emergencies

WRAP Plan

- A WRAP Plan (Wellness Recovery Action Plan) is a personal wellness and recovery tool. It helps people identify what keeps them well, recognize challenges early, and create a plan for staying healthy and managing stress.
- WRAP is self-directed. Each person creates their own plan based on their strengths, goals, wellness strategies, and support system.
- A WRAP Plan includes a “wellness toolbox.” This is a list of activities, supports, and coping strategies that help a person feel well and maintain their recovery.

WRAP Plan

- Official WRAP information and materials: <https://ahpnet.com/wrap>
- Free WRAP template (PDF):
https://namirockland.org/wp-content/uploads/sites/344/2023/11/blank_wrap_forms_with_mc_permission.pdf
- Free WRAP worksheet: <https://psychology.com/tools/wellness-recovery-plan>

Section #3: Communication Strategies and Self-Advocacy

Preparing for Visits

- Make sure to call to confirm, reschedule, or cancel appointments
- Setting alarms and calendar reminders for appointments
- Items to bring to visits
 - Snacks
 - Stimmies/stim toys
 - Your medical information (including WRAP and care plan, emergency contacts)
 - Communication devices or visuals (for those using alternative communication methods)
 - Your medicine (if requested)
 - State ID or driver's license
 - Insurance Card
 - Optional, but helpful: support person(s)

Scripts or Phrases to Use During Your Medical Visits

- Autistic Self-Advocacy Network provides a toolkit of questions and things to ask during your appointment, along with ways to prepare for your doctor visits
 - Link:
<https://autisticadvocacy.org/2026/02/self-advocacy-for-autistic-adults-in-medical-settings-practical-tools-that-reduce-overwhelm/>
- Examples of what to ask for or to discuss during your medical visit
 - Discuss YOUR plans and goals for treatment with your doctor
 - Ask clarifying questions about your health (Ex. “Which medicine do I take for my anxiety? What are the side effects of the medicine I’m taking?”)
 - Give or deny consent to examine parts of you
 - Can you record the conversation for note taking, or provide detailed, clear notes after visit?

Scripts or Phrases to Use During Your Medical Visits

- More phrase or prompts to use
 - "I take things very literally. If you mean a specific action, please tell me the direct step rather than using figures of speech."
 - "The environment in here is a bit overwhelming for my senses right now. May I wear my noise-canceling headphones / sunglasses, or turn down the overhead light?"
 - "I am starting to feel overwhelmed or shut down. Can we take a two-minute pause in silence so I can reset?"

Scripts or Phrases to Use During Your Medical Visits

- More phrase or prompts to use
 - "Could you please rephrase that or write down the main points? Spoken instructions are hard for me to remember right now."
 - "Before we do this examination, can you tell me exactly what you are going to do and what it will feel like?"
 - "Can we go through my concerns one at a time? Multitasking or jumping between topics makes it hard for me to track."
 - "I am neurodivergent (autistic / ADHD / sensory processing differences). Processing verbal information takes me a little extra time, so I appreciate your patience."
 - "If I have questions after I leave, is it okay to message through the patient portal rather than calling?"

Examples of Accommodations to Ask for During Doctor Visit

- Clear, detailed instructions
- Written notes and printed summary of today's visit and the next steps
- Speak one idea at a time, using universal, plain-language
- Ask for more time to process information
- Asking for step-by-step details on examinations or taking medication
- Needing time to relax before taking vitals
- Getting opportunity to communicate with doctor via online portal instead of phone

Navigating Conflict or dismissal, seeking second or multiple opinions

- Sometimes, you may disagree with the treatment plan or diagnosis, or you may experience discrimination and mistreatment. It's okay to go to another doctor or clinic to seek multiple opinions.
- Let your doctor know if they are saying something problematic about your disability, race, etc.
 - If you feel dismissed, calmly repeat your concern and ask for it to be documented.
 - Use direct statements such as:
 - "I do not feel my concern has been fully addressed."
 - "Can you explain the clinical reason for that decision?"
 - "Please note in my chart that I requested further evaluation."
- Have a support person with you to help advocate on your behalf

Navigating Conflict or dismissal, seeking second or multiple opinions

- If You Experience Mistreatment or Discrimination
 - Document what happened as soon as possible, including dates, times, names, and details.
 - Save copies of correspondence, medical records, and appointment summaries.
 - Request access to your medical records if you believe concerns were overlooked or inaccurately documented.
 - Seek a second opinion if you feel your symptoms are being dismissed.
 - Report discriminatory behavior through the clinic, hospital, health system, licensing board, or patient-relations office when appropriate.
 - Consider contacting a disability rights or patient advocacy organization for support.
 - Remember that seeking respectful, competent care is a reasonable expectation, not an unreasonable demand.

Navigating Conflict or dismissal, seeking second or multiple opinions

- Self-Advocacy Reminders
 - You are entitled to ask questions.
 - You are entitled to accommodations.
 - You are entitled to be treated with dignity and respect.
 - You are entitled to seek another provider if a clinician is not meeting your needs.
 - Your communication style does not make your symptoms or concerns less valid.

Telling Your Story

- Telling your story about your healthcare experience is powerful for you and others around you. Do not be afraid to share your story.
- Ways to share your healthcare experience
 - Blog, Vlog, Write Op-Ed or Letter to Editor, Social Media
 - Talk to, or write to, your local legislator about your healthcare experience and how they can make it better for you and fellow neurodivergent people
 - Post or speak your public comment on laws affecting healthcare for neurodivergent people

Section #4: Writing Your Care Navigation Plan

What is a Care Navigation Plan?

A **care navigation plan** is a personalized guide that helps a person get the supports and services they need. It helps organize important information about the person's strengths, goals, preferences, and support needs so that healthcare providers, caregivers, educators, and other supporters can work together more effectively.

What is a Care Navigation Plan for Neurodivergent People?

A care navigation plan is a personalized roadmap that helps neurodivergent people identify their health, support, and daily living needs—and how to access the right resources and accommodations.

It typically includes:

-  **My Profile:** Strengths, communication preferences, sensory needs, and what support looks like.
-  **My Goals:** Health, well-being, education, work, or independent living goals.
-  **My Supports:** Trusted people, professionals, and community resources.
-  **My Plan:** Steps to take, who to contact, and accommodations or tools that help.
-  **When Things Change:** Strategies for challenges, crisis support, and plan updates.

This plan empowers neurodivergent people to self-advocate, make informed choices, and get the support they need—on their own terms.

Alt-text: A person wearing glasses writes in a notebook labeled “Care Navigation Plan” with sections for My Profile, My Goals, My Supports, My Plan, and When Things Change. The desk has sticky notes with encouraging messages and a plant.

Image source: Original image created for illustrative purposes.



What is a Care Navigation Plan?

A care navigation plan may include:

- The person's strengths, interests, and preferences
- Communication and sensory needs
- Health, education, employment, or independent-living goals
- Important supports, services, and community resources
- Accommodations that help the person succeed
- Action steps and contact information for key supporters

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My Supports: Trusted people, professionals, and community resources.



My Plan: Steps to take, who to contact, and accommodations or tools that help.



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Image source: Original image created for illustrative purposes.



What Can You Put in Your Care Navigation Plan

- Core health priorities/information
- Medical summary (allergies, surgeries, medication, treatments, etc.)
- Questions to ask your provider or specialist
- Sensory regulation tools or ways to decompress during visits/stressful situations
- List of support persons
- Notes and scripts to say/give to providers

What Can You Put in Your Care Navigation Plan

- Care network (insurance information, primary care provider, medical team, support persons, emergency contacts)
- Appointment routines
- Problem-Solving plans and scripts
- Tracking progress, milestones, health reminders, etc.
- Blood Type
- Allergies (including food allergies/sensitivities)

WRAP and Care Navigation Plan Workshop

- If you want an e-copy go to the following links:

- WRAP Plan (Condensed Version):

<https://www.carepatron.com/files/WRAP-plan-template.pdf> or Five Key Concepts of WRAP

Worksheet:

https://www.idahorca.com/Five_Key_Concepts_to_Guide_Your_Path_to_Wellness.pdf

- Complete Care Plan/Care Navigation Plan

<https://www.cdc.gov/caregiving/media/pdfs/Complete-Care-Plan-Form-5081.pdf>

Reaching Out to T.J.

- Email T.J. at timotheus.tj.gordonjr@gmail.com (for anything, including booking me for presentations and speaking engagements) or tgordo7@uic.edu (for research and advocacy opportunities)
- Email T.J. at timotheus.tj.gordonjr@gmail.com for workshop slide deck copies
- Check out his works at
 - <https://linktr.ee/chidpocc>
 - <https://linktr.ee/timotheusgordonjr>
 - <https://linktr.ee/blackautist>

Resources

- [CAYR Connections](#) (has list of resources and “freebies”)
- [Illinois Department of Public Health Advanced Directives](#)
 - Includes links to Declaration of Mental Health Treatment Form, Living Will, Practitioner Orders For Life-Sustaining Treatment, and Power of Attorney for Health Care forms
- [Resource Roundup: Neurodiversity & Mental Health](#)
- [Championing Intersectional Advocacy for Neurodivergent and Disabled Communities](#)

Resources

- [Discerning Autism Resources Using the Models of Disability Framework](#)
- [Neuro-Affirming Communication Supports Across the Lifespan: Creating Access, Not Conformity](#)
- [Therapist Neurodiversity Collective®](#)
- [All Brains Belong VT \(Neuroinclusive Healthcare Education Hub\)](#)
- [Neuro-affirming Practice Resources](#)

Resources

- [Neurodiverse Connection Resources Library](#)
- [Neurodivergent Insights](#)
- [Autistic and ADHD Affirming Resources](#)
- [Divergent Futures Neurodiversity-Affirming Resources](#)
- [NeuroQueer Recommended Resources and References for Neurodiverse Patients](#)

Resources

- [Illinois Department of Human Services Neurodivergent Disorder Resources](#)
- [The Arc of Illinois](#)
- [Illinois LEND](#)
- [The Institute on Disability and Human Development](#)
- [Rush University Resources for Adults with Autism](#)
- [Illinois DocAssist \(Neurodiversity\)](#)

Resources

- [Autistic Self-Advocacy Network resources](#)
- [Autistic Women & Non-Binary Network resources](#)
- [Neurobloom: Neurodivergent-Affirming Therapy in Chicago](#)
- [Positive Regard Therapy](#)
- [Finding BIPOC Therapy: A Resource for People of Color Seeking Care](#)
- [Vivient Health](#)

Resources

- [Brave Space Alliance](#)
- [Affinity](#)
- [Center of Halsted](#)
- [Invisible to Invincible](#)
- [Life is Work Resource Center](#)
- [Taskforce Chicago](#)
- [Speak Des Plaines LGBTQIA+ Resources](#)
- [Mental & Behavioral Health Services for LGBTQ+ Patients](#)
- [Howard Brown Health](#)

Resources

- [My WRAP Plan](#)
- [Five Key Concepts of WRAP Workbook](#)
- [WRAP Plan Template](#)
- [Complete Care Plan](#)
- [Person Centered Plan Template](#)

- PDF Version:

<https://acrobat.adobe.com/id/urn:aaid:sc:US:0cac124d-dc4e-497b-8100-b10d50eebe45>

Resources

- [Plain Language COVID-19 Information](#)
- [A Self-Advocate's Guide to Managed Long-Term Supports and Services](#)
- [Making the Most of Medicaid: a Medicaid 1115 Waiver Advocacy Toolkit](#)
- [Accessing Home and Community-Based Services: A Guide for Self Advocates](#)
- [Tools for Autistic Adults and Healthcare Providers](#)
- [Real Talk: Improving Quality of Sexual Health Care for Patients with Disabilities](#)
- [Take Charge! A Reproductive Health Guide for Women with Disabilities](#)

Resources

- SARTAC Resource Library (Plain-Language)
 - [Mental Health Resources](#)
 - [Health Resources](#)
- [Health Care for Adults with Intellectual and Developmental Disabilities \(Toolkit\)](#)
- [Healthcare Toolkit for Patients & Supporters](#)
- [Autistic Self Advocacy Network Resource Library](#)
- [National Roadmap for Disability-Inclusive Healthcare](#)
- [Improving Access to Care for People with Disabilities \(CMS.gov\)](#)
- [Online Patient Education Tools](#)

Resources

- [Getting the Care You Need – A Guide for People with Disabilities](#)
- [Healthcare disability accommodations and Long COVID](#)
- [Advice from People with Disabilities on Providing Quality Health Care: What Health Care Providers Really Need to Know](#)
- [Guide to Disability For Healthcare Insurance Marketplace Navigators](#)

Resources

- [Health Care for Adults with Intellectual and Developmental Disabilities \(Toolkit\)](#)
- [ASAN Health Self-Advocacy Tools](#)
- [Accessible Healthcare for People with Disabilities: An Implementation Guide for Healthcare Organizations](#)
- [T.J.'s List of Neurodivergent Healthcare Resources](#); this includes WRAP plan workbook
(Note: some resources are generated by CoPilot; with any information, ALWAYS check your sources)