Family-Centered Care Coordination for Children with Neurodevelopmental Disabilities

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Objectives

1. Define Care Coordination and differentiate from other similarly named care management approaches
2. Describe the Shared Plan of Care approach to care coordination
3. Identify 3 positive outcomes from implementation of care coordination
4. Identify 3 care coordination strategies to apply in your practice

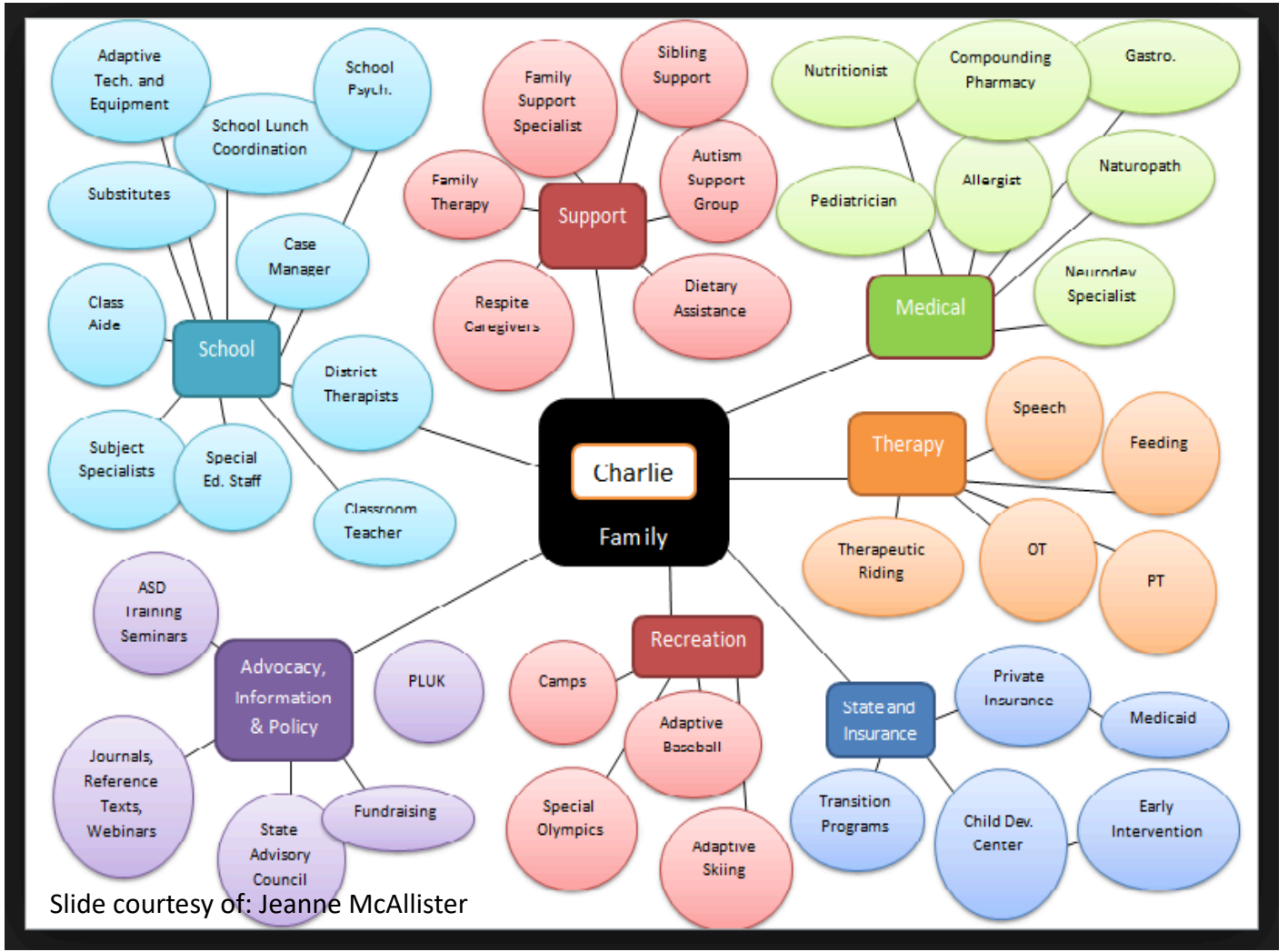
Caring for Children with Neurodevelopmental Disabilities is Complex

Children with NDDs have many challenging unmet medical and non-medical healthcare needs

For children with ASD (compared to other CSHCN), research suggests:

- Higher unmet needs
- Poorer access to needed care
- Greater family financial problems (e.g., pay more than $1000 year for care)
- More caregivers stop work to care for children
- Caregivers spend ≥ 10 hours per week providing/coordinating care

Berry et al., 2013; Kuo et al., 2011; Kogan et al., 2008



Slide courtesy of: Jeanne McAllister

Access to quality care is complicated by:

- Risk factors related to family social determinants of health (socioeconomic, racial/ethnic, geographic, etc.)
- Limited provider time, expertise, & resources to address needs effectively
- Under-resourced community, education, and health care systems

Eilenberg, J. et al., 2019; Zablotsky et al., 2019; Mandell et al., 2009

Families ask for:

- Communication with healthcare team
- To be heard, respected, and valued as an expert on their child/family
- Access to the care their child needs
- Providers (PCPs) who are knowledgeable about the interventions/ resources their child needs

Levy, S. et al., 2016

Primary Care Providers report:

- Feeling unsure about their role in ASD/NDD care
- Having gaps in knowledge to adequately oversee care for patients
- Having little time, support staff or resources to adequately address needs
- Poor reimbursement for coordination around care needs

Pediatric Care Coordination

A “patient- and family-centered, assessment-driven, team-based activity designed to meet the needs of children and youth while enhancing the care giving capabilities of families” Antonelli, McAllister & Popp, 2009

“A cross-cutting system intervention” that is the deliberate organization of patient care activities IOM, 2001

Ideally positioned within the patient/family-centered medical home AAP, 2014

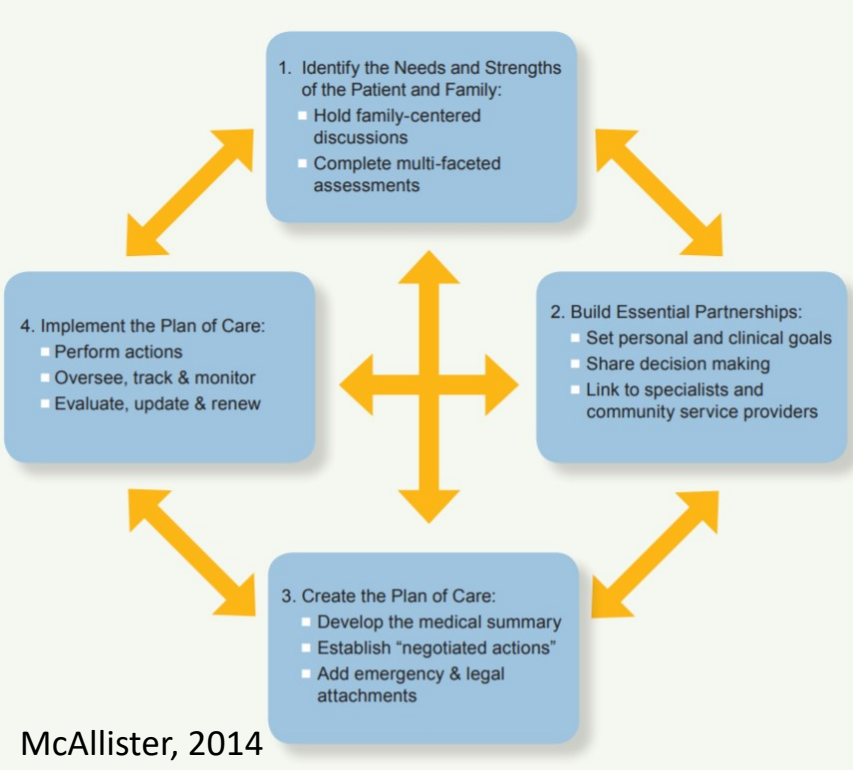
Shared Plan of Care Approach

Model Implementation Guide McAllister, 2014

- SPoC is the tool that drives family-centered, individualized coordinated care
- Two components:

  Medical Summary

  Negotiated Actions



McAllister, 2014

10 Steps to Achieving SPoC Approach

1. IDENTIFY who will benefit from SPoC
2. DISCUSS with families/team the value of using a SPoC
3. Conduct ASSESSment to guide development of the SPoC
4. Set shared personal family and clinical GOALS
5. Identify needed PARTNERS in the planning process

Lucile Packard Foundation for Children's Health

https://www.lpfch.org/publication/achieving-shared-plan-care-children-and-youth-special-health-care-needs

10 Steps to Achieving SPoC Approach

6. Develop the SPoC MEDICAL SUMMARY
7. Establish SPoC NEGOTIATED ACTIONS
8. Ensure the SPoC is accessible and SHARE it with care neighborhood
9. USE the SPoC to track, monitor, and oversee care
10. Systematically implement model with a POPULATION of patients and families

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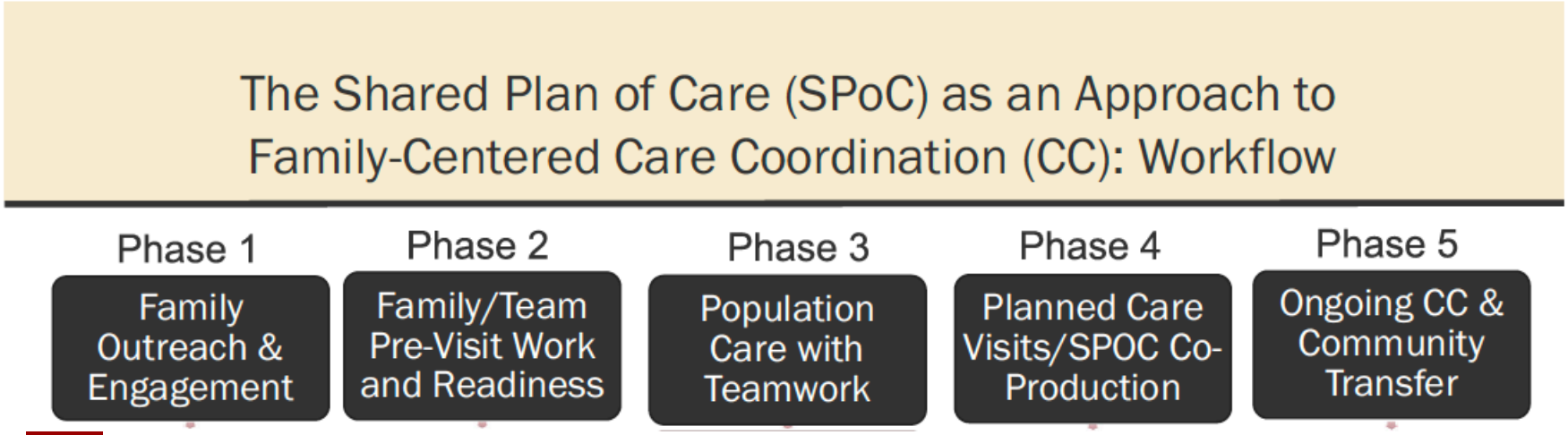
Riley Care Coordination Program: 2015-2016

- Children ages 2-12 with identified NDD and referred by Riley NSBS subspecialty programs

J.W. McAllister et al. / Journal of Pediatric Nursing 43 (2018) 88–96



Riley Care Coordination Program

Outcomes for 6 months of CC:

- Improved caregiver ratings of SPoC use, family/professional partnership
- 54% of goals completed
- Increase in “needs met”
- Increase in caregiver perceptions of family empowerment
- Reduced worry

McAllister, McNally Keehn, Rodgers, Mpofu, Monahan & Lock, 2018

Riley Care Coordination Program (RCCP); family and team quotes.

Family quotes	• "If you can bring us real care coordination, you will have saved our family" (Parent of a 9-year-old child with autism spectrum disorder) • "I have felt so alone in this but care coordination has opened my mind. I now know how to use the many special services available to our daughter" (Parent of a 5-year-old with autism spectrum disorder). • "No one has ever asked questions about what matters to us before" (Parent of two children, ages 3 and 5, with neurodevelopmental disabilities).
RCCP team members	• "I can focus on my clinical responsibilities when I know my care coordination team members are following up with the children and families I see; I am confident they are getting the help they need" (Child Psychologist) • "I have spent a lifetime learning the evidence-based strategies for children and families, yet the constraints of our payment system prevent me from ensuring that families access best practices and optimal services. Care coordination addresses this dilemma head on. It makes a difference" (Developmental Pediatrician). • "Learning family goals and using them to drive care coordination activities is far better, more effective. I cannot go back to working the way I did before" (Care Coordinator).

McAllister, McNally Keehn, Rodgers, & Lock, 2018

Additional Evidence for Care Coordination

Improves:

Family-professional partnership

Family satisfaction with care

Family perception of family-centered care

Reduces:

Unmet needs

ED visits

Missed appointments

Duplication of services

Family burden & time spent

Adams et al., 2013; Turchi et al., 2009; Farmer et al., 2011; Klitzner et al., 2010; Moeenuddin et al., 2019; Katz et al., 2012

AAP Recommendations Care Coordination Policy Statement, 2014

- Establish formal responsibilities among team members and patient/family
- Foster strength-based relationships with patient/family
- Collaborate with all team members and providers involved in a patients' care
- Communicate across all medical and non-medical systems involved
- Facilitate transitions among teams and across time
- Assess needs and establish clear goals for patient, family, health team, system
- Create, update a formal written plan of care that evolves over time
- Establish linkages with others in the community/system
- Use quality improvement strategies to facilitate implementation

What have you tried/could you try?

Start with a few small steps:

- Develop a small team who is passionate about change/progress
- Adapt a SPoC for your team
- Determine a way to monitor and track
- Identify a few families who might benefit
- Try it out
- Assess how it went

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Resources

American Academy of Pediatrics Care Coordination Resources

https://www.aap.org/en-us/professional-resources/practice-transformation/managing-patients/Pages/Care-Coordination.aspx

Lucile Packard Foundation for Children's Health

https://www.lpfch.org/publication/achieving-shared-plan-care-children-and-youth-special-health-care-needs

Family Voices Indiana – YouTube Care Coordination Educational Videos

https://www.youtube.com/user/fvindiana/videos