

Appendix A



Fact Sheet

April 2019

An Almost Complete List of Services Used by Families and Children with Special Health Care Needs

by Edward L. Schor, MD

Children with chronic and complex health conditions and their families require access to a wide array of health care and other services to function optimally. These needs can be identified by patients and families in the creation of shared care plans, or consequent to screenings and assessments. Various referral policies and practices have been developed to facilitate access to these services. The following lists are intended to provide a classified enumeration of services that may be used and of value to children with special health care needs and their families. It can be used for care mapping, care planning, resource database creation and referral system development.

Family Services

Formal Family Support & Advocacy

- Advocacy services
- Care navigation
- Child care
- Family resource center services
- Homemaker services
- Organizing health records
- Parent-to-parent support
- Respite care
- Spiritual support and faith communities
- Categorical/Disease-specific organizations
- Voluntary organizations
- Blogs
- List serv
- Social media

Informal Family Supports

- Blogs
- Extended family
- Friends of child
- Friends of parents
- Neighbors
- Support groups for child, siblings and parents
- Clubs
- Cultural organizations/groups

Social Services

- Human Services Agency (Medicaid, IHSS)
- Child Protective Services (CPS)
- Child welfare agency and foster care
- Court Appointed Special Advocates (CASA)
- Financial assistance (SSI/SSDI)
- Home visiting
- Independent living
- Housing assistance
- Transportation assistance (payers, dispatchers, bus drivers)
- Voluntary organizations (Easter Seals, etc.)
- Food subsidies (Women, Infants and Children Food and Nutrition Service (WIC), food stamps)

Advocacy

- Advisory committees and councils
- Public testimony
- Non-profit voluntary organizations

Employer/Work

- Employer
- Worksite accommodations
- Disability benefits/Ticket to work
- Vocational rehabilitation
- Job placement

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Health Services

Physical Health

- Primary pediatric care
- Primary adult care
- Pediatric subspecialty care
- Adult subspecialty care
- Surgical care
- Hospitals
- Emergency departments
- Urgent care
- Dialysis
- Chemotherapy
- Home health care
- Palliative care
- Hospice
- Dental care
- Nutrition education/consultation
- Vision care
- Complementary and alternative medical care (chiropractic, acupuncture, homeopathy, naturopathy)
- Traditional healers

Mental Health

- Behavioral therapy
- Family therapy
- Parent/child dyadic therapy
- Marital counseling
- Mental health care: child
- Mental health care: adult

Ancillary Services

- Interpretation/translation
- Service animals
- Laboratory
- Radiology/imaging
- Participation in research projects
- Genetic counseling
- Pharmacy and medication reconciliation

Developmental Disabilities & Rehabilitation

- Applied Behavioral Analysis (ABA) therapy
- Developmental screening
- Durable Medical Equipment (DME)
- Equipment repair
- Individual Education Planning (IEP)
- Individual Family Service Planning (IFSP/IPP)
- Modification of vehicles
- Needs assessment
- Paratransit and other accommodated transportation (handicapped parking)
- Physical accommodations in home
- Physical therapy
- Music therapy
- Equine therapy
- Feeding therapy
- Occupational therapy
- Speech/language therapy
- Psychological testing/treatment
- Protective supervision

Care/Service Coordination

- Assessment
- Care planning
- Case management
- Coordination among medical providers
- Coordination between medical providers and other community services
- Emergency care planning
- Patient advocacy
- Self-management education and supports
- Transition planning
- Visiting nurses

Long Term Care

- In-home health services (IHSS, private duty nursing)
- Medical supplies
- Residential care

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Community Services

Education

- Schools
- Accommodations, modifications, and other services (504 plan)
- Americans with Disabilities Act (ADA) accommodations
- Child care/Head Start/Preschool/Pre-K
- Home schooling
- Individual Education Plan (IEP)
- Public libraries
- School administrators
- School aide
- School nurse
- School teachers
- Special education teacher
- School-based therapists
- Vocational services
- Sign language
- Physical therapy
- Occupational therapy
- Speech therapy
- After-school care

Recreation & Community Resources

- Individual lessons
- Individual recreation
- Teams and group activities and clubs
- Accommodations to access public spaces
- Camps
- Special programs (Special Olympics, community events)

Public Safety

- 5-day supply of medication
- Earthquake preparedness/Earthquake kit
- Evacuation chairs
- First Responders (EMT, police)
- Emergency backup for power outages

Legalistic Services

Legal

- Private and legal aid attorneys
- Conservatorship
- Financial planning, wills, and trusts
- Guardianship
- Durable power of attorney
- Advance healthcare directive
- Public benefits eligibility (health care, SSI, disability care)
- Public benefits denial, reduction, or delay (insurance, treatment)
- Special education services
- Accommodations
- Supported decision-making

Juvenile Justice

- Expungement of records
- Mental/behavioral health services
- Substance abuse/addiction services
- Access to health care
- Medication management
- Special education
- Trauma informed care

Insurance and Financing

- Private health insurance company
- Health plan
- Insurance advocacy
- Public health plan (Medi-Cal/Medicaid, TRICARE)
- Special grants

ABOUT THE FOUNDATION: The Lucile Packard Foundation for Children's Health is a public charity, founded in 1997. Its mission is to elevate the priority of children's health, and to increase the quality and accessibility of children's health care through leadership and direct investment. Through its Program for Children with Special Health Care Needs, the Foundation supports development of a high-quality health care system that results in better health outcomes for children and enhanced quality of life for families.

The Foundation encourages dissemination of its publications. A complete list of publications is available at <http://www.lpfch.org/publications>

CONTACT: The Lucile Packard Foundation for Children's Health, 400 Hamilton Avenue, Suite 340, Palo Alto, CA 94301; cshcn@lpfch.org (650) 497-8365

An Almost Complete List of Services Used by Families and Children with Special Health Care Needs

Appendix B

by *Jeanne W. McAllister, BSN, MS, MHA*

Families have long been asking for parent/professional partnerships with easy access to a team of professionals where their children obtain care. They also want and need a plan of care that summarizes coalesced information about their child and family, including medical history, recommendations, preferences, and actionable next steps. An implementation guide¹ from the Lucile Packard Foundation for Children’s Health includes operating principles and suggests the use of a 10-step process for professionals to coproduce a plan of care with children and families (Table 1). The product resulting from these outlined steps is a shared plan of care (SPoC). The SPoC is a representation of the dynamic efforts of a trusting family and professional team partnership. A shared plan of care includes critical summative medical information as well as short- and long-term goals resulting from negotiated shared decisions.

Currently, a shared plan of care is being tested through implementation in varying contexts across the country. One study of its implementation² summarizes the effects of such an endeavor. Many of the recommendations and ideas outlined below stem from lessons resulting from this study. These ideas hold relevance for a variety of children and families and the health care and community environments that support them.

*Table 1
Ten Steps to
Achieving a
Shared Plan
of Care¹*

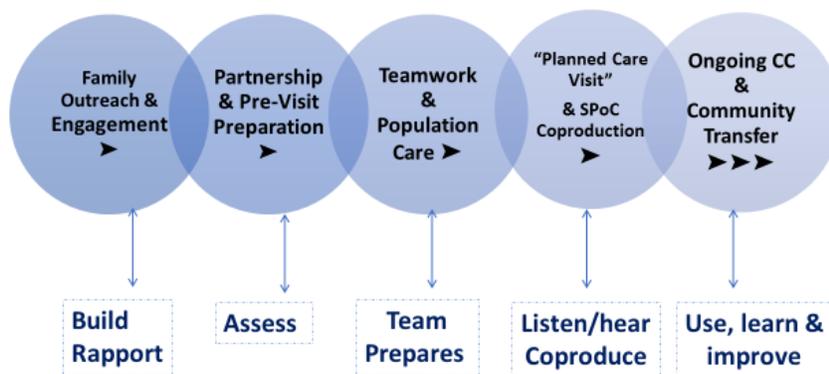
- Step 1** Identify who will benefit from having a shared plan of care (SPoC).
- Step 2** Discuss with families and colleagues the value of developing and using a comprehensive and integrated plan of care.
- Step 3** Select, use, and review multifaceted assessments with the child, youth, and family.
- Step 4** Set shared personal (child and family) and clinical goals.
- Step 5** Identify other key partners (subspecialists, community resource providers, and others) and link them into the plan of care process. .
- Step 6** Develop the medical summary for the plan of care and merge it with the negotiated actions in step 7.
- Step 7** Establish the negotiated actions for the plan of care and merge them with the “medical summary” in step 6.
- Step 8** Ensure that the plan of care is accessible, retrievable, and available.
- Step 9** Provide tracking, monitoring, and oversight for the plan of care.
- Step 10** Systematically use the plan of care model process as a life course and a population health approach.

While the 10-Steps to Creating a Shared Plan of Care serves to walk one through the necessary people, process, and tools for this approach, it is important to start with a prepared, proactive team that possesses the intention to provide evidence-based care coordination. This warrants preparation via a few other essential considerations: identify core team members with clearly articulated roles, who will support one another in care coordination efforts; identify as a team an explicitly named, shared, and generally endorsed care coordination definition and framework; have the team help develop or customize a workflow spelling out phases and responsibilities; and have the team follow the workflow as a directional tool, which also represents quality improvement opportunities. This means the pathway to using a SPoC in partnership with family requires testing and informed improvements as a result of these quality improvement tests of change. In other words, families benefit from care coordination achieved in partnership with a committed core team, one that is willing to test new ideas, discuss results, learn together with families, and redesign accordingly.

Figure 1 illustrates 1 workflow example that could be adapted to local context. Notice within its 5 phases how there is a “run-up” to the actual joint creation, or coproduction, of the SPoC. These run-up or preparatory phases are designed to: 1) gain family agreement to take such an approach together; 2) reach out to families for pre-visit information to begin population of a plan of care; 3) prepare for visits using family input, teammate suggestions, and medical and other sources of data; 4) dedicate time during a care visit to hear what matters most to the family and reflect back what is being heard about its unmet needs, concerns, and priorities and begin to generate a draft plan; and 5) complete the SPoC with family affirmation of its content and use it as a “script” for subsequent care coordination functions and activities. Phase 5 is a specified period of continuous care coordination which includes reevaluation and follow-up. This workflow example was designed for use with a children’s specialty hospital initiative; note that communication and collaboration with primary care is an articulated priority.

Figure 1 An approach that uses team preparation and agreement paves the way for the care planning process and tools to generate better outcomes. Table 2 details considerations and/or recommendations for implementing care coordination using the 10 steps toward achieving a shared plan of care.

Workflow: Five Phases Using a SPoC as an Approach to Family-Centered Care Coordination



Appendix B

continued

Shared Plan of Care: Ten Steps Toward Implementation

Table 2 *Shared Plan of Care: Ten Steps Toward Implementation*¹

Steps	People and Processes with Special Considerations	Tools (*Samples Available)
<p>Step 1 Identify who will benefit from having a shared plan of care (SPoC).</p>	<p>Identify a target population/subpopulation that would benefit from having an accessible, comprehensive, integrated, and shared plan of care. Consider the following:</p> <ul style="list-style-type: none"> • Is there a current organizational population of focus or priority? • May a parent partner or family advisor participate in population selection? • What population is of concern to you/the team right now? • Will the decision about who requires a shared plan of care create lessons that are relevant for children with special health care needs and/or all children? • Has a family or group of families been asking for extra help with navigation? Are there common traits among them? • Have any families been teaching the practice or clinical team lessons resulting from their own extensive efforts? • Will you use levels of complexity in this work; if so how will that process guide you? • What about considerations of broader social determinants of health? 	<p>Population or subpopulation criteria (predetermined and articulated by the team)*</p> <p>Complexity levels tool*</p>
<p>Step 2 Discuss with families and colleagues the value of developing and using a comprehensive and integrated plan of care.</p>	<p>Describe the rationale behind using a SPoC approach with families; explain how it is designed to reflect “what matters” to them and how these priorities are integrated with clinical concerns to guide continuous care coordination.</p> <ul style="list-style-type: none"> • Explain how a well-developed SPoC coalesces information and guides prioritized next-step actions. • Discuss how a SPoC is coproduced, meaning the team and family create it together; it is not done to a family but with them going forward. • Share how other families have found a SPoC useful as an approach to care coordination and provide examples of other family goals (eg, areas with which they have asked for help). • Link the plan of care to better health care, population health, potential costs per capita, and professional joy (The Triple and Quadruple Aims). 	<p>Lucile Packard SPoC Guide</p> <p>Family goal examples*</p>

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continued

Shared Plan of Care: Ten Steps Toward Implementation *continued*

Steps	People and Processes with Special Considerations	Tools <i>(*Samples Available)</i>
<p>Step 3 Select, use, and review multifaceted assessments with the child, youth, and family.</p>	<p>Take every opportunity to help families reflect on their priorities, unmet needs, and concerns they want to address.</p> <ul style="list-style-type: none"> • Use a simple assessment tool to help families realize the scope of content areas that can be addressed (eg, medical, dental, school, social determinants); this can be done using a pre-visit contact or before a visit. • Take advantage of every interaction with the family to ask, listen, hear, and reflect back child and family needs, strengths, and challenges; discover what their child enjoys or receives well. • During a visit, (or ideally during a specified planned care visit) take time to engage in a goal-directed, open-ended interview to allow families the opportunity to describe their typical day with their child and to reveal their challenges, inherent strengths, and frustrations. • If time does not allow for this, assign a team member (eg, a coordinator) to have this conversation prior to the clinical encounter; explain to the family how information will be captured and shared across the team. 	<p>Pediatric care coordination assessment (or pre-visit assessment* [eg, What I Need])*</p>
<p>Step 4 Set shared personal (child and family) and clinical goals.</p>	<p>Build upon the steps above, reflect back to the family the priorities heard; gain the family’s affirmation or any deletions and additions. Add essential clinical concerns and/or priorities and gain the families agreement to include these items by using the following approaches:</p> <ul style="list-style-type: none"> • Suggest that starting with 3 to 4 goals is good. • Encourage families that you believe the team can help them address their needs and goals. 	<p>SCRIPT: 3 open-ended, goal-directed interview questions related to activities of daily living, self-management, care partnership support, or system navigation (eg, Can you describe a typical day and the most challenging areas for your child [or you]?)</p>

Appendix B

continued

Shared Plan of Care: Ten Steps Toward Implementation *continued*

Steps	People and Processes with Special Considerations	Tools <i>(*Samples Available)</i>
<p>Step 5 Identify other key partners (subspecialists, community resource providers, and others) and link them into the plan of care process.</p>	<p>The child and family probably have a “care neighborhood” of key multidisciplinary professionals (specialists, primary care, educational, therapists, etc.) essential to helping them (and you) achieve their goals.</p> <ul style="list-style-type: none"> • Ask who these critical members are and whether the SPoC can be shared with them (gain releases). • Determine if there is a designated locus of clinical coordination; if not, determine with each family if this should be you/your team/practice or not? If not, with whom and where can this occur? • Communicate with care neighborhood partners about the SPoC and care coordination process; ask for their input, participation, and help with addressing goals. 	<p>Care mapping (highlight key critical partners)</p> <p>Communication agreements^{4*}</p>
<p>Step 6 Develop the medical summary for the plan of care and merge it with the negotiated actions in step 7.</p>	<p>Steps 6 and 7 reflect the engagement and trust-building work achieved in prior steps. A SPoC template (identified before beginning) includes both the medical summary and negotiated action sections. Once developed, these can be merged.</p> <ul style="list-style-type: none"> • The SPoC template should include core elements, while being flexible to the local context; periodically, a team should revise and improve the template using family and team experiences as input. • The medical summary is populated in real time during interactions with the family. Send a blank template to families to acquaint them with the tool; this also allows them to gather and share content (and offer feedback). <ul style="list-style-type: none"> ~ Be clear that they are not expected to complete the entire document on their own. • Capture family cultural beliefs and preferences; ask how they like to receive information and/or communications (written, oral, online/video). 	<p>Sample care plan (on the Lucile Packard Foundation for Children’s Health [LPFCH] website⁵)*</p>

Appendix B

continued

Shared Plan of Care: Ten Steps Toward Implementation *continued*

Steps	People and Processes with Special Considerations	Tools <i>(*Samples Available)</i>
<p>Step 7 Establish the negotiated actions for the plan of care and merge them with the medical summary in step 6.</p>	<p>Once family priorities are established and essential clinical goals are integrated, following are steps to take and data to include to complete the negotiated actions section:</p> <ul style="list-style-type: none"> • List goals, note aligned strategies next to the goals, and allocate responsibilities (who, by when). • Include relevant resource people, contact information, and links to help with the goals—this helps all partners to learn (draw from care mapping). • Practice “anticipatory guidance” to help families understand what to expect that may lead to important goals. For example, consider pending transitions (between school levels and from hospital to home and pediatric to adult-focused health care) or preemptive nutrition and activity guidance to help with endurance and stamina. • Plan ahead with families for necessary revisions, updates, continuances, or reframing. These activities comprise ongoing care plan development and implementation. • Create and/or use an indicator of progress against set goals (eg, goal is completed, in progress, on hold, or dropped). 	<p>Sample care plan (the Lucille Packard Foundation for Children’s Health sample care plan is on the LPFCH website)*</p> <p>(and/or replace with your action grid or add as another example)</p>
<p>Step 8 Ensure that the plan of care is accessible, retrievable, and available.</p>	<p>Electronic medical records (EMRs), while helpful, are insufficient for properly sharing a SPoC; think of multiple ways to make the plan available (eg, as the idea goes, communicate 7 times in 7 ways).</p> <ul style="list-style-type: none"> • Use the SPoC (in whatever form is allowable, such as an editable word document, a scanned version, or an attachment to a secure email) to help make plans sharable and accessible for families and their care partners. • Attach emergency plans, condition-specific guidance, and legal documents to the SPoC. • Use the EMR, family, and team members to notify others of the existence of each SPoC; refer to the plan at every health care encounter or interaction. • Remind families to use their SPoC; emphasize all of the ways it can help them to communicate, advocate, or complete eligibility applications. 	<p>(EMR, paper, email, scan—7 times in 7 ways)</p> <p>Provide guidance to the family regarding the benefits of using the completed shared plan of care.</p>

Appendix B

continued

Shared Plan of Care: Ten Steps Toward Implementation *continued*

Steps	People and Processes with Special Considerations	Tools <i>(*Samples Available)</i>
<p>Step 9 Provide tracking, monitoring, and oversight for the plan of care.</p>	<p>Continued, feasible use of the SPoC requires ongoing progress tracking (see above), care coordination monitoring of performed functions, and documentation of overall effort.</p> <ul style="list-style-type: none"> Track population goals to understand needs and to demonstrate how care coordination helps to better meet set family goals. Evaluate care coordination implementation and determine its value through efforts with families, teams, and leadership, based on its effectiveness, impact, and fidelity to national standards. 	<p>The Pediatric Care Integrated Care Survey</p> <p>Coding (for care conferencing and care plan oversight)</p> <p>Family surveys* (Plan of care/utility, empowerment, unmet needs, worry, coding of goals and progress)</p>
<p>Step 10 Systematically use the plan of care model process as a life course and a population health approach.</p>	<p>After following steps 1 to 9 and subsequently demonstrating value with families and improved joy of clinical staff, persistent system support for a SPoC approach to care coordination with pediatric populations should follow.</p>	<p>Family surveys*</p> <p>Adaptive reserve*</p> <p>Other staff joy measures (available at the Institute of Healthcare Improvement website [ihi.org])</p>

Table 3 describes the use of a SPoC approach to care coordination and particular workflow phases to guide a team in its efforts.

VB, a 3-year-old boy with developmental delay, and his family (Burmese refugees) were referred by pediatric neurology for care coordination

*Table 3
The vignette describes a child-, family- and team-based care coordination effort addressing all 5 workflow phases. The vignette is contributed by Holly Paauwe, team care coordinator; Rebecca McNally Keehn, PhD, team clinician; and Jeanne W. McAllister, BSN, MS, MHA, program director.*

Phase 1: Family outreach/engagement

The parents were invited and provided with a thorough description of what a care coordination intervention could do to help them and their son, and they agreed to participate.

Phase 2: Family and team pre-visit work

An assigned care coordinator reached out and learned that VB's family had no means of transportation, the father had no work leave time, and their English was very limited. They would require the following supports to ensure a successful period of care coordination: a Medicaid cab, a car seat, a specific dialect translator, and a visit timed to the schedule of VB's father, as he does the communication for the family.

Phase 3: Population-based teamwork

The team members shared insights into Burmese culture and addressed the interventions needed to help the family attend a planned care visit (transportation, interpretation, safety, etc.). They reviewed the medical record and other documents and began to populate the medical summary.

Phase 4: Planned-care visit/SPoC “coproduction”

Using an open-ended, goal-directed interview, the clinician and care coordinator met with VB, his father, mother, their infant, and the Chin interpreter available through the health system. The team observed that VB is a bright, active boy and enjoys loving, engaged parents who work hard to navigate the American experience, while parenting VB and his infant sister. They are working to tackle VB's medical and developmental needs in spite of significant barriers.

The following goals emerged and were captured in an initial shared plan of care (including a medical summary and negotiated next steps): obtain outpatient habilitation therapy within the limits of the family's schedule and transportation access; get support to successfully navigate recommended evaluations and treatments while better understanding VB's needs; and establish adequate health care financing.

Phase 5: Ongoing care coordination and community transfer

A more complete SPoC was translated into Chin for the family's use and shared with partners across the family's care neighborhood (care map). The care coordination team worked with the family to address its goals and integrate care across VB's general pediatrician at a community health center, as well as with multiple specialists within the children's specialty hospital system (eg, physicians, technicians, schedulers, language services). The care team also coordinated with the state's Children's Special Health Care Services and the Bureau of Developmental Disability Services. As a result of continuous, ongoing care coordination, VB and his family accessed options for therapeutic interventions that meet the family's location, transportation, and schedule needs; achieved a neurology consult and 2 genetic assessments; successfully and independently initiated contact with the hospital's language line to maintain communication with the care team; and obtained diapers through Medicaid, which significantly helps the family's budget. The “locus” of care coordination was transitioned back to the general pediatrician and nurse manager, with translation support at the federally qualified community health center, which serves as the family's “medical home.”

A Few Other Implementation Lessons Learned

The results of implementation, including family goals, progress against those goals, and building of skills and confidence, are described in the above referenced paper.² Families and team members agreed that coproducing a shared plan of care was a win-win for all. Coordinating from family goals means everyone is working in agreement. The expression “it’s more fun” was frequently used to describe caring in this way. Care neighborhood partners stated they had better, more useful information, which taught them how to help families meet their needs.

Care coordination also served to integrate and inform primary care and various subspecialists, fostering communication with one another. Intention of purpose was a requirement, as was goal prioritization and persistence to achieve them. Families began to learn to use and refer to their SPoCs when speaking with primary and specialty care (and others) team members. Achieving a shared plan of care with children and families meant families, coordinators, and clinicians all learned from and taught one another. Learning is an essential element of a care coordinator’s role, and time must be dedicated to learning about families, specialists, systems, services, resources, changes, and communities. A part of team time can be devoted to learning and sharing; this builds infrastructure and spreads capacity.

Care coordination, when coproduced among families and health professionals as a team-based approach, drives better family-centered care, teamwork, care integration, and population health. Care coordination using this approach requires a learning organization environment using quality improvement strategies and studied implementation.

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