



Steering Group for Whole Person Supports

4/1/25

Facilitated by Sachs Policy Group

Meeting Agenda

- Recap of origin, goals & principles of Whole Person Supports
- Recap “case for change” <http://wholepersonsupports.org>
- Membership of Steering Group & introductions
- Functions and role of 3 groups (Advisory, Input, Steering)
- Getting the work done: operating principles, logistics
- Timeline
- Next Steps

The Case for Change

1. **Between 2020-2022, OPWDD spent 5% less per individual served in the waiver.**
2. **The number of people estimated to need I/DD services is nearly 100K more than those currently served.**
3. **Numerous studies show inadequate access to mental health, dental, and physical healthcare services for PWIDD.**
4. **There has been a 7.5% increase in demand for supports for individuals with Autism (ASD) per year for 5 years.**
5. **People in the OPWDD system over the age of 60 years old has grown by 13.5% in the last 5 years.**
6. **Hundreds of individuals with I/DD and complex needs are stuck in hospital beds, shelters, or other institutions each year because their needs cannot be adequately met for a return to community setting (average of 113 days).**
7. **Nearly 50% of individuals with I/DD have a co-occurring mental health condition.**
8. **There continue to be workforce shortages (do I really need to prove this to you? – you have the data!)**
9. **The number of people under 21 needing I/DD services is growing 40% faster than over 21.**

[1115 waiver estimates of “look alikes”](#)

[Health Service Utilization for I/DD Individuals.](#)

[Unmet Service Need](#) for I/DD individuals.

I/DD Individuals as a [medically underserved population](#)

[HANYS survey](#) from 50 hospitals cited 66 cases in one quarter during 2022.

https://legacy.nationalcoreindicators.org/upload/core-indicators/NCI_DualDiagnosisBrief_Oct072019.pdf

<https://cpstate.org/wp-content/uploads/2022/10/At-the-Crossroads-MH-Policy-Paper-2022-Final.pdf>

Goal of Whole Person Supports & Groups

Create a forum for the open sharing of ideas that result in the discovery and advancement of better models of support for people with I/DD that are more flexible, timely, person-centered, holistic, and sustainable and for the system that supports individuals with I/DD.

Principles of Whole Person Supports

- **Achieve Full Equity and Better Outcomes**
 - Strive for full equity in health, mental health, and life outcomes for individuals with I/DD.
 - Ensure that better outcomes for people with I/DD remain a primary goal of any new systems or supports.
- **Inclusive and Collaborative Approach**
 - Involve individuals with I/DD and their families in all conversations, ensuring their voices are heard and valued.
 - Seek input and collaboration from self-advocates, families, direct support professionals, the state, service coordinators, and other interested parties.
- **Accessible and Coordinated Services**
 - Create changes that simplify access to services, making them more navigable for all stakeholders.
 - Strive for a system that coordinates the full array of necessary services and supports.
- **Flexibility, Choice, and Innovation in Support Models**
 - Seek and implement innovative and flexible provider-led models of support that allow for self-direction and individual and family input.
 - Ensure the system can scale successful pilot programs quickly.
 - When modifying or changing existing systems or supports, ensure that individuals and families have the choice to keep the services they currently have.
- **Sustainable and Flexible Financing**
 - Develop a financing system that allows for flexibility in service delivery while ensuring provider sustainability.
 - The system must result in maintaining or improving current service levels for individuals and families.

Membership of Advisory Group - 22

Name	Affiliation	County
Amy Barker	Provider	New York
Ann Scherff	Family Member	Genesee County
Bin Feng	Family Member	Queens
BJ Stasio	Self-Advocate	Western NY
Cris Marchionne	Provider	Richmond
Danielle Lanzetta	Self-Advocate	New York
Elizabeth Martin	Provider	Albany
Eunice Beck	Family Member	Kings
Heather Burroughs	Family Member	New York
Jill Gentile	Provider	Westchester, Rockland, Orange, All 5 Boroughs
Joanne Siegal	Provider	New York (Bronx)
Katy Faivre	Family Member	N/A
Lisa Meyer Fertal	Provider	Suffolk
Matt Hofele	Self Advocate	Suffolk
Max Donatello	Family Member	Western
Meri Krassner	Family Member	New York
Miriam Franco	Family Member	Manhattan
Renee Filip	Family Member	Western
Ronald Colavito	Provider	Pike County PA
Roy Probeyahn	Family Member	Suffolk
Shameka Andrews	Self-Advocate	Capital Region
Steve Gonyea	Family Member	Oneida

Membership of Input Group - 25

Name	Affiliation	County
Anne Ormiston	Family Member	Monroe
Austin Rynne	Provider	Ulster
Chris Palega	Family Member	Monroe
Cris Donovan	Provider	Tompkins
Deborah Peeters	Family Member	NY
Diane Marrone	N/A	Suffolk
Eileen Bisordi	Provider	Westchester, Manhattan, NYC
Eileen Egan	Provider	Nassau
Eleanor Block Ph.D	Family Member	Brooklyn, Kings County
Heather Aylward	Provider	Nassau
Jacqueline Chambers	Family Member	Bronx
Karen Nagy	Family Member	Saratoga
Kent Ng	Provider	Nassau/Suffolk
Kristi Moscato	Family Member	Erie
Lisa Burch	Provider	Nassau
Mary McGuire-Weafer	Family Member	Manhattan
Mary Rafferty	N/A	Nassau
Michael Seereiter	Family Member	Albany
Mike Alvaro	Provider	Albany
Miraline Rivera	N/A	Rockland
Monica Lynch	Family Member	N/A
Rachelle Kivanoski	Family Member	Brooklyn
Robert Goldsmith	Family Member	Suffolk
Stuart Flaum	Family Member	Manhattan
Susan Platkin	Family Member	Suffolk

Membership of Steering Group – 15 – **Need a DSP!**

Name	Affiliation	County
Brad Pivar	Family Member	N/A
Chester Finn	Self-Advocate	Capital Region
Dustyn Green	Self-Advocate	Cattaraugus
Elly Rufer	Family Member	New York
Gary Bencivenga	Family Member	Nassau
Helena (Linky) le Roux Ohm, Ph.D.	Provider	Monroe
Kathy Bunce	Family Member	Erie
Latavia Sturdivant	Self-Advocate	Westchester
Marco Damiani	Provider	NYC
Maria Cristalli	Provider	Monroe
Matthew Maclean	Self-Advocate	Erie
Max Donatelli	Family Member	Erie
Nicholas Cappoletti	CCO	Onondaga
Stanfort Perry	Provider	Nassau
Walter W Stockton	Provider	NYC

Functions and Role of Advisory Group

- The Advisory Group will provide input to the steering group on various policy recommendations and whole person care models reviewed by the coalition. This input will include:
 - Suggestions/support for models that may better and more wholistically support people with I/DD
 - Justifications for why the model will help (or not help) improve supports for people with I/DD
 - Implementation considerations for each model and a summary of feedback from the input group
 - Operational issues that can be turfed to a “operational solutioning” group
- The Advisory Group will be tasked with representing a wide range of views and should consider the diversity of needs for people with I/DD. They may also raise additional issues that the coalition should address and consider, as they pertain to whole person care. This will include the identification of additional models for review and analysis by the coalition including the entire advisory board and the steering committee.

Functions and Role of Input Group

- The Input Group will react to the proposed recommendations of the advisory board before those recommendations are considered by the Steering Group. This input will include:
 - Suggestions/support for models that may be better and more wholistically support people with I/DD
 - Justifications for why the model will help (or not help) improve supports for people with I/DD
 - Implementation considerations for each model
 - Identify operational issues that can be turfed to an “operational solutioning” group
- The Input Group will be tasked with representing a wide range of views and should consider the diversity of needs for people with I/DD. They may also raise additional issues that the coalition should address and consider, as they pertain to whole person care. This will include the identification of additional models for review and analysis by the coalition including the entire advisory board and the steering committee.

Functions and Role of Steering Group

- The Steering Group will develop and vote to finalize the following core components of the coalition:
 - Key principles of the coalition for whole person supports
 - Recommendations to be presented to the state on clinical/supportive and/or operation models
 - Determine if/how the coalition should exist in the future
 - Oversee the work of the coalition related to policy analysis and partnerships with other organizations
- The Steering Group will also be responsible for the development of policy recommendations to be provided to NYS that revolve around the models of integrated care that the coalition reviews.
- Serve as representation for the providers, individuals, and families within the region they are nominated from by aggregating ideas and feedback to include in the deliberation process and recommendations.

Getting the Work Done

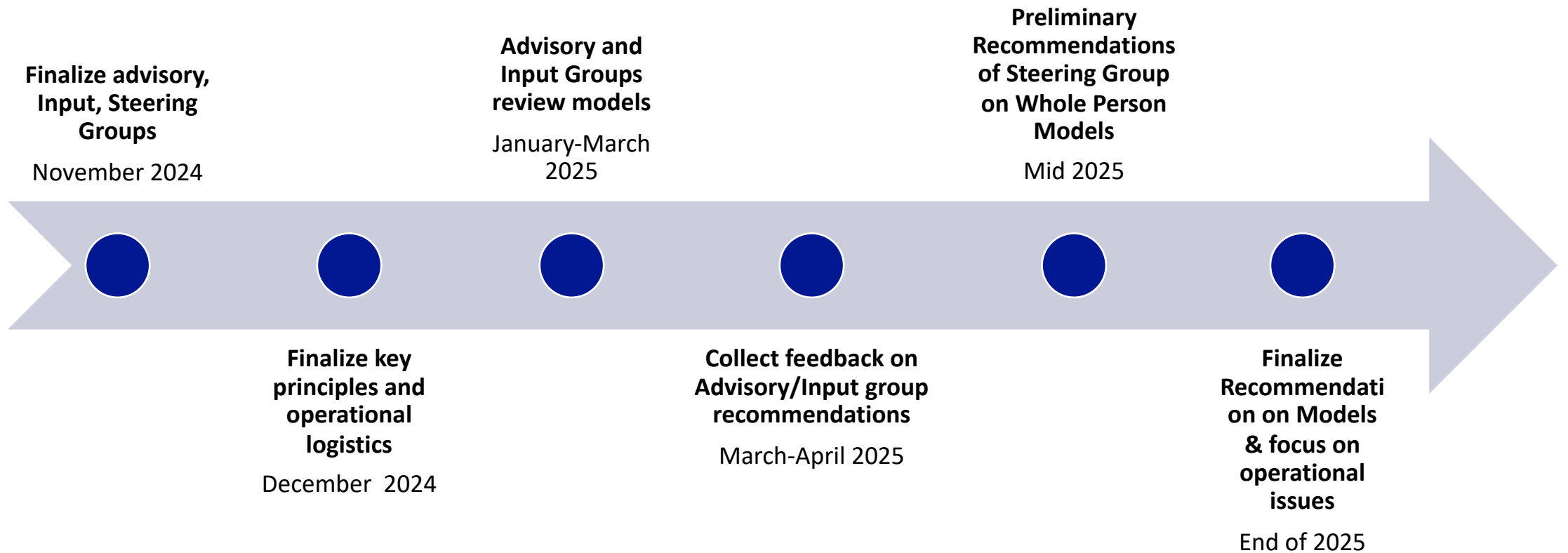
Operating Principles

- Diverse representation of input
- Open mindedness
- Recognize diversity of people being supported
- Honest and respectful dialogue
- Progressive attitude
- You agree with the case for change
- Commitment to making the **system** better for each individual and family that is supported

Logistics

- Meeting every 2 weeks for at least an hour to get through tasks
- Gather Input in between meetings
- Complete “homework assignments”
- Future have open meetings but time for both participants discussion then observer input

Timeline



Next Steps

- Agree to role and goals
- Review recommendations of the advisory and input groups
- Discuss of the recommendations and make additions/changes
- Possibly meet with the Advisory and Input Groups
- Recommend additional ideas and models for exploration and webinars throughout 2025
- Determine actions steps for success – (e.g., bring more voices to table? Meet with agencies aside from OPWDD? Campaign?) – hire a lobbyist?
- Determine who you want to be in the future (e.g., should the group think about sustainability or these recommendations one-time in nature?)
- What operational issues can the coalition help with?