CSHS Care Coordination Toolkit

Children’s Special Health Services (CSHS)
Louisiana Office of Public Health

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Using the Toolkit

This toolkit is designed to assist practices with improving care coordination processes or implementing new care coordination services.

The resource section of the kit includes standalone tools along with state and national resource links to support a variety of QI programs.

For inquiries using this toolkit, please contact CSHS at (504) 568-5055
Children’s Special Health Services (CSHS) is a Title V program under the Office of Public Health. CSHS is the principle public program ensuring that children and youth who have special health care needs in Louisiana have access to health care services designed to minimize their disabilities and maximize their probabilities of enjoying independent and self-sufficient lives. A central mission of CSHS is to increase medical home capacity in the state of Louisiana.

In 2006, the CSHS team, in collaboration with Louisiana State University Health Sciences Center Department of Pediatrics and Children’s Hospital New Orleans, developed and tested a Care Coordination Medical Home Model in an urban academic pediatric clinic. Since its inception, the model has been refined, streamlined, and successfully implemented in over 15 academic practices across the state. This Care Coordination Model employs a “back to basics” approach to service delivery and was cited in the American Academy of Pediatrics (AAP) 2014 Policy Statement on Care Coordination. This toolkit is guided by that AAP 2014 Policy Statement and the TigerCare- Care Coordination Medical Home Model. The TigerCare model grew from participation in the 2003 National Initiative for Children’s Healthcare Quality (NICHQ) Medical Home Learning Collaborative (MHLC) using tools from the Center for Medical Home Improvement (CMHI) and The Child and Adolescent Health Measurement Initiative (CAHMI).

As a program, CSHS works to provide resources and technical assistance to providers and organizations interested in implementation of new care coordination services or improving existing programs.

**Care Coordination**

Care Coordination is the collaborative organization of patient care activities across all practice domains, designed to facilitate delivery of appropriate, patient centered health care services. The “coordination of care across settings permits an integration of services that is centered on the comprehensive needs of the patient and family” which leads to “decreased health care costs,

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reduction in fragmented care, and improvement in the patient/family” care experience.³ In pediatric populations, “successful care coordination takes into consideration the continuum of health, education, early child care, early intervention, nutrition, mental/behavioral/emotional health, community partnerships, and social services.”⁴

The AAP Policy Statement heralds care coordination as an “essential element of a transformed American health care delivery system”.⁵ Coordinated care is championed as a cross cutting system intervention which emphasizes “optimal quality and cost outcomes”.⁶ The care coordination service model supports the Institute for Healthcare Improvement’s (IHI) ‘Triple Aim’ framework to improve patient (family) experience of care, reduce per capita costs of health care and improve population health.⁷ Effective care coordination processes eliminate redundancy and save time through facilitated communication and timely connections between multiple layers of the health care system. Coordinated care is seen as a value to all patient populations but is absolutely essential for meeting the needs of children/youth with special health care needs (CYSHCN), patients with developmental disabilities, and all patients with complex or multiple chronic conditions.⁸

Care Coordination programs differ from case management as they are not condition or disease specific. While certainly there is an overlap of the 2 service models, case management services usually focus on a limited set of predetermined health care conditions and outcomes and may include eligibility criteria.⁹ Care coordination is not explicit to chronic condition management but rather encompasses a holistic approach to support “optimal health and wellness outcomes.”¹⁰ Care coordination attends to the interrelated needs that impact health and may include medical, educational, developmental, mental health, social, and financial elements. Strong community partnerships and liaisons with public health agencies offer resources for these interventions and are a major benefit to practices.

³ Ibid. p 1451.
⁴ Ibid. p 1452.
⁵ Ibid, p 1451.
⁷ Safety Net Medical Home Initiative, May 2013. Care Coordination: Reducing Care Fragmentation in Primary Care. www.safetynetmedicalhome.org
The TigerCare framework utilizes a whole team approach. It is built around a designated care coordinator (CC) working with and supporting the primary care provider (PCP) and healthcare team. The framework incorporates patient/family centered care, systematic identification and stratification of high need patients, active care plans for high need patients, therapy and specialist coordination, community referrals, developmental screening and surveillance, transition support, and ongoing quality improvement. Through facilitated communication, the care coordination framework supports consistent follow-through and follow-up that may get lost in the shuffle as an informal process.

All primary care practices provide some level of care coordination service to their patients such as organizing and scheduling diagnostic test, specialist and therapy referrals. For many clinics, focusing on effective communication processes and closing minor gaps is all that is required to improve care coordination and meet benchmark goals.

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5 Steps to Implementation

Step 1 - Getting Started
- Meet with leadership
- Select/hire a care coordinator
- Select a measurement tool for monitoring outcomes, set initiative goals and collect baseline data
- Inform and educate the entire team on care coordination model and initiative goals

Step 2 – Identify and Stratify Children and Youth with Special Health Care Needs (CYSHCN)
- Implement the Children with Special Health Care Needs (CSHCN) Screener
- Use Developmental Screening tools per AAP Guidelines
- Stratify CYSHCN population by complexity of needs

Step 3 – Coordinate comprehensive care services
- Develop care plans for level 2 (high need) patients
- Create an easy access resource library
- Partner with public health and community agencies

Step 4 – Design or refine care coordination processes and workflow
- Review clinic workflow from screening to documentation of care plans
- Integrate care coordination activities into the EMR
- Clearly define/outline team member duties and deliverables

Step 5 – Prioritize continuous quality improvement
- Review/Analyze outcome measures
- Incorporate evidence based practices to address QI issues
- Disseminate clinic quality reports to entire clinic staff

National centers, non-profits and government entities offer learning programs on care coordination program implementation, medical home transformation and cultivating care coordination skillsets. The resource section of this toolkit includes a comprehensive list of agency and resource links.
Step 1 – Getting Started

Meet with leadership

☐ Outline the benefits care coordination (CC) affords patients, their families and clinic staff.
☐ Secure commitment for at least 0.5 FTE care coordinator position. This dedicated staff time is essential to implementing sustained care coordination. If CC is funded through MCO contracts, third party payers, or CPT code reimbursement, expansion of existing staff is recommended; if CC is unfunded, realignment of duties with existing staff may preferable.
☐ Meet with information technology (IT) staff early in the process to support integration of CC activities into the Electronic Medical Record (EMR). Many EMR systems contain built-in case management or care coordination templates.

Select/hire a clinic care coordinator

☐ Using the TigerCare Framework practices have successfully engaged RNs, developmental specialists, occupational therapists, social workers, and LPNs in the role of care coordinator.
☐ Suggested care coordinator skills include: ability to interview and counsel patients and families on sensitive topics, ability to assess family needs, knowledge of basic community and public health resources, a general understanding of the Individuals with Disabilities Education Act (IDEA), patient teaching and health education competencies, and the ability to manage timelines.

Select a measurement tool for monitoring outcomes, set program goals, and collect baseline data

☐ The Louisiana model uses the Medical Home Index-short version from the Center for Medical Home Improvement (appendix A). Other options include patient satisfaction surveys, formal medical home recognition program assessments and the Care Coordination Measures Atlas. Using a standardized measurement tool permits benchmarking with other sites.
☐ Set SMART goals for the CC initiative: Specific, Measureable, Achievable, Relevant, Time specific.
☐ The care coordinator collects baseline data before process changes are implemented.

Inform and educate entire team on the care coordination model and goals

☐ A Title V representative, a lead physician, or the care coordinator can support education efforts.
☐ Implement regular planning and evaluation meetings. Meetings should occur at least quarterly depending on the scope of the project and staff schedules.

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Step 2 – Identify and Stratify CYSHCN

Implement the Children with Special Health Care Needs (CSHCN) Screener
- The TigerCare Model utilizes a modified version of the CSHCN Screener (appendix B).¹⁴ The screener operationalizes the Maternal and Child Health Bureau (MCHB) definition of CYSHCN, and will result in identification of 20-50% of patients in the practice depending on the risk level of the population. Only about 10% of these patients require the ongoing services of the care coordinator.
- CYSHCN status can change from visit to visit. Providing the screener to all patients, at every visit, permits identification of changes in CYSHCN status due to new onset or resolution of conditions.
- CYSHCN status must be indicated in a prominent position in the medical record. This can range from a color-coded sticker on the front of a paper record to an identifier on the opening page of the EMR.

Use Developmental Screening tools per AAP Guidelines
- Developmental screens augment identification of CSHCN.
- AAP guidelines recommend developmental surveillance at every preventative care visit throughout childhood and administration of standardized developmental screens for all children at 9, 18, 30 (or 24) months and anytime a parent or surveillance assessment yields a concern.¹⁵ Autism screens are recommended at 18 and 24 months.¹⁶

Stratify CYSHCN population by complexity of needs
- The care coordinator or the PCP determines CYSHCN complexity through a brief interview using the CSHS Levels of Care tool (appendix C).
- The care coordinator completes a comprehensive CC assessment with patients identified as level 2 (medically complex or high need). A sample assessment template is included in the toolkit (appendix D).

Level 1 – Low complexity patients: routine referrals such as subspecialty appointments and labs can be handled by front desk staff.
Level 2 – Medically complex or high need patients: communication and collaboration with educators, referrals to early intervention programs, securing DME and multiple or complex public health, specialist, mental health or family support referrals require the expertise of the care coordinator.

*Complexity levels are fluid. Once a ‘level 2’ patient’s needs are met, they may become a ‘level 1’ patient. For example, if a patient with level 1 complexity is admitted to the hospital, he becomes a level 2 patient until he is discharged and any new needs are addressed.

Step 3 - Coordinate Comprehensive Care Services

Develop care plans for level 2 patients

☐ A level 2 care plan is developed in collaboration with the medical plan of care. This comprehensive care plan addresses all interrelated medical, social, developmental, behavioral, educational and financial needs identified from the CC assessment.17
☐ Care plans are created by the PCP, the care coordinator and family and consider input from the health care team, specialist, education professionals, therapist and community partners. The toolkit includes a sample care plan template (appendix E)
☐ The level 2 care plan is located in the patient chart and includes a running care coordinator progress note. This progress note provides the health care team with a current status of care plan activities. Early consultation with IT staff can assist practices with maximizing use of the EMR system to support intra-office communication and collaborative documentation of care plan activities. IT staff can also assist with the design of chart identifiers for CYSHCN records.

Create an easy access resource library

☐ Resource libraries include brochures for public health and community resources, patient education materials, screening tools, and transition resources for youth transitioning to adult healthcare, work and independence. Easy access to resources is critical. Many practices utilize an open file bin prominently placed near the exit path.
☐ Resource libraries consider the community’s health literacy and language preferences, as well as common conditions treated in the clinic.
☐ The care coordinator maintains master copies of resources and tools to assure no one uses the last copy without reordering.

Partner with public health and community agencies

☐ Public Health and non-profit agencies make excellent community partners and can provide access to information resources.
☐ The Office for Citizens with Developmental Disabilities (OCDD) is an excellent one-stop-shop for resources. There is an OCDD office in every region of Louisiana.
☐ In Louisiana, Families Helping Families (FHF) is the family advocacy organization that provides support and resource information to families of CYSHCN. There is a FHF office located in each of Louisiana’s 9 regions. FHF sponsors workshops and webinars on topics such as special education legislation and IEP development. In many states these services are provided by Family Voices programs.

Step 4 - Design or Refine Care Coordination Processes and Workflow

Review clinic workflow from patient screening to documentation of care plans

- Plan a workflow that supports care coordinator interaction with patients and families before or after healthcare provider encounters. Ideally, the care coordinator completes an in-person interview with all patients that screen positive and develops comprehensive care plans for level 2 patients. Initially it may be difficult for the care coordinator to assess all patients with positive screens while they are on-site. Communication with the PCP can help to prioritize patients in need of immediate care coordination assistance. In some instances, phone interviews to address urgent issues may be required.
- The Care Coordination/Communication Assessment Tool can be helpful to review current clinic processes and identify gaps (appendix F).
- Developmental screenings should be a standard component of the clinic workflow. Developmental screens are completed on all patients at 9, 18 and 30 or 24 months and autism screens at 18 and 24 months. Care coordinators can assist with distribution and scoring of developmental screens.
- Transition support programs for youth transitioning to adult healthcare, work and independence should be standardized within the practice. CSHS offers a set of region specific transition tools to support transition services (appendix G).

Integrate care coordination activities into the EMR

- A chart identifier for CYSHCN is an important component of care coordination integration. The care coordinator can easily complete chart checks prior to scheduled visits and update care plans. Many clinics routinely schedule longer appointments for level 2 patients when status is prominently displayed in the chart and in the appointment system.
- Maximize the functionality of EMR systems, using sort and reporting functions for tracking and trending care coordination activities.
- Non-EMR practices can create Excel registries or utilize other existing clinic data bases to identify and track CYSHCN. Registries do not replace the patient care plan and the progress note contained within the patient chart.

Clearly define/outline team member duties and deliverables

- Clearly designate staff duties. For example, identify staff members responsible for distributing and collecting patient screens. For practices with part-time care coordinators, screens may be reviewed days after the patient encounter. Therefore, a designated secure storage location is essential.
- Ensure staff have the tools required to carry out assigned tasks from initiation to completion. For example, private phone access, computer permissions to document care coordination activities, and time to complete care coordinator assessments and follow up are necessary to support care CC activities.

Keep entire staff abreast of changes. Solicit staff feedback. Set-up a clinic feedback email, or use a suggestion box to support receipt of timely staff feedback.

☑️ Checklist reminders can be helpful to support staff through process changes.
Step 5 - Prioritize Continuous Quality Improvement

Review/Analyze outcome measures
☐ CC initiatives should be built around a continuous quality improvement framework.
☐ The care coordinator is lead for clinic care coordination QI initiatives.
☐ Project outcome data can be collected and disseminated by the care coordinator.

Incorporate evidence based practices to address QI issues
☐ Evidenced informed decision support tools and practice guidelines are important for consistent and quality healthcare services.
☐ Clinics should systematically collect, analyze and address family feedback.
☐ QI activities should include periodic evaluation of clinic processes and protocols to ensure current best practices are followed.

Disseminate clinic quality reports to entire clinic staff
☐ The framework of the TigerCare model incorporates quarterly “medical home” clinic meetings led by the care coordinator. The care coordinator develops an agenda for meetings with input from the entire team which includes dissemination of clinic quality data.
☐ All staff are encouraged to participate in quality initiatives.
☐ Quarterly meetings can be used to discuss best practices, new referral sources, identified problems and progress toward benchmark goals.

☑ Plan Do Study Act (PDSA) cycles provide a framework for performance improvement programs. Recommended by agencies such as the Institute for Healthcare Improvement (IHI), and the Agency for Healthcare Research and Quality (AHRQ), PDSA cycles are an excellent tool for care coordination initiatives. The resource list includes links which explain the technique in detail (appendix H).
Measurement/Evaluation

Evaluation is a key element of effective programs and change initiatives. QI initiatives oblige development of meaningful, measurable outcomes. Numerous tools are available to support outcome and progress measurement of care coordination services and medical home initiatives. Practices working toward medical home certification can use components of the credentialing requisites to track and trend progress.

The Agency for Healthcare Research Quality (AHRQ) publishes the *Care Coordination Measures Atlas*. The Atlas contains an organized list of outcome measures from which a practice can choose. The framework uses domain specific items and relates to 3 perspectives: patient/family, health care professional, and system representative (organizational). While a large volume text, this is an excellent resource for program planners and evaluators.

The Medical Home Index (MHI) is a qualitative measurement tool which helps to operationalize medical home and care coordination concepts. It is an excellent teaching tool as well as measurement instrument. It is available in short and long versions for pediatric and adult populations. A family Medical Home Index survey is also available. The latest revision of the pediatric MHI is the revised short form (RSF) available through AHRQ.

The Consumer Assessment of Healthcare Providers and Systems (CAHPS) surveys are free, non-proprietary instruments designed to support standardized measurements of patient experiences in a variety of healthcare settings. There is a CAPHPS survey specific to measuring patient perceptions and satisfaction with services in the Patient Centered Medical Home.

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20 CMHI 2006.
21 AHRQ 2012. Medical Home Index-Revised Short Form (MHI-RSF) for the National Evaluation of the CHIPRA Quality Demonstration Grant Program.
Care plans are an important health care team tool. An effective “plan of care not only summarizes current and historical medical information, but should also “document goals, strategies and progress over time, including a designation of responsibility for each task or agreed to intervention.” The AAP Policy Statement on Care Coordination states that care plans should include actionable interventions with assigned tasks/roles, a medical summary and/or an emergency information which includes a “past medical history and salient specialist information”.

Coordinated plans of care are individualized, action oriented, and dynamic.

The patient and their family are full participants in the development and implementation of the care plan. Care plans are a collaborative process which considers input from the entire care team; the PCP, sub-specialist, therapist, community partners, education professionals and most importantly the patient and family. Patients and families require timely, relevant, reliable and easy to understand information related to health conditions and treatment interventions. Care plan collaborations work to fully engage the patient and family and work to strengthen provider partnerships.

The Lucile Packard Foundation publication, *Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs: An Implementation Guide*, is an excellent tool especially for staff in the care coordinator role. The resource is a modulated how-to guide for care plan development.

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The Medical Home Index - Short Version:
Measuring the Organization and Delivery of Primary Care for Children with Special Health Care Needs

The Medical Home Index - Short Version (MHI-SV) represents ten indicators which have been derived from the Center for Medical Home Improvement’s (CMHI) original Medical Home Index (MHI). This short version can be used as an interval measurement in conjunction with the original MHI or it can be used as a quick “report card” or snapshot of practice quality. CMHI recommends the use of the full MHI for practice improvement purposes but offers this short version for interval or periodic measurement and/or when it is not feasible to use the full MHI.

The Medical Home Index is a nationally validated self-assessment tool designed to quantify the “medical homeness” of a primary care practice. The MHI contains twenty-five indicators which detail excellent, pro-active, comprehensive pediatric primary care. It functions both as a quality improvement tool and as a self-education medium relevant to the medical home.

The Medical Home Index: Short Version (MHI-SV) is a brief representation of the more complete measurement tool. It scores a practice on a continuum of care across three levels:

- Level 1 is good, responsive pediatric primary care.
- Level 2 is pro-active pediatric primary care (in addition to Level 1)
- Level 3 illustrates pediatric primary care at the most comprehensive levels (it is in addition to Levels 1 and 2).

As the reporter for your entire practice and in response to each of the ten indicators - please score your medical home at: Level 1, Level 2 “partial”, Level 2 “complete”, Level 3 “partial”, or Level 3 “complete”.

Both the full 25-item Medical Home Index and this 10-item Medical Home Index – Short Version can be downloaded from the CMHI website at [www.medicalhomeimprovement.org](http://www.medicalhomeimprovement.org).
<table>
<thead>
<tr>
<th>Medical Home Index – Short Version (MHI-SV)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Level 1</strong></td>
</tr>
<tr>
<td># 1 Family Feedback</td>
</tr>
<tr>
<td>Requires both MD &amp; key non-MD staff person’s perspective.</td>
</tr>
<tr>
<td>( # 1.5 MHI-Full Version )</td>
</tr>
<tr>
<td># 2 Cultural Competence</td>
</tr>
<tr>
<td>Pediatric primary care without the elements detailed in levels 2 and 3.</td>
</tr>
<tr>
<td>( # 1.6 MHI-FV )</td>
</tr>
<tr>
<td>#3 Identification of Children in the Practice with Special Health Care Needs</td>
</tr>
<tr>
<td>Pediatrict primary care without the elements detailed in levels 2 and 3.</td>
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<tr>
<td>( # 2.1 MHI-FV )</td>
</tr>
<tr>
<td>#4 Care Continuity</td>
</tr>
<tr>
<td>---</td>
</tr>
<tr>
<td>Pediatric primary care without the elements detailed in levels 2 and 3.</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>#5 Cooperative Management Between Primary Care Provider (PCP) and Specialist</th>
<th>Level 1</th>
<th>Level 2 (in addition to level 1)</th>
<th>Level 3 (in addition to level 2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pediatric primary care without the elements detailed in levels 2 and 3.</td>
<td>☐ Level 1</td>
<td>☐ PARTIAL ☐ COMPLETE</td>
<td>☐ PARTIAL ☐ COMPLETE</td>
</tr>
</tbody>
</table>

The team (including PCP, family, and staff) develops a plan of care for CSHCN which details visit schedules and communication strategies; home, school and community concerns are addressed in this plan. Practice back up/cross coverage providers are informed by these plans.

The practice/teams use condition protocols; they include goals, services, interventions and referral contacts. A designated care coordinator uses these tools and other standardized office processes which support children and families.

The PCP and family set goals for referrals and communicate these to specialists; together they clarify co-management roles among family, PCP and specialists and determine how specialty feedback to the family and PCP is expressed, used, and shared.

The family has the option of using the practice in a strong coordinating role; parents as partners with the practice manage their child’s care using specialists for consultations and information (unless they decide it is prudent for the specialist to manage the majority of their child’s care).
# Medical Home Index – Short Version (MHI-SV)

<table>
<thead>
<tr>
<th>Level 1</th>
<th>Level 2 (in addition to level 1)</th>
<th>Level 3 (in addition to level 2)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>#6 Supporting the Transition to Adulthood</strong></td>
<td>Pediatric primary care without the elements detailed in levels 2 and 3.</td>
<td></td>
</tr>
</tbody>
</table>
| | Pediatric and adolescent PCPs support youth & family to manage their health using a transition timeline & developmental approach; they assess needs & offer culturally effective guidance related to:  
  - health & wellness  
  - education & vocational planning  
  - guardianship and legal & financial issues  
  - community supports & recreation  
  When youth transition from pediatrician to adult provider:  
  **Pediatricians** help to identify an adult PCP and sub-specialists and offer ongoing consultation to youth, family and providers during the transition process.  
  **Adult Providers** offer an initial “welcome” visit and a review of transition goals. | Progressively from age 12, youth, family and PCP develop a written transition plan within the care plan; it is made available to families and all involved providers.  
Youth and families receive coordination support to link their health and transition plans with other relevant adolescent and adult providers/services/agencies (e.g. sub-specialists, educational, financial, insurance, housing, recreation, employment and legal assistance). |
| #7 Care Coordination /Role Definition | Pediatric primary care without the elements detailed in levels 2 and 3. | |
## Medical Home Index – Short Version (MHI-SV)

<table>
<thead>
<tr>
<th>#8 Assessment of Needs/ Plans of Care</th>
<th>Level 1</th>
<th>Level 2 (in addition to level 1)</th>
<th>Level 3 (in addition to level 2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pediatric primary care without the elements detailed in levels 2 and 3.</td>
<td></td>
<td>The child with special needs, family, and PCP review current child health status and anticipated problems or needs; they create/revise action plans and allocate responsibilities at least 2 times per year or at individualized intervals.</td>
<td>The PCP/staff and families create a written plan of care that is monitored at every visit; the office care coordinator is available to the child and family to implement, update and evaluate the care plan.</td>
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<td>(# 3.4 MHI-FV)</td>
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<thead>
<tr>
<th>#9 Community Assessment of Needs for CSHCN</th>
<th>Level 1</th>
<th>Level 2</th>
<th>Level 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pediatric primary care without the elements detailed in levels 2 and 3.</td>
<td></td>
<td>Providers raise their own questions regarding the population of CSHCN in their practice community(ies); they seek pertinent data and information from families and local/state sources and use data to inform practice care activities.</td>
<td>At least one clinical practice provider participates in a community-based public health need assessment about CSHCN, integrates results into practice policies, and shares conclusions about population needs with community &amp; state agencies.</td>
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<td>(# 4.1 MHI-FV)</td>
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<thead>
<tr>
<th>#10 Quality Standards (structures)</th>
<th>Level 1</th>
<th>Level 2</th>
<th>Level 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pediatric primary care without the elements detailed in levels 2 and 3.</td>
<td></td>
<td>The practice has its own systematic quality improvement mechanism for CSHCN; regular provider and staff meetings are used for input and discussions on how to improve care and treatment for this population.</td>
<td>The practice actively utilizes quality improvement (QI) processes; staff and parents of CSHCN are supported to participate in these QI activities; resulting quality standards are integrated into the operations of the practice.</td>
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<tr>
<td>(# 6.1 MHI-FV)</td>
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DEFINITIONS OF CORE CONCEPTS (Words in italics throughout the document are defined below.)

**Children with Special Health Care Needs (CSHCN):**
Children with special health care needs are defined by the *US Maternal and Child Health Bureau* as those who have, or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who require health and related services of a type or amount beyond that required by children generally (USDHHS, MCHB, 1997).

**Medical Home:**
A medical home is a community-based primary care setting which provides and coordinates high quality, planned, family-centered health promotion and chronic condition management. According to the American Academy of Pediatrics (AAP) “medical home” is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent.

**Family-Centered Care** (*US Maternal and Child Health Bureau, 2004)*:
Family-Centered Care assures the health and well-being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions and expertise that everyone brings to this relationship. Family-Centered Care is the standard of practice which results in high quality services.
**Care Coordination Activities:**

Care and services performed in partnership with the family and providers by health professionals to:

1) Establish family-centered community-based “Medical Homes” for CSHCN and their families.
   - Make assessments and monitor child and family needs
   - Participate in parent/professional practice improvement activities

2) Facilitate timely access to the **Primary Care Provider (PCP)**, services and resources
   - Offer supportive services including counseling, education and listening
   - Facilitate communication among PCP, family and others

3) Build bridges among families and health, education and social services; promotes continuity of care
   - Develop, monitor, update and follow-up with care planning and care plans
   - Organize wrap around teams with families; support meeting recommendations and follow-up

4) Supply/provide access to referrals, information and education for families across systems.
   - Coordinate inter-organizationally
   - Advocate with and for the family (e.g. to school, daycare, or health care settings)

5) Maximize effective, efficient, and innovative use of existing resources
   - Find, coordinate and promote effective and efficient use of current resources
   - Monitor outcomes for child, family and practice

**Chronic Condition Management (CCM):**

CCM acknowledges that children and their families may require more than the usual well child, preventive care, and acute illness interventions. CCM involves explicit changes in the roles of providers and office staff aimed at improving:

1) Access to needed services
2) Communication with specialists, schools, and other resources, and
3) Outcomes for children and families.
GLOSSARY OF TERMS* (continued)

Quality:
Quality is best determined or judged by those who need or who use the services being offered. Quality in the medical home is best achieved when one learns what children with special health care needs and their families require for care and what they need for support. Health care teams in partnership with families then work together in ways which enhance the capacity of the family and the practice to meet these needs. Responsive care is designed in ways which incorporate family needs and suggestions. Those making practice improvements must hold a commitment to doing what needs to be done and agree to accomplish these goals in essential partnerships with families.

Office Policies
Definite courses of action adopted for expediency; “the way we do things”; these are clearly articulated to and understood by all who work in the office environment.

Practice:
The place, providers, and staff where the PCP offers pediatric care

Primary Care Provider - (PCP):
Physician or pediatric nurse practitioner who is considered the main provider of health care for the child

United States Maternal and Child Health Bureau - (USMCHB):
A division of Health Resources Services Administration

Requires both MD and key non-MD staff person’s perspective - you will see this declaration before select themes; the project has found that these questions require the input of both MD and non MD staff to best capture practice activity.

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Children & Youth with Special Health Care Needs
CSHCN Screener*(Modified)

Child’s Name ____________________________  Child’s Date of Birth ____________________________

Today’s date: ____________________________  Medical Record #__________________________

If you have not filled out a screener for your child, please answer questions 1-6. If you have completed a screener at another visit and there are no changes to report, check the box below. When your name is called, give the completed form to the clinic staff member.

☐ No changes since last screen

1. Does your child need or use medicine prescribed by a doctor?
   ☐ Yes
   ☐ No

List prescription medicines your child takes on a regular basis:

2. Does your child need OR use more medical care than other children the same age?
   ☐ Yes
   ☐ No

3. Does your child have trouble doing things most children the same age can do?
   ☐ Yes
   ☐ No

4. Does your child need OR get special therapy, such as physical therapy, occupational, or speech therapy?
   ☐ Yes
   ☐ No

5. Does your child need counseling or treatment for behavior problems, emotional problems, or delays in walking, talking, or activities other children his age can do?
   ☐ Yes
   ☐ No

6. If you answered yes to any question: Has this problem lasted or is expected to last at least 12 months?
   ☐ Yes
   ☐ No

7. Optional - what is your child’s race and ethnicity? (Information used for Federal grant reporting only):
   Race: ☐ Black/African Am. ☐ White ☐ Asian ☐ Am. Indian/Alaskan-native ☐ Pacific Islander/Native-Hawaiian
   Ethnicity: ☐ Hispanic ☐ Non-Hispanic

| Positive (+) Screener Levels of Care  
| Medical Home Care Coordination |

| **Level I**  
| Minimal Intensity of Services  
(0-4 hour of staff time per month) | **Level II**  
| Moderate Intensity of Services  
(5 or more hours of staff productivity per month) |

**Criteria**
- Routine diagnosis, care and sick visits
- Routine exams
- Simple specialty or service referrals
- Long term but stable diagnosis
- Periodic consultations, screenings and referrals
- Ongoing, long term services or therapies requiring referral updates and renewals
- Office visits at least every 6 months

**Criteria:**
- Complex diagnosis and/or mental, psychosocial issues
- Multiple co-morbidities
- Unstable conditions requiring multiple interventions (intense services)
- Complex and/or unusual specialty needs

**Guideline Examples:**
- Annual well care visits and screenings
- Routine immunizations
- Simple to moderate behavioral health referrals and follow up
- Simple to moderate educational needs
- Mild to moderate Down Syndrome and CP requiring custodial care
- Mild to moderate Down Syndrome
- Stable, custodial CP whose services are established requiring routine renewal of services

**Guideline Examples:**
- Unstable or new diagnosis of moderate to severe CP, genetic disorders
- Potentially life threatening diagnosis
- Multiple ER visits/hospital admissions, (three or more annually)
- Suspected child abuse, neglect
- Frequent noncompliance issues with caretaker or patient

**Application of Criteria:**
*Staff productivity includes time spent by MD, front office, clinic team, care coordinator (faxing, referrals, phone calls etc)
Level I – care coordination provided by PCP, medical residents and office staff and as needed consult with care coordinator
Level II – care coordination provided by PCP, medical residents, office staff and care coordinator

**Additional Information**
- Care coordination is an interdisciplinary, team approach
- Levels of Care are assigned after initial consultation with physician and in the case of possible Level II, assessment by care coordinator in cases that appear to be Level II
- Levels of Care are not static as intensity of services can either increase or stabilize therefore LOC should be evaluated with each visit and more often as the patient's condition changes
- Identified CYSHCN patient charts (electronic or hard copy) are labeled/flagged per practice protocol (+/-, level I/II)
# CSHS Care Coordination Assessment Form

## Patient Information

<table>
<thead>
<tr>
<th>Field</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Name</td>
<td>M.R. #</td>
</tr>
<tr>
<td>DOB</td>
<td>Sex</td>
</tr>
<tr>
<td>Race</td>
<td></td>
</tr>
<tr>
<td>Address</td>
<td>ID#</td>
</tr>
<tr>
<td>Payor</td>
<td></td>
</tr>
<tr>
<td>Contact</td>
<td></td>
</tr>
<tr>
<td>Relationship</td>
<td>Phone Number</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Contact</td>
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<tr>
<td>Relationship</td>
<td>Phone Number</td>
</tr>
<tr>
<td></td>
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</tbody>
</table>

## Medical History

<table>
<thead>
<tr>
<th>Field</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary Diagnosis</td>
<td></td>
</tr>
<tr>
<td>Secondary Diagnosis</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
<tr>
<td>Brief History</td>
<td></td>
</tr>
</tbody>
</table>

## ER Visits (last 12 months)

<table>
<thead>
<tr>
<th>Date</th>
<th>Reason</th>
<th>Date</th>
<th>Reason</th>
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</thead>
</table>

## Hospitalizations (last 12 months)

<table>
<thead>
<tr>
<th>Date</th>
<th>Reason</th>
<th>Date</th>
<th>Reason</th>
</tr>
</thead>
</table>

## Procedures/Treatments

<table>
<thead>
<tr>
<th>Date</th>
<th>Date</th>
</tr>
</thead>
</table>

## Psychosocial

<table>
<thead>
<tr>
<th>Field</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary Language</td>
<td></td>
</tr>
<tr>
<td>Housing</td>
<td></td>
</tr>
<tr>
<td>Temp/Perm Apt</td>
<td></td>
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<tr>
<td>Trailer</td>
<td></td>
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<tr>
<td>SF</td>
<td></td>
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<tr>
<td>Public Transportation</td>
<td></td>
</tr>
<tr>
<td>Private</td>
<td></td>
</tr>
<tr>
<td>Support System (family)</td>
<td></td>
</tr>
<tr>
<td>Occupants in house</td>
<td></td>
</tr>
<tr>
<td>Number of siblings</td>
<td></td>
</tr>
</tbody>
</table>

## Education

<table>
<thead>
<tr>
<th>Field</th>
<th>Value</th>
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</thead>
<tbody>
<tr>
<td>School</td>
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<tr>
<td>Grade Level</td>
<td></td>
</tr>
<tr>
<td>Special Education</td>
<td>IEP</td>
</tr>
<tr>
<td>504</td>
<td></td>
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<tr>
<td>Therapies</td>
<td></td>
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</tbody>
</table>

## Behavioral/Mental Health Concerns

## Financial and Community Resources – Existing

<table>
<thead>
<tr>
<th>Field</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Food Stamps</td>
<td></td>
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<tr>
<td>SSI</td>
<td>FITAP</td>
</tr>
<tr>
<td>Waiver Programs</td>
<td>WIC</td>
</tr>
<tr>
<td>Office of Child Services (foster care)</td>
<td></td>
</tr>
<tr>
<td>CSHS</td>
<td>OCDD</td>
</tr>
<tr>
<td>Early Steps</td>
<td>Child Search</td>
</tr>
<tr>
<td>EPSDT</td>
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</tbody>
</table>

## Remarks

<table>
<thead>
<tr>
<th>Remarks</th>
<th>Date</th>
<th>Update</th>
<th>Date</th>
<th>Date</th>
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<th>Date</th>
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</thead>
</table>

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TigerCare Pediatrics
©ES 2007,ARW 2009
<table>
<thead>
<tr>
<th>Problem</th>
<th>Date ID’d</th>
<th>Referred to</th>
<th>Ref Date</th>
<th>Result</th>
<th>Clinic F/u Date</th>
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</thead>
<tbody>
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</tr>
<tr>
<td>Clinic Protocols and Processes</td>
<td>Yes</td>
<td>No</td>
<td>Tracking Mechanism (EMR, Log, etc.)</td>
<td>Responsible/Initiating Staff (PCP, RN, Office Manager, CC, MA)</td>
<td>Current Process Effectiveness: 1=weak 2=inconsistent 3=mostly effective 4=very effective Score</td>
</tr>
<tr>
<td>-----------------------------------------------</td>
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<tr>
<td>Intra-office Communication</td>
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<tr>
<td>Team communication (email, message system, huddles, morning meetings)</td>
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<tr>
<td>ID high need population (screening/identification methodology)</td>
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<tr>
<td>Population management/tracking (EMR, database, registry)</td>
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<tr>
<td>Patient Education/Self-care Support</td>
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<tr>
<td>Standardized patient/family health education (patient visit summary, teaching tools, handouts)</td>
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<tr>
<td>Health literacy assess/document teaching outcome (assess patient/family understanding of care plan)</td>
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<tr>
<td>Chronic condition management (handouts, teach back, phone follow-up)</td>
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<tr>
<td>Community resource referrals (call list, resource guides, handouts, brochures)</td>
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<tr>
<td>Care Plan Dissemination/Integration of Care All Service Follow-up</td>
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<tr>
<td>PCP/Nurse/Care Coordinator call-back (patient/family phone contact-request)</td>
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<tr>
<td>PCP office re-check</td>
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<tr>
<td>Care coordinator assessment/ follow-up</td>
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<tr>
<td>Electronic connectivity (patient portals, email, text messaging )</td>
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<tr>
<td>CQI</td>
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<tr>
<td>Scheduled audits/process evaluation</td>
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<tr>
<td>Patient/family feedback - satisfaction surveys</td>
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<tr>
<td>Meaningful Use EMR/Electronic communication links (La HIE/share platforms, facilities, insurers, providers)</td>
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<tr>
<td>Scheduled quality meetings</td>
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</table>
### Care Coordination/Communication Assessment

<table>
<thead>
<tr>
<th>Clinic Protocols and Processes</th>
<th>Yes</th>
<th>No</th>
<th>Tracking Mechanism (EMR, Log, etc.)</th>
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</tr>
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<tbody>
<tr>
<td><strong>General</strong></td>
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<tr>
<td>Appointment scheduling</td>
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<tr>
<td>(including missed f/u)</td>
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<tr>
<td>Test/Procedure Scheduling/Prior-auths</td>
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<tr>
<td>(Receive/Review/Action/Document)</td>
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<tr>
<td>Medication Refills/Prior-auths</td>
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<td>(Receive/Review/Action/Document)</td>
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<tr>
<td><strong>Consult Reports</strong></td>
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<tr>
<td>(Receive/Review/Action/Document)</td>
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<tr>
<td>Labs/Procedure /Therapy Reports</td>
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<td>(Receive/Review/Action/Document)</td>
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<tr>
<td>Inpatient Admit Discharge Summary:</td>
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<td>(Receive/Review/Action/Document)</td>
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<tr>
<td>ER Visit Notice/Report:</td>
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<tr>
<td>(Receive/Review/Action/Document)</td>
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</table>

**Instructions:** This tool is a scan assessment of a clinic’s internal and external communication processes designed to identify communication gaps and inefficient processes. To begin, simply note if a process currently exists (yes/no). For all ‘yes’ answers, complete the item assessment (tracking mechanism, responsible/initiating staff, written policy) and score process effectiveness (1-4). Once complete, examine absent (‘no’) or low scoring items (1-2) for selecting QI initiatives.

The tool includes a **Plan, Do, Study, Act** (PDSA) worksheet to support QI planning, implementation and evaluation. **PLAN:** Identify target for improvement. Tackle easy item first as success breeds success and builds project momentum. Develop measurable goals to support evaluation. Set/disseminate a project timeline. Engage frontline team members in QI plan. For each cycle, identify a cycle leader to assist staff with troubleshooting. Cycle leaders collect outcome data/feedback. **DO:** Ensure the entire team is made aware of changes before they occur; communication and education are key to effective initiatives. Printable checklists or reminders for process changes are helpful for maintaining consistency. Implement plan with ongoing process adjustments per interval feedback/assessment. **STUDY:** Evaluate and analyze outcome measurement data. **ACT:** Edit or reformulate plan as indicated. Formalize policy when effective processes are attained and sustained. Document barriers and achievements and begin next cycle. ([www.deming.org](http://www.deming.org))

**Initiative Cycle #:** _____  **Date:** ____________  **Start Date:** ________  **End Date:** ________  **Cycle Lead:** ______________________

**Plan:**

**Do:**

**Study:**

**Act:**

**Goal/Rationale:**

**Measure:**

**Identified Barriers:**

**Achievement(s):**

**PDSA learning links:** [http://www.ihi.org/resources/Pages/HowtoImprove/default.aspx](http://www.ihi.org/resources/Pages/HowtoImprove/default.aspx)  [http://www.mchnavigator.org/trainings/quality-improvement-spotlight.php](http://www.mchnavigator.org/trainings/quality-improvement-spotlight.php)

(Rev 11/14 PB©)
Provider Transition Guide:

✓ Identify adolescents in your clinic who have special health care needs
✓ Mark their charts for quick identification during clinic visits
✓ Allow for more time during their appointments
✓ Ensure that your staff know to engage adolescent patients privately during office visits
✓ Inform your adolescent patients’ family that he/she will speak one-on-one with you and your staff during office visits
✓ Make a care plan to ensure all health care transition topics have been covered
✓ Have in place a Practice Transition Policy that discusses the steps involved for transferring adolescent patients with special health care needs to providers who care for adults with special health care needs

Action points to include:

Encourage medical responsibility for presenting conditions

☐ Review medical history, baseline data, treatments, and medications with your adolescent patient and provide him/her copies
☐ Speak to your adolescents more frequently about test results, treatment plans, etc., to engage him/her in becoming more active with his/her care
☐ Teach your adolescent patients on how to recognize warning signs/symptoms that warrant emergency assistance
☐ Identify any cultural or treatment beliefs that may influence your adolescent patients’ agreement with medical guidance, and/or ability to incorporate them into his/her lifestyle

Provide anticipatory guidance for:

☐ Health insurance coverage after age 18 or 26; discuss with adolescent/family and refer as needed
☐ Safety in being independent and having an emergency information form with them at all times
☐ Any nutritional or weight concerns, and discuss exercise/activity program
☐ Educational goals: High school Diploma; GED; GEE; LEAP; I-LEAP; LAA2 advise the adolescent accordingly
☐ Social predictors for health: sexuality and special health care needs, family planning and inheritable traits, drug abuse (drug interactions), and mental and behavioral health
☐ Waiver programs through OCDD (www.jphsa.org or www.mhsdla.org)
☐ Consent and confidentiality issues, and how this changes when the adolescent patient turns 18
☐ A plan, if necessary for a Power of Attorney, or Guardianship (www.advocacyla.org)

Discuss readiness for transition:

☐ Discuss insurance programs with the adolescent/family and waiver programs when appropriate
☐ Discuss potential adult providers and sub-specialists to see when he/she is an adult and give a list
☐ Encourage your adolescent patients to meet with various adult providers to select a their new PCP

Transfer to a new health PCP:

☐ After selection of a PCP, write a medical summary and transfer records to the new PCP, and provide a copy to the adolescent as well
✓ Arrange a meeting with the adolescent and their family after the adolescent has transferred in order to ensure satisfaction and that the transfer was minimally disruptive to their health condition status
✓ Contact the new PCP as needed for any follow-up

Community Resource: Families Helping Families provides information and parent-to-parent support for families of children with special health care needs. Two offices: In Orleans Parish (504) 943-0343, and in Jefferson Parish (504) 888-9111 www.fhfsele.org; www.fhfjefferson.org

Information provided by Louisiana Children’s Special Health Services (CSHS). For more information about CSHS call 504-568-5055 or visit the website www.dhh.la.gov/cshs
Transition Checklist and Timeline for the Parishes of:
Jefferson, Orleans, Plaquemines, St. Bernard

Name: _______________________________________________ MR # ___________________________
Physician: ____________________________________________ Date initiated ________________

Use clinical judgment as to which items apply to the youth. Mark NA if item does not apply.
Mark an X when item is discussed and completed for each age group interval.

<table>
<thead>
<tr>
<th>HEALTH CARE</th>
<th>Ages 12-15</th>
<th>Ages 16-18</th>
<th>Ages 19-21</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Youth meets privately with MD/staff for part of the office visit</td>
<td>☐</td>
<td>☐</td>
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</tbody>
</table>

Encourage the adolescent to assume increasing responsibility for his/her health care management:

<table>
<thead>
<tr>
<th></th>
<th>Ages 12-15</th>
<th>Ages 16-18</th>
<th>Ages 19-21</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Assess youth’s understanding of his/her health condition and medications</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>• Assess ability of youth to understand and manage self-care</td>
<td>☐</td>
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</tbody>
</table>

Assess youth/family readiness for transfer to adult health care providers:

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<thead>
<tr>
<th></th>
<th>Ages 12-15</th>
<th>Ages 16-18</th>
<th>Ages 19-21</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Discuss transfer to adult health care providers</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>• Identify possible adult health care providers/sub-specialists</td>
<td>NA</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>• Encourage youth/family to meet with adult health care providers</td>
<td>NA</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

Implement the transfer to adult health care providers:

<table>
<thead>
<tr>
<th></th>
<th>Ages 12-15</th>
<th>Ages 16-18</th>
<th>Ages 19-21</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Send copies of medical record to identified adult health care providers along with discharge summary</td>
<td>NA</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

Assess youth’s ability to make independent decisions for health care, finances and concerns for determining guardianship/conservatorship:

<table>
<thead>
<tr>
<th></th>
<th>Ages 12-15</th>
<th>Ages 16-18</th>
<th>Ages 19-21</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Initiate referral for assessment of competence, as needed</td>
<td>NA</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>• Follow-up on consent, guardianship and confidentiality processes</td>
<td>NA</td>
<td>☐</td>
<td>☐</td>
</tr>
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</table>

HEALTH INSURANCE:

<table>
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<th></th>
<th>Ages 12-15</th>
<th>Ages 16-18</th>
<th>Ages 19-21</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Verify current insurance; Discuss future insurance needs; inform/discuss SSI Disability, Medicaid- Bayou Health Plans and/or Healthcare Marketplace [<a href="http://www.healthcare.gov">www.healthcare.gov</a>]; Advocacy Center [<a href="http://www.advocacyla.org">www.advocacyla.org</a>]; Pharmacy assistance programs</td>
<td>☐</td>
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EDUCATION & WORK - independent vs. sheltered:

<table>
<thead>
<tr>
<th></th>
<th>Ages 12-15</th>
<th>Ages 16-18</th>
<th>Ages 19-21</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Discuss types of HS Diplomas; IEP - transition plan; education beyond high school</td>
<td>☐</td>
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</tr>
<tr>
<td>• Referral to LA Rehab Services: [<a href="http://www.laworks.net/WorkforceDev/LRS/LRS_Main.asp">www.laworks.net/WorkforceDev/LRS/LRS_Main.asp</a>]</td>
<td>NA</td>
<td>☐</td>
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INDEPENDENT LIVING:

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<tr>
<th></th>
<th>Ages 12-15</th>
<th>Ages 16-18</th>
<th>Ages 19-21</th>
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</thead>
<tbody>
<tr>
<td>• Assess adult habitation plans; check status on Waiver list</td>
<td>NA</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>• Referral to: Office for Citizens with Developmental Disabilities, Independent Living Program, Community and Family Support; Resources for Independent Living- [<a href="http://www.noril">www.noril</a>]</td>
<td>NA</td>
<td>☐</td>
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ANTICIPATORY GUIDANCE:

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<thead>
<tr>
<th></th>
<th>Ages 12-15</th>
<th>Ages 16-18</th>
<th>Ages 19-21</th>
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</thead>
<tbody>
<tr>
<td>• Discuss Safety concerns &amp; when to call 911 for emergencies</td>
<td>☐</td>
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<tr>
<td>• Discuss dental, nutrition/weight concerns</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>• Discuss social relationships, sexuality, mental and behavioral health</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
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<tr>
<td>• Discuss leisure activities</td>
<td>☐</td>
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</tbody>
</table>

Family Community Referrals:
Family Resource Center – 504-896-1340 (located in room 2020 - Children’s Hospital New Orleans)
Families Helping Families – 504-888-9111 Jefferson Parish [www.fhjefferson.org]
504-943-0343 Parishes of Orleans, St. Bernard, Plaquemines [www.fhfsela]
LA Children’s Special Health Services (CSHS) 504-568-5055 - electronic resource access [www.dhh.la.gov/cshs]
Office for Citizens with Developmental Disabilities (OCDD) – 504-599-0245

(CSHS © 4/14)
Transition Health Care Information-Greater New Orleans Metropolitan Area  
For youth (ages 12 and up) with special health care needs and disabilities

Take charge of your health information:
- Do you know what medicines you are taking and WHY? If NO – ASK!
- Call your drugstore for your own medicines. The phone number is on the bottle.
- Do you know your health insurance plan name? What does it cover? Are you on a waiver program or list? Go to: www.jphsa.org or www.mhsdla.org to find out.
- Do you know your doctor’s address? Phone number? Write it down, keep for emergencies.
- Keep a Medical Notebook that has your medical reports, medications, operations, & results of medical tests; your doctors will want to see these.
- Keep a short outline of your health condition & put it in your Medical Notebook.
- Do you know how to order and take care of any special equipment or supplies you use?

Be your own health care advocate:
- Do you know what your health issues are?
- Do you know the danger signs that mean that YOU need emergency help very soon?
- Do you know who to call in case of an emergency? Carry that information with you everywhere.
- Do you know how to make your own medical appointments?
- Write down any questions you have before you go to see your doctor.
- Meet with your doctor and other staff by yourself.
- Ask your doctor and other staff questions. If you don’t understand, ask again.
- Talk to your doctor about adult things: How will my special health care need affect my romantic relationships? Do I know the real dangers of drug use and drug interactions? Thinking and planning for my future family, would birth control help me plan and be ready to care for my own children?
- Tell your doctor/staff if you are feeling down or are being bullied. They can help!
- Ask your doctor to talk about all of your medical tests and what the results mean. Keep copies in your Medical Notebook!
- Always carry your insurance card with you, and bring your Medical Notebook to doctor visits.
- Let your doctor know what’s important to you; what your beliefs are. Let them know if you will do what they say or tell them why you can’t.

Plan for transfer to a doctor who treats adults:
- Talk to your doctor about how and when you should start seeing a doctor who treats adults.
- Ask your doctor about any resources they know that might be helpful for you.
- Meet and talk with your new adult care doctor before you switch from your old doctor.

Plan for independence:
- Know what you feel comfortable doing on your own and what new skills you want to have to experience new events on your own. What are the social skills that adults have? Make a list & talk with your family and doctor.
- What health insurance plan will you have when you’re 18 or 26? Who will pay for your medical visits?
- Do you know what type of job you want? What can you do on your own? Talk with your family and doctor.
- Getting around town – Do you have transportation? How will you get to your doctor’s office or get food?
- Do you know where will you live? How will you get enough money to live on your own? What exactly is a budget anyway? Do you need to know this?? YES!
- Can you make your own decisions? Do you need a Power of Attorney? Talk with your family and contact the advocacy center if you need help. → www.advocacyla.org

Resources: Family Resource Center assists families with locating resources for children and youth with special health care needs (504) 896-1340. Families Helping Families provides information and parent-to-parent support for families of children with special health care needs. There are two offices: Orleans Parish (504) 943-0343; Jefferson Parish (504) 888-9111 www.fhfseola.org ; www.fhfjefferson.org

Information provided by Louisiana Children’s Special Health Services (C SHS), additional information/resources available at www.dhh.la.gov/cshs. 
(CSHS © 9/14)
# CARE COORDINATION-MEDICAL HOME TOOLKITS/RESOURCES

## Care Coordination

<table>
<thead>
<tr>
<th>Resource</th>
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<tbody>
<tr>
<td>Care Coordination Model: Better Care at Lower Cost for People with Multiple Health and Social Needs Institute for Healthcare Improvement Innovation Series</td>
<td><a href="http://www.ihi.org/resources/Pages/IHIWhitePapers/IHICareCoordinationModelWhitePaper.aspx">2011 http://www.ihi.org/resources/Pages/IHIWhitePapers/IHICareCoordinationModelWhitePaper.aspx</a></td>
</tr>
<tr>
<td>Children’s Special Health Services Louisiana-Regional Resource Guides/Provider and Family Resources</td>
<td><a href="http://www.dhh.la.gov/cshs">www.dhh.la.gov/cshs</a></td>
</tr>
<tr>
<td>Patient- and Family-Centered Care Coordination: A Framework for Integrating Care for Children and Youth Across Multiple Systems (AAP Policy Statement May 2014)</td>
<td><a href="http://pediatrics.aappublications.org/content/133/5/e1451.full">http://pediatrics.aappublications.org/content/133/5/e1451.full</a></td>
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</table>

## Medical Home

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<tr>
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<tbody>
<tr>
<td>Center for Medical Home Improvement</td>
<td><a href="http://www.medicalhomeimprovement.org/">http://www.medicalhomeimprovement.org/</a></td>
</tr>
<tr>
<td>Joint Commission’s Primary Care Medical Home</td>
<td><a href="http://www.jointcommission.org/accreditation/pchi.aspx">http://www.jointcommission.org/accreditation/pchi.aspx</a></td>
</tr>
<tr>
<td>National Center for Medical Home Implementation</td>
<td><a href="http://medicalhomeinfo.org/">http://medicalhomeinfo.org/</a></td>
</tr>
<tr>
<td>Patient-Centered Primary Care Collaborative</td>
<td><a href="http://www.PCPCCP.org">www.PCPCCP.org</a></td>
</tr>
<tr>
<td>URAC’s Patient Centered Medical Home Toolkit</td>
<td>[<a href="https://www.urac.org/accreditation-and-measurement/accreditation-programs/all-programs/patient-centered-medical-home">https://www.urac.org/accreditation-and-measurement/accreditation-programs/all-programs/patient-centered-medical-home</a> program-toolkit/](<a href="https://www.urac.org/accreditation-and-measurement/accreditation-programs/all-programs/patient-centered-medical-home">https://www.urac.org/accreditation-and-measurement/accreditation-programs/all-programs/patient-centered-medical-home</a> program-toolkit/)</td>
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## Care Coordination/CPT Codes

<table>
<thead>
<tr>
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<tbody>
<tr>
<td>American College of Physicians -What Practices Need to Know about Transition Care Management Codes</td>
<td><a href="http://www.acponline.org/running_practice/payment_coding/coding/tcm_codes.htm">http://www.acponline.org/running_practice/payment_coding/coding/tcm_codes.htm</a></td>
</tr>
<tr>
<td>CMS – Transitional Care Management Services, Medicare Learning Network service descriptors and billing guidance</td>
<td><a href="http://www.nacns.org/docs/TransCareMgmtFAQ.pdf">http://www.nacns.org/docs/TransCareMgmtFAQ.pdf</a></td>
</tr>
</tbody>
</table>
### Cultural Competence

**National Center for Cultural Competence**
http://nccc.georgetown.edu/

National Center for Cultural Competence PROMOTING CULTURAL and LINGUISTIC COMPETENCY Self-Assessment
http://nccc.georgetown.edu/documents/Checklist%20PHC.pdf

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### QI/Plan Do Study Act

**Agency for Healthcare Research Quality (AHRQ)-CAHP Surveys PDSA**

**Agency for Healthcare Research Quality (AHRQ)-Health IT- PDSA Cycles**

**Safety Net Medical Home Initiative- Quality Improvement Strategy Implementation Part 1**
Tools to Make and Measure Improvement

**Safety Net Medical Home Initiative- Quality Improvement Strategy Part 2**
Optimizing Health Information Technology for Patient-Centered Medical Homes

**Your Medical Home: Well Designed Using a Quality Improvement Process**
http://www.pediatricmedhome.org/qib/
http://www.pediatricmedhome.org/qib/example.aspx

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### Youth Transitions

**Children’s Special Health Services (CSHS) Louisiana – Transition Tools For Healthcare Providers**
www.dhh.la.gov/cshs

**Got Transition: The National Alliance to Advance Adolescent Health/HRSA/MCHB**
http://www.gottransition.org

**HEATH Resource Center at the National Youth Transitions Center:** information exchange of educational resources, support services and opportunities
http://heath.gwu.edu/

**Policy Statement: Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home**
AAP, AAFP, and ACP, Authoring Group
http://pediatrics.aappublications.org/content/128/1/182.full

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