



Westchester Institute
for Human Development

<https://www.wihd.org>

Welcome!

Community Support Network Transition Institute 2022

What I've learned so far...

My journey of self-advocacy and Independent living

By Hannah Badain

hannah.badain@gmail.com

Member of the WIHD Speakers Network



Self-Advocate? Is that me?



I am just trying to live my life to the fullest.

Taking charge of my future

A few years ago I found myself ready to create a vision for my life. I had graduated from college, had a job I loved, an amazing service dog and yet I felt that I was struggling to stay afloat. I wanted to keep going but needed more support.





Taking charge of my future

I hit a major roadblock

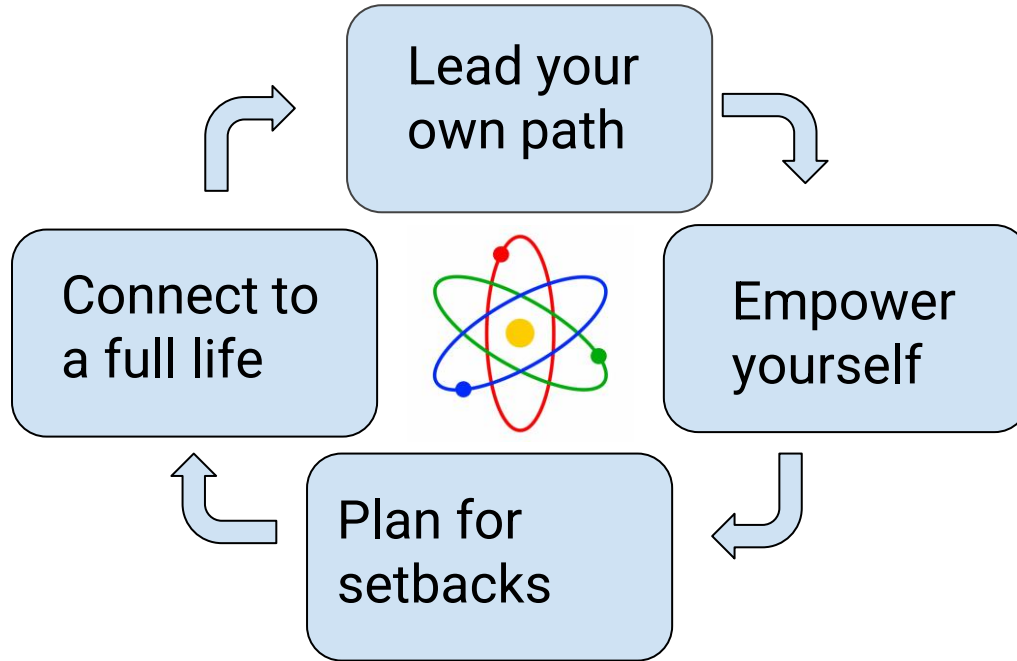
My application to OPWDD was denied and I was sent to the “nebulous world of the second step review”



DENIED



My Self-Advocacy skills



Lead your own path



Be the architect of your path: Own your actions



Explore for yourself what services/supports can do for you



Take charge of the conversation about the services/supports you need to be successful





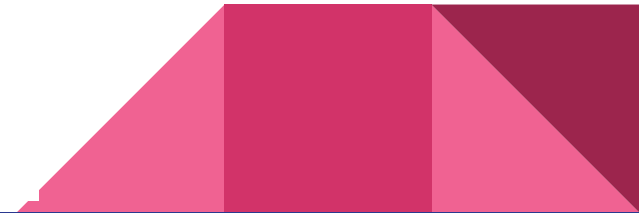
Be comfortable with
your needs, they don't
make you more
disabled.



Empower yourself



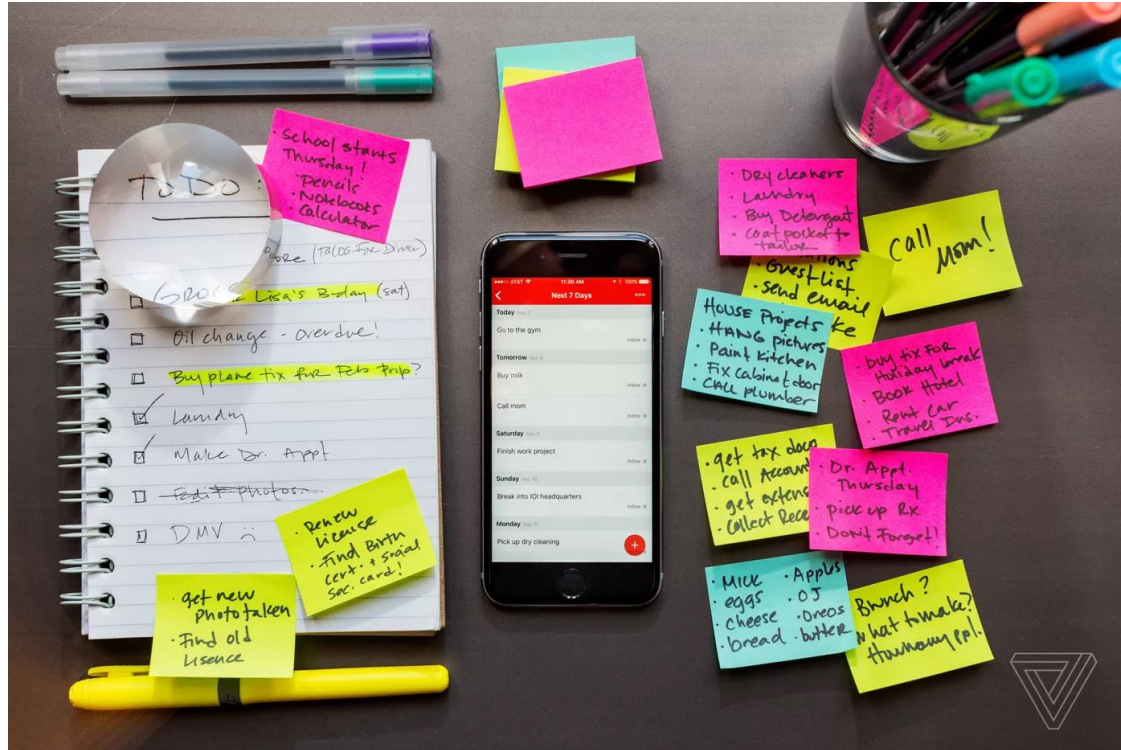
Be a gatherer of information!
Keep an open mind.



Flip your disability skills upside down and learn to use them to your advantage



Don't stay still - keep moving



Plan for setbacks

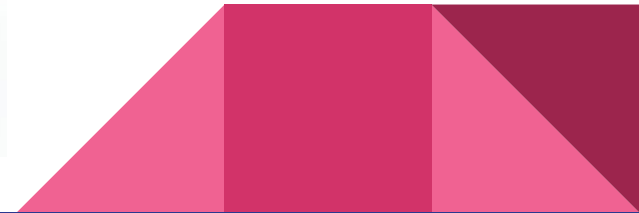


It is ok if you sometimes want to give up,
make a plan on how to move forward

Progress is never a straight line



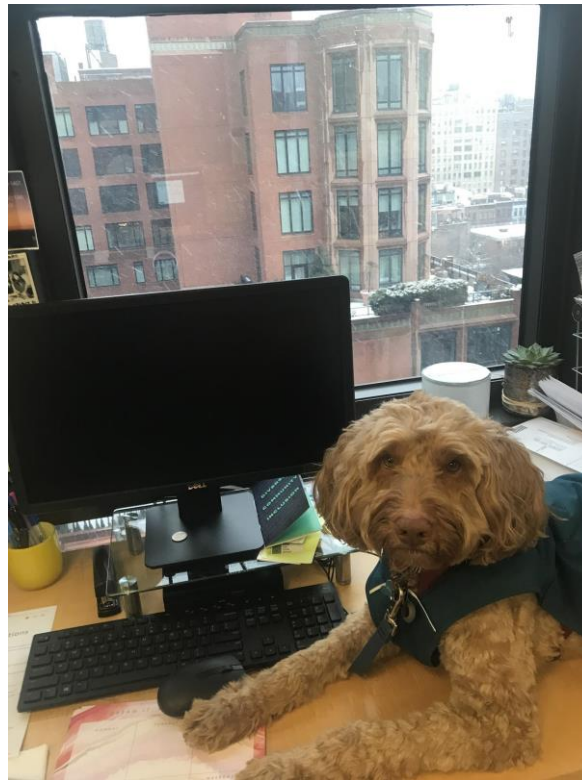
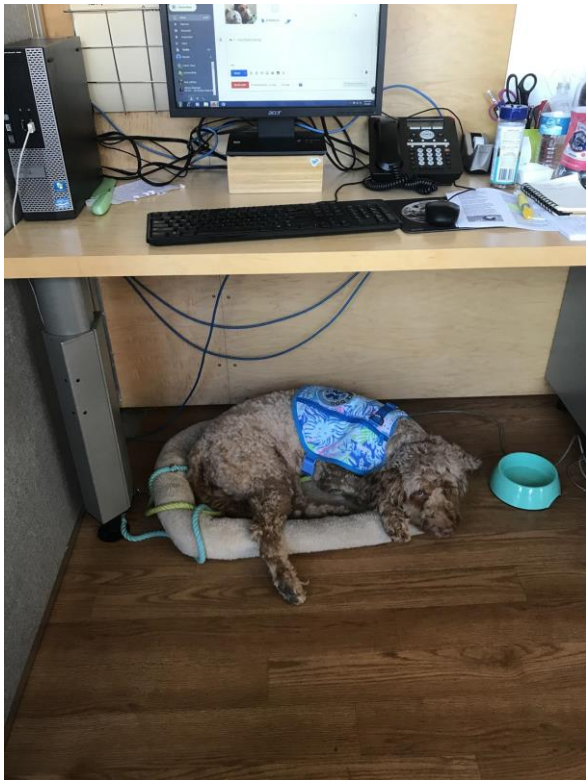
The path to progress can be bumpy, find ways to work around them




Connect to a full life



Find people that “get it”



Find your tribe in life

 Connect to a full life



Take risks: you might like the results



Don't be so hard on yourself, everyone makes mistakes.



Seek out connections all around you



and finally...



OPWDD ELIGIBILITY!!!





**Any questions
so far?**



NOW WHAT?




Making services work for my life



Started receiving services 8 months ago




Care Manager


- A care manager is the person who helps you translate the support that you need into services/supports approved by OPWDD.
 - They know the OPWDD and Medicaid language, terminology and forms to fill out to get things done.
 - They make sure your paperwork is properly filled out and submitted wherever is needed.
 - The relationship between you and your care Manager should feel like a partnership.
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Care Manager

When it works:

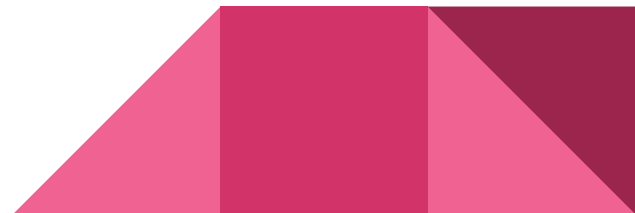
- Communication feels natural and candid between you and your care manager
 - Your concerns and questions are validated and listened to by your care manager
 - You trust your care manager's expertise on OPWDD services and supports
 - You feel part of a team
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Circle of Support


- A circle of support is a group of people that you trust. They understand your goals and want to empower you to achieve them.
 - Your circle of support is unique to you and you should not feel pressure to include anyone in particular.
 - Every person in your circle of trust should bring a specific skill that will help you move forward.
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Life Plan goals

- A life plan is a document that reflects the person's wants, needs and goals
- It should give an overview of the supports and services the person has and how they are working to help the person achieve goals.
- It should also provide updates on the whole person.



A personal connection to your Life Plan


- Your life plan becomes a reflection of where you are in your life and your wishes for your near future.
 - It should feel very personal and tailored to your needs and wants.
 - Even though several people have input into your life plan, it should still feel like you wrote it yourself.
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Working with community habilitation staff


- Finding people that work well with you can be a trying process
- Everyone talks about a staffing shortage, yet you need help now. Have a plan to let others know you need staff.
- Remain hopeful, there are good people working in this field.
- Know the qualities you need in a direct care provider. You should feel comfortable around them and having them in your home.



Be willing to jump in and help the process.

- Some of this process is tedious busy work, it will involve lots of phone calls, emails and follow up communications.
 - If something matters to you, don't be afraid to jump in and do some of the work.
 - Be number 1 on your priority list.
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Become an informed consumer

- Remember that no one has all the information.
 - Ask lots of questions and keep a journal of the information you find.
 - Do your research and use any trainings that might benefit your situation.
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Life moving
forward...



Case Studies

Learning to establish healthy boundaries:

The housekeeper story



What is going on in my mind?

What can't this be easier?

It is hard to find new staff

I have to be flexible

I don't want to have an argument

What if this never gets better?

I have to speak up!

This is affecting my quality of life

Who should I reach out to for help?

What is the next person in worse?



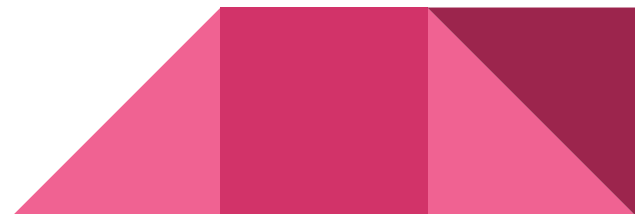
How should I move forward?



Case Studies

Learning to establish healthy boundaries:

**My Care Manager: When is
it time to move on?**



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How should I move forward?





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Resources

[Adaptive sport, recreation & adventures in Utah - National Ability Center \(discovernac.org\)](https://discovernac.org)

[Psychiatric Service Dog Partners: Guidance, Info, & Support \(psychdogpartners.org\)](https://psychdogpartners.org)

[Lifespire](#)

[HeartShare Human Services of New York | Homepage](#)

YAI workshops

[Free Workshops | YAI](#)

[SLMS - New York Statewide Learning Management System - NY.gov](#)

