



Care Coordination Using a Shared Plan of Care Approach: From Model to Practice



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ABSTRACT

Introduction: Children and youth with special health care needs (CYSHCN) need, but do not have, adequate care coordination (CC); CC leads to better pediatric care, improved family/professional experience of care, and enhanced population health. Current CC initiatives are promising but lack adherence to emerging definitions/standards. A Lucile Packard Report provides guidelines for using a Shared Plan of Care (SPoC) as a CC approach; studied implementation is needed.

Purpose: The studied implementation of the Riley Care Coordination Program (RCCP) set out to: 1) illuminate components of family-centered, interdisciplinary, team-based care/coordination and SPoC, use 2) underscore family participation/engagement 3) reveal implementation processes/lessons learned.

Methods: Children (ages 2–10) with neurodevelopmental disabilities were referred by subspecialists; families agreed to participate in RCCP from a children's hospital ambulatory care setting. RCCP team used a five-phase workflow to implement CC: (1) Family Outreach/Engagement 2) Family and Team Pre-Visit Work, 3) Population-Based Teamwork, 4) Planned-Care Visits/SPOC "Co-Production", 5) Ongoing Care Coordination and Community Transfer. Family surveys and SPoC goals informed an evaluation.

Results: Children (268) with neurodevelopmental disabilities enrolled/completed the 6-month RCCP; it was a feasible endeavor. The co-produced SPoC supported families/care neighborhood partners to meet goals/unmet needs. Team plan-do-study-act improvement cycles informed RCCP enhancements.

Discussion/Conclusion: Eliciting/using family goals to drive CC emphasized family priorities; children/families gained interventions, treatments, confidence and navigation skills. Going beyond episodic, reactive care, RCCP achieved better CC with care neighborhood learning partnerships. Investing in this quality care coordination with fidelity to national standards holds promise.

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Introduction

Families caring for children and youth with special health care needs (CYSHCN) report many unmet, challenging, medical and non-medical needs (Berry, Agrawal, Cohen, & Kuo, 2013; Kuo, Cohen, Agrawal, Berry, & Casey, 2011). This population of children and youth are those who have one or more chronic physical, developmental, behavioral, or emotional condition requiring health and related services beyond that required by children generally (McPherson et al., 1998). For example, children with neurodevelopmental disabilities (such as autism) have complex lifelong disorders affecting their physical, cognitive, social, and behavioral development (Hodgetts, Zwaigenbaum, & Nicholas,

2015; Kogan, Strickland, Singh, Perrin, & Dyck, 2008). Their families report similar unmet needs further complicated by social determinants of health risk factors (Spencer, 2003). Pediatric professionals are particularly challenged to serve this subpopulation, as their care requires specific knowledge, time, and resources (Carbone, Behl, & Azor, 2010; Levy et al., 2016). Additionally, many of these children and families reside in remote communities ill-equipped to help them navigate complex healthcare, financing and educational systems (Hodgetts et al., 2015; Kogan et al., 2008).

Increasingly many families of CYSHCN report that they need, but do not have, adequate care coordination (CAHMI, 2018). Care coordination can lead to better pediatric care, improved family and professional experience of care, and enhanced population health when implemented as a patient- and family-centered, assessment driven, team-based, and continuous activity (American Academy of Pediatrics, 2014; Berwick, Nolan, & Whittington, 2008). Care coordination, by design, should meet bio-psychosocial needs while enhancing family and professional

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care-giving skills and capabilities (McAllister, Presler, Turchi, & Antonelli, 2009). The literature highlights the Shared Plan of Care (SPoC) as important to the care coordination process, but suggests that variations in practice make research challenging (Baker et al., 2016; Berry, 2015; Lindeke, 2015).

Current care coordination initiatives are promising (Cady et al., 2015), however efforts still lack application of consistent definitions and standards recommended for CYSHCN (Kuo, McAllister, Rossignol, Turchi, & Stille, 2018). This results in professionals operating from disparate perspectives. Families can be uncertain about what care coordination means and whether or not they are experiencing authentic coordination. To address these concerns, a transdisciplinary development team (families, nurses, doctors, social workers, researchers and policy makers) was convened to help create a care coordination white paper and implementation guide; this effort was funded by the Lucile Packard Foundation for Children's Health. The subsequent report (McAllister, 2014) provides guidelines for approaching care coordination using a Shared Plan of Care (SPoC). It includes 10 action steps: 1) identify who will benefit from a SPoC; 2) discuss with families/colleagues the value of this approach; 3) select and use a multi-faceted biopsychosocial assessment tool; 4) help families identify goals and integrate these with clinical priorities; 5) identify care partners and link them into the goal & planning process; 6) develop the Medical Summary (assets, historical data, partners) portion of the SPoC; 7) establish the SPoC's Negotiated Actions (goals/strategies); 8) ensure the SPoC is available, accessible, and retrievable; 9) use this plan with tracking, monitoring and oversight; and 10) systematize the care coordination model with an identified group of patients and families as a population approach.

Purpose

Because little work has been reported on the “real-life” implementation of these theoretical ideals, particularly with a population having complex medical and psychosocial needs, implementation with study to identify best practices is called for (Berry, 2015; Lindeke, 2015). The purpose of this paper is to: 1) describe the development of a model care coordination program using a SPoC approach, while applying related components of family-centered, interdisciplinary, team-based care, 2) underscore the importance of family participation and engagement at multiple programmatic levels, and 3) share lessons learned from analyzed program development.

Design and Methods

Setting and Team Development

Riley Hospital for Children at Indiana University Health is a free standing 280-bed facility located in downtown Indianapolis, Indiana. It serves as the pediatric tertiary and quaternary care resource for both the metropolitan region and state at large, evaluating and treating high numbers of children with complex medical conditions. The Riley Care Coordination Program (RCCP) was designed as a partnership initiative in that a multidisciplinary team worked with families of children with neurodevelopmental disabilities to collaborate across tertiary and community organizational boundaries and barriers to effectively marshal available resources. A goal was to address care coordination standards of care (AMCHP, 2014) with efforts to facilitate access to needed interventions and services, eliminate barriers to care, address unmet needs, and clarify shared responsibilities for a population with complex needs.

The application of the SPoC model (McAllister, 2014) was used as the basis of program development as it emphasizes family-centered and team-based care. Therefore, program leaders, including a content expert and family policy advisor (JM & RR), assembled a multidisciplinary care coordination team. They recruited three subspecialty clinicians

(developmental pediatrician, Med/Peds physician, and clinical psychologist) and three care coordinators (family advocate, registered nurse, and clinical social worker) to ensure an interdisciplinary perspective and approach. The intent was to form a prepared team who could adapt the “Achieving a Shared Plan of Care” model to the local context, incorporating its principles and ten implementation steps. An original workflow was designed for testing, improvement and finalization in order to achieve these goals at the localized level (Fig. 1).

RCCP program design called for clinicians with expertise caring for CYSHCN, (specifically neurodevelopmental disabilities) and prepared care coordinators to work together in small teams with each family for 3–6 months. An approach to care coordinator staffing was for an essential group of professionals to team up with clinicians to achieve coordinated care with families. Program leaders set out to recruit an experienced registered nurse, clinical social worker, and family advocate to fill these roles. Each position description was specific to their discipline/licensure and to shared care coordination responsibilities. The premise was that each discipline was essential and the combination of their talents optimal.

Nursing was specifically essential to this care coordination approach as nurses bring a broad lens and a critically important holistic view. Nurses understand the implications of chronic pediatric conditions and social determinants of health upon children and families. Well-prepared nurses analyze and synthesize multiple viewpoints/recommendations to help families pull together treatment and recommendation puzzle pieces. Nurses facilitate boundary spanning in order to help families link well with broader care partners, their interventions cut across the organizational and disciplinary boundaries that present challenges to the achievement of positive child and family outcomes. The RCCP plan was for *all* team members to cross-function wherever permissible and possible to benefit from one another's disciplines and perspectives to help provide enhanced care coordination with children and their families. Nursing contributions were identified as a much-needed driver of this team-based approach.

A detailed workflow (Fig. 1) with outlined care processes and functions guided the work of the entire multidisciplinary team. An original SPoC template was framed, and outcome measures determined. Implementation called for weekly all team member meetings to address needs including program development and evaluation, patient specific planning, and team process requirements. Twenty percent of clinical faculty time was supported by the program and focused on face-to-face care coordination service delivery, clinical oversight and coordinator supervision, as well as general program development. The care coordinators (with experience and training in nursing, social work, and family advocacy) were recruited into newly formed, full-time university positions with role descriptions based upon core care coordination competencies and functions outlined in a Commonwealth Fund Report (Antonelli, McAllister, & Popp, 2009), later reiterated by the American Academy of Pediatrics (American Academy of Pediatrics, 2014). Coordinators were oriented and supported in real time by program leaders and coordinator input and reflections were used to help with learning and program direction. A culture in which all team members would learn, teach, and collectively contribute to what “better” care and care coordination should look like was intentionally encouraged (Berwick et al., 2008).

Child Population and Family Recruitment

Families of children ages 2–10 with a diagnosis of autism spectrum disorder, developmental delay, and/or intellectual disability were invited by their child's subspecialist to participate. Referring subspecialists included child development, developmental pediatrics, child psychiatry, neurology, genetics, and primary care clinical services. Program leaders (JM and RR) presented program parameters to each subspecialty division to facilitate recruitment/referrals to the RCCP; they explained the program's eligibility criteria and distributed referral forms and

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