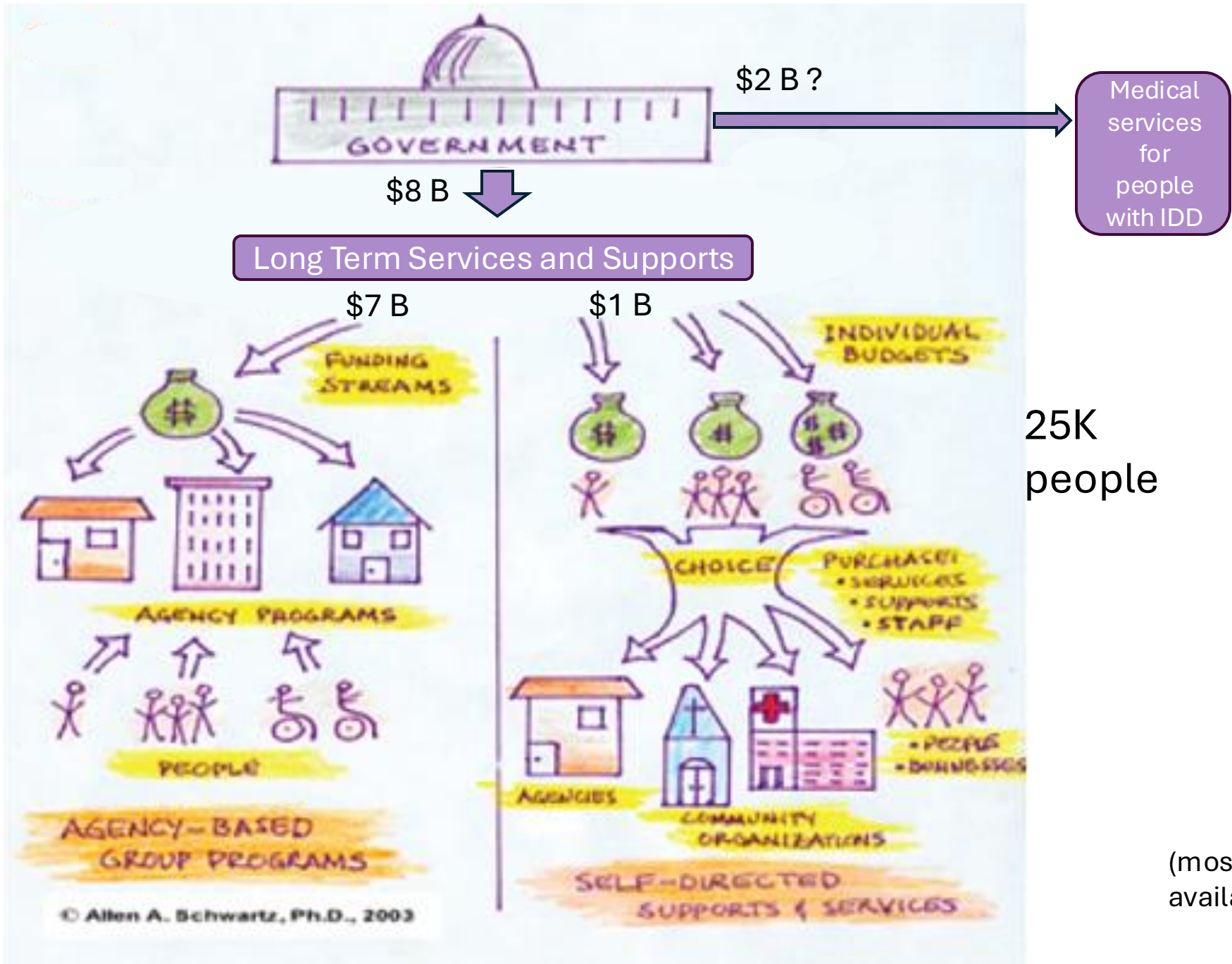


Self-Direction and Whole Person

Brad Pivar and Jim Karpe

Oct 2, 2024

2022 How the Money Flows



100K
people

25K
people

(most recent figures
available: 2022)

Self-Direction produces better health and well-being

- 2007- **Fewer unmet needs**

“[self-directing] treatment group members were much less likely than control group members to report unmet needs, and much more likely to report high satisfaction with their paid care.”

From [Effects of Cash and Counseling on Personal Care and Well-Being](#) Cash and Counseling was “a consumer-directed care program providing a cash-like benefit within the constraints of Medicaid's service delivery model”.

- 2018- **Better health**

“Individuals participating in self-directed programs have consistently demonstrated improved physical and mental health ([Caldwell & Heller, 2007](#); [Gross et al., 2013](#); [Heller, Arnold, van Heumen, McBride, & Factor, 2012](#); [Matthias & Benjamin, 2008](#)).”

From [Implementation of Self-Directed Supports for People With Intellectual and Developmental Disabilities in the United States](#)

- 2022- **Satisfaction**

“personalized budget users tend to benefit in terms of well-being and service satisfaction outcomes”

From [The Effects and Costs of Personalized Budgets for People with Disabilities: A Systematic Review](#)

What Do We Mean By: Whole Person Supports in Self-Direction

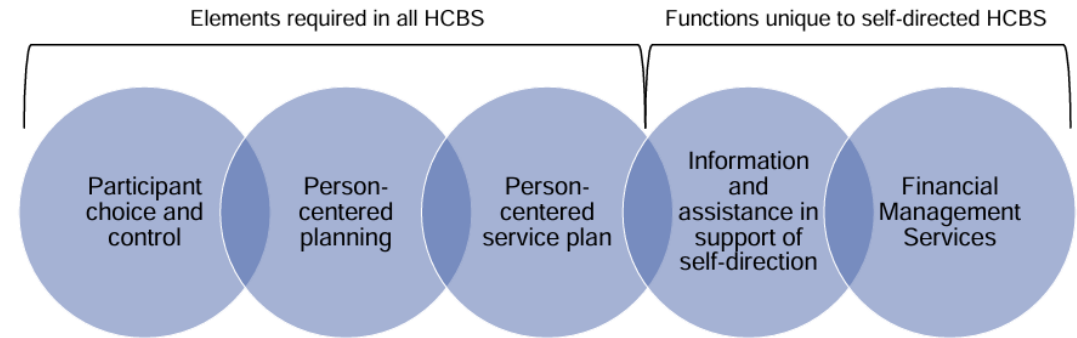
- WPS-SD fits the definition of the CWPS – it means person-centered services to support people with the what/when/where they need over the changing needs of a lifetime.*
- Self-Directed services and supports should be available to anyone who wants them.*
- Self-Directed services and supports should be able to adapt to the changing participation of the COS.* Unfortunately, for many individuals, self-direction is not a lifeplan – it's a half-life plan, which only lasts until the parents are gone.

* Fixing this requires removal of current barriers related to acuity of disability, availability of financial resources, and weakness of natural supports.

Self-Direction Is

- Person-centered service delivery
- Based on Personal Agency and Freedom of Choice with Full Budget Authority
- Individualized budgets that are acuity based “Money follows the person”
- Flexibility to purchase services
- A way to support people in the most integrated setting that works for them
- Available to and suitable for all who wish to use it, including those who need support 24/7
- A way to expand capacity, including expanding the work force

Key Components of Self-Direction

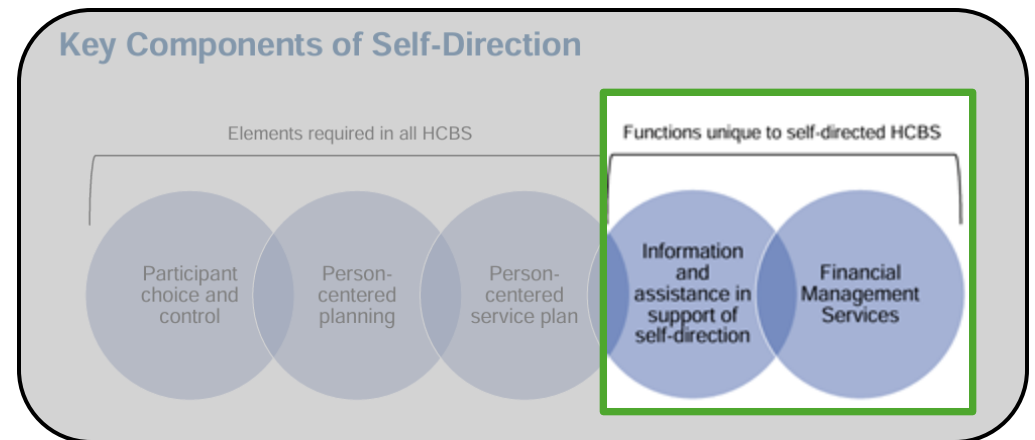


From:

www.medicaid.gov/home-community-based-services/downloads/undrstnd-bdgt-athry-slf-drcted-hcbs-may-2024.pdf

What does WPS-SD look like?

Changes in Support of Self-Direction



- Supports currently handled by multiple entities (Fiscal Intermediary, Care Manager and Support broker) would instead be managed by each prototype provider.
 - Improve communication
 - Improve efficiency
 - Facilitate measuring performance and governmental oversight
- Prototype participants would have full budget authority.
- Each participant will select from a menu of options which includes all existing services and supports, and additions:
 - administrative supports, such as staff hiring & training, approval of staff billing, expense submission. See appendix for longer list.
 - services, such as Home Enabling Supports, emergency staff, behavioral supports.
 - services suited to the person's changing needs including, but not limited to
 - Transition to non-certified residence
 - Aging, of the participant and their parents

Simplified Benefit for Children*

- Most children are in school up to 8 hours a day.*
- Exactly the same qualifications must be met, to get either
 - full SD
 - or this streamlined cash benefit to be used as the family sees fit.
- Currently admin costs are excessive—likely approaching 50 cents of each dollar.*
- NYS must determine how much SED needs to step up, and how much needs to be supplemented by OPWDD and other agencies.

* of course one-size does not fit all, so full SD should still be an available option at any age.

Enhanced Supports for people living with their family

Allow aging parents to continue to support their adult child.
Start with:

- Live-in Caregiver
- Paid Neighbor
- Home Enabling Supports
- Home maintenance

Wraparound Services

Providers have already succeeded in transitioning individuals **from** Supervised IRAs and the CRO list **to** non-certified residences **with** innovative services and supports.

The innovations include some items which are currently not reimbursed:

- A cold-call line
- On-call staff
- Scheduling and transportation for health-care appointments
- Home maintenance support

A Whole Person Self-Direction Prototype

OPWDD should fund one or more prototype providers in each of several locations.

- **Step one** – A multi-stakeholder design and oversight team to
 - finalize program details,
 - determine goals and measurements,
 - participate in process to select prototype providers,
 - review and modify program,
 - determine outcomes to be used for value-based rewards
- **Step two** – Where possible, allow current services that are limited by type of residence to be used across all types. For example:
 - Home Enabling Services to support individuals in certified residences
 - Live-In Caregiver and Paid Neighbor for an individual living with parent
- **Step Three** – Prototype Providers will deliver new services after asking:
 - People on CRO or in a residence, if they wish to move to a non-certified setting
 - People living with aged parents, if they want to stay there with additional supports
 - Parents of children, if they want to try out a simplified benefit

Validating the Enhanced Self-Direction Prototype

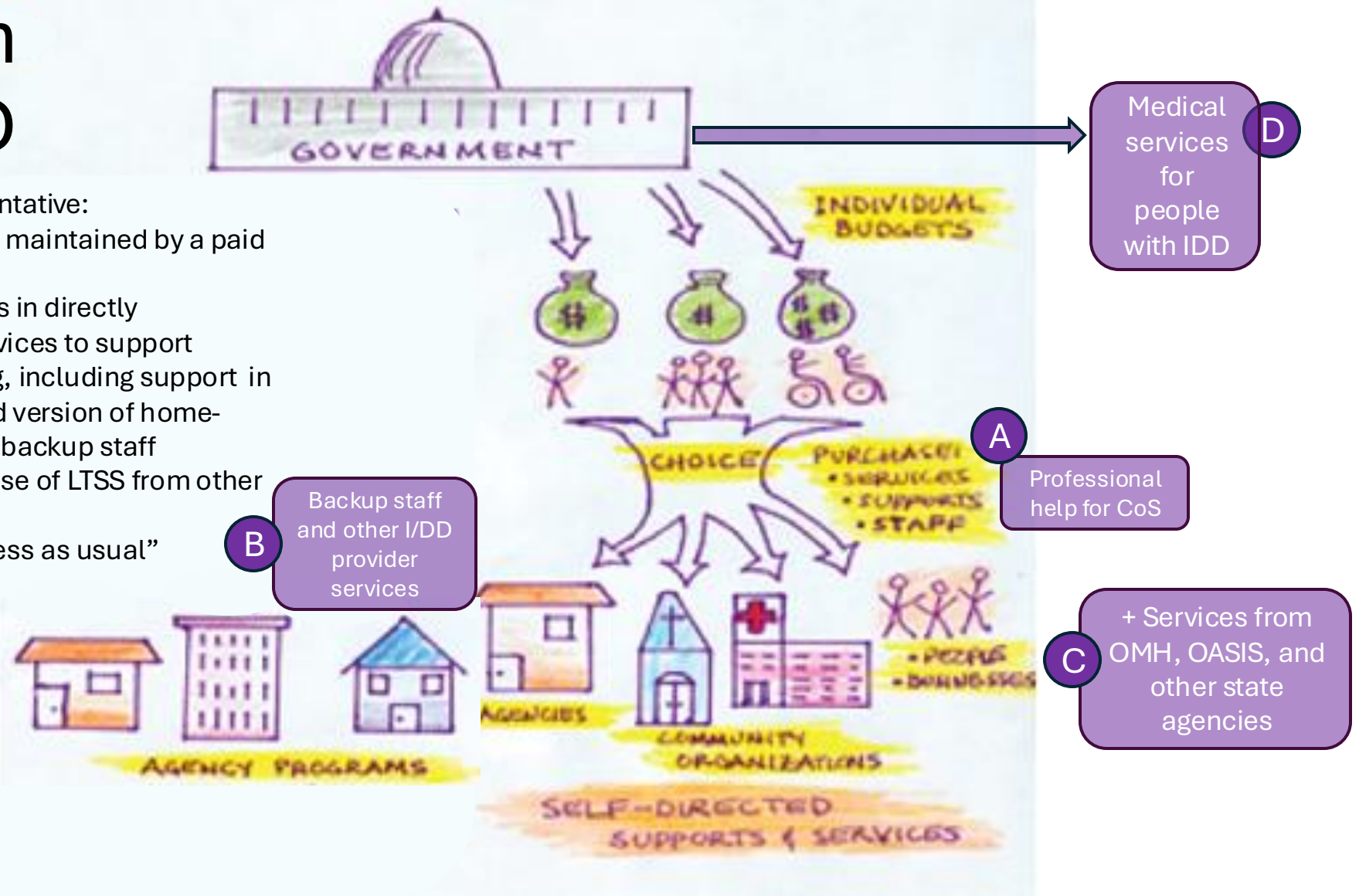
- Numbers– evaluate costs and outcomes.
- Children are 50% of self-direction today– how many will be better served by a reduced benefit that is simpler?
- Sustainability, exploring multiple options including
 - What are the costs to replace the Circle of Support with professionals?
 - Costs of professional facilitation to recruit new members into the CoS as parents age?
 - Can unpaid supports be maintained through relationships with
 - mission-driven groups such as religious communities
 - other naturally-occurring ‘communities of caring’ such as veterans
 - senior oriented communities?

Enhanced Self-Direction will have a Positive Impact on Traditional Services

- Self-Direction already includes some of the difficult-to-implement elements of whole-person supports:
 - Individualized budgets based on service needs
 - Money follows the person
 - Person-centered service deliverymaking it an easier pathway to validate a whole-person system.
- Providers of Certified Residences will be able to concentrate on Staffing issues and service needs of a more complex and aging population, as the prototype expands housing options for those people who want to
 - move to non-certified housing, or
 - stay longer in the family home.

Whole Person Supports - SD

- A. Options for Designated Representative:
 - Personal Support Network maintained by a paid professional
 - Provider organization steps in directly
- B. Easier access to all provider services to support individual in their desired setting, including support in their home through an enhanced version of home-enabling supports that includes backup staff
- C. Enhanced budget allows purchase of LTSS from other agencies, when needed
- D. Medical services remain "business as usual"



In Closing

Let's seek opportunities for immediate action

- Doing nothing is not an option
- Instead let's prototype new models

Traditional providers and Self-Direction have much in common

- Improving Self-direction isn't new: Enhanced Brokers, Housing Navigators
- Traditional Providers already transition individuals into non-certified housing and continue to support them



Q&A

Appendix

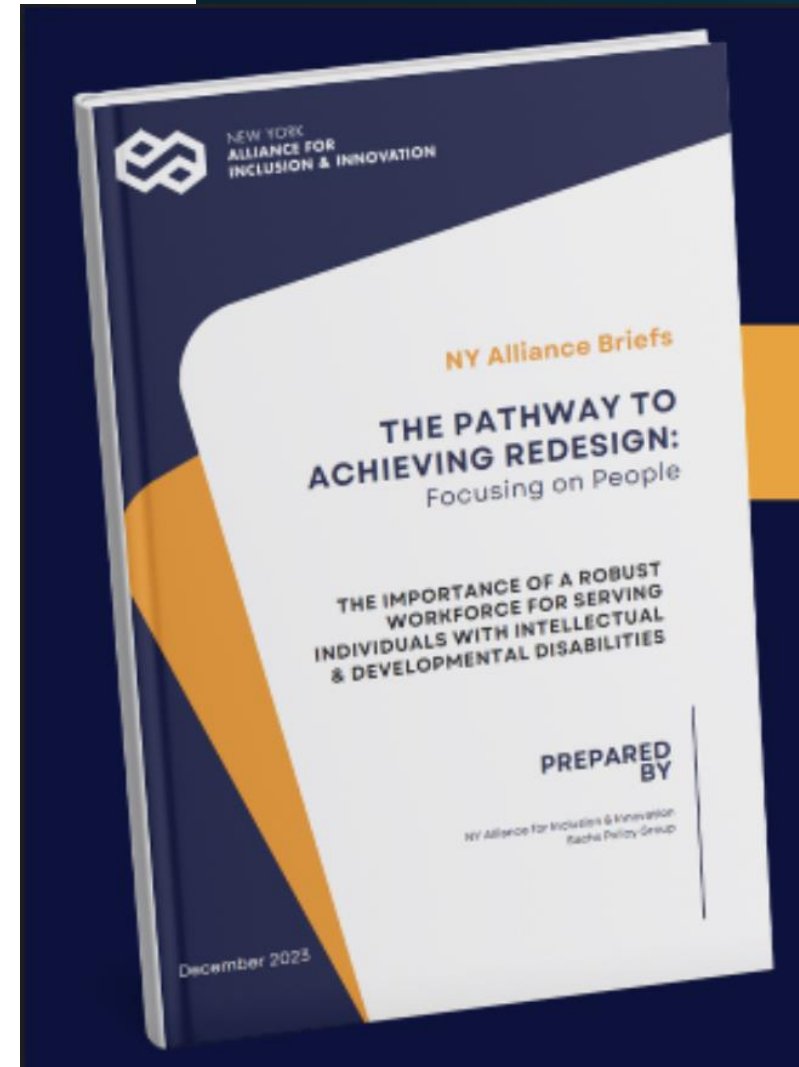
Additional Administrative supports

- Money Management
 - assist with budget decisions, setting wages, paying bills
- Health and Safety
 - monitor and address medications, preventative and emergency care including transportation, diet and exercise
- Staffing Supports
 - recruit, onboard, train, schedule
- Residential Admin supports
 - arrange routine maintenance, deal with urgent issues such as flooding, arrange repairs

Whole Person Supports – Self-Direction

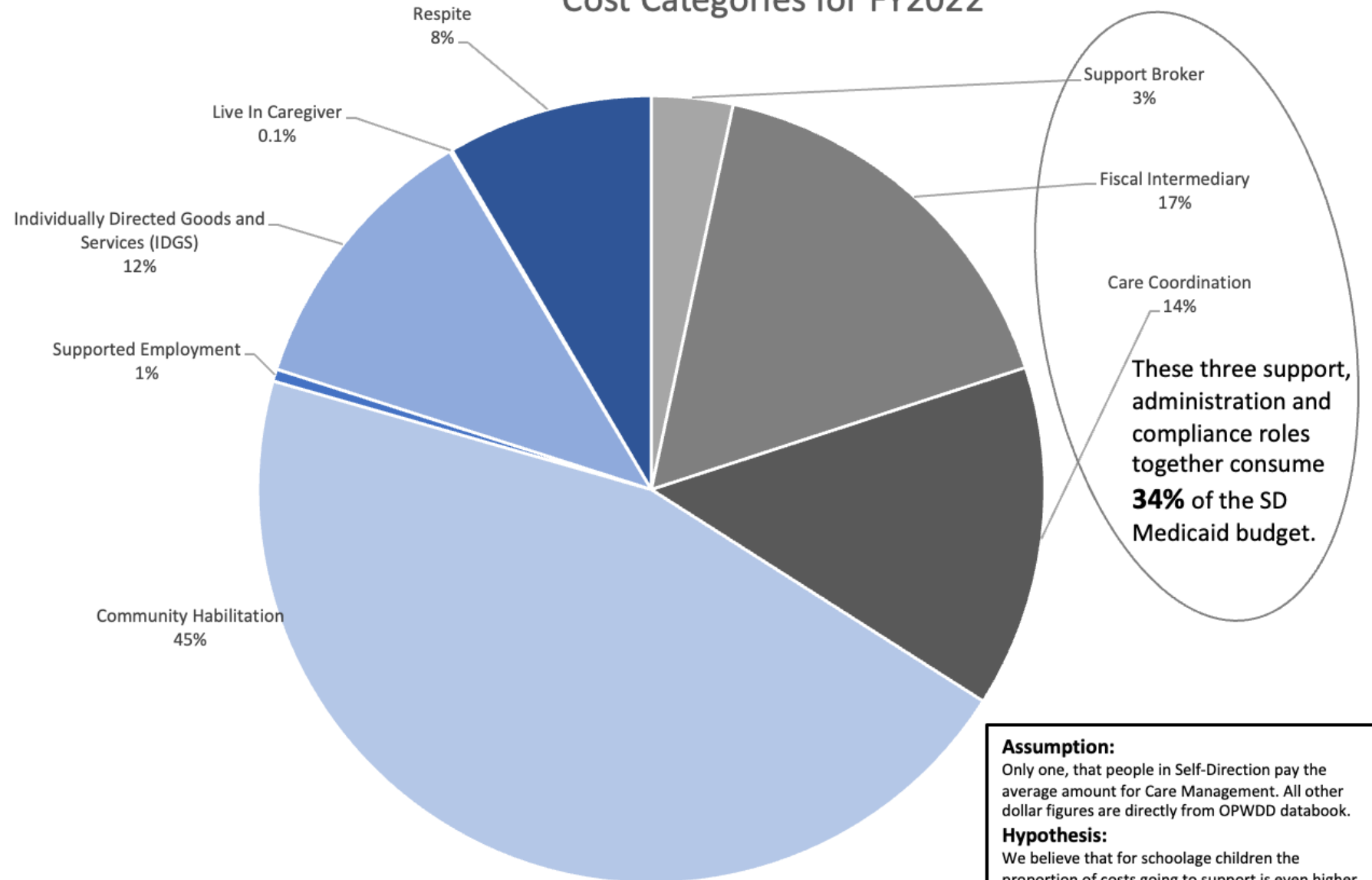
Aligns with recent NY Alliance recommendation that:

- “OPWDD should quickly invest resources in exploring models that rely more on individual’s self-determination and technological assistance...”



Average Costs

Self-Direction Cost Categories for FY2022



Assumption:
Only one, that people in Self-Direction pay the average amount for Care Management. All other dollar figures are directly from OPWDD databook.

Hypothesis:
We believe that for schoolage children the proportion of costs going to support is even higher, approaching 50%. And therefore the proportion for adults is closer to 20%. However, NYS has not yet supplied data in form that allows this to be verified.