SELF DIRECTION – a Powerful Complement to Community Living



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At HOPE NC Summit – November 8, 2026

What we will cover today

What is Self Direction?

Mechanics of how it works

Personal stories

Our Coalition

Q&A

WHAT IT MEANS

Self Direction, in plain English

- Self direction is considered a “service delivery model”; it is not a service.
- People who self-direct their Medicaid Waiver services take **more direct responsibility** for how certain authorized supports are delivered. With that also comes **more choice**. **And many benefits.**
- People who self-direct can have help making decisions and managing services.
- 522 individuals using Innovations Waiver in NC currently self-direct as an Employer of Record
- 40 States have self direction options for people with IDD.

HOW BEAUTIFUL IT CAN BE!

Start with the life, not the service or agency

Friends. Work. Belonging.

Choice. Community. A place to call home.

Moving from theory to reality.



What if you had more say?

WHO provides support?

WHEN does support happen?

HOW can support fit the person?

HOW can the person continue to learn and grow in their life?



What if this could happen?

YOU or your LOVED ONE had stable, long-term staff with few needs to fill-in ?

CHANGES to the short-run goals and daily tasks could be quickly made by you?

STAFF were well paid and incentivized?



Some basics of how Self Direction works in NC

First steps:

1. Talk with your Care Manager about Individual and Family Directed Services (IFDS = self direction).
2. There are certain choices they will discuss with you.
    - Which services to self direct?
    - **Employer of Record** or Agency with Choice (hybrid)
3. Eligibility: Person can live on their own or in family home (or group home in some cases.)

Once you are ready, these happen once:

- ✔ Care Manager will send you simple paperwork to enroll
- ✔ Person receiving services becomes either Employee of Record (EOR) or has an EOR Representative (usually a parent)
- ✔ You will receive training
- ✔ You will select a Community Navigator
- ✔ You will select an FSA agency (two choices) that manages payroll, workers comp insurance, and other things including billing the MCO
- ✔ Create a Job Description for the DSPs, build a staff or transfer existing.

These happen regularly:

- ✔ Annually:
  - ISP plan development with a team, like before; **Budget meeting** with Comm. Navigator
  - **You** create the Short Range Goals, and daily tasks;
  - Annual Review (audit) s done by the MCO.
- ✔ Quarterly: submit some documentation to the Care Manager
- ✔ Monthly: visit each staff
- ✔ Twice monthly: approve time sheets online
- ✔ As needed:
  - Create staff schedules; updates SRG's;
  - Hire, terminate, train and/or purchase training for staff

ILLUSTRATIVE EXAMPLE

A week shaped around a real person

Monday: Support at work

Tuesday: Community activities

Wednesday: Time with friends

Thursday: Learning daily living skills

Friday: Doctor or dentist

A schedule that fits the person

And next week may be entirely different!



The heart of how Self Direction is different:

Because you create goals and tasks, you can be more **responsive and nimble** to benefit the person receiving the services.

Because you hire directly, you build a **direct relationship** with staff.

Because there is no Provider Agency, there can be **Accrual of Funds:**

- To allow for *higher overall compensation* for staff, and other perks that create l**ong-term staff stability**.
- YOU decide, within established policy and law.



YES IT'S WORTH IT!

Real people and their choices. Different positive outcomes.

DEMI ECKHOFF

JANIE DESMOND

ADAM STROM

BEN HOLLAND



Individual experiences of self direction, with permission.

Janie’s experience

The Gasoline Debacle

The Voting Packet Dilemma

This is how I do it Mom/Housemate/Staff

I can’t bowl those strikes!

growth and maturity, commitments, self confidence,

agency over health.



Adam’s experience

How profound is the impact of paying competitive wages?

At Cambridge Village of Apex since 2019 working 20 hours per week at > than minimum wage.

15 years same staff

Stability > dependability

SSDI on own record. Medicare eligible.

ABLE account

Employee of the Month recently!





Ben's experience: "I am convinced that self-directing let me save my son from institutionalization"

a.



Jeff's son's experience

1. Ben's very difficult behavior at family home
2. Moved to own place
3. Dad hired/trained staff to be:
   a. specific
   b. consistent
4. No evictions

Success!

BE PREPARED

More choice and funding comes with responsibility

…For the workers (recruitment, etc)

…Documentation

…Health and safety planning

…Communication with the support team

…Thinking beyond our lifetimes

PEOPLE WHO CAN HELP

You do not have to do it alone

Your care manager

A Community Navigator

Financial support services

Trusted family and supporters

Other self-directing families



What keeps more people from self-directing?

The Self-Direction Coalition of NC

A COMMUNITY OF FAMILIES & ADVOCATES

Learn from one another.

Connect with experienced families.

Advocate for greater access and flexibility.

In person and online opportunities.

http://selfdirectionnc.org



OUR COLLECTIVE VOICE

Help make the system work better

Clearer and consistent information

Less administrative complexity

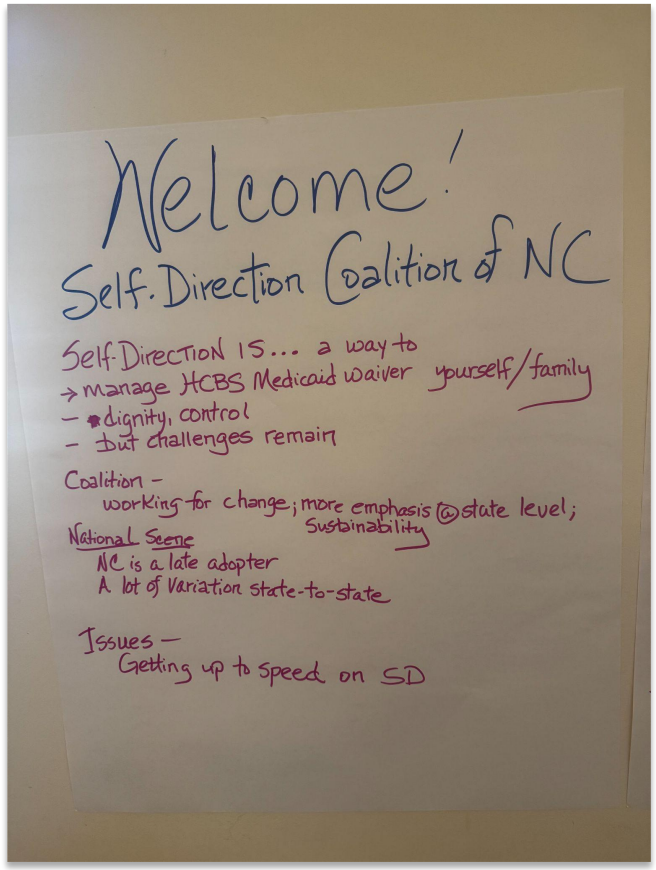
More practical flexibility

Meaningful input from/to people

Discover best practices outside of NC

Improve sustainability

http://selfdirectionnc.org



YOUR NEXT MOVE

One step can open a door

Ask about self-direction.

Connect with others who have done it.

Help shape a more accessible Innovations Waiver.

http://selfdirectionnc.org

Our CONFERENCE is April 22, 2027

Join us!



KEEP THE CONVERSATION GOING

Questions?

What would your family member like more control over?

What questions would help you decide whether self-direction is a good fit?

Contact me at: betsymacmichael@pm.me or Chair@selfdirectionnc.org