**Coordinating Care for Children with Genetic Disorders**

**Sharing Exemplary Practices from Primary and Specialty Care Providers**

A project of the Medical Home Workgroup of the National Coordinating Center (NCC) for the seven Regional Genetic Service Collaboratives.

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**ABSTRACT**

Twenty-four programs were nominated for providing exemplary care in coordinating services for children with heritable disorders. Individuals representing the programs participated in qualitative telephone interviews. The nominees represented a variety of primary care and specialty practices and community-centered programs. Key themes and strategies emerged from the interviews, several of which crossed settings – details are offered herein. Providing coordinated care is rewarding for the clinic staff and deemed valuable by patients and families, but it is time-consuming and not adequately reimbursed by third-party payers. Developing and maintaining committed staff and financial support are ongoing challenges for the programs interviewed.
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The NCC Medical Home Workgroup acknowledges the individuals who participated in these interviews for their tireless dedication to improving care for the patients and families they serve.

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Executive Summary

Objective
Through its Medical Home Workgroup, the National Coordinating Center (NCC) for the seven Regional Genetic Service Collaboratives (RCs) sought to identify exemplary care coordination and team-based care practices for children and youth with genetic conditions.

Methods
The NCC Medical Home Workgroup developed a “wanted” notice requesting nominations of clinics or programs that provide outstanding care coordination or team-based care. The notice was distributed via e-mail to members and networks of the seven RCs, the American College of Medical Genetics and Genomics (ACMG), the National Genetics Education and Consumer Network (NGECN, housed at Genetic Alliance), and the American Academy of Pediatrics (AAP). Thirty practices from across the country were nominated. Semi-structured, qualitative, one-hour telephone interviews were conducted with 24 individuals representing the programs willing to share their practices.

Results
The 24 participants represented primary general pediatric care (n=1), comprehensive programs that provide primary care for complex patients, including those with genetic conditions (n=4), specialty care (n=11), regional or community-based programs (n=7), and a center for fetal diagnosis and treatment (n=1). The specialty care programs all hold genetic disease-specific multidisciplinary clinics. The conditions treated by these programs include: 22q11 deletion syndrome; craniofacial disorders; cystic fibrosis; inborn errors of metabolism; neurogenetics; sickle cell disease; skeletal dysplasias; and Prader-Willi syndrome. The frequency of these clinics ranged from daily to less than one day per month. Seven nominated programs were regional or community-based organizations, including the national coordinating center for hemophilia treatment centers, a statewide genetics center, three community-based care coordination programs, and two patient education and support programs. Exemplary practices and factors that enable their success are discussed in this paper, along with common barriers, strategies for mitigating challenges, and policy implications.

Exemplary practices
- Foster interdisciplinary partnerships with subspecialists and clinicians to provide patient care and education.
- Develop community partnerships with agencies and organizations such as family support networks, coordination programs, Medicaid waiver programs, and home health programs.
- Create individualized and comprehensive care plans with input from multiple specialties to organize patient information and prioritize action steps.
- Conduct an educational forum for families and healthcare providers regarding transitions to adult care and encourage other clinicians, residents, and staff to attend.
- Employ quality improvement techniques to make incremental changes in the program.
- Manage patients who require coordination through a computer-based patient registry.
- Develop emergency plans and letters and implement mechanisms to ensure they are readily available to parents and healthcare providers in the event of an emergency or hospital admission.
- Create a hospital-wide anesthesia protocol for children with inborn errors of metabolism.
Exemplary Practices in Care Coordination for Children with Genetic Conditions

• Involve patients in shaping programs by including them on committees, advisory boards, or workgroups
• Provide patient education and support outside traditional clinic settings.

Supporting Implementation
• Obtain institutional support for program start-up and for components that are not paid for by third party insurance.
• Recruit and maintain staff who are passionate about what they do.
• Identify resources and tools that can be adapted to meet your program’s needs
• Communicate frequently as a team and meet regularly to discuss patients
• Strengthen your team through cohesion and good leadership
• Advocate for social workers – who bring key skills and perspectives – to be a core component of your team.
• Generate and share outcome data with your institution, other funders, and other programs.

Strategies for Overcoming Barriers
• Identify creative solutions to fund care coordinators’ salaries, including grants, institutional support, managed care pilot programs, philanthropic donations, and partnerships with community organizations.
• Measure your program’s return on investment.
• Develop metrics for patient outcomes and program impact and value.
• Improve relationships with administrators and clinical colleagues and generate support for the ongoing provision of coordinated care.
• Recruit passionate and organized staff to serve as care coordinators.

Discussion
Children and youth with heritable disorders often have multiple organ system issues and require care from several medical and therapeutic specialties, as well as community-based, social, and behavioral health services. Children and their families may also benefit from educational accommodations, recreational adaptations, financial advice/assistance, and other services. Care coordination aims to improve communication among providers and families, optimize access to and timeliness of care, eliminate duplicative and ineffective care, and enhance patient outcomes. While providing coordinated care is time consuming and not yet adequately compensated by third party payers, creative solutions for maintaining financial support exist. Those who coordinate services and provide comprehensive care for children with complex and genetic conditions are encouraged to collect and share process, cost, and outcomes data to support the spread and study of these approaches and the assessment of their value.

Comments from the Medical Home Workgroup
Our workgroup began this effort with a particular interest in care coordination by primary care practices and were surprised that only one was nominated, despite seeking nominations through distribution lists that included state chapters of the AAP and families of patients with heritable disorders. This might reflect the fact that insurance reimbursement for services in primary care generally does not include compensation for care coordination, as mentioned by the San Ramon Valley Pediatric Group. Most of our nominees received support from institutional resources, with the acknowledged intent to cover important services that could not be billed to patients or third parties. The sustainability of this form of support is unknown, as is whether evolving approaches to paying for health care, including Accountable
Care Organizations, bundled payments (e.g., episodes of care), or at-risk contracting will result in more primary care practice-based care coordination.

The goals of care coordination include optimizing clinical outcomes, optimizing use of available resources and services, and avoiding unnecessary, duplicative, and/or harmful services. It is generally assumed that another result will be a reduction of cost, though this is hard to prove, particularly for children who had not previously been receiving optimal care. The expenses for these children might reasonably be expected to rise as care coordination leads to a recognition of gaps in care and identifies opportunities to enhance function. We are aware of no studies that have addressed the long-term outcomes of effective care coordination for children with heritable conditions and we recognize the difficulties of measuring both outcomes and cost over the long time frames that would best assess the return on investments in children’s health.

Insurers may be reluctant to compensate for care coordination because of the lack of proven short-term financial benefit and because they are already providing case management services (generally focused on managing covered benefits rather than all the services from which patients might benefit). That the provision of case management/care coordination is a criteria for NCQA certification likely leads insurers to provide this in-house, where personnel and services can be easily managed, rather than pay for such services to be delivered by their numerous contracted primary care providers, who might each have only a few patients insured by that company who need substantial coordination.

Families often find themselves needing to coordinate their child’s coordinators – from insurers, home health agencies, Title V programs, disabilities waiver programs, etc. – leaving them frustrated and wondering about the value of care coordination services. Often families find that care coordinators in some of these agencies do not have adequate knowledge or understanding about the individualized care and services that a child with a heritable disorder may need. It seems to this workgroup that the best coordination would be provided by the clinical team with which the family/patient most closely partners in ongoing care. Over a lifetime, the primary care practice would likely serve as the source of care coordination. However, particularly for children with complex conditions, a specialty practice may be a better source, at least for some period of time or for a range of specialized services.

We recommend that families, advocacy organizations, disability specific organizations, government agencies, insurers, and professional organizations:

- develop a universal and/or broad definition of care coordination;
- promote and support ongoing implementation and improvement of care coordination services in clinical practices serving children with heritable conditions;
- support the development of tools, resources, and collaborations to enable such implementation and improvement;
- develop and implement measures to evaluate the long-term impact of care coordination on clinical, educational, social, and societal outcomes and costs; and
- work together on advocacy initiatives at both the state and national levels.
Introduction

Background
The cumulative number of children and youth with genetic disorders and the cost of their care are substantial, but difficult to assess. The prevalence of individual heritable conditions ranges from 1 in 11 to 1 in 20 for conditions like attention deficit-hyperactive disorder (ADHD) and asthma, where genetics play a substantial role, to 1 in 700 for Down syndrome, the most common chromosomal disorder, to 1 in 10,000 for phenylketonuria (PKU), the first condition screened for routinely in newborns, to 1 in 100,000 for Hurler syndrome, and to 1 in 2,000,000 for arginase deficiency. No study of the collective costs of these disorders has been published, but their significance is suggested by McCandless, et al., who found that approximately 71 percent of pediatric inpatients had an underlying disorder with a significant genetic component (McCandless, 2004). The heritable disorders of many children lead to multi-organ system issues that require management from multiple specialty providers. Caring for their related conditions often benefits from educational, social, recreational, financial, and other community-based services and resources. Advances in medical technologies and treatments over the past several decades have led to considerably improved health and lifespans for many patients with genetic conditions, as well as much greater and ongoing expenses and, as these children now frequently survive into adulthood, challenges for adult providers who are unfamiliar with their conditions.

Parents and families must coordinate the care of children with multiple needs through their life course but they may lack the knowledge and skills to do that well. Expert care coordination may optimize outcomes for children by improving access to care and beneficial services and resources and reduce costs by helping them avoid unnecessary, duplicative, and potentially harmful care. The American Academy of Pediatrics (AAP) describes a medical home as providing care that is "accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective." (2002) Care coordination is a major component of the medical home approach and has been shown to improve outcomes (Homer et al., 2008) and satisfaction for patients and their families. There is growing interest nationwide in care coordination as an integral component of comprehensive, high quality care for children with genetic conditions, as well as for the broader category of children and youth with special health care needs (CYSHCN). Most states’ Title V programs fund care coordination for CYSHCN, but these services, generally delivered by the Title V agency, are often limited by block grant or state funding (though several states have expanded such services by blending funds from Title V and Medicaid). Many insurers provide case management for enrollees with complex or chronic conditions, generally focusing on coordinating benefits and limiting excess cost. However, there are substantial barriers to integrating care coordination into primary or specialty care practices, where it might be most effective. A key barrier is the lack of insurer compensation for these services.

The National Coordinating Center (NCC) for the Regional Genetic Service Collaboratives (RCs), through its Medical Home Workgroup, sought to learn, from existing exemplary practices, how best to coordinate care for children and youth with genetic conditions and/or provide them with team-based care across specialties, disciplines, and settings. Whether accomplished through hard work, innovation, or the force of unique personalities, the NCC Medical Home Workgroup wanted to learn about approaches to care coordination that result in better communication, collaboration, and satisfaction among patients, families, and healthcare providers and that might serve as models or stimuli for other clinics and healthcare systems.
Data Source
The NCC Medical Home Workgroup developed a “wanted” notice that was distributed via e-mail to the seven RCs, the ACMG, the NGECN, and the AAP, for distribution to their membership and through their networks. Nominations could be returned via e-mail, fax, or by completing a form online in SurveyMonkey. Nominators could request anonymity. They were asked to include: the approach to care coordination or team-based care with genetic conditions that they believed was exemplary; what kinds of patients/families or population benefit from the exemplary practice; what kinds of clinicians, other professionals, organizations, or other entities are involved in the practice; and contact information for the nominee. Thirty clinics/programs from across the country were nominated. Nine of the nominees were primary care or complex care providers, and 19 were specialty care providers. Twenty-four clinics/programs agreed to participate in a qualitative interview.

Semi-structured qualitative telephone interviews, each approximately 60 minutes in length, were conducted with a physician or program coordinator from each of these 24 clinics/programs. Participants reviewed the questionnaire prior to the interview and provided: demographic data on the practice; the background and training of the care coordination personnel; business structure; approximate payer mix; and number of staff FTEs devoted to care coordination. The interviews were conducted by Natalie Mikat-Stevens, MPH who took notes on and recorded the calls. Natalie Mikat-Stevens received a BS from the University of Illinois in Urbana-Champaign and an MPH from the University of Illinois in Chicago in Maternal and Child Health. Natalie has a background in life sciences research and public health programs. While at the American Academy of Pediatrics, she managed the Genetics in Primary Care Institute, which focused on the education of the primary care provider workforce regarding new technologies and advances in genetics for the improved identification and management of children with heritable disorders. She is particularly interested in quality improvement and systems-level change for improved health outcomes. She currently works at the Center for Quality at University of Chicago Medicine as a Quality Improvement Manager.

During the interview, participants were asked to describe the practice for which they were nominated and offer advice to other clinicians or clinics that might want to implement the practice. In regards to their care coordination practice, respondents were asked about each of the following:

1) When did you begin?
2) How many clinicians and staff are directly involved?
3) What barriers have you overcome in initiating and sustaining the practice? 3) What barriers remain?
4) What benefits do you and your colleagues accrue?
5) What benefits do your patients/families accrue?
6) Do you bill for this service (If Yes, to whom or to what entities? Approximately what proportion of the associated costs are covered by the compensation received?) (If No, Are your related costs covered by other payment mechanisms, e.g., PMPM, global payments, etc.)?
7) How do you document the services provided?

The following overarching definitions were used to classify the practices into one of three settings for care coordination:

Primary Care – provides primary medical care, including programs that serve as medical homes for CYSHCN who are medically complex.
Specialty Care – provides medical care primarily for patients with genetic conditions and/or offers genetic disease-specific multidisciplinary clinics. In multispecialty clinics, patients meet with multiple specialists in one clinic visit.
Community and/or Region-Based Care – provide educational support or coordinated care and services, separately from the direct provision of clinical services, for a community or across a geographic region.
Results

Exemplary Practice Profiles
The 24 participants represented primary care (n=1), complex care programs that include primary care (n=4), specialty care (n=11), and regional or community-based programs (n=7) who provide care coordination services for children with heritable disorders. Appendix A provides a detailed summary of each of the practices interviewed, and summaries of the three main categories follow.

Table 1: Respondent and Practice Characteristics

<table>
<thead>
<tr>
<th>Category</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Respondents</td>
<td>24</td>
</tr>
<tr>
<td><strong>Respondent Type</strong></td>
<td></td>
</tr>
<tr>
<td>Physician</td>
<td>18</td>
</tr>
<tr>
<td>Genetic counselor</td>
<td>2</td>
</tr>
<tr>
<td>Nurse Practitioner</td>
<td>1</td>
</tr>
<tr>
<td>Program coordinator</td>
<td>3</td>
</tr>
<tr>
<td><strong>Specialty type</strong></td>
<td></td>
</tr>
<tr>
<td>Primary Care</td>
<td></td>
</tr>
<tr>
<td>Pediatrics (General)</td>
<td>1</td>
</tr>
<tr>
<td>Pediatrics (Complex)</td>
<td>4</td>
</tr>
<tr>
<td>Obstetrics</td>
<td>1</td>
</tr>
<tr>
<td>Specialty</td>
<td></td>
</tr>
<tr>
<td>Genetics</td>
<td>8</td>
</tr>
<tr>
<td>Other (hematology/neurology/craniofacial)</td>
<td>6</td>
</tr>
<tr>
<td>Community program</td>
<td>4</td>
</tr>
<tr>
<td><strong>Regional Collaborative (RC) Region</strong></td>
<td></td>
</tr>
<tr>
<td>New England Genetics Collaborative (NEGC)</td>
<td>0</td>
</tr>
<tr>
<td>New York Mid-Atlantic Region (NYMAC)</td>
<td>8</td>
</tr>
<tr>
<td>Southeastern Regional Collaborative (SERC)</td>
<td>6</td>
</tr>
<tr>
<td>Region 4</td>
<td>3</td>
</tr>
<tr>
<td>Heartland</td>
<td>1</td>
</tr>
<tr>
<td>Mountain States (MS)</td>
<td>2</td>
</tr>
<tr>
<td>Western States (WS)</td>
<td>3</td>
</tr>
<tr>
<td>National (Not applicable)</td>
<td>1</td>
</tr>
<tr>
<td><strong>Practice Size (Number of Physicians)</strong></td>
<td></td>
</tr>
<tr>
<td>0 (Not Applicable)</td>
<td>1</td>
</tr>
<tr>
<td>1–2</td>
<td>5</td>
</tr>
<tr>
<td>3–5</td>
<td>5</td>
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<tr>
<td>6–12</td>
<td>6</td>
</tr>
<tr>
<td>13+</td>
<td>7</td>
</tr>
<tr>
<td><strong>Primary Care Coordination Funding Mechanism</strong></td>
<td></td>
</tr>
<tr>
<td>Hospital Support</td>
<td>8</td>
</tr>
<tr>
<td>Grant or philanthropy Support</td>
<td>8</td>
</tr>
<tr>
<td>Clinic absorbs Cost (E.g., volunteer staff time)</td>
<td>5</td>
</tr>
<tr>
<td>Government funded (Title V, Military, etc.)</td>
<td>3</td>
</tr>
</tbody>
</table>
Primary care and primary care provided in complex care or other programs
Six clinicians who provide primary care were interviewed, including one general pediatrician whose practice includes a large number of patients with complex and genetic conditions. Four of the clinicians represented practices that serve as medical homes for CYSHCN who are medically complex, and one practice in a center for fetal diagnosis and treatment, providing prenatal care for mothers with babies with fetal anomalies and coordinating postnatal care for the infants.

Care coordination in primary care means managing the various contributors to the child's care, including subspecialists, therapists, and others, and helping patients and parents interpret the information they get back from specialty visits. The referral process for children who need to see multiple providers, sometimes at multiple tertiary care centers, involves a coordinator who can facilitate referrals with up to dozens of third party payers and schedule appointments.

Best practices in coordinating care within a primary care practice include:
• Maintaining a practice registry of CYSHCN;
• Providing family-centered care;
• Building care coordination into the medical home model and striving towards medical home accreditation;
• Increasing access to care and providing expanded appointment times and opportunities for patients to have direct telephone access to providers;
• Following up on referrals using an electronic “tickler” file; and
• Tracking referral information with checklists in patients’ paper or EMR charts

Specialty care

The 11 specialty care programs that were interviewed care primarily for patients with genetic conditions and held genetic disease-specific multidisciplinary clinics. The conditions cared for by these programs included: 22q11 deletion syndrome; craniofacial disorders; cystic fibrosis; inborn errors of metabolism; neurogenetics; sickle cell disease; skeletal dysplasias; and Prader-Willi syndrome. The frequency of these clinics’ sessions vary; while some of these practices provide multispecialty care daily, others did so only periodically, ranging from less than one to four days per month. In the multispecialty clinics, patients meet with multiple specialists in one clinic visit and are subsequently provided with a care plan, which is developed as a collaborative effort by the entire team. These clinical models were typically developed through institutional support as a way to provide exemplary patient care. Common characteristics of these specialty programs include:
• Development of patient and family support groups;
• Providing patient education outside of the clinic or in a focused program (e.g., on transition to adulthood) to enhance patients’ self-sufficiency;
• Maintaining strong ties to other disciplines to

“For rare condition we learn how to coordinate care through self-guided learning. In most situations, the child has already been seen by a genetic specialist and we get all relevant information from the specialists. I've learned that while I do not need to be an expert in that syndrome, I know which resources to reference to know the highlights for that syndrome. Often there are multiple specialists involved in the care, and we try to coordinate it. The parents get confused about who said what or what needs to be done, and they are getting overwhelmed. It is our responsibility as a primary care practice to figure out what is going on and help the families navigate their care. We’ve never given up and are always improving.”

– Tracy Trotter, MD, San Ramon Valley Primary Care Medical Group

Exemplary Practices in Care Coordination for Children with Genetic Conditions
enhance communication, but not necessarily having every specialty included as part of the core team;
• Developing comprehensive care plans with input from multiple specialties;
• Meeting frequently as an interdisciplinary team through team huddles and post-clinic conferences; and
• Providing the patients’ primary care providers (PCPs) with regular updates and a copy of the care plan and involving the PCP as much as she/he desires in the long-term management of the patient.

Regional and community-based programs
Seven nominated programs were regional or community-based organizations, including a national coordinating center for hemophilia treatment centers, a statewide genetics center, three community-based care coordination programs, and two patient education and support programs.

Care coordination activities performed by the staff vary based on the program and the needs of the patient. The following describes the structure of one collaborative community care coordination model:

“When children with complex conditions are admitted as in-patients, there is no care plan for the multiple physicians involved in the child’s care. A care coordinator can serve a critical role in compiling information and occasionally convening a family- or a physician-only conference. A care coordination team can provide continuity of care between the different hospitalizations and ensure that a high quality of care following discharge occurs. As the children return to the community, care coordinators facilitate communication with the PCPs and subspecialists, sharing key progress notes, lab/radiology results, etc. The care coordination model links between other clinics and services and fills gaps in communication and care management.”

Summary and Select Examples of Common Themes
The 24 programs highlighted care for a range of patient populations and represent a variety of specialties, clinical and geographical settings, and funding structures. Despite these differences, the programs share a common thread in that they all aim to provide comprehensive and coordinated care for children with genetic conditions in order to optimize their health outcomes.

In the following section you will find examples of strategies that the nominees have found to be effective, as described by the nominees themselves.

Exemplary Practices Identified
• Foster interdisciplinary partnerships with subspecialists and clinicians to provide patient care and education.
• Develop community partnerships with agencies and organizations such as family support networks, coordination programs, Medicaid waiver programs and home health nurses.
• Create individualized and comprehensive care plans with input from multiple specialties to organize patient information and prioritize action steps.
• Conduct an educational forum for families and healthcare providers regarding transitions to adult care and encouraging other clinicians, residents, and staff residents to attend.
• Employ quality improvement techniques to make incremental changes in the program.
• Manage patients who require coordination through a computer-based patient registry.
• Develop emergency plans and letters and implementing mechanisms to ensure they are readily available to parents and healthcare providers in the event of an emergency or hospital admission.
• Create a hospital-wide anesthesia protocol for children with inborn errors of metabolism.
• Involve patients in shaping programs by including them on committees, advisory boards, or workgroups.
• Provide patient education and support outside traditional clinic settings.

**Fostering interdisciplinary partnerships with subspecialists and clinicians**

• When initiating a multidisciplinary program, recruit as many interested clinicians and staff with whom to partner as possible. Establish collaborative relationships within the institution and the community.
• In providing patient education, it is helpful to partner with individuals from other disciplines, including psychology, social work, child life, and nutrition.
• Social work and nutrition schools may be able to provide student volunteers to assist with support groups and educational events.
• Younger staff or students are often able to provide fresh and creative ideas shaping your program. One program described their social work interns as invaluable because they have a vested interest in learning and contribute energy and creativity.
• Consider collaborating with clinics that are nearby and with whom you share patients to hold jointly sponsored educational or other outreach events.

**Developing partnerships with multiple stakeholders such as businesses, agencies, and community organizations**

• Having a multidisciplinary, coordinated approach to delivering care involves a lot of time, relationship building, and addressing problems not traditionally encountered in medicine. One way to identify creative solutions to problems that are encountered is to include individuals on your Board of Directors who do not represent traditional medical models.
• Local foundations may be able pay for additional services that families need (e.g., transportation).
• Care coordination programs tend to become isolated within the tertiary care hospital, so engage multiple stakeholders in program implementation and sustenance. Establishing connections with agencies and community organizations, such as family support networks, coordination programs, Medicaid waiver programs and home health nurses, increases opportunities to provide better patient care.

“There are two things that are unique about this center. In most places, patients might have to go to three separate clinics to see all of their providers. We have all of those people housed in one clinic and see patients together. We are able to communicate with each other well and everybody recognizes the entire picture for that patient. The second piece is the part involving transition of care for young adults. Many patients had heart repairs done as babies and when we first started the clinic we picked up a large population of patients from cardiology who had not been previously diagnosed with 22q11 deletion syndrome. There have been overtures with the adult providers so we can continue to care for the adult patients. It has been critical to find a good partner, someone who has a real interest in treating these patients as adults.”

– Lisa Kobrynski, MD, 22q Specialty Clinic, Children's
• Elicit help from the community you’re serving; for example, use trained patient-peer volunteers to work with your patients. Have the psychology department assist with screening and interviewing candidates.

Providing patients with individualized care plans and contact information for all specialists
• Create individualized and comprehensive care plans with input from multiple specialties to organize and prioritize patient information and action steps.
• In the care coordination plans (either in the EMR or on paper), list the patient history, demographics, specialists, hospitalizations, surgeries, and information regarding any medical equipment and medications. Include a section for goals and objectives regarding patient/family needs or required action steps and document the person responsible for those steps (nurse, case manager, etc.).
• After action steps on the care plan have been updated, provide patients with a copy.
• Provide patients with information regarding their subspecialists, including contact information and anticipated frequency of visits.

“Beginning transitions to adult care discussions early (12-14 years of age) and revisiting issues often
• Begin with a transition template that has already been developed; allow patients to modify this template as needed.
• Solicit feedback from patients regarding which resources they need and what questions they have regarding transitions to adult care.

We understand this is a lot of information [regarding transitions] that they are getting at one time, and some families aren’t ready emotionally to tackle the issue, because they haven’t gotten over their own challenges as parents in dealing with their child’s disability. Occasionally we will get a call from a family who has attended the forum but then they waited to take necessary steps. If they wait until the crisis situation then it can become very difficult to deal with some of the policies, especially the legal and financial ones.”
– Roger Akins, MD, Neurodevelopmental Pediatrics, Naval Medical Center Portsmouth

• Revisit the topic of transitions to adult care early and frequently. One program conducts a transition forum several times per year and encourages families to attend more than once during patients’ adolescence to increase their readiness for change.
• The Sickle Cell Transition Program at the University of Miami is composed of 10 modules, any of which may be repeated over the transition period. Modules may be conducted individually or in a group, are a combination of presentation and discussion, and several include guest speakers. Topics include: Health Promotion; Sickle Cell Disease; Transition to College: Genetic counseling; Social Work Evaluation; Psychological Evaluation: Second Session on SCD Education; Peer Tutorial; and “Passport” Summary and Transfer Care.

Involving patients in shaping programs
• Involve patients in shaping programs by including them on committees, advisory boards, or workgroups.
• Conduct satisfaction surveys to assess program effectiveness and make necessary adjustments.
Utilizing quality improvement techniques to make incremental changes

- Identify your target population, start with one or two changes, evaluate a few months later how these changes are working, and then move forward to the next changes. Involve all providers and staff members in care coordination; help them feel involved and accountable.
- Consider using the Medical Home Index (medicalhomeimprovement.org/pdf/CMHI-MHI-Pediatric_Full-Version.pdf) or a similar tool once a year to reflect on progress and future goals.

Maintaining and using a registry of patients who require coordinated care

- Manage patients who require coordination through a computer-based patient registry and update it at least annually (preferably monthly).
- When creating a patient registry, start with a manageable number of patients, such as those with metabolic conditions, and gradually increase the registry size to include patients with chronic conditions and other issues, e.g., children in foster care, who have significant care coordination needs.
- Keep children with chronic health problems who are doing well on the registry and check up on them annually.
- Integrate the social worker and/or case manager into the care of those patients who have psychological issues and significant stress as well as complicated medical issues.
- Provide each family with a binder to organize their health information. The binder should include information about diagnosis, medications, history, etc. from both the PCP and specialists involved in the care of their family member.

Creating emergency plans and letters to share with patients and EMR

- Provide patients with contact information for each staff person in your practice.
- The “Emergency Access Initiative” is a grant-funded opportunity that provides patients with emergency phone number to use in the event of an emergency, as well as a USB drive containing their emergency letter. The hospital EMR has an alert system so that the ER team will not miss the condition for these patients when they are admitted to the hospital and can check specific indicators for those patients. For any emergency plans that are developed, all of the notes are sent directly to the family, the PCP, and the school nurse.

Implementing anesthesia protocols for children with inborn errors of metabolism

- Through a collaborative effort, the metabolism/genetics and anesthesia teams in one children’s hospital have prepared a protocol that improves communication regarding the needs of metabolic patients (e.g., special medications, NPO recommendations, IV fluid recommendations) before, during, and after surgery. This communication occurs as a written pre-anesthesia communication note that is placed in the chart by the metabolism/genetics team using a standard template. The contents of the note are reviewed by the anesthesia team (and often discussed one-on-one with the metabolism/genetics team) during pre-anesthesia clinic visits.

“I provide my patients with my cell phone number to use in emergencies, and after 15 years it has only been used inappropriately once. Knowing my patients personally helps me manage them in a way that is less frightening for the patient.” – Ada Hamosh, MD, Institute of Genetic Medicine, Johns Hopkins
prior to planned procedures or as part of an inpatient anesthesia consult when emergent procedures are needed. All patients having planned procedures are referred for a pre-anesthesia clinic evaluation. This allows the anesthesia team to ask questions about the underlying disorders and special recommendations. The anesthesia team also communicates with the metabolism/genetics team following procedures to discuss the course of the procedure. The protocol includes guidelines for particular disorders, NPO guidelines per anesthesia, and contact information for both teams.

Providing patient education and support outside traditional clinic settings

- Consider alternative methods for providing education regarding condition management, transitions, or other topics relevant to your patient population. Often, meaningful education and adherence for these patients can't be achieved in a clinical setting.
- One program holds a 2.5-day “Boot Camp” for adult and adolescent patients with PKU to address psychosocial needs and provide education regarding diet, genetics, and other medical needs. The genetic counselors in this program are also initiating a telemedicine program for PKU patients, which will provide educational outreach to PCPs in remote areas.
- A number of disease-specific support groups exist that can provide patients and their families with emotional support and practical solutions for disease management. Providers are encouraged to connect their patients with appropriate patient support groups.

Providing patient-centered supports for long-distance patients

- If patients travel long distances to attend clinic and need to stay overnight, attempt to provide housing through a local Ronald McDonald House or other venues.
- Coordinate appointments so patients can have as much done as possible in one day.

Enabling factors to support implementation and sustainability
Implementing and sustaining the exemplary practices described above require creativity, innovation, and dedication. Respondents offered practical suggestions to improve the likelihood that their programs would be successful.

- Obtain institutional support for program start-up and for components that are not paid for by third party insurance.
- Recruit and maintain staff members who are passionate about their work.
- Identify resources and tools that can be adapted to meet your program’s needs.
- Communicate frequently as a team and meet regularly to discuss patients.
- Strengthen your team through cohesion and good leadership.
- Advocate for social workers to be a core component of your team; they bring key skills and perspectives.
- Generate and share outcome data with your institution, other funders, and other programs.
Strategy: Obtain institutional support for program start-up and for components that are not paid for by third party insurance

- Negotiate with the hospital administration when beginning a multi-specialty clinic and be persistent, as it could take several months or years until implementation.
- When making a case for providing care coordination or expanding programmatic services, demonstrate that improving care for a cohort of patients will keep them within your hospital system, which is ultimately advantageous for the hospital.

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“We have never had any major barriers because I keep in mind that I work for the hospital, and they either do or do not support the program. At times, we’ve needed to expand and the hospital has been resistant. If I can’t have what I’m asking for, if I can’t take care of more patients, then I ask “where can I send these patients,” implying that they will need to seek care elsewhere. Of course the hospital doesn’t want to lose any patients, so this is an effective strategy. The easiest way to overcome the obstacle is working with the administration to identify their expectations for your program.” – Michael Cunningham, MD, Craniofacial Center, University of Washington, Seattle Children’s Hospital

Lisa Kobrynski, MD, 22q Specialty Clinic, Children’s Healthcare of Atlanta at Scottish Rite

“One of the ways we were able to sell this to the hospital system is that we follow a very large cohort of patients. We have data on 400 patients with 22q11 deletion syndrome, and in the past we have used this data to collaborate with other departments, such as psychiatry and cardiology, on research projects, which helps with visibility for the school of medicine. We are a referral center from the Southeast (GA, AL, FL) because we have expertise in the care of these families. We follow patients from infancy through adulthood, and provide general anticipatory guidance that is tailored to the chronic disease, always incorporating best practices.” – Ada Hamosh, MD, Institute of Genetic Medicine, Johns Hopkins

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Exemplary Practices in Care Coordination for Children with Genetic Conditions
Strategy: Recruit and maintain staff who are passionate about their work

- Identify the non-physician players who will do the bulk of the work of coordinating services, facilitating communication, and gathering patient information.
- One of the biggest assets of any program that provides coordinated care is the passion that each team member has for treating and managing the patients. Developing a team that wants to be involved and cares about the mission and the goals of the program is key to a successful program.
- Obtain administrative support for involving other disciplines and specialties. The team needs to be dedicated, particularly the leader, so it is important to make sure you have time, both in- and out-of-clinic hours.
- Anyone who is passionate about taking care of people can learn this work. Finding dedicated team members who are willing to meet on weekends and after clinic is a core element of success.
- Provide adequate training to your staff and maintain high standards and expectations. Provide an environment that reduces staff turnover. Educating staff to understand the complications of the disorder and their role in prevention and patient interface is also critical.

“There isn’t a pipeline of physicians doing the work that I am doing. For nurses and social workers, it is hard to find the right individuals, as the team can get burned out fairly quickly. My advice for recruiting is to hire only people who are passionate about this population. If the candidate is looking to just fill a job, it is likely that they won’t continue. You also never know when someone will be a match or not. I found a very passionate person, but when it came down to doing the day-to-day implementation, she couldn’t do it successfully. So having staff who are organized, able to get things done, follow-up are important qualities. Social complexities of the families are enormous, and need staff that is resilient and tough. These individuals need to be able to work well in a team and collaborate with others. Staff need to be comfortable reaching out to others for help.”

– Savithri Nageswaran, MD, Brenner Children’s Hospital of Wake Forest Health Sciences

Strategy: Identify existing resources and supports, don’t reinvent the wheel

- Don’t reinvent the wheel. Find tools that will simplify and streamline the care coordination/referral services. Use existing resources for medical home development, including forms, checklists, electronic tools, and other resources from the American Academy of Pediatrics, American Academy of Family Physicians, NCC, and others.
- Some rare disease foundations will provide funding for staff to attend national conferences and trainings, sometimes in exchange for patient data. For example, the Cystic Fibrosis Foundation emphasizes staff training and has a formal mentoring program.
- Use grant opportunities to develop and sustain the program.

Strategy: Communicate frequently as a team and meet to discuss patient cases

- Meet regularly as a team, both to celebrate successes and identify failures.
- In a multidisciplinary clinic, meet weekly to review individual needs of patients with each provider and agree on a plan of care. Utilize care coordinators to facilitate communication between physicians.
Strategy: Build a cohesive team

- Leadership means empowering your team and staff and developing a system to sustain the program even if the original leader or champion is no longer a part of the program.
- Being a good leader means supporting your staff to achieve their goals and understanding that the success of the program relies on the collaborative successes of each team member.
- Develop a cohesive team through strong leadership. When your team isn’t cohesive, communication will suffer, your patients will notice, or the outcomes will be affected.
- Strong leaders know the success of their program will be measured by the accomplishments of their team, so they support their staff in achieving their individual goals.

“Overall, the secret to a strong team is not rocket science. Emphasize communication, and altruism. If staff is worried about their own success instead of the group’s success, that won’t lead to effective teamwork. Develop teams with real security and opportunities for professional growth, and that will keep the team doing well. If the team isn’t doing well, the families and patients will be getting mixed messages from providers. Need to buy into it, have someone in a leadership position that truly wants this, then it happens naturally. Many leaders are hung up on their own success but they don’t realize that you look the best when you make other people successful. I talk to everyone on the team about what they want, what they aspire to do.” – Michael Cunningham, MD, Craniofacial Center at the University of Washington, Seattle Children’s Hospital

Strategy: Social workers are essential to strong care coordination models

- Having a social worker as part of a care coordination program is the key to many programs’ success. Used effectively, social workers meet every new patient and are present at all subsequent visits for certain patients. This approach provides continuity of care and an understanding of family dynamics and is beneficial in improving adherence, management, and identifying contributing factors to poor health.

“At an annual progress meeting, we explained that we were drastically understaffed for social work. One of the VPs said that some hospitals don’t even have social workers. I responded with the argument that if they want our hospital to be ‘average’ then we don’t need social workers either.” – Michael Cunningham, MD, Craniofacial Center, University of Washington, Seattle Children’s Hospital

“Exemplary Practices in Care Coordination for Children with Genetic Conditions
Strategy: Generate and share outcomes data with your institution, other funders, and other programs

- Programs providing coordinated care should publish their outcomes. Insurance companies will increasingly be looking at science and gauging patient outcomes based on the literature.
- In the medical home community, it is not about stealing ideas; rather, it is important to share experiences, even failures. Programs learn through the successes and failures of others and benefit from sharing at national conferences.

Barriers to Coordination

Respondents described the challenges that they overcame or mitigated in implementing their programs and approaches to care. The most commonly mentioned challenges included:

- funding care coordinators’ salaries;
- maintaining support from hospital administration;
- inconsistent and unsustainable grant funding;
- finding the right staff and individuals to do this work;
- the expense and time needed in order to providing good coordination of care;
- a lack of metrics for patient outcomes and measuring impact and value;
- resistance to change; and
- obtaining physical space for multidisciplinary clinics, especially as they grow in volume.

Many challenges were overcome, in particular those relating to interpersonal communication and generating initial support and logistics. However, significant barriers resulting from the broader healthcare system remain. “Providing coordinated care is time consuming and expensive. In the multidisciplinary clinics, each patient may have a 4-hour visit with five or six different specialties. This is expensive, and the biggest challenge going forward is to show that there is value in this approach” - Cathleen Raggio, MD and Jessica Davis, MD, FACMG, Kathryn O. and Alan C. Greenberg Center for Skeletal Dysplasia, Hospital for Specialty Surgery.

“Showing the outcome for one good care letter, which results in better patient compliance and better outcomes, is key. People don’t understand that if you have a specific multi-organ specialty disorder, it is so important to get as much done in one day, especially managing the logistics, managing the patient’s pain for the day, etc. This type of center should be a model for the way care is delivered and we need to break down barriers in healthcare systems and with insurance companies to facilitate it.” – Cathleen Raggio, MD, Kathryn O. and Alan C. Greenberg

Several participants primarily serve a vulnerable patient population who face social issues, such as poverty and access to care and health insurance. Having a social worker as part of the team is critical to ensuring health outcomes are optimized. Another challenge with transitions to adult care is ensuring continuity of care given the lack of case management and social work on the adult side. “For vulnerable populations and youth with complex conditions, a successful transition to adulthood is not achievable without a team approach. There needs to be more hands-on time to support the patients when they go through this time period.” - Ofelia Alvarez, Pediatric Sickle Cell Clinic, University of Miami Hospital.
Financial
The most frequently mentioned financial barrier was the lack of support for staff to perform care coordination activities. Some programs were able to hire staff, including social workers and case managers, through grants, while others successfully advocated for existing staff to have protected time to perform care coordination activities (ranging from 0.05 – 0.5 FTE). Those that were able to obtain staff did so by demonstrating to their administrators that having dedicated staff to support their patients’ needs would improve health outcomes and increase the likelihood that the patients would stay within the hospital network. However, other programs have not yet been able to meet their staffing needs; in these situations the sustainability of care coordinating activities is dependent on the donated physician and staff time, which, in turn, is dependent on the passion of existing staff. When one program wanted to start having an in-patient service as part of their center, they bargained to give a lecture a week to the residents in exchange for two third year residents to staff the outpatient clinic. Some programs provide publications and other academic incentives that are deemed beneficial by the institution in exchange for needed resources.

The principal remaining barrier was compensation for the time needed to provide coordinated care, including time spent managing patient care and developing care coordination plans (which can take 45 minutes or longer each) and to counsel and educate patients. A lack of pre-authorizations for genetic tests was also mentioned as a challenge. Some respondents receive no third-party reimbursement for their services. There is also inadequate reimbursement for palliative care for children. Decreased access to care within managed care organizations is another ongoing challenge.

Finally, the cost to patients was mentioned as a barrier. With fixed annual funding, many programs have needed to trim their budgets without cutting services to families. Several programs maintain a pool of funds to assist their most needy families to pay for necessary health care services.

Communication
Communication within the organization as well as across specialties was initially a major barrier to establishing the programs, but have commonly been resolved through patience, persistence, and a focus on establishing better relationships. Respondents described overcoming barriers to communication through meeting with administrators, developing clear goals for improved communication across specialties, and providing education to staff and clinicians throughout the institution on the program/practice/policy that had been established. Often different specialties use different terminologies; clarifying these differences and understanding how to improve communication with each other can be quite valuable. Some practices engage in ongoing education of providers in the region about the services they provide, as well as what constitutes an appropriate referral.

Logistical/Structural
Several respondents described the logistical and structural barriers they face, including lack of physical space, time, and general clinic flow issues. Lack of time encompassed several issues, such as time needed to develop care plans and to communicate with patients. Organizing key details, such as efficient provider workflow during clinic, managing the EMR systems for reporting and data polling, developing written procedures, patient scheduling, and obtaining pertinent medical records in advance of the clinic were mentioned as key components to running a smooth clinic.
Staff and Resources
Many programs overcame issues related to staffing and resources. In addition to finding the right staff, several programs were able to identify key partners and resources, including guest speakers, educational materials, and models. Program staff needed time to become familiar with existing resources, to better understand the role of genetics in prevention, and to research the multiple issues involved in the transition process.

In addition to justifying the need for funding to bring on care coordinators and social workers, participants described the challenges of identifying the right staff. “For these families, this program is their medical home, when the other places don’t necessarily want to take care of their kids. We haven’t had a problem justifying the need to hire staff; instead, the challenge has been about finding the right people.” Kathryn Scharbach, MD, LINCS, Children’s Hospital at Montefiore.

Institutional Buy-In
Obtaining and maintaining institutional support was a challenge for many programs. Programs needed to combat skepticism and raise awareness of the importance and value of coordinated care. Current metrics of patient satisfaction, which drive some institutional perspectives, seem not to assess the absence of services that patients are unaware might be offered. Cost metrics are limited by access to data. Provider organizations generally know only about the services they provide and the related costs. Insurers know much more about total expenditures, but very little about clinical outcomes. Collaboration among providers and insurers to optimize care and outcomes while avoiding unnecessary costs may be coming, but seems a long way off. In the meantime, programs caring for children with complex heritable disorders are left to develop and support care coordination services with limited resources.

Patient barriers
Respondents mentioned several patient-related barriers, including cultural myths regarding genetics in the Latino community, readiness for change, and geographic access. Inability to speak English (and programs’ lack of Spanish- or other language-speaking staff) seems to be an increasing issue, despite interpretation services. Readiness for change is particularly important as regards the transition to adult care; planning for transition can take years, and families may not decide to follow through on necessary action steps until late in the process. Access to care at specialty clinics due to distance is a significant challenge for many patients. Insurance issues are a huge barrier and a common cause of fragmented care.

Perceived Patient and Provider Benefits to Coordinating Care
Participants described coordinated care for children with heritable disorders as a higher standard of care. Many of the programs experienced significant challenges in implementing their programs, but once programs were functioning in a multidisciplinary, coordinated fashion, staff were highly motivated to seek creative ways to sustain their programs.

Provider Benefits
Nearly all interviewees described two major personal benefits of coordinating care for their patents: 1) the intrinsic satisfaction of providing better care and 2) improved communication and relationships with families and other providers. Working as part of a team increases knowledge, as providers learn from...
each other and draw from the expertise of other team members. For those in diagnosis-specific clinics, working with a small number of patients who are seen frequently allows staff to get to know them and their families well and to share in their journeys.

Better communication among providers was recognized as contributing to improved patient care, as well as to rewarding professional relationships. Several respondents mentioned enhanced efficiency and less frustration once consistent communications were implemented and relationships established. Parents’ appreciation for, and often surprise about, physicians talking to one another reinforces the practice. Such communication also translates into team members feeling supported by each other.

Coordination among medical providers can set the stage for engaging other providers and disciplines. For example, one program partnered with the Department of Social Services (DSS) and their local department for children in foster care. Their collaboration with the staff in these systems and their sharing of children’s comprehensive care plans are helping with the placement of these children.

**Patient Benefits**

Coordinating care for children with genetic conditions is key to providing patient-centered care. For children with complex, multi-organ system issues, successfully navigating systems of care is time-consuming, stressful, and, at times, may make a huge difference in clinical outcomes. The practices highlighted in this report described several categories of benefits that patients received, including: improved patient outcomes; increased access to care; increased knowledge/competence; improved quality of care; and convenience. Increased access to care for several practices meant providing their patients with 24/7 access to a provider.

Improved patient outcomes included keeping the children at home and out of the ER and hospital as much as possible. One such strategy included using telemedicine capabilities with a home-visit nurse during the winter. Several respondents reported being able to: deliver care with higher safety standards and coordination across specialties; provide continuous care; ensure a high level of complex, sophisticated decision making, diagnosis and treatment; and avoid duplication of services.

Another patient benefit was increased knowledge and competence in self-management. Several programs discussed how providing education about their patients’ disorders and guidance about navigating various systems of care and advocating for their own health was invaluable to the patients and their families. Coordinating care for children with heritable disorders often involves coordinating across many systems of care. This includes parent-to-parent social support opportunities, educational support, and community resources and services.

Patients with heritable conditions and their families are often isolated from each other and do not know another person with their condition. Specialty clinics offer the opportunity for patients to develop social networks that promote peer learning and teaching and to gain confidence in their ability to manage their conditions.

The emphasis on education and competence in care management becomes even more critical during adolescence and is crucial for enhancing patient outcomes during adulthood. Often families are confused about where to begin with planning for the transition. Having clear conversations and providing an action plan is a key to success.
Development of several of the multi-disciplinary programs highlighted in this report was spurred by patients detailing what had not been working well in their care. Scheduling multiple provider visits during a single clinic visit is a component of coordination that can substantially help families. The need to take time off from work and/or school and to travel long distances to see specialists (sometimes across state lines), can be a major barrier to receiving optimal care. The kind of communications made possible when clinical teams can meet during or after a patient’s visit can enhance both efficiency and quality of care.

Policy Recommendations
• Develop and provide effective incentives for PCPs or specialists to take on complex patients and support delivery of integrated care to this high-risk population.
• Develop robust outcome measures to assess the value of coordinating care, including the benefits to both providers and patients.
• Encourage clinical genetics programs to expand beyond diagnostic clinics and support disease management through focused clinics or educational programs that enhance the ability of PCPs to provide comprehensive care for children with heritable disorders.
• Limit barriers to insurance coverage for genetic testing and counseling by working with experts to develop guidelines for testing and, as the science evolves, periodically reevaluate those guidelines.
• Develop and implement strategies to mitigate potentially devastating financial burdens on families of children with complex heritable disorders.
• For states that did not expand Medicaid with the Affordable Care Act, develop provisions to ensure that young adults who have chronic health conditions, but are not disabled, continue to receive access to healthcare.
• Support improved access to behavioral health services, including social work, for children with complex heritable disorders and their families.

Conclusion
Children and youth with heritable disorders often have multiple organ system issues and require care from several medical specialties and therapies. Managing the child’s care can be challenging for families and providers. The need of many individuals for other services and resources – social services, behavioral health, educational accommodations, recreational adaptations, financial advice/assistance, and more – presents further challenges to achieving coordinated care. Care coordination aims to improve communications among providers and families, optimize access to and timeliness of care, eliminate duplicative and ineffective care, and enhance patient outcomes. Parents of children with complex and heritable conditions often become experts in their child’s condition and are ultimately responsible for managing their child’s care, including coordinating their coordinators. Providing coordinated care is time consuming and not yet adequately compensated by third party payers; maintaining financial support is an ongoing challenge faced by many programs. Those who coordinate services and provide comprehensive care for children with complex and genetic conditions are encouraged to collect and share process, cost, and outcomes data to support the spread and study of these approaches and assessment of their value.
Appendix A: Participant Profiles

Primary Care
Six clinicians who provide primary care were interviewed, including one general pediatrician whose practice includes a large number of patients with complex and genetic conditions. Four of the clinicians were from clinics that serve as medical homes for medically complex children and youth with special health care needs (CYSHCN), including many with heritable disorders.

San Ramon Valley Primary Care Medical Group (WS)\(^1\)
This private clinic provides care coordination for patients with complex conditions or special health care needs. Since 1981, when the founder was a solo practitioner, the practice has grown to include eight pediatricians and two pediatric nurse practitioners. The clinic expanded into adult medicine 15 years ago with the addition of two internists and now includes five internists and a family physician.

The clinic absorbs the costs of care coordination, which have been non-reimbursable in their market. For this clinic, care coordination for children with genetic conditions means managing the various players involved in their care, including subspecialists, therapists, etc., and helping patients and their parents interpret the information received from specialty visits. A referral coordinator works with more than 30 payers, coordinates multiple referrals, and facilitates processes as needed, which may include scheduling appointments. Over the last 10 years, two staff members (one full-time referral coordinator and about 20 percent of a nurse practitioner’s time) have become adept at this. The latter uses an electronic tickler file to follow up on referrals; it prompts her to look for a consult letter/report, which she then ensures that the responsible physician reviews.

“It enhances patient care dramatically. One of the greatest anxieties for CYSHCN is coordinating appointments. We explain to them that, while they are going to have multiple expert physicians, we also need an expert parent. I’ll tell the parents, “All of the specialists know pieces of the kid, and our job is to coordinate all of the pieces. We’ll talk about your priorities right now, so we can do what is reasonable.” This means taking the burden and saying, “I’ll share it with you,” and sometimes that involves making their appointments.”

Beacon Program at Children’s Mercy Hospital (Heartland)\(^2\)
This clinic was initiated in late 2013 by the Division of General Academic Pediatrics within Children’s Mercy Hospital in Kansas City and in 2014 received a Centers for Medicare and Medicaid Services Innovation Center (CMMI) Coordinating All Resources Effectively (CARE) Program grant to deliver coordinated care for complex pediatric patients. The clinic operates within a referral-based network and uses a complexity scoring system, based on a standard one-page referral form, completed by the primary care clinician and scored by program’s team, to determine patient eligibility. The clinic provides primary, team-based care for nearly 200 medically complex children and their siblings and offers 24/7 direct phone access to a Beacon provider.
The CARE Program is a demonstration project funded by CMMI to inform sustainable change in the care of children with medical complexity (CMC) through new and innovative care models and payment reform. At the core of the new care model is a tiered system through which CMC receive care coordination and management from a hospital-based complex care program or a community-based pediatric practice, depending on their health status and the complexity of their care. Community practices participating in CARE work closely with a practice facilitator to personalize the model for their practices and providers.

The Beacon Program approach provides: a patient-centered medical home; weekly case conferences; coordinated appointments with other specialties; inpatient consults and follow-up; sibling care; and home visits. Home visits are provided for patients who have hospice care or are unable to travel due to physical limitations. In those cases, Beacon providers go to the patient’s home to conduct what is essentially the same as a clinic visit. In the near future, Beacon anticipates conducting in-home illness visits, so that the most technology-dependent patients can stay at home and a nurse tele-facilitator can conduct the visits there via telemedicine. Through the CARE grant, Beacon providers are also beginning the co-management of patients being seen by community providers outside the metropolitan Kansas City area. Visits for those patients will be conducted by telemedicine at facilities that are close to them.

“Having access 24/7 to a provider is exceptional for these patients. The patients have a whole team of people who are dedicated to them. We are involved in every aspect of their care and can help build that trusting relationship with them. We offer to follow their siblings as well. It is very family-centered. All of our families have our email addresses with signed email consents and access via the patient portal so they are able to contact us. But if it is urgent, they know they need to use a phone call to reach us immediately and that a provider is available 24/7.”

Linking Individual Needs of Children with Services (LINCS) at the Children's Hospital at Montefiore (NYMAC)

Linking Individual Needs of Children with Services (LINCS) serves as a primary care clinic for nearly 300 medically complex children and their siblings. This hospital-based program in the Bronx, New York, uses extensive care coordination and a multidisciplinary team-based approach to address the medical and social needs of its patients, 95 percent of whom are Medicaid recipients.

The program’s structure has evolved over approximately two decades. The program was begun as a two-hospital partnership by developmental pediatricians for children with perinatally-acquired HIV and developmental disorders who were in need of ongoing and coordinated care. In fact, the program was a medical home before the medical home concept was widely accepted. When Montefiore Hospital and Jacobi Hospital split, the program at Montefiore continued to grow into its current role as a medical home for children with complex conditions. As the services offered to children at Montefiore expanded, LINCS has continued to evolve. For example, now that Montefiore does pediatric heart transplants, these patients receive ongoing care from the LINCS team. The clinic coordinates all care for children with complex conditions, including those with defined genetic disorders and those whose health issues have a genetic component. Program staff work with the children’s parents, schools, geneticists and other specialists, as well as with in-patient care if a child is admitted to the hospital.
The LINCS program includes three physicians, a nurse, a social worker, and a patient representative/case manager who provide team-based care. The team meets once a week before clinic to discuss patients in the following priority order: high-risk patients (as defined by the Administration for Children’s Services and Department of Children and Families criteria for social service involvement); children whose parents have any type of limitation; patients on home hospice and palliative care; inpatients; new referrals; and other patients.

The clinic attributes its success to its social worker who coordinates care and services. A clearly defined protocol is used to assess the level of social work involvement each patient/family requires. High-risk children are seen by a social worker at every visit. Other patients see a social worker on a case-by-case basis. The social worker also communicates with local agencies as needed to ensure all relevant patient and family issues are identified. In certain cases, in-person meetings between the LINCS team and relevant community agencies (such as the Administration for Child Health Services, preventive care, etc.) are held at the clinic.

**Medical Home Project at the Child Health Clinic, Michigan State University (Region 4)**

The Child Health Care Clinic at Michigan State University serves as the medical home for many patients with complicated medical problems. Its patients are referred from the hospital’s newborn intensive care unit (ICU), pediatric ICU, and pediatric floor, as well as from physicians in the community. In 2006, the practice received funding from Michigan’s Title V program to establish a family-centered medical home for CYSHCN as a demonstration project. This funding allowed the practice to hire a social worker and a nurse coordinator, who use a computer-based patient registry to support care coordination. Clinic staff develop care plans and provide families with a binder containing relevant medical information. Transition planning begins at age 14. Since its inception, the program has sought parental input through ongoing meetings of its parent advisory group and yearly parent focus groups.

In 2014, the Health Team Child Health Clinic was selected to participate in the Michigan Primary Care Transformation Project (MiPCTP), a medical home demonstration funded by Medicare, Medicaid, and a few commercial insurance companies. This enabled the clinic to add a nurse case manager to its team. The goals of MiPCTP include evaluating the impact of coordinated care using a population-health design and identifying effective strategies to optimize patient outcomes.

“For rare conditions we learn how to coordinate care through self-guided learning. In most situations, the child has already been seen by a genetic specialist and I get all of the information available from the specialist. I’ve learned to go to different websites to learn more about the metabolic and genetic disorders we see in our patients. I don’t try to be an expert in each syndrome, but rather to familiarize myself with the highlights of the disorder. With multiple specialists involved in patient care, we try to coordinate it in a way that minimizes confusion for the parents. The parents may be overwhelmed with information, and it is our responsibility as a primary care practice to figure out what is going on and help the families through it. We’ve never given up and are always improving.”

**Premier Kids Program at La Rabida Children’s Hospital (Region 4)**

The Premier Kids Program began in 2005 when the medical director recognized a gap between the healthcare services children with multiple medical problems needed and those they were
The program initially focused on children who did not qualify for NICU follow-up and thus not did not receive critical care coordination and services. The program expanded almost immediately after its inception to include not only children born prematurely, but all children with complex medical problems, multisystem disorders, genetic disorders, and developmental disorders.

The program began with a grant from the Illinois Chapter of the American Academy of Pediatrics to La Rabida Hospital and a promise from the hospital administrators that they would continue to support the program if needed. The program organized a one-stop shop for care that included nutrition, dietary, developmental, and psychosocial services, nurse case management, and social work. Program staff knew little about the medical home concept then, but they embraced it; it has guided their provision of coordinated care for medically complex children, many with genetic disorders.

The program provides comprehensive, multidisciplinary, and primary care for medically complex patients from birth through age six. Interdisciplinary team meetings are held two to three times per week with a physician, nurse case manager, registered dietician, infant developmental therapist, social worker, volunteer, and family advocate and focus on coordinating medical and rehabilitative care and educational needs. Any child who “graduates” from the program can keep her/his primary care doctor as her/his medical home.

**Specialty Care**

Eleven nominated specialty care programs that care primarily for patients with genetic conditions hold genetic disease-specific multidisciplinary clinics.

**Neurogenetics Clinic, Children’s National Medical Center (NYMAC)**

The multidisciplinary Neurogenetics Clinic at the Children’s National Medical Center (CNMC) has several roles. It is a diagnostic clinic that also helps children with neurogenetic issues navigate the medical system. It also identifies and notifies patients who are eligible to participate in internal CNMC protocols and provides patient and caregiver education.

Twice each month, the clinic sees patients for team-based care; patients are able to meet with all their providers during a single clinic visit. New patients are slotted for an hour-and-a-half visit. The clinic director is boarded in child neurology, genetics, and developmental pediatrics, and other team members include a genetic counselor, a nurse practitioner who is also a care coordinator, a developmental pediatrician, a speech and language specialist, medical residents, genetics fellows, and a research assistant who manages the clinical database and enrolls patients in clinical trials. There are additional ad hoc specialists that work in the clinic on occasion, including a neuro-ophthalmologist, an autism developmental specialist, complex care physicians, genetics fellows, speech and language pathologists, and general pediatricians. A patient navigator works with the neurogenetics team, and the genetic counselor also assists with pre-authorization for genetic testing. Patients and their family may participate in a biorepository study of biological samples and a speech and language database, as well as gain information about departmental studies of mitochondrial disease and urea cycle disorders.
Prior to the semi-monthly clinic, team members communicate extensively with each other and develop a medical summary for each patient. The team decides which providers need to see each patient and in what order, and cases are assigned to the resident and fellows rotating in the clinic to review. A pre-clinic conference, which includes a radiology review, is held just before the clinic. Following the clinic, one person is in charge of reviewing the notes. The program maintains a database of all testing and referrals, which guides development of a summary of tests and recommendations; this summary is given to each patient/parent and sent to her/his primary care provider.

The Neurogenetics Clinic provides comprehensive, team-based care that helps eliminate duplication of resources and is provided by individuals who work well together. The program director believes that the key to a successful multidisciplinary neurogenetics clinic is access to an interested and available neuropsychologist.

Institute of Genetic Medicine, Johns Hopkins (NYMAC)\textsuperscript{10}

At the Johns Hopkins Institute of Genomic Medicine, interdisciplinary care is coordinated across settings for patients with genetic disorders and multiple organ system issues. The program was structured as a consultative model until 2004, when the practice was converted into a primary care model. New patients are seen quarterly for the first year and then every two years, unless a new issue arises. Very stable patients are seen every three years.

The clinic provides comprehensive, continuous, and patient-centered care across the age span. Care teams provide services for several specialty genetics clinics, which include: general genetics, inborn errors of metabolism, lysosomal storage disorders, connective tissue disorders, and skeletal dysplasias. For each clinic, a member of the team is designated as the care coordinator. This person is responsible for conducting all patient follow-up, scheduling services, and providing care plans, assistance with transition to adult care and other services as needed to the child’s school and primary care provider. The program hired a nurse practitioner to support coordination of care. This position is funded by the hospital with the expectation that patients receiving coordinated services will be more likely to stay within the hospital system and use other billable services.
Cystic Fibrosis Program, Kaiser Permanente-Northwest Region (Western States)\textsuperscript{11}

The Cystic Fibrosis (CF) Program at Kaiser operates as an independent affiliate of Oregon Health and Science University. The CF program serves approximately 70 patients, offering same-day appointments and 24/7 access to an on-call clinician. The clinic provides comprehensive, interdisciplinary care for patients with cystic fibrosis in both the clinic and the hospital. Program staff include two general pediatricians, two adult pulmonary critical care physicians, a nurse practitioner, a social worker, a dietician, one respiratory therapist, a medical assistant, and a data coordinator. Team members are physically together one day a month for multidisciplinary clinic, but communicate frequently through their EMR when not physically together. Care coordination activities are primarily performed by the clinic coordinator/nurse practitioner and the social worker.

The social worker also coordinates a monthly family support group that is highly regarded by the community and is very well attended. She holds web-based support groups for adults living with CF, as they are not permitted to be in the same room as each other for reasons of infection control. The clinic started a CF Patient and Family Advisory Committee in 2008; this was the first group of its kind to be developed at Kaiser Permanente NW. The group provides valuable patient and family perspectives on the experience of attending the Kaiser CF clinic and has fostered a valuable partnership between providers and families. The CF Patient and Family Advisory Committee has developed a bi-annual newsletter that provides information and support to the CF community served by Kaiser.

Other successful initiatives include holding an annual patient and family forum and improving BMI and nutritional status in CF patients, which has, in turn, resulted in improved lung function and well-being. The Kaiser Permanente CF clinic director spearheaded support for newborn screening for CF in the state of Oregon in 2006, before other states were doing it. As a result, the program has been able to diagnose CF earlier, before symptoms develop and to focus on prevention and improving outcomes. The clinic has also worked on improving adherence to medication and treatment regimens.

Pediatric Sickle Cell Clinic, University of Miami Hospital (SERC)\textsuperscript{12}

The Pediatric Sickle Cell Clinic at the University of Miami Hospital provides comprehensive, multispecialty care coordination for children and young adults with sickle cell disease (SCD). Patients with SCD have a much higher mortality rate in their early twenties than in childhood. To improve health outcomes for young adults with SCD, the medical director of the program developed a formal, 10-stage transition to adult care curriculum for adolescent patients. The curriculum is individualized for each patient, and modules may be repeated if necessary over a period of transition that usually takes several years. The 10 modules cover topics that include; health education and promotion; transition to college; genetic counseling; social work; psychology; peer tutorials; managing the health insurance world; and introductions to the adult hematologist who will take over their care.

Craniofacial Center, University of Washington, Seattle Children's Hospital (Western States)\textsuperscript{13}

The Craniofacial Center at Seattle Children’s Hospital provides comprehensive, team-based care for children with complex and chronic genetic disorders, managing and coordinating outpatient...
care, as well as inpatient care and surgical procedures. Its goal is to improve outcomes and quality of life for patients and their families. The Center’s large multidisciplinary team values the input of each provider, regardless of his/her discipline. The team communicates about each patient through written notes on the day of clinic visits with multiple providers or through in-depth discussion during a conference involving all members. The same providers care for patients during inpatient and outpatient visits, providing continuity of care that is valued by families. Each patient is assigned to a general pediatrician who has had additional training in craniofacial medicine or genetics and brings both perspectives to discussions about surgical recommendations. The pediatricians also provide comprehensive perspectives on the needs of the patient and family to discussions with the entire craniofacial team.

Patients with conditions ranging from cleft lip and palate to syndromic craniosynostosis benefit from this center. Because Seattle Children’s cares for children from the Washington, Wyoming, Alaska, Montana, and Idaho (WWAMI) region, families in remote Alaska receive the same consideration and care as families from Seattle.

**22q Specialty Clinic, Children’s Healthcare of Atlanta at Scottish Rite (SERC)**

This program serves as a medical home for pediatric patients with 22q11.2 deletion. The clinic was created in 2006 to help address the complex medical needs of these patients and to create a multi-disciplinary environment for studying associated medical issues. Extensive collaborations were formed with several School of Medicine departments, beginning with pediatric gastroenterology and endocrinology. Close interactions with other departments, such as cardiology and the craniofacial clinic, give the program the ability to provide optimal care to patients who have multiple medical needs.

“One of the ways we were able to sell this to the hospital system is that we follow a very large cohort of patients. We have data on 400 patients with 22q11 deletion syndrome and, in the past, we have used this data to collaborate with other departments, such as psychiatry and cardiology, on research projects. This helps bring visibility to the School of Medicine. We are a referral center for the Southeast (GA, AL, FL) because we have expertise in the care of these families. We follow patients from infancy through adulthood and provide general anticipatory guidance that is tailored to the chronic disease, always incorporating best practices.”

**Anesthesia Guidelines for Patients with Inborn Errors of Metabolism, Baylor College of Medicine/ Texas Children’s Hospital (Mountain States)**

The Baylor College of Medicine/Texas Children’s Hospital’s anesthesia guidelines for children with inborn errors of metabolism has improved care coordination for children with genetic disorders. The guidelines were developed because of confusion that too often resulted from a lack of communication between the metabolism/genetics team and the anesthesia team regarding the special needs of patients with inborn errors of metabolism in the peri-operative period.

Since they were put in place two years ago, the guidelines have been used in more than 30 patient encounters. Overall, the guidelines have led to improved communication among all providers involved in the peri-operative care of these children and have resulted in improved patient safety. This model has also been adapted (e.g., as a written note) and used for
Appendix A: Participant Profiles

communication with external anesthesia and surgical teams when patients from the metabolic clinic have surgical procedures or require sedation at other medical institutions.

Kathryn O. and Alan C. Greenberg Center for Skeletal Dysplasia at the Hospital for Specialty Surgery (NYMAC)\textsuperscript{21}

The Kathryn O. and Alan C. Greenberg Center for Skeletal Dysplasia exists within the Hospital for Specialty Surgery, a freestanding orthopedic hospital in New York City. The center was started in 2003 to provide an accessible, comprehensive, holistic program for patients with skeletal dysplasias. The Center is driven by the premise that care should be patient-centered and research driven and focus on the education of patients and of the medical community.

The Center began with a nucleus of providers: a clinical geneticist; a genetic counselor, who also serves as a coordinator; and a social worker, who conducts clinical nutrition/psychosocial assessments. Because patients with skeletal dysplasias are now surviving into adulthood and finding no medical professionals with training or experience to provide them expert care, the core team expanded to include cardiologists, foot specialists, and other physicians. The Center serves as a hub for care coordination and as a medical home for their patients.

The program meets formally on Mondays, when patients are seen in the morning by the entire team of five providers/clinicians; the team conferences in the afternoon. In the case conference, patients are discussed and care plans are updated. Patients receive a three-page letter summarizing their visit and indicating which appointments need to be coordinated. If the patients are local, the coordinator will make the appointments, which could include cardiology, pulmonology, urology, sleep studies, EMT, MRIs, blood tests, metabolism, etc. The Center cares for 400 patients of all ages (55% are adults), who come for clinic at variable frequencies, depending on their issues.

Prader Willi Clinic at the Children's Hospital of San Antonio (Mountain States)\textsuperscript{22}

The Prader Willi Clinic at the Children's Hospital of San Antonio began in spring 2014. Eighteen clinicians and six other staff members convene for one half-day per month to provide care for 10 to 12 patients per clinic. The team holds a pre-clinic “huddle” and uses a dry erase board to track which patients need to be seen by each physician. After all patients have been seen, the team holds a lunch conference to review each case and allow each subspecialist to discuss her/his concerns. A consent to be photographed is obtained from each patient so the team can display patients’ pictures in the conference. The program director summarizes the recommendations in a one to two page summary letter, which is given to the family, the pediatrician, and any other community partners who are providing services for the child.

“It was a fortunate cascade of events that led to this program being operational, and each specialty invited was enthusiastic about getting involved.” The hospital was looking for program excellence and practices that would make it stand out. The new administrators, the ambulatory clinic director, and the nursing department supported this idea. The program is a collaboration between the endocrinology and the genetics divisions. Fortunately, the hospital agreed to support a genetics clinic coordinator, who does all of the referrals, follow-ups, letters, and reminders. The genetics coordinator is a new position that was approved as the number of
The program initially focused on children who did not qualify for NICU follow-up and thus not receive critical care coordination and services. The program expanded almost immediately after its inception to include not only children born prematurely, but all children with complex medical problems, multisystem disorders, genetic disorders, and developmental disorders.

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The program provides comprehensive, multidisciplinary, and primary care for medically complex patients from birth through age six. Interdisciplinary team meetings are held two to three times per week with a physician, nurse case manager, registered dietician, infant developmental therapist, social worker, volunteer, and family advocate and focus on coordinating medical and rehabilitative care and educational needs. Any child who “graduates” from the program can keep her/his primary care doctor as her/his medical home.

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Neurogenetics Clinic, Children’s National Medical Center (NYMAC)⁹
The multidisciplinary Neurogenetics Clinic at the Children’s National Medical Center (CNMC) has several roles. It is a diagnostic clinic that also helps children with neurogenetic issues navigate the medical system. It also identifies and notifies patients who are eligible to participate in internal CNMC protocols and provides patient and caregiver education.

Twice each month, the clinic sees patients for team-based care; patients are able to meet with all their providers during a single clinic visit. New patients are slotted for an hour-and-a-half visit. The clinic director is boarded in child neurology, genetics, and developmental pediatrics, and other team members include a genetic counselor, a nurse practitioner who is also a care coordinator, a developmental pediatrician, a speech and language specialist, medical residents, genetics fellows, and a research assistant who manages the clinical database and enrolls patients in clinical trials. There are additional ad hoc specialists that work in the clinic on occasion, including a neuro-ophthalmologist, an autism developmental specialist, complex care physicians, genetics fellows, speech and language pathologists, and general pediatricians. A patient navigator works with the neurogenetics team, and the genetic counselor also assists with pre-authorization for genetic testing. Patients and their family may participate in a biorepository study of biological samples and a speech and language database, as well as gain information about departmental studies of mitochondrial disease and urea cycle disorders.
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Appendix A: Participant Profiles

Cystic Fibrosis Program, Kaiser Permanente-Northwest Region (Western States)\textsuperscript{11}

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22q Specialty Clinic, Children’s Healthcare of Atlanta at Scottish Rite (SERC)¹⁴
This program serves as a medical home for pediatric patients with 22q11.2 deletion. The clinic was created in 2006 to help address the complex medical needs of these patients and to create a multi-disciplinary environment for studying associated medical issues. Extensive collaborations were formed with several School of Medicine departments, beginning with pediatric gastroenterology and endocrinology. Close interactions with other departments, such as cardiology and the craniofacial clinic, give the program the ability to provide optimal care to patients who have multiple medical needs.

“One of the ways we were able to sell this to the hospital system is that we follow a very large cohort of patients. We have data on 400 patients with 22q11 deletion syndrome and, in the past, we have used this data to collaborate with other departments, such as psychiatry and cardiology, on research projects. This helps bring visibility to the School of Medicine. We are a referral center for the Southeast (GA, AL, FL) because we have expertise in the care of these families. We follow patients from infancy through adulthood and provide general anticipatory guidance that is tailored to the chronic disease, always incorporating best practices.”

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Since they were put in place two years ago, the guidelines have been used in more than 30 patient encounters. Overall, the guidelines have led to improved communication among all providers involved in the peri-operative care of these children and have resulted in improved patient safety. This model has also been adapted (e.g., as a written note) and used for
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The Center began with a nucleus of providers: a clinical geneticist; a genetic counselor, who also serves as a coordinator; and a social worker, who conducts clinical nutrition/psychosocial assessments. Because patients with skeletal dysplasias are now surviving into adulthood and finding no medical professionals with training or experience to provide them expert care, the core team expanded to include cardiologists, foot specialists, and other physicians. The Center serves as a hub for care coordination and as a medical home for their patients.

The program meets formally on Mondays, when patients are seen in the morning by the entire team of five providers/clinicians; the team conferences in the afternoon. In the case conference, patients are discussed and care plans are updated. Patients receive a three-page letter summarizing their visit and indicating which appointments need to be coordinated. If the patients are local, the coordinator will make the appointments, which could include cardiology, pulmonology, urology, sleep studies, EMT, MRIs, blood tests, metabolism, etc. The Center cares for 400 patients of all ages (55% are adults), who come for clinic at variable frequencies, depending on their issues.

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The Prader Willi Clinic at the Children's Hospital of San Antonio began in spring 2014. Eighteen clinicians and six other staff members convene for one half-day per month to provide care for 10 to 12 patients per clinic. The team holds a pre-clinic “huddle” and uses a dry erase board to track which patients need to be seen by each physician. After all patients have been seen, the team holds a lunch conference to review each case and allow each subspecialist to discuss her/his concerns. A consent to be photographed is obtained from each patient so the team can display patients’ pictures in the conference. The program director summarizes the recommendations in a one to two page summary letter, which is given to the family, the pediatrician, and any other community partners who are providing services for the child.

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Appendix A: Participant Profiles
clinical geneticists grew from one to four. Going forward, the program will need to develop outcomes data to support its continued funding.

Middle Tennessee Sickle Cell Network for Coordinated Care and Education, Vanderbilt University Medical Center (SERC)\textsuperscript{24}

The Middle Tennessee Sickle Cell Network for Coordinated Care and Education was developed in January 2012 as a partnership among Vanderbilt University Medical Center, Nashville General Hospital, and the Matthew Walker Comprehensive Health Center (MWCHC), a federally qualified health center (FQHC) in Nashville that cares for children and adults with sickle cell disease (SCD). The impetus for transitioning care for patients with SCD from a tertiary health care setting to the community was to: (1) increase the proportion of children and adults with SCD that have a Medical Home; (2) provide preconception hemoglobinopathy trait testing at the MWCHC; and (3) increase the knowledge base about SCD management among primary health care providers in Middle Tennessee.

The program fulfilled the vision of a pediatric hematologist, newly recruited to Vanderbilt. He was concerned that, while more effective management has changed SCD from a life-threatening progressive disease to a chronic condition with which many adults now live, healthcare systems have not adapted to the changing demographics of individuals living with SCD. Too few adult providers can deliver appropriate care. Also, a disproportionate number of individuals with SCD are poor. Among children with SCD, 70 percent receive Medicaid, and this trend continues into adulthood.
Appendix A: Participant Profiles

Genetics Center at the Children’s Hospital of Wisconsin (Region 4)\textsuperscript{23}

The pediatric genetic counselors at Children’s Hospital of Wisconsin (CHW) serve as the primary care coordinators for the vast majority of children with genetic conditions followed at the institution. CHW genetic counselors ensure that recommended clinical surveillance plans are in place, appropriate testing is ordered, and test results are communicated to and understood by families. This model was established in response to patient requests for help pulling all of the care components together. Dating back to 1981, feedback from parents and primary care physicians in the community prompted the genetics service to change from a consultative service to a case management service. Given that this genetics service is located in the state’s only institution devoted entirely to children, the recommended follow-up testing and evaluations were often most effective if completed at CHW with CHW genetic counselors assisting.

Eventually, the genetics service expanded to provide care coordination wherever children receive services, including nonmedical support services. Both primary care providers and parents felt it was critical for someone to understand all the priority issues, necessary care components, and recommended next steps for their patients/children. The following multi- and interdisciplinary clinics and programs work with the genetics program: Metabolic Clinic; Neurofibromatosis Clinic; PKU Clinic; VCFS/22q Clinic; Hereditary Connective Tissue Disorders Clinic; Fetal Concerns; and Whole Exome Program. Each of these bring together various types of specialists and therapists relevant to the needs of the specific patient population being served. The genetic counselors also serve on many other multidisciplinary teams that are based in other departments, including hematology, plastics surgery, renal, pulmonary, and cardiology, just to name a few. The genetic counselors are the primary point of contact for patients, and stay in touch with patients, even as they become more stable, in order to monitor their health and ensure all of their needs are being met.

Regional and Community-based Programs

Seven nominated programs were regional or community-based organizations, including a national coordinating center for hemophilia treatment centers, a state-wide genetics center, three community-based care coordination programs, and two patient education and support programs.

Regional Genetics Clinics, Greenwood Genetic Center (SERC)\textsuperscript{9}

The Greenwood Genetic Center (GGC) is a non-profit independent genetic institute with satellite clinics across South Carolina (SC). GGC provides multidisciplinary care for patients with genetic conditions and coordinates clinical care, research, education, and additional patient services and supports. This center is unique because of its strong partnerships with state agencies, mainly the SC Department of Intellectual Disabilities, and with the philanthropic community. The latter allows them the freedom and flexibility to provide services without worrying about cost and reimbursement issues. Care coordinators work with each patient, collaborating with primary care providers and subspecialists, following guidelines for each condition, and coordinating diagnostic testing and clinical research for conditions that are as yet unidentified.

Although the founder was told 40 years ago that, “this won’t work, it will never succeed,” and the GGC has seen numerous administrative changes, the Center has maintained strong support
and continues to grow. The key to continued success is its strong relationships with key stakeholders. “Go to these state agencies and show them why it helps them meet their mission and serve the individuals they are entrusted with serving as well, and this mutually beneficial goal will help in obtaining support.”

**Pediatric Enhanced Care Program, Brenner Children's Hospital, Wake Forest School of Medicine (SERC)**

The Pediatric Enhanced Care Program, which began as a consultative palliative care program, has evolved over the past six years to include four programs that provide or coordinate care for children with heritable disorders and other complex conditions. The programs have been funded through grants from the Health Resources and Services Administration (HRSA), the Centers for Medicare and Medicaid Services (CMS), and Duke Endowment.

The program began in 2008 with funding for palliative care from the Duke Endowment. In 2009, the program expanded to become a community-based program for children with medical complexity. HRSA funding supported a social worker to help coordinate care among specialists and provide emotional and practical support to patients and families. In 2011, with new funding for additional care coordinators, the program grew to include seven rural counties. That same year, the hospital initiated the Declan Donahue Collaborative Care Program, which includes a half-time nurse coordinator and focuses on patients who have no diagnosis but have multiple system involvement. The Child Health Accountable Care Collaborative (CHACC) began in 2012 when the Center for Medicare and Medicaid Innovation (CMMI) funded Community Care of North Carolina to support nurses and patient coordinators. They coordinate care across academic centers and focus on transitions from inpatient care to home and community-based care. The three-year CHACC demonstration grant at Brenner Children’s Hospital is integrated into the Pediatric Enhanced Care Program.

Care coordination activities vary across the programs and reflect the needs of specific patients, but generally include: the development of care plans with physicians during hospitalizations; coordination with community providers and services; symptom management with the primary care providers; and hospice care.

**Community Care of Western North Carolina (SERC)**

This community-based health care delivery system provides care coordination services for children with complex health problems who receive Medicaid. Enrollees are assisted with establishing a medical home and coordinating health care and other services. With funding from CMS, Community Care of North Carolina focuses on the 5 percent of children and youth with special health care needs (CYSHCN) in North Carolina who account for 50 percent of all pediatric service expenditures. The specialty care manager, who is embedded within the hospital, coordinates care, particularly for children with complex illnesses, children with frequent hospitalizations, or children who are in or have graduated from the NICU. The coordinators assist in developing comprehensive care plans and improving communications between the family and all providers.

**National Hemophilia Treatment Center, American Thrombosis and Hemostasis Network (National Coordinating Center)**
The National Hemophilia Program Coordinating Center (NHPCC) is supported by a cooperative agreement between HRSA and the American Thrombosis and Hemostasis Network to expand access to care for individuals with bleeding disorders. The NHPCC has established partnerships with 135 Hemophilia Treatment Centers (HTC) in eight regional networks and with patent advocacy groups, payers, and other stakeholders to engage in multidisciplinary efforts to improve the quality of care for those with bleeding disorders and their families.

The core staff of each HTC includes a hematologist, nurse coordinator, social worker, and physical therapist, all specialized in the clinical practice of treating blood disorders; there are approximately 1000 core staff in centers across the country. Depending on the size of the HTC, there may be additional staff, including genetic counselors, psychologists, researchers, and pharmacists. Other HTCs coordinate these services with designated providers in the community. All centers coordinate services such as orthopedic surgery, obstetrics-gynecology, dental care, emergency room support, as well as psychosocial and vocational counseling, dietary advice, and genetic testing, with community providers.

HTCs serve as disease specialists or centers of excellence, since care for individuals with bleeding disorders cannot be delivered through just one organization or type of provider. A variety of strategies are used to improve access to care and clinical outcomes. An individual care plan is developed for each patient, and ongoing care management is coordinated with the patient’s PCP and community providers. HTCs provide education to the patients’ schools, workplaces, and third party payers on the services available through the HTC. There is a national system to provide standardized education to HTC staff, and centers share educational materials with each other. Each center enters data into a national database housed at the NHPCC; this data is used to identify the best practices for improving patient outcomes. This information is shared across the HTC network to improve the quality of care for all persons with bleeding disorders.

Transition Forum for Military Youth with Special Health Care Needs, Naval Medical Center Portsmouth (NYMACT)

The Department of Neurodevelopmental Pediatrics at the Naval Medical Center in Portsmouth, New Hampshire holds team-based, educational/training forums on transitions to adulthood for children and youth with special health care needs. All military families who have a CYSHCN are invited to participate in the forums, which are held three times each year. The forums average 40 to 50 participants per session. Families may participate more than once during their child’s adolescence. Physicians and hospital staff are invited to attend, and residents are encouraged to attend at least one forum during their training.

The forum is a collaborative endeavor involving diverse military and civilian agency experts. Participants receive education on legal planning, which encompasses guardianship, alternatives to guardianship, and the establishment of special needs trusts. Agency representatives present topics that include the Social Security Administration, medical waivers, academic consideration, housing options, and independence/career. Unique military considerations for children with disabilities are also addressed. These events are funded by the military treatment facility (MTF)/hospital, with 2.5 FTE staff dedicated to care coordination and program management. The transition forum is coordinated by a masters-level social worker on staff.
The forums offer a comprehensive, cohesive, and efficient way to share information. They result in fewer adult patients seeking care from emergency services and mental health providers without the required medical power of attorney, guardianship, etc. They increase awareness among the young adults and their families around how to best navigate the maze of military and community resources that are available to assist with the transition process. Widespread knowledge and experience of the program among clinicians has led to a Community of Practice, in which knowledge is transferred both formally and informally. As an example, the two program leaders were asked to take the lead in developing new policies for treatment of incapacitated adults throughout the regional healthcare system, with forum experts serving as critical consultants.

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For the last six years, the Section of Genetics and Metabolism at the Albany Medical Center has held an annual two-and-a-half day “Boot Camp” for adult and adolescent patients with phenylketonuria (PKU). The goal is to address psychosocial needs and provide education regarding diet, genetics, and other medical issues and thus improve patient adherence and physical and mental health outcomes. This program has been supported by grants and by formula companies. The clinic has also implemented a regional telemedicine program for patients with PKU and conducts outreach and community education to PCPs, schools, and group home settings to raise awareness of, and improve management for patients with, PKU.

“There are a variety of issues relating to long-term follow-up of patients with genetic conditions. In terms of education, intermittent clinic visits do not provide a lot of benefit to patients. Patients don’t get a lot of information from the handouts that we give them in clinic. I typically will ask some of the older patients who are doing well to co-teach a class with me, as they are wonderful support for their peers on the same journey. It is hard to make the things that improve long-term adherence to a diet work in a traditional clinic setting. “

**Care Connection for Children, Hospital of the King’s Daughters (NYMAC)**

Care Connection for Children, one of six such centers funded by Virginia’s Title V program, offers community care coordination for pediatric patients with special health care needs. The program began by delivering clinical services to low-income CYSHCN, but now solely offers care coordination to all CYSHCN, regardless of their insurance status. A community-based care coordinator assesses and assists families with accessing all eligible services and teaches them how to navigate systems of care independently. Successful strategies include: the use of home visits and parent navigators; establishing and connecting families to parent support groups; and holding educational events with guest speakers on topics such as advocacy, special needs trusts, and Medicaid waivers.
clinical geneticists grew from one to four. Going forward, the program will need to develop outcomes data to support its continued funding.

Middle Tennessee Sickle Cell Network for Coordinated Care and Education, Vanderbilt University Medical Center (SERC)²⁴

The Middle Tennessee Sickle Cell Network for Coordinated Care and Education was developed in January 2012 as a partnership among Vanderbilt University Medical Center, Nashville General Hospital, and the Matthew Walker Comprehensive Health Center (MWCHC), a federally qualified health center (FQHC) in Nashville that cares for children and adults with sickle cell disease (SCD). The impetus for transitioning care for patients with SCD from a tertiary health care setting to the community was to: (1) increase the proportion of children and adults with SCD that have a Medical Home; (2) provide preconception hemoglobinopathy trait testing at the MWCHC; and (3) increase the knowledge base about SCD management among primary health care providers in Middle Tennessee.

The program fulfilled the vision of a pediatric hematologist, newly recruited to Vanderbilt. He was concerned that, while more effective management has changed SCD from a life-threatening progressive disease to a chronic condition with which many adults now live, healthcare systems have not adapted to the changing demographics of individuals living with SCD. Too few adult providers can deliver appropriate care. Also, a disproportionate number of individuals with SCD are poor. Among children with SCD, 70 percent receive Medicaid, and this trend continues into adulthood.
The pediatric genetic counselors at Children's Hospital of Wisconsin (CHW) serve as the primary care coordinators for the vast majority of children with genetic conditions followed at the institution. CHW genetic counselors ensure that recommended clinical surveillance plans are in place, appropriate testing is ordered, and test results are communicated to and understood by families. This model was established in response to patient requests for help pulling all of the care components together. Dating back to 1981, feedback from parents and primary care physicians in the community prompted the genetics service to change from a consultative service to a case management service. Given that this genetics service is located in the state's only institution devoted entirely to children, the recommended follow-up testing and evaluations were often most effective if completed at CHW with CHW genetic counselors assisting.

Eventually, the genetics service expanded to provide care coordination wherever children receive services, including nonmedical support services. Both primary care providers and parents felt it was critical for someone to understand all the priority issues, necessary care components, and recommended next steps for their patients/children. The following multi- and interdisciplinary clinics and programs work with the genetics program: Metabolic Clinic; Neurofibromatosis Clinic; PKU Clinic; VCFS/22q Clinic; Hereditary Connective Tissue Disorders Clinic; Fetal Concerns; and Whole Exome Program. Each of these bring together various types of specialists and therapists relevant to the needs of the specific patient population being served. The genetic counselors also serve on many other multidisciplinary teams that are based in other departments, including hematology, plastics surgery, renal, pulmonary, and cardiology, just to name a few. The genetic counselors are the primary point of contact for patients, and stay in touch with patients, even as they become more stable, in order to monitor their health and ensure all of their needs are being met.

Regional and Community-based Programs

Seven nominated programs were regional or community-based organizations, including a national coordinating center for hemophilia treatment centers, a state-wide genetics center, three community-based care coordination programs, and two patient education and support programs.

Regional Genetics Clinics, Greenwood Genetic Center (SERC)

The Greenwood Genetic Center (GGC) is a non-profit independent genetic institute with satellite clinics across South Carolina (SC). GGC provides multidisciplinary care for patients with genetic conditions and coordinates clinical care, research, education, and additional patient services and supports. This center is unique because of its strong partnerships with state agencies, mainly the SC Department of Intellectual Disabilities, and with the philanthropic community. The latter allows them the freedom and flexibility to provide services without worrying about cost and reimbursement issues. Care coordinators work with each patient, collaborating with primary care providers and subspecialists, following guidelines for each condition, and coordinating diagnostic testing and clinical research for conditions that are as yet unidentified.

Although the founder was told 40 years ago that, “this won’t work, it will never succeed,” and the GGC has seen numerous administrative changes, the Center has maintained strong support
and continues to grow. The key to continued success is its strong relationships with key stakeholders. “Go to these state agencies and show them why it helps them meet their mission and serve the individuals they are entrusted with serving as well, and this mutually beneficial goal will help in obtaining support.”

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Appendix A: Participant Profiles
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<table>
<thead>
<tr>
<th>Program</th>
<th>Organization</th>
<th>Specialty</th>
<th>Region</th>
<th>Exemplary Practice</th>
<th>Years Since Initiation</th>
<th>Patient Population</th>
<th>Annual Patient Visits or # Patients in Program</th>
<th># Physicians</th>
<th># Staff</th>
<th>Care Coordinator FTE</th>
<th>Care Coordination Funding Mechanism</th>
<th>Freq. of Clinic or Program</th>
<th>Medicaid</th>
<th>Uninsured</th>
</tr>
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<tbody>
<tr>
<td>Beacon Program</td>
<td>Mercy Children's Hospital</td>
<td>A. Pediatric primary care (medically complex)</td>
<td>Heartland</td>
<td>Medical home for children with complex conditions</td>
<td>1</td>
<td>Children with complex conditions 200 patients</td>
<td>4</td>
<td>1</td>
<td>Hospital support</td>
<td>Daily</td>
<td>85%</td>
<td></td>
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<tr>
<td>Linking Individual Need of Children with Services</td>
<td>LINCS, Children's Hospital at Montefiore</td>
<td>A. Pediatric primary care (medically complex)</td>
<td>NYMAC</td>
<td>Medical home for children with complex conditions</td>
<td></td>
<td>Children with complex conditions 265 patients</td>
<td>3</td>
<td>0.8</td>
<td>Hospital support</td>
<td>Daily</td>
<td>85% 1%</td>
<td></td>
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<tr>
<td>Premier Kids Program</td>
<td>La Rabida Children's Hospital</td>
<td>A. Pediatric primary care (medically complex)</td>
<td>Region 4</td>
<td>meets the needs of medically complex children and their families from birth through the age of six.</td>
<td>10</td>
<td>medically complex children 0-6 yrs 300 patients</td>
<td>2</td>
<td>8</td>
<td>Grant from IL AAP</td>
<td>Weekly</td>
<td>95%</td>
<td></td>
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<tr>
<td>HealthTeam Child Health Clinic</td>
<td>Michigan State University</td>
<td>A. Pediatric primary care clinic</td>
<td>Region 4</td>
<td>Comprehensive and coordinated primary care for children with genetic conditions</td>
<td>8</td>
<td>Pediatric patients, and patient registry for CYSHCN 15400 visits; 100 in registry</td>
<td>8</td>
<td>7</td>
<td>Grant funding</td>
<td>Daily</td>
<td>57% 2%</td>
<td></td>
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<tr>
<td>Pediatric Primary Care</td>
<td>San Ramon Valley Primary Care Group</td>
<td>A. Primary care</td>
<td>WS</td>
<td>Coordinating care for pediatric patients with complex conditions</td>
<td>15</td>
<td>General pediatrics</td>
<td>14</td>
<td>0.4</td>
<td>Private practice support</td>
<td>Daily</td>
<td>5% 3%</td>
<td></td>
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<tr>
<td>Genetics Center</td>
<td>Children's Hospital of Wisconsin</td>
<td>B. Comprehensive case management</td>
<td>Region 4</td>
<td>and point of contact for children with genetic conditions being followed.</td>
<td>15</td>
<td>Children with genetic conditions 2750 visits</td>
<td>5</td>
<td>18</td>
<td>Hospital support</td>
<td>Daily</td>
<td>20%</td>
<td></td>
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<tr>
<td>22q11 Specialty Clinic</td>
<td>Children’s Healthcare of Atlanta at Scottish</td>
<td>B. Specialty (22q Deletion Syndrome)</td>
<td>SERC</td>
<td>Developing a medical home for pediatric patients with the 22q11.2 deletion.</td>
<td>8</td>
<td>Patients with 22q11 deletion syndrome 75 patients</td>
<td>8</td>
<td>2</td>
<td>Hospital support</td>
<td>Monthly</td>
<td>50%</td>
<td></td>
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<tr>
<td>Anesthesia/Genetics Guidelines</td>
<td>Baylor College of Medicine/Texas Children's Hospital</td>
<td>B. Specialty (collaboration anesthesia and metabolics)</td>
<td>MS</td>
<td>Anesthesia protocol for patients with inborn errors of metabolism in the perioperative period.</td>
<td>1</td>
<td>Children with IEM 615 patients with IEM</td>
<td>115 Physicians and Clinicians 0</td>
<td>n/a</td>
<td>Monthly or as needed</td>
<td></td>
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<tr>
<td>Craniofacial Center</td>
<td>University of Washington, Seattle Children's Hospital</td>
<td>B. Specialty (craniofacial genetics)</td>
<td>WS</td>
<td>Providing multidisciplinary, comprehensive, and team-based care for children with craniofacial needs</td>
<td>15</td>
<td>Children with genetic conditions requiring craniofacial care 14,411 patients</td>
<td>25</td>
<td>14</td>
<td>Hospital support</td>
<td>Daily</td>
<td>50%</td>
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<tr>
<td>Cystic Fibrosis Program</td>
<td>Kaiser Permanente-Northwest Region</td>
<td>B. Specialty (Cystic Fibrosis)</td>
<td>WS</td>
<td>Providing comprehensive, interdisciplinary care for patients with cystic fibrosis both in the clinic and the hospital.</td>
<td>13</td>
<td>Patients with CF 280 visits; 78 patients</td>
<td>4</td>
<td>6</td>
<td>Clinic absorbs cost</td>
<td>Varies</td>
<td>12% 0%</td>
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<tr>
<td>Institute of Genetic Medicine</td>
<td>Johns Hopkins</td>
<td>B. Specialty (genetics)</td>
<td>NYMAC</td>
<td>Coordinating multidisciplinary, multi-setting care for complex patients with multiple organ system issues.</td>
<td>Patents with genetic conditions 3586 visits</td>
<td>12</td>
<td>3</td>
<td>0</td>
<td>Clinic absorbs cost</td>
<td>28% 0%</td>
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<td>Neurogenetics clinic</td>
<td>Children's National Medical Center</td>
<td>B. Specialty (neurology)</td>
<td>NYMAC</td>
<td>Multidisciplinary neurogenetics clinic</td>
<td>Children with neurogenetic needs 10500 visits</td>
<td>31</td>
<td>6</td>
<td>1</td>
<td>Hospital support</td>
<td>Bi-monthly</td>
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<td>Practice Demographics</td>
<td>Description</td>
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<td>Pediatric Sickle Cell Clinic</td>
<td>University of Miami Hospital</td>
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<td>B. Specialty (Pediatric Hematology-Oncology/SCD)</td>
<td>SERC</td>
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<tr>
<td>Providing comprehensive, multispecialty care coordination for children and young adults with sickle cell disease and developing a Transition Program</td>
<td>2 Patients with SCD</td>
<td>6475 visits, 57 patients in transition program</td>
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<td>Prader-Willi Clinic</td>
<td>Children's Hospital of San Antonio</td>
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<tr>
<td>B. Specialty (Prader Willi)</td>
<td>MS</td>
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<tr>
<td>Multidisciplinary team approach and comprehensive care for children with Prader Willi Syndrome</td>
<td>1 Children with Prader Willi Syndrome</td>
<td>1400 visits, 35 patients in program</td>
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<td>Middle Tennessee Sickle Cell Network</td>
<td>Vanderbilt University Medical Center</td>
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<td>B. Specialty (SCD)</td>
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<td>Coordinate multidisciplinary care for children with SCD</td>
<td>1 Patients with Sickle Cell Disease (data for pediatric only)</td>
<td>1300 visits, 1400 patients, 5 grants or philanthropy</td>
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<td>Alan C. Greenberg Center for Skeletal</td>
<td>Hospital for Specialty Surgery</td>
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<td>B. Specialty (skeletal dysplasias)</td>
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<td>Those with skeletal dysplasias; comprehensive clinical services and coordination of care</td>
<td>14 Patients with skeletal dysplasias</td>
<td>400 patients, 5 grants or philanthropy</td>
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<td>Community Care of Western North Carolina</td>
<td>Community Care of Western North Carolina</td>
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<td>C. Care coordination for complex, Medicaid pediatrics</td>
<td>SERC</td>
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<td>A community-based health care delivery system to coordinate care and other health care services.</td>
<td>2 (3-year grant) CYSHCN and are Medicaid recipients</td>
<td>125 patients, 3 patients in program, 3 CMS grant</td>
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<td>Care Connection for Children</td>
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<td>C. Community care coordination</td>
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<td>Community based care coordinator assists in navigating systems of care and access to services.</td>
<td>13 CYSHCN (must meet criteria)</td>
<td>700 visits, 0 patients, 9.5, 8.5 VA Title V program</td>
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<td>Section of Genetics and Metabolism</td>
<td>Albany Medical Center</td>
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<td>C. Educational Event (genetics)</td>
<td>NYMAC</td>
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<td>Boot Camp for Patients with PKU</td>
<td>5 Adults and adolescents with PKU</td>
<td>4000 visits, 116 in program, 6.25 patients, 0 Grant funding</td>
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<td>Transition Forum for CYSHCN</td>
<td>Naval Medical Center Portsmouth</td>
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<td>C. Educational event for families and providers</td>
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<td>Based, educational and training forum on transitions to adulthood for children with special health care needs.</td>
<td>9 Adolescents and families with CYSHCN</td>
<td>4127; 35 attendees per forum, 6.1.5, 2.5 Government funded</td>
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<td>Pediatric Enhanced Care Program</td>
<td>Brenner Children’s Hospital, Wake Forest School of Medicine</td>
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<td>C. Pediatric palliative care</td>
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<tr>
<td>Four care coordination programs that serve CYSHCN across 20 counties</td>
<td>6 Children with complex conditions</td>
<td>100 patients, 2 patients, 6 patients, 5 Grant funding (HRSA)</td>
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<td>Genetics</td>
<td>Greenwood Genetic Center</td>
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<td>C. Specialty (genetics)</td>
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<td>Multidisciplinary, coordinated clinic care for patients with genetic conditions across South Carolina</td>
<td>40 Patients with genetic conditions</td>
<td>6,000 patients, 13 patients, 13 patients, 12 Grant funding (HRSA)</td>
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<td>National Hemophilia Treatment Center</td>
<td>American Thrombosis and Hemostasis Network</td>
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<td>C. Specialty coordination multi-setting (hemophilia)</td>
<td>n/a, National</td>
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<td>Providing multidisciplinary, comprehensive care to persons with inherited bleeding disorders through renatalized networks of care.</td>
<td>30 Patients with hemophilia</td>
<td>25,000 patients, 324 patients, 500+ patients, 135 Grant funding (HRSA)</td>
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**Note:** The table above lists various practices and their associated demographics, services, and funding sources. Each practice is categorized under a specific type of care (e.g., Sickle Cell, Prader-Willi, Genetics), and the data includes patient numbers, visit counts, and funding sources. The table also includes details about the types of care provided, such as clinic visits, patient programs, and funding mechanisms.
Appendix C: Contact Information

Primary Care

Beacon Program at Children’s Mercy Hospital
Ingrid Larson MBA, MSN, RN, APRN, CPNP
Director, Beacon Program
Division of General Academic Pediatrics
Children’s Mercy Clinics on Broadway
816-960-8040
ialarson@cmh.edu

Linking Individual Needs of Children with Services (LINCS) at the Children’s Hospital at Montefiore
Kathryn Scharbach, MD, MS
Medical Director, LINCS
Department of Pediatrics
Children’s Hospital at Montefiore
718-741-2450
kscharba@montefiore.org

Medical Home Project at the Child Health Clinic, Michigan State University
Yakov Sigal, MD
Department of Pediatrics and Human Development at the College of Human Medicine
Michigan State University
517-355-4715
sigal@msu.edu

Premier Kids Program at La Rabida Children’s Hospital
Edith J. Chernoff, MD, FAAP
Assistant Professor, Department of Pediatrics
University of Chicago
echernoff@larabida.org

San Ramon Valley Primary Care Medical Group
Tracy L Trotter, MD
925-314-2522
ttrotter@srvpc.com

Specialty Care

22q Specialty Clinic, Children’s Healthcare of Atlanta at Scottish Rite
Lisa Kobryniski, MD, MPH
Associate Professor of Pediatrics
Marcus Professor of Immunology
lkobryn@emory.edu
Anesthesia Guidelines for Patients with Inborn Errors of Metabolism, Baylor College of Medicine/ Texas Children's Hospital
Lindsay C. Burragge, MD, PhD
Department of Molecular and Human Genetics
Baylor College of Medicine
Burrage@bcm.edu

Craniofacial Center, University of Washington, Seattle Children's Hospital
Michael L. Cunningham MD, PhD
Medical Director, Seattle Children's Craniofacial Center
Seattle Children's Craniofacial Center
Seattle Children's Hospital
206-987-2528
Michael.cunningham@seattechildrens.org

Cystic Fibrosis Program, Kaiser Permanente-Northwest Region
Jennifer Bass, MD
Director, Cystic Fibrosis Program
Kaiser Permanente, Northwest Region
503-331-5217
Jennifer.L.Bass@kp.org

Genetics Center at the Children's Hospital of Wisconsin
Genetics Center
Children's Hospital of Wisconsin
414-266-3347

Institute of Genetic Medicine, Johns Hopkins
Ada Hamosh, MD
Program Director
Institute of Genetic Medicine
Johns Hopkins
410-614-3313
Ahamosh@jhmi.edu

Kathryn O. and Alan C. Greenberg Center for Skeletal Dysplasia at the Hospital for Specialty Surgery
Cathleen Raggio, MD and Jessica Davis, MD, FACMG
Kathryn O. and Alan C. Greenberg Center for Skeletal Dysplasia
Hospital for Specialty Surgery
212-606-1339
Raggioc@hss.edu; Davisje@hss.edu

Middle Tennessee Sickle Cell Network for Coordinated Care and Education, Vanderbilt University Medical Center
Adeola Davis, PhD, MPA
615-322-8512
Adeola.r.davis@vanderbilt.edu
Neurogenetics Clinic, Children’s National Medical Center
Andrea L. Gropman, M.D., FAAP, FACMG
Chief, Division of Neurogenetics and Developmental Pediatrics
Professor in Neurology and Pediatrics
Children’s National Medical Center
202-476-2120

Pediatric Sickle Cell Clinic, University of Miami Hospital
Ofelia Alvarez, MD
Medical Director
Pediatric Sickle Cell Clinic
University of Miami Hospital
305-243-0846
OAlvarez2@med.miami.edu

Prader Willi Clinic at the Children’s Hospital of San Antonio
Elizabeth Roeder, MD
Prader Willi Clinic
210-872-1665
Elizabeth.roeder@bcm.edu

Regional and Community-based Programs

Boot Camp for PKU, Albany Medical Center
Kayt Marra, MA, CD-N, CCRP
Albany Medical Center, Section of Genetics and Metabolism
518-262-5730
MarraK@mail.amc.edu

Care Connection for Children, Hospital of the King’s Daughters
Cyndi Fisher
Director, Case Management
757-668-8465
cyndi.fisher@chkd.org

Community Care of Western North Carolina
Sherry Noto, RN
Pediatric Program Coordinator
828-348-2829
Snoto@ccwnc.org
www.communitycarewnc.org

National Hemophilia Treatment Center, American Thrombosis and Hemostasis Network
Ann Forsberg
Associate Director, NHPCC
508-400-6686
Pediatric Enhanced Care Program, Brenner Children's Hospital, Wake Forest School of Medicine
Savithri Nageswaran, MD, MPH
Associate Professor
Pediatrics, Social Sciences & Health Policy
Wake Forest School of Medicine
Pediatric Enhanced Care Program
Brenner Children's Hospital
(336) 716 6508
Snageswa@wakehealth.edu
www.brennerchildrens.org/enhanced-care

Regional Genetics Clinics, Greenwood Genetic Center
Steve Skinner, MD
Medical Director
Greenwood Genetic Center
864-388-1061

Transition Forum for military youth with special health care needs, Naval Medical Center Portsmouth
Glenda Lewis-Fleming, MSW, ACSW, FAHM
Management Analyst/Disability Consultant
Naval Medical Center Portsmouth
757-953-7379
Glenda.e.lewisfleming.civ@mail.mil
Appendix D: Resources and References

Resources for Clinicians and Care Coordinators

Center for Medical Home Improvement (medicalhomeimprovement.org)

- Medical Home Index
  This resource can help to establish principles and practices of family-centered medical home.
  medicalhomeimprovement.org/pdf/CMHI-MHI-Pediatric_Full-Version.pdf

American Academy of Pediatrics (aap.org)

- Genetics in Primary Care Institute (geneticsinprimarycare.org)
- National Center for Medical Home Implementation (medicalhomeinfo.org)

National Coordinating Center for the Regional Genetic Service Collaboratives (nccrcg.org)

Example Care Planning Tools – attached as Appendix E
pp. 53-56 – from the Pediatric Primary Care Clinic, Michigan State University
pp. 57-59 – developed by Jenna Robinson, Southpoint Pediatrics, West Jordan, Utah
  (contact jennar@wastachpeds.net for an editable Word version)
pp. 60-64 – Care Coordination Strengths and Needs Assessment Tool, from the Massachusetts Child Health Quality Coalition
  (masschildhealthquality.org/work/care-coordination)

Medical Home Portal (medicalhomeportal.org)
The Medical Home Portal provides information for clinicians, families, and care coordinators about caring and advocating for children with special health care needs (many of whom have heritable conditions), providing them with a medical home, coordinating their care, and connecting with local service providers in several states.
Resources For Patients and Families

Genetic Alliance (geneticalliance.org)
Genetic Alliance is a health advocacy organization that engages individuals, families, and communities to transform health. It is home to many patient and provider resources and tools, including Baby's First Test, Genes in Life, BioTrust, and Expecting Health. The Trust it or Trash it Tool helps patients judge the quality of health information.

➢ Trust it or Trash it (trustitortrashit.org)

Mayo Clinic (mayoclinic.org)

References


Appendix E: Exemplary Care Planning Tools

Pediatric Primary Care Clinic - Michigan State University
Michigan State University
804 Service Road, A110
East Lansing, MI 48824
5173533003 Fax: 5173535514

EMR Peds 1 Test  MRN #: testped9876
Male DOB:02/02/2010

04/05/2013 - Clinical Lists Update: Pediatric Medical Home - Care Plan
Provider: Jane L. Turner MD
Location of Care: Pediatric Primary Care Clinic - Michigan State University

Pediatric Medical Home - Care Plan

Demographic Information
Name: EMR Peds 1 Test  Nickname: Em Complexity Level: 3
Date of Birth: 02/02/2010  Age: 3 Years & 2 Months Old  Sex: Male  MRN: 987654321
Child Resides With: Mother 48823
Mother / Guardian Name: Mary Lou Grimm
Father / Guardian Name: John Bartholomew
Comments: joint legal custody

Insurance Information
Primary Insurance: Medicaid  United
CSHCS: Yes

Diagnosis Information
Primary Diagnosis: DIABETES-TYPE 1 (ICD-250.01)
Secondary Diagnosis: ASTHMA (ICD-493.90)
Secondary Diagnosis: FAMILY HISTORY OF BLEEDING DISORDER (ICD-V18.3)

Healthcare Providers
Primary Care Provider: Jane Turner
Specialist: Pediatric Endocrinology
Name: Dr. Sugar
Address: 1200 E Michigan Ave
Lansing

Specialist: Pulmonologist
Name: Dr. Alveoli
Address: 1200 E Michigan Ave

Specialist: Child psychologist
EMR Peds 1 Test  MRN #: testped9876
Male  DOB: 02/02/2010

Name: Dr. Nice
Address: 
Okemos

Dental: Healthy Smiles
Name: Dr. Brush
Address: 
S Cedar
Lansing

Medications

Medications:
NOVOLOG FLEXPN SOLN (INSULIN ASPART SOLN)
FLOVENT HFA 110 MCG/ACT AERO (FLUTICASONE PROPIONATE HFA) 2 puffs twice daily
PROAIR HFA 108 MCG/ACT AERS (ALBUTEROL SULFATE) 2 puffs every 4-6 hours as needed for cough or wheeze

Allergies:
 PENICILLIN (Critical)
* PEANUTS (Mild)

Pharmacy Used: Meijer
Address: 
Lake Lansing Road
Special Medication Needs: needs insulin pen for accurate dosing by multiple care givers

Diet

Typical Diet: 5 meals a day
Nourishment By: Mouth
Frequency / Time For Feedings: every 2 - 3 hours
Registered Dietician: Patty Delicious
Special Dietary Needs: carb counting by parents and care givers; avoid foods containing peanuts

Emergency Plan

Admit To: Sparrow Hospital
(In the event of an emergency room visit or hospitalization)
Notify: Endocrinologist and primary care

Advance Directives

Advance Directives: Family wants everything possible done.
Appendix E: Exemplary Care Planning Tools

Pediatric Primary Care Clinic - Michigan State University
Michigan State University
804 Service Road, A110
East Lansing, MI 48824
5173533003  Fax: 5173535514

EMR Peds 1 Test  MRN #: testped9876
Male  DOB: 02/02/2010

Family Information

Primary Caregiver(s): Mother
Siblings (Name/Age): Jeremy
Emotional / Family / Spiritual Supports & Needs: Parents working together and father takes him for half days.
Grandparents help with care.

Mother's Employer: MSU
Father's Employer: Wendy's

Transportation:
Car To Meet Child's Health Needs: Yes

Special Family / Financial / Transportation Needs: Mother drives a pick up – toddler seat in front

School Information

School Attending: Headstart  District: Lansing
School Nurse: none on site

Special School Needs: Blood sugar tested at HeadStart – insulin given by health aide.

Equipment (DME) / Assistive Devices

Equipment (DME) / Assistive Devices: Glucose Monitor

Community Services

Other: Care manager
Location: United Health Care
Phone: 800 555 2345

Hospitalizations In Past Year

Dates: 11/13/2012-11/15/2012
Hospital: Sparrow
Care: Floor
Reason: Asthma exacerbation
Appendix E: Exemplary Care Planning Tools

Pediatric Primary Care Clinic - Michigan State University
804 Service Road, A110
East Lansing, MI 48824
5173533003 Fax: 5173535514

EMR Peds 1 Test MRN #: testped9876
Male DOB: 02/02/2010

Dates: 6/22/2012-6/26/2012
Hospital: Sparrow
Care: Floor
Reason: new onset type 1 diabetes with ketoacidosis

Pediatric Medical Home Care Plan

Persons Involved in Completing This Care Plan:
Ms. Grimm, Katie Martin and Dr. Turner

Date Care Plan Prepared: 07/09/2012 Date Care Plan Reviewed: 04/08/2013

Concern / Goal #1: Control asthma and avoid problems with breathing
Related Information: asthma care plan reviewed
Plan: Continue inhaled steroids FLOVENT even when well; get flu shot
Who Will Do: flu shots in clinic

Concern / Goal #2: Control diabetes with blood sugars in target range (and no episodes of hypoglycemia)
Related Information: missed last appt with endocrinologist; mother requests meeting with diabetes team to review diet and insulin doses
Plan: see diabetes team
Who Will Do: referral in place - mother to call diabetes clinic directly for appt to be seen within two weeks

Concern / Goal #3: Improve attendance in school and plan for transition to kindergarten
Related Information: he has missed school because of illness and because others are ill
Plan: improve control of asthma; influenza immunizations
Who Will Do: both parents will meet with Headstart teacher and arrange to meet with principal of elementary school in their neighborhood

Concern / Goal #4: Father wants to be more involved in care
Related Information: child will be spending weekends with father
Who Will Do: father to attend appts with diabetes team

Concern / Goal #5: Jeremy (older brother) is struggling with having ill sibling -- too much attention
Plan: explore opportunities for siblings - counseling or program for sibling
Who Will Do: clinic social worker will look into community resources and mother will call the Family Center

Electronically signed by Jane L. Turner MD on 04/08/2013 at 8:03 AM
# Patient Information:

**Patient Name:** Enter patient name

<table>
<thead>
<tr>
<th>Complexity Level</th>
<th>Insurance: Insurance Policy</th>
<th>Chart Number: Number</th>
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</thead>
</table>

**Date of Birth:** Enter DOB  
**Parent:** Enter name  
**Relationship:** Choose an item  
**Phone:** Enter phone number  

**Respite care?**  
☐ yes  
☐ no  
If yes:  
**Enter provider name**  
**Phone:** Enter provider’s phone number

---

## Educational Information:

**School Information:** Educational setting:  
**School Name:** Enter name of school  
**Grade:** Choose an item.  
**Person of contact:** School personnel/job.  
**Phone:** Enter phone number

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## Challenges:

- □ Behavioral  
- □ Learning  
- □ Physical Anomalies  
- □ Respiratory  
- □ Communication  
- □ Sensory  
- □ Orthopedic/Musculoskeletal  
- □ Feeding/Swallowing  
- □ Hearing/Vision  
- □ Stamina/Fatigue  
- □ Other: Click here to enter text.

## Equipment Needs & Assistive Technologies:

- □ Gastrostomy  
- □ Adaptive Seating  
- □ Wheelchair  
- □ Orthotics  
- □ Stander/Walker  
- □ Crutches/Braces  
- □ Tracheostomy  
- □ Suction  
- □ Nebulizer  
- □ Communication Device  
- □ Hearing Aids/Cochlear  
- □ Monitors:  
  - □ Apnea  
  - □ O2  
  - □ Glucose  
  - □ Cardiac  
- □ Other: Enter text.

## Special Clinical Accommodations:

- □ Room immediately  
- □ Dim lighting  
- □ Low volume  
- □ Sensory toys  
- □ Minimize wait  
- □ Picture communication  
- □ Wheelchair access  
- □ Other: Click here to enter text.
## Chronic Condition Management:

### Problem List:

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<th>Diagnosis</th>
<th>ICD-10 Code</th>
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<td>Secondary diagnosis</td>
<td>ICD 10 code</td>
</tr>
</tbody>
</table>

### Treatment:

<table>
<thead>
<tr>
<th>Clinical Goals</th>
<th>Specialist/Care Provider Responsible</th>
<th>Follow-Up Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enter clinical goal 1</td>
<td>Specialist:</td>
<td>Click here to enter a date.</td>
</tr>
<tr>
<td>Enter clinical goal 2</td>
<td>Specialist:</td>
<td>Click here to enter a date.</td>
</tr>
<tr>
<td>Enter clinical goal 3</td>
<td>Specialist:</td>
<td>Click here to enter a date.</td>
</tr>
<tr>
<td>Enter clinical goal 4</td>
<td>Specialist:</td>
<td>Click here to enter a date.</td>
</tr>
<tr>
<td>Enter clinical goal 5</td>
<td>Specialist:</td>
<td>Click here to enter a date.</td>
</tr>
</tbody>
</table>

### Medications: Choose an item.

<table>
<thead>
<tr>
<th>Name</th>
<th>Dosage</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enter medication name</td>
<td>Enter medication dose</td>
<td>Enter dose frequency</td>
</tr>
<tr>
<td>Enter medication name</td>
<td>Enter medication dose</td>
<td>Enter dose frequency</td>
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<td>Enter medication name</td>
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</tr>
<tr>
<td>Enter medication name</td>
<td>Enter medication dose</td>
<td>Enter dose frequency</td>
</tr>
</tbody>
</table>

### Allergies: Choose an item.

Enter allergies here

### Recent Labs: Choose an item.

<table>
<thead>
<tr>
<th>Type</th>
<th>Result</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Choose lab type</td>
<td>Lab result:</td>
<td>Click here to enter a date.</td>
</tr>
<tr>
<td>Choose lab type</td>
<td>Lab result:</td>
<td>Click here to enter a date.</td>
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<tr>
<td>Choose lab type</td>
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</tr>
<tr>
<td>Choose lab type</td>
<td>Lab result:</td>
<td>Click here to enter a date.</td>
</tr>
</tbody>
</table>
### Care Team Information:

<table>
<thead>
<tr>
<th>Provider</th>
<th>Location</th>
<th>Phone</th>
<th>Fax</th>
</tr>
</thead>
<tbody>
<tr>
<td>PCP: Choose an item.</td>
<td>Southpoint Peds</td>
<td>801-565-1162</td>
<td>801-565-1168</td>
</tr>
</tbody>
</table>

**Specialist Type:** Enter specialist name  
Enter practice location  
Enter phone number  
Enter fax number

**Specialist Type:** Enter specialist name  
Enter practice location  
Enter phone number  
Enter fax number

**Specialist Type:** Enter specialist name  
Enter practice location  
Enter phone number  
Enter fax number

**Specialist Type:** Enter specialist name  
Enter practice location  
Enter phone number  
Enter fax number

**Specialist Type:** Enter specialist name  
Enter practice location  
Enter phone number  
Enter fax number

**Specialist Type:** Enter specialist name  
Enter practice location  
Enter phone number  
Enter fax number

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**Home Health Agency/Nursing?**  
☐ Yes  
☐ No

If yes, organization & phone: Click here to enter text.

---

X  
Physician/Provider Signature

X  
Family/Guardian Signature

---

Developed by Jenna Robinson at Southpoint Pediatrics in West Jordan, UT
Care Coordination Strengths and Needs Assessment Tool
Part A: Demographics/Child & Family Strengths

Child/Youth Name: ________________________________
Date of Birth: ________________________________
Parents/Guardian: ________________________________
Phone/email: ________________________________
Accommodations needed for visits: ________________________________
Reason for CC Referral: ________________________________
*Other Identifier: ________________________________
*Other Identifier: ________________________________
*Other Identifiers include insurance information, referral source, MRN/patient number, etc. as needed

Child/Youth’s Strengths
What would you like us to know about your child?
What do you enjoy about your child? What does he/she do well? Like? Dislike?

Issues/Concerns
What matters most to you right now?
Recent changes, priorities to be addressed TODAY (Connect to GOAL SETTING in Action Plan)

Date of Contact: __________ Type: Phone / Clinic / Home Visit / Pre-Visit Questionnaire / ____________
Family Assets/Stresses
Primary language, learning styles, identify supports
Are there any family problems/concerns that might affect your child?

“The following people in my life can support my family’s health care goals”;
“1 learn best by…”
“Sometimes I need help understanding written healthcare information”; “Interpreter needed”
What would you like us to know about your family? ? Checklist? (eg separation/divorce, death/illness, work issues, substance abuse, violence exposures, immigration, move, siblings)

Consents
Are there forms to be signed for sharing info? Is there information you are not comfortable sharing?

Facilitating communication among team members, ensuring informed consent… Cover Advanced Directives?

Part B: Help Needed by Domain

Medical
Referrals needed, medications, blood/lab tests, functional status, self-care, DME, managing special health problems (growth/nutrition, sleep, etc.)
- DME needs checklist (mobility devices, hearing, vision, etc.)
- Include oral health/access to dental care
- Include transition to adult care if older than 14
Behavioral
Help managing behavioral issues, meeting child’s emotional needs, behavioral issues/risky behaviors as barriers to care.
Connect to resources for support: behavioral problems at school (need IEP evaluation?); at home (CBHI evaluation for in-home therapy? After school academic support for homework issues?); transitioning to adult care.

Social
Making/keeping friends, family support network/caregiver needs, family issues (siblings, divorce, etc.), parenting groups, recreational programs/other community resources.

Educational
Learning/school performance, IEP/504 plans/ADA/Individual Health Plans at school, educational advocates/lawyers, literacy, ESL, GED, tutoring, after-school pgm; Make connections between school issues and mental health issues (home schooling, extended absences, home tutoring for suspensions… medical absences)
Identify when/what PCP and behavioral health providers need to communicate with school, when schools need to communicate back, and ensure consent forms are in place.

Financial/Insurance
Understanding insurance, helping paying for things insurance doesn’t cover (includes dental insurance); Income assistance (SSI, SS-DI, TANF), job training.
Other

- Food assistance (SNAP, WIC, Food Pantries)
- Child care/transportation/other assistance programs
- Housing assistance, utility assistance, home safety/landlord issues

- Guardianship issues, wills/trusts, advanced directives
- Independent living
- Immigration
- Other
Part C: Action Plan

<table>
<thead>
<tr>
<th>Action</th>
<th>Goal</th>
<th>Person Responsible</th>
<th>Time Frame</th>
<th>Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
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<td>4.</td>
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<td>7.</td>
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</tr>
</tbody>
</table>

Include tests ordered, consults needed, labs needed, DME ordering, community resource connections, family supports. *use extra pages or add additional lines as needed*

Patient: ___________________________  Family: ___________________________  Key Care Integrator Contact: ___________________________  Date: __________

Contact: info@masschildhealthquality.org
### Part C: Care Team Members/Referral Checklist

<table>
<thead>
<tr>
<th>Name/Contact Info</th>
<th>Referral / Follow-Up Needs Date/Time Frame</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Primary Care Pediatrician</td>
<td></td>
</tr>
<tr>
<td>□ Neurology Specialists</td>
<td></td>
</tr>
<tr>
<td>□ Endocrine</td>
<td></td>
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<tr>
<td>□ Gastroenterology</td>
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<tr>
<td>□ Orthopedics</td>
<td></td>
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<tr>
<td>□ Neuromotor</td>
<td></td>
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<tr>
<td>□ Cardiology</td>
<td></td>
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<tr>
<td>□ OT/PT/Speech Therapies</td>
<td></td>
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<tr>
<td>□ Behavioral health</td>
<td></td>
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<tr>
<td>□ Geneticist</td>
<td></td>
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<tr>
<td>□ Other:</td>
<td></td>
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<tr>
<td>□ Other:</td>
<td></td>
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<tr>
<td>□ School/Day Care/EI:</td>
<td></td>
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<tr>
<td>□ Payer Case Manager:</td>
<td></td>
</tr>
<tr>
<td>□ Pharmacist:</td>
<td></td>
</tr>
</tbody>
</table>

Include needs for unrelated medical issues as appropriate (e.g. oral health); Identify any outstanding consent forms needed.

**NOTE:** This checklist developed for neurology specialty care; alternatives for PCMH/Primary Care and for NICU transfers also available.