HEALTH MANAGEMENT ASSOCIATES

University of Michigan Rare Disease Day 2022

Holistic Coordination for People with Intellectual and Developmental Disabilities

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Re-thinking coordination, connections and integration for people with I/DD

Seeking A New Vision for Coordination

Project Research

- Environmental scan, literature review
- Stakeholder interviews
- Key themes, functions and characteristics identified

Currently available U.S. coordination models often fall into one of several categories:

- Driven and led by clinical care providers, focused on medical services
- Managed care orientation, focused on care management, access, provider networks, utilization, cost savings
- Designed for specific high-risk subpopulations – metrics focused on reducing hospitalization/institutional stays, crisis
  - older adults and people with complex medical needs – transitions
  - people with significant BH/SUD support needs
  - Children and Youth with Special Health Care Needs (CYSHCN)
- Patient-centered care coordination models often designed with medical/clinical care as leader or driver
- Medicaid HCBS case management, focused on community-based daily support but often limited in medical/clinical care integration

Thanks to support from:

institute for exceptional care

https://www.ie-care.org/

FORDFOUNDATION

https://www.fordfoundation.org/

Special Olympics

https://inclusivehealth.specialolympics.org/

Language and definitions: A few words about words

Multiple phrases and definitions describe the process of assisting people with disabilities in the coordination, integration and management of health and health-related supports and services across the life course, with significant variation in the goals and the expected outcomes

Terminology varies across systems, sectors, populations, domains, geography, including dozens of descriptions/definitions in the literature, each with multiple uses and inferences, including:

- Case Management
- Care Coordination
- Service Coordination
- Care Management
- Support Brokering
- Service Facilitation
- Support Counseling
- Case Monitoring
- Support Navigation
- Community Coordination

Stakeholders note the word “care” may be negatively associated with medical models, deficit-based orientation, paternalism

- Patient-centered ≠ person-centered
- Pediatric coordination (family-centered) distinct from adult coordination (person-centered)
- “I am not a case and I don’t need to be managed”

Project terminology - **“holistic coordination,”** drawing upon elements from multiple approaches and perspectives, seeking to avoid preconceptions

Tomato, tahmato… many definitions

+ **Care coordination** involves deliberately organizing patient care activities and sharing information among all of the participants concerned with a patient's care to achieve safer and more effective care. This means that the patient's needs and preferences are known ahead of time and communicated at the right time to the right people, and that this information is used to provide safe, appropriate, and effective care to the patient. (AHRQ)
+ **Case Management** is a collaborative process that assesses, plans, implements, coordinates, monitors, and evaluates the options and services required to meet the client's health and human service needs. It is characterized by advocacy, communication, and resource management and promotes quality and cost-effective interventions and outcomes. (CCMC)
+ **Community-based case management** is a multi-dimensional and collaborative process. It involves a set of interventions for assessment, planning, coordinating and review of the options and services required to meet the client’s health-related needs, and support them to reach their goals related to participation in life roles (BICM-T)
+ **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, regardless of the funding source for the services to which access is gained. The core functions require an assessment of needs; development of a person-centered service plan; referral and linkages to supports and services; and monitoring activities. (CMS)

Sources: https://www.ahrq.gov/ncepcr/care/coordination.html; https://ccmcertification.org/about-ccmc/about-case-management/definition-and-philosophy-case-management; http://hdl.handle.net/2123/17000; https://wms-mmdl.cms.gov/WMS/help/35/Instructions_TechnicalGuide_V3.6.pdf

Experiences of people with I/DD and their families – challenges and opportunities

- People with I/DD are a heterogenous population with a wide range of coordination, integration, support and service goals, interests and needs involving health, human services, education, employment, housing and other health-related domains – across the life span.
- Surveillance and prevalence data is very limited; people with I/DD disproportionally rely on publicly-funded health coverage but also participate in commercial/private insurance. The vast majority live with family, including as adults.
- People with I/DD and their families experience:
  - Health and socioeconomic disparities, social isolation
  - High burden of navigating and managing clinical, social, educational and other systems
  - Health providers with inadequate time, limited knowledge of non-clinical community supports
  - Multiple coordinators across systems and life domains – limited collaboration, poor responsiveness
  - "Revolving door" of coordinators – high turnover, challenges with longevity
  - Misalignment of goals, needs, priorities across systems and supports; lack of outcome data
  - Little flexibility in coordination capacity and access
  - Fragmentation – "no right door"
  - Especially for adults, limited opportunity beyond Medicaid to access coordination across sectors/domains
  - Tension between "gatekeeper" functions on behalf of payers, and coordination functions to address individual preferences and needs

Current coordination ecosystem includes most key elements but fragmentation interferes

Goal of coordination for people with I/DD and their families --

- Improving health, well-being, and quality of life outcomes through holistic coordination across domains and systems, throughout the life course
  - Person-centered: balanced and driven by individual needs and preferences, culturally respectful and responsive
  - Contextual: considers environmental, personal, temporal factors
  - Inclusive: increases participation in social, community and economic life roles
  - Flexible: Capacity is available when needed, transitions are anticipated
  - Relationship-oriented: trust, longevity, responsiveness
  - Values-oriented: self-determination, choice, dignity, autonomy
  - Holistic and collaborative across domains/sectors: health care, social services, education, employment, community participation, housing, transportation, recreation, financial/futures, justice, etc.

- **Not a single type of intervention** -- interdependent actions designed, communicated and delivered in an organized manner intended to achieve a person's goals, address their preferences, meet their needs, improve self-defined quality of life factors

What is the Role? Working list of holistic coordination functions

- **Information and referral** – helping people learn about, and find their way to services and supports
- **Eligibility and enrollment** - helping people understand and meet requirements to access certain programs or services
- **Assessment** – listening, gathering information, identifying needs, and helping people share what is important for them
- **Person-centered planning** – working with people to discover what is both important to them and for them, and trying to match supports and resources to their needs, interests, preferences and goals
- **Support plan documentation** – creating, updating and keeping track of formal plans for support based on assessments, person-centered planning and system rules
- **Individual engagement** – actively listening to the person, offering comfort or empathy, helping them solve problems, supporting self-determination, self-efficacy skills development and increased confidence
- **Circles of support** – helping to develop and engage other people important to the person (family, friends, community) to support the person
- **Coordinating and communicating** – working with the person, their family/friends, providers and others (representing systems or domains -- healthcare, education, social services, employment, housing, technology, etc.) to make sure all of the pieces fit together (cohesion)
- **Systems navigation** – actively helping people find their path through systems, paperwork, complicated processes to access goods, services or supports, or to get their needs met in other ways (including assistance with self-direction)
- **Monitoring for health and safety** – making sure that people at risk have the support and help they need
- **Service oversight** – making sure that people's services and supports are doing things according to their interests, needs, plans and goals and the rules of the system
- **Advocacy** – serving as an ally and an advocate when a person asks for help to make their voice heard, fix a problem, protect their rights, or address other needs
- **Decision support** – helping people get and understand information they need to make their own informed choices, and helping them communicate their decisions
- **Transition assistance** – anticipating changes whenever possible, and making sure that when change is happening, supports are adapting as needed

Holistic Coordination Functions: A Balancing Act

Assessing and Planning
Information and referral
Eligibility and enrollment
Assessment
Person-centered planning

Engaging and Facilitating
Individual Engagement
Circles of Support
Systems Navigation
Advocacy
Decision support

Collaborating and Coordinating
Information and Referral
Coordinating and Communicating
Service Oversight
Transition Assistance

Monitoring and Documenting
Support Plan Documentation
Monitoring Health and Safety

Quality Measurement
Utilization/Efficiency Efforts

Coordination Characteristics and Skill Sets

If I could design a great coordinator, they would be like…

+ **An Orchestra Conductor** who helps me and all the musicians in my life to play my chosen music, in harmony
+ **A Navigator** with a really good, easy to understand road map
+ **Mother Teresa** combined with the most fierce litigator you've ever met, who can speak 18 languages
+ **Peers and other families** who have lived experience that looks like mine
+ **Like a Community Health Worker** someone from my community who "gets" me
+ **A Quarterback** with a focused and winning team

Responses from interview participants, 2021

Coordinator accountable to the person/family:

- Someone to "walk alongside me" – responsive, trusted, reliable
- Of the local community, connected
- Great communicator
- Creative problem-solver
- Longitudinal, relational, historian
- Life coach – less social work "helper"
- Culturally respective, responsive and effective
- Adequate time and capacity
- Knowledgeable, well trained
- Understands and offers anticipatory guidance
- Independent, conflict-free

System supports:

- Collaboration across team
- Improved assessment approaches
- User-friendly electronic information easily available across systems
- Communication infrastructure
- Reduce paperwork and documentation burden
- Low caseloads aligned with coordination needs
- Shared financing and accountability across systems
- Separate "gatekeeper" functions – eg eligibility determinations, resource allocation, utilization management – from coordination

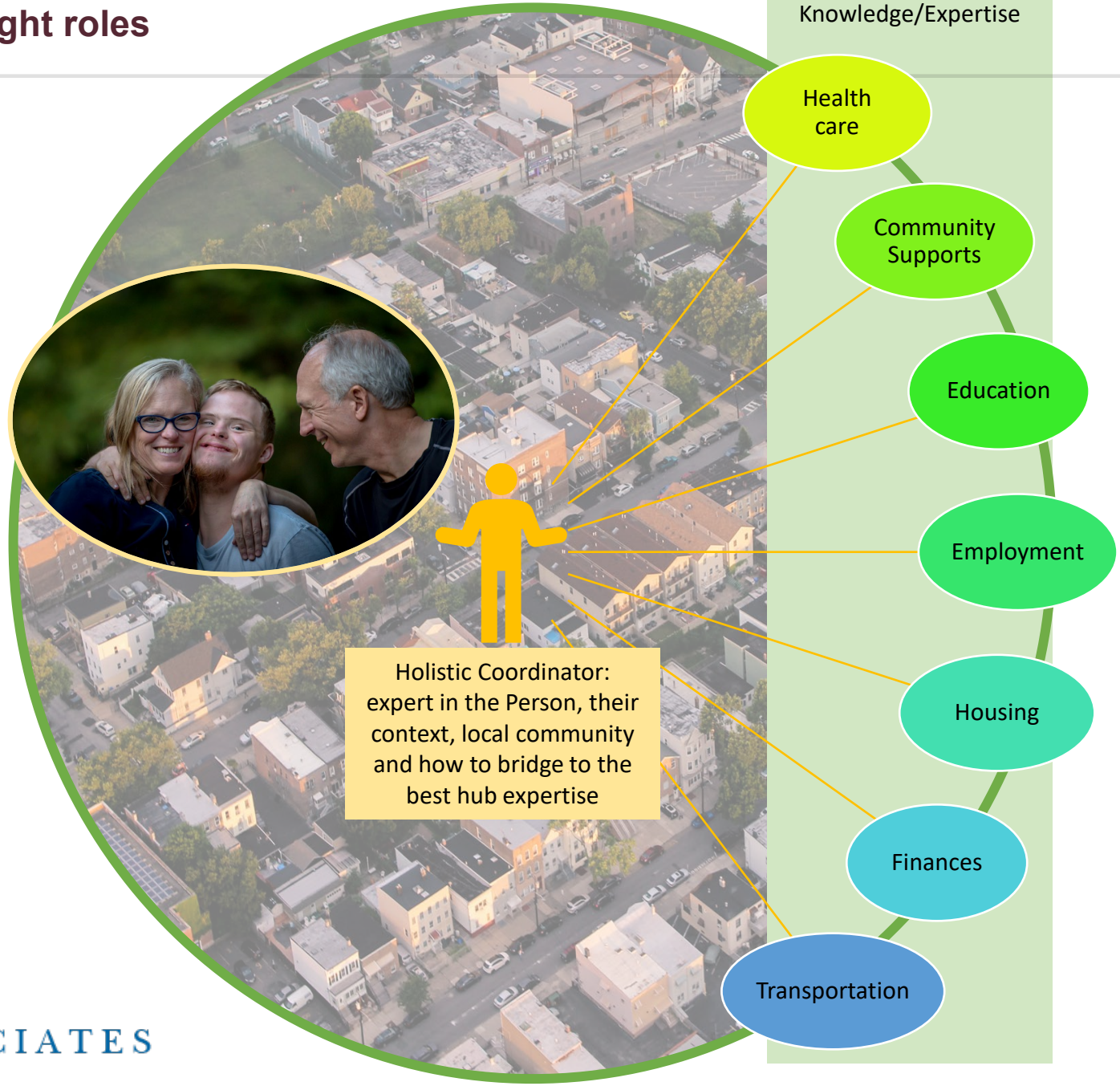
Putting the right people/organizations in the right roles

Health Care Clinicians

- Be team members, not leaders of coordination
- Medical records are accessible and key pieces of information are easily available and connected to other systems as desired by the person/family
- Ensure health issues are well understood by the team
- Clinicians have limited time; physician practices are expert in physical care but not as knowledgeable about everything else
- Patient-centered is not the same as person-centered -- most people are patients a very small portion of their days
- Pediatricians often play an outsized role as the historian, keeper of the long knowledge, ability to spend time - challenges for people to move to adult care

Insurers/Health Systems

- Buy and contract – don't build
- Use the data infrastructure
- Support quality measurement development
- Let coordination be local and independent



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QUESTIONS?

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