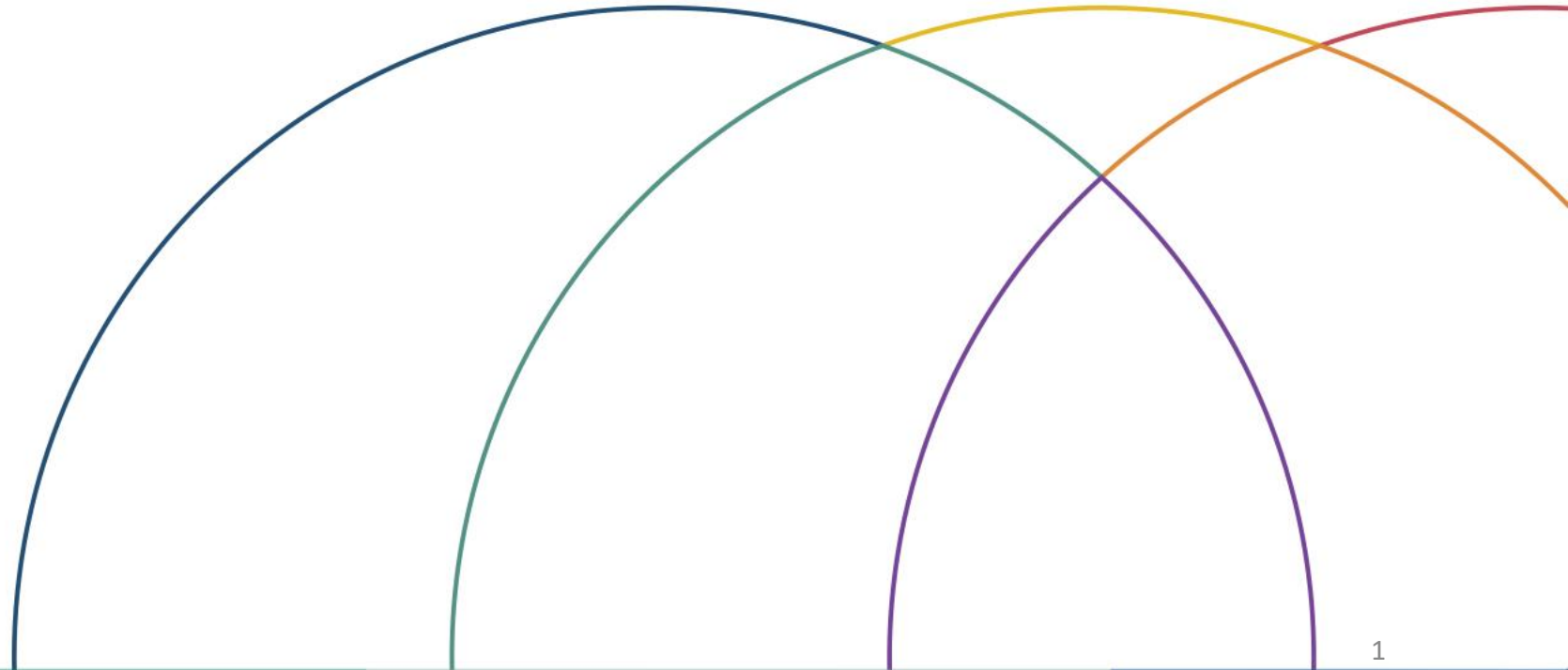


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Holistic Coordination for People with Intellectual and Developmental Disabilities

November 2025



Executive Summary

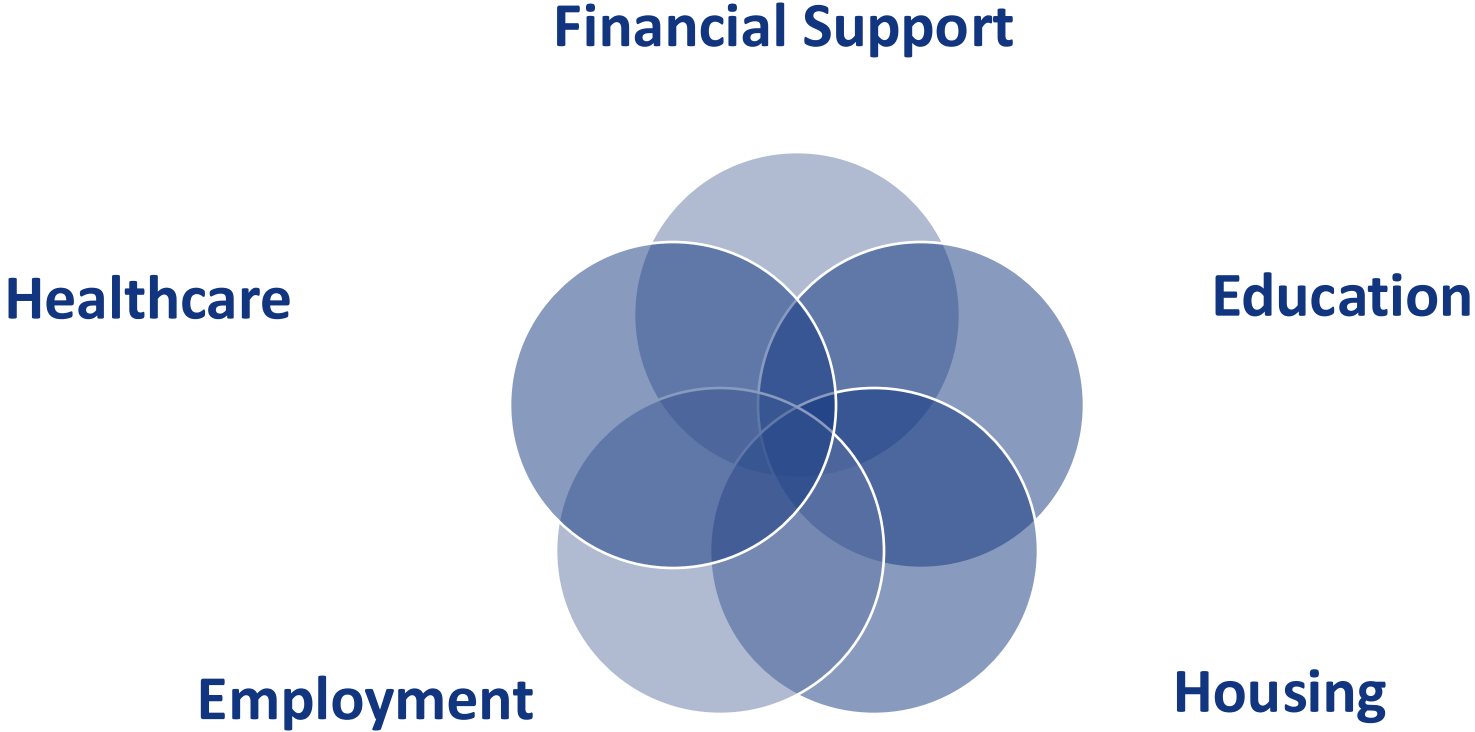
- Institute for Exceptional Care (IEC) Contracted with Health Management Associates (HMA)
- Interviews involved **28 stakeholders** in September and October 2021
 - People with IDD, families, state disability agency and Medicaid policymakers, experts in clinical and home-and-community based service (HCBS) systems, health plan executives, and researchers
- **Literature review and stakeholder interview to evaluate models** of holistic care coordination for people with intellectual and developmental disabilities (IDD) and their families
 - Evaluating how care coordination is defined, existing frameworks, barriers, and the role of internal and external stakeholders within the model
 - Findings provided **limited evidence of other models using cross-sector frameworks**

Current Landscape

- People with IDD represent between one and four percent of the US population
 - **1.5 million people** with IDD receive publicly funded case management through state developmental agencies
 - In 2017, **\$71 billion public dollars** spent on IDD care, but despite this,
- Living with IDD requires tailored support due to its unique challenges
 - Face avoidable health disparities, shorter life expectancies, and difficulty accessing holistic wellness
 - Less likely to earn a high school diploma, attend college, or be employed and more likely to live in poverty with **access barriers exemplified for those in racial or ethnic minority groups**

Project Approach

Need cross-sector collaboration with the aim to improve individual health, well-being, and quality of life across multiple sectors



Defining Coordination

- **Lack of consensus on definition of care coordination** leads to difficulty in designing and improving care coordination models
 - Only **one-third of frameworks include a formal definition** or adopt a patient - centered approach
 - Disability stakeholders prefer person-centered approaches emphasizing strengths and holistic support
- Proposing new coordination model responsive to the **holistic life needs of people with IDD** that will require diverse care and service systems and structures to **share resources, collaborate, and cede control** to develop truly person-centered and comprehensive coordination approaches

Coordination Concepts

Care Coordination: Deliberately organizing patient care activities and sharing information among all of participants concerned with a patient's care to achieve safer and more effective care

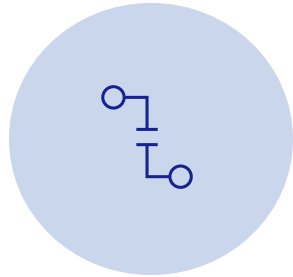
CYSHCN Care Coordination Standards: Define care coordination as patient-and-family-centered, assessment-driven, team-based, activities designed to meet the needs of children and youth

Case Management: Collaborative process that accesses, plans, implements, coordinates, monitors, and evaluates the options and services required to meet the client's health and human services needs

Community-Based Case Management: Multi-dimensional and collaborative process involving assessing, planning, coordinating, and reviewing options to meet client needs

Medicaid HCBS Case Management: Services assist participants in gaining access to needed waiver and other state plan services as well as medical, social, educational, and other services

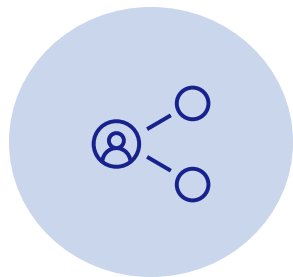
Coordination Gaps for People with IDD



Fragmented Systems: People with IDD and their families must navigate disconnected health, education, and social services systems



Family as Coordinators: Lead coordination across disjointed systems as many coordinators lack authority or capacity to take on primary role



Poor Information Sharing: Multiple, unaligned plans and incompatible data systems hinder communication and coordination



Inequitable Outcomes: Access to timely and appropriate services and support depends on individual and family capacity

Current Coordination Approaches

- Care coordination provided by health provider systems
- Case management provided by managed care organizations
- Coordination models designed for specific high-risk subpopulations to address acute or episodic needs to bridge transition across settings
- Medicaid home and community-based services case management
- Medicaid health home models delivered through health providers or teams
- Non-health coordination or case management services

Current models lack support of research on holistic, person-centered coordination approaches to meet the explicit needs of those with IDD or the effectiveness of these efforts

Existing Studies on Coordination Models

- **Comparative Effectiveness Review**
 - 46 studies that found no consistent pattern of effectiveness in care coordination for adults with disabilities
 - Literature lacked details on key coordination dimensions
- **Managed Care Organization Study**
 - Positive experiences with coordinators. Better service appraisals and fewer unmet needs
 - People with IDD report lower satisfaction than other disability groups
- **Medical Home Models for Aging Adults with IDD**
 - Focused on preventative care in group homes
 - Reported improved self-management, timeliness, and medication safety
- **Pediatric Care Coordination**
 - National Care Coordination Standards (2020) define family-centered, team-based coordination
 - Inclusive of children with IDD, but not IDD specific
 - Identified coordinator, shared plan of care, needs assessment, family support
- **International Models**
 - WHO Integrated People-Centered Health Services Framework: Promotes coordination across sectors, shared responsibility, life-long care
 - Local Area Coordination (New Zealand, Australia, UK): small-caseloads, relationship-based support, positive outcomes

Expert Perspectives: Necessary Components of Model

Continuity and Relationships: Accessible, timely, and responsive through a trusted care coordinator

Single Point of Contact: Simplicity of a single person with benefits of a network of experts

Small Caseloads & Flexibility: Care coordinators need to have time to work with people on consistent, flexible basis

Person-Centered Approach: Individualized care through a whole-person perspective with flexibility in engagement

Neutral Coordination: Movement away from provider or payor structure to eliminate conflicts of interest

Universal Access: Comprehensive, cross-sector coordination available, not limited to programs such as Medicaid HCBS

Information Sharing: Sharing between medical, educational, and other services

Outcome Measurement: Focus on health and quality of life outcomes

Blue Sky: Creating a Different Coordination Model

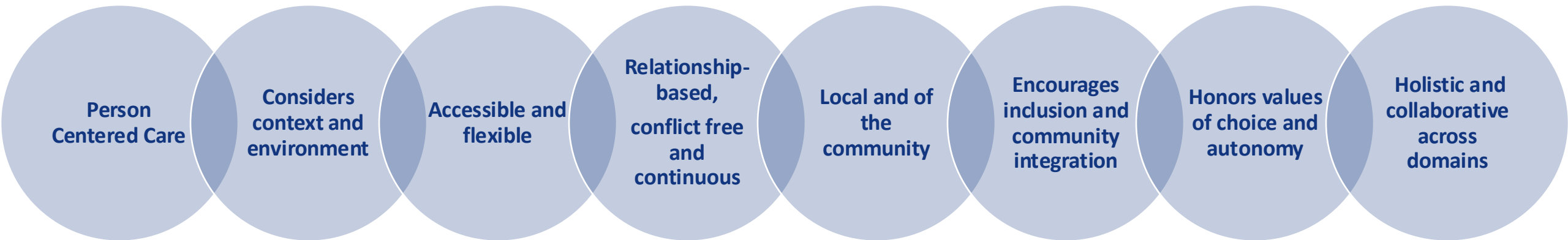
Individual Health

Well-Being

Quality of Life

- **Singular Intent:** Rooted in a clear purpose & goal
 - Individual health, well-being, quality of life
 - Belief that accountability to the people and their preferred outcome will result in positive impacts on provider outcomes
- **Two-fold approach to create bridges across complex landscape and lifespan**
 - Longitudinal coordination across all domains without being centered in one system
 - Focus on person with IDD without conflicting requirements designed to meet the needs of payors and regulators
- **Portable service** across public and private payors
 - Equitable regardless of health insurance status; educational attainment; life stage; level of functional, behavioral or medical support necessary; geography, race, and culture, family and community context

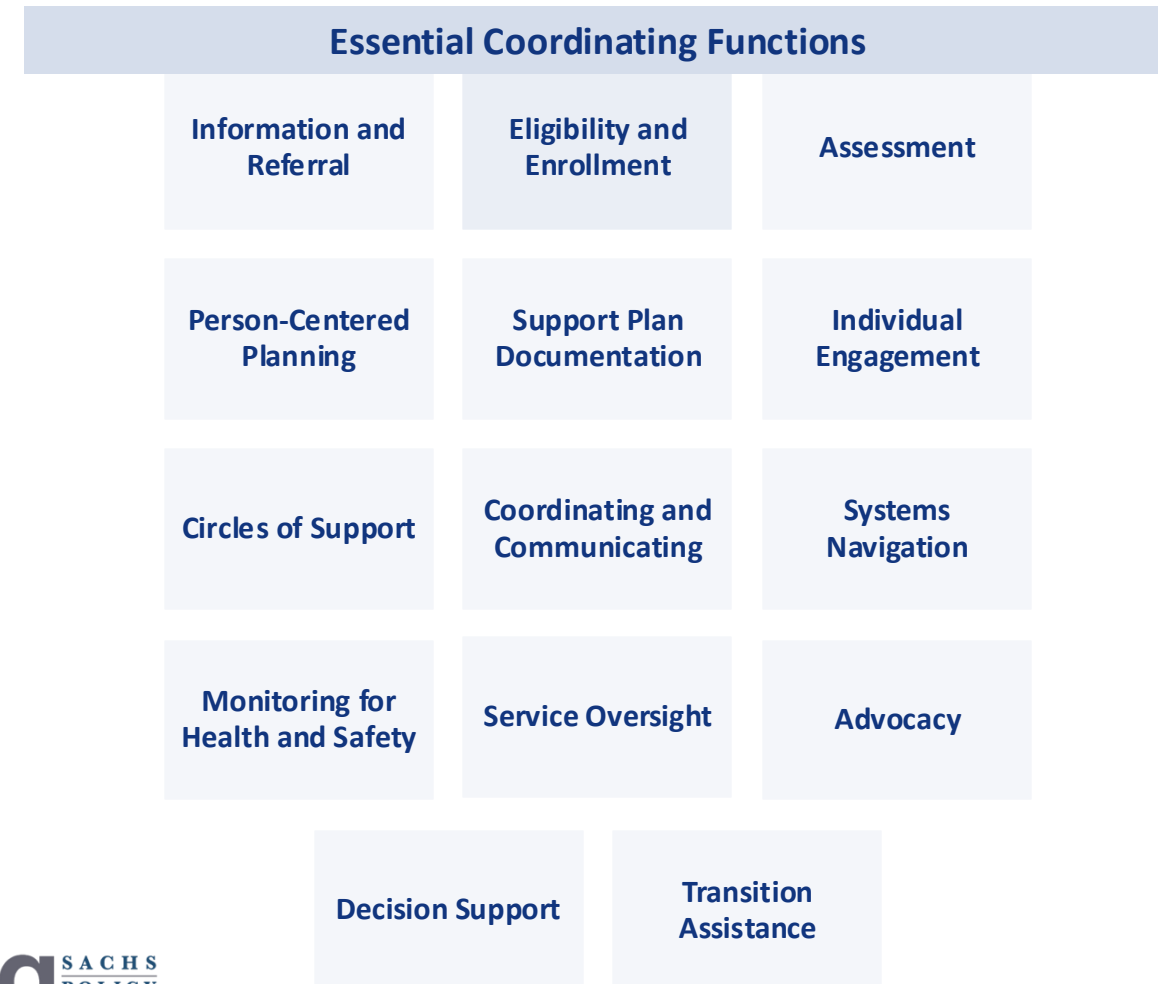
Key Characteristics of Holistic Coordination



Improve health, well-being, and quality of life outcomes for people with intellectual and developmental disabilities throughout their lives, by delivering holistic, trusted and consistent coordination support across domains and systems.

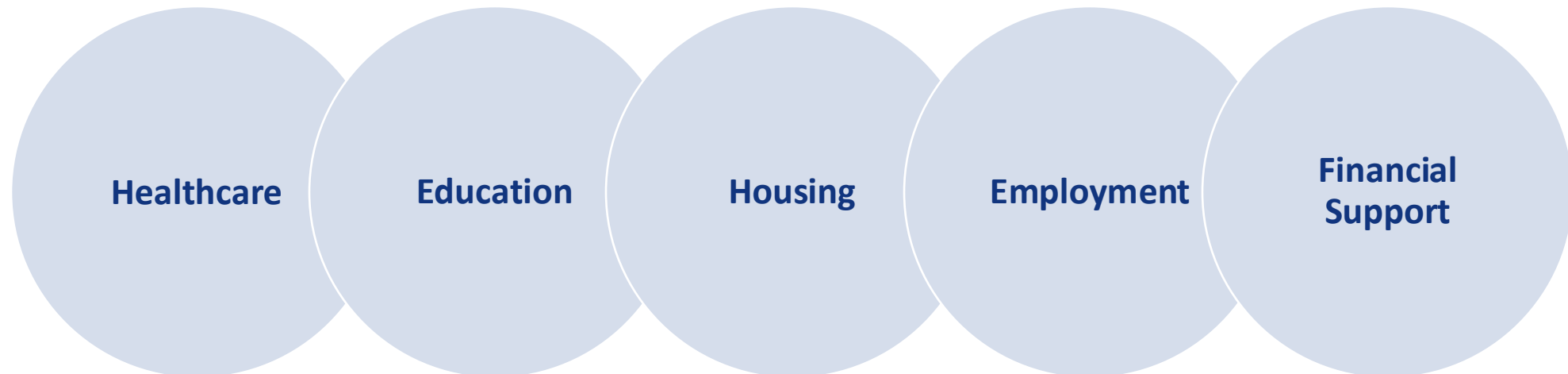
Functions of Holistic Coordination

- Reframing of coordination approach that considers the **perspective of those living with IDD**
 - Efforts towards achieving a person's goals, addressing their preferences, and improving health, well-being, and quality of life factors
- Incorporate multiple interdependent actions in an organized, reliable, and responsive manner
 - Coordination must be **iterative, non-linear, and cyclical**



Towards a New Approach

- Rooted in a defined coordination goal focused on **improving quality outcomes** for people with IDD
- Dedicated to building off existing support in local communities
- **Committed to using coordination** across multiple systems and people such that models will be able to able to achieve more and obligate payors and policymakers to consider shared accountability



By My Side Model

Next steps: To implement this model, the program needs coordination staff that are experts in the Person, their context, local community, and how to bridge to the best hub expertise:

Independent Coordinator

- Candidates include social workers, nursing professionals, experienced family caregivers

Training & Technical Support

- Knowledge of IDD core competencies such as those developed by Ohio State University
- 'Hub and Spokes' model to allow for coordinators to be 'experts in the person' rather than experts in every field
- Training on common process of accessing and using health insurance, public disability benefits, and educational accommodations

Cases

- Target case load of 50-60 people with IDD and their families with relationships sustained over different life stages and changes in insurance coverage

Compensation

- Per-person-per-year payment of \$1500-\$3000 from private or public insurers, disability service agencies, as an employer-sponsored wellness benefit, and/or families

Accountability

- The entity paying the coordinator measures meaningful process and outcomes, such as clear documentation of and progress toward person-centered goals. Accountability can take the form of public reporting, feedback report to coordinator's clients, and/ or financial incentives

Opportunities for Enhanced Self-Direction and Workforce

- Core competencies & curriculum for microcredentials that allow frontline workforce (e.g., DSP, MSW, CHW) to get certifications in areas such as behavioral health, serving complex individuals, complex medical navigation, etc. would be developed
- DSPs/MSWs could “hang a shingle” once credentialed, build a team practice, or stay in their current agencies while taking on new clients through this model
- Management Services Organizations (MSOs) could also be formed to provide back-office support for DSPs
- Creates an option for navigation support for self-advocates not in OPWDD system
- Families could still choose CCO or other option
- Model would open the market to allow self-advocates & families direct choice of provider and a longitudinal relationship

Implementation Stages

Development of Training Process:

Identify candidates and training process, establish requirements for delivering training, and develop agreements with entities that will finance curriculum development, credentialing & training



Pilot Implementation in Selected Communities:

Develop KPIs, data collection methods & enroll participants. Implement coordination practices within one or more communities



System Integration & Scaling:

User friendly communication and information systems, established structures for assessing and sharing data and records, shared financial accountability, and development of staff competencies