Background
The Affordable Care Act (ACA) and other health reforms within states bring significant change to the health system landscape. Although the primary goal of federal and state health reform is to extend health insurance coverage to millions of uninsured children and adults, it also presents an opportunity to improve the quality of care and improve health outcomes for one of our nation’s most vulnerable groups: children and youth with special health care needs (CYSHCN). Key stakeholders, such as Title V CYSHCN programs, families and consumers, health plans, private insurers, state Medicaid and CHIP agencies, pediatricians and family physicians, can seize this opportunity and work together to create a comprehensive, quality system of care for CYSHCN and all children. A robust system of care for CYSHCN strengthens the overall pediatric health care infrastructure, benefiting all children and supporting the potential for a healthy, productive adulthood.

To foster action within states to improve the quality of systems of care for CYSHCN, in 2013 the Lucille Packard Foundation supported the Association of Maternal and Child Health Programs to convene a workgroup of national and state leaders—representing state Title V CYSHCN programs, health plans, Medicaid and CHIP agencies, pediatric providers, children’s hospitals, insurers, health services researchers, families/consumers, and others—to develop a set of structure and process standards that together represent the necessary components of a comprehensive, quality system of care for CYSHCN. Based on existing standards work and discussions in several national expert meetings, the workgroup agreed upon a set of standards called The National Standards for Systems of Care for CYSHCN. These standards are grounded in the six core outcomes for systems of care for CYSHCN that were developed by the federal Maternal and Child Health Bureau, Health Resources and Services Administration and based on a comprehensive review of the literature, key informant interviews, case studies of standards for CYSHCN currently in use in Title V, Medicaid and health plans within selected states and consensus from the national work group. A detailed description of how the national standards were developed is available by clicking here or visiting http://cshcn.wpengine.netdna-cdn.com/wp-content/uploads/2014/03/Developing-Structure-and-Process-Standards-White-Paper.pdf.

The workgroup’s national consensus standards are organized into the 10 domains listed below. (Copies of the detailed standards under each domain area can be found by clicking here or visiting http://cshcn.wpengine.netdna-cdn.com/wp-content/uploads/2014/05/Developing-Structure-and-Process-Standards-Charts.pdf.)

1. Screening, Assessment and Referral
2. Eligibility and Enrollment
3. Access to Care
4. Medical Home, including Pediatric Preventive and Primary Care; Care Coordination; and Pediatric Specialty Care
5. Community-based Services and Supports, including Respite Care; Palliative and Hospice Care; and Home-based Services
6. Family Professional Partnerships
7. Transition to Adulthood
8. Health Information Technology
9. Quality Assurance and Improvement
10. Insurance and Financing
Purpose of the Standards Presentation Tool
This tool is designed to be used as an orientation and discussion tool for agencies, organizations and stakeholders serving CYSHCN stakeholders seeking to understand and apply the standards within states. Organizations who should consider using this tool include Title V CYSHCN programs, state Medicaid and CHIP, health plans, provider groups, families and family partner organizations. The tool was developed to be used in conjunction with the national standards, and can also be used with other standards-based tools including organizational and systems assessment tools.¹

How to Use the Tool
This tool can be used by single organizations, multi-agency teams, and CYSHCN stakeholder groups to orient themselves and others to the standards. The tool consists of a set of PowerPoint presentation slides that can be used as is, or customized to fit a particular discussion or meeting. Four levels of orientation to the standards are possible with these slides:

- An “ultra-broad” orientation/discussion consists of 2 slides (Slides 1-2) which show a picture of the front cover of the standards document with a hyperlink, followed by a slide that quickly summarizes the purpose for the standards and shows the 10 Domain areas.
- A “broad” orientation/discussion consists of the slides mentioned above, as well as one additional slide (Slide 3) that, when in Slide Show mode, is animated to reveal 3 to 4 main focus areas of each Domain. Slides 2 and 3 can be easily printed and shared as handouts (the text on Slide 3 will be difficult for audience participants to read from the projected slide, so handouts will be useful.)
- A “detailed” orientation/discussion consists of the slides mentioned above, as well as an additional slide for each of the ten Domains (Slides 4, 6, 8, 10, 15, 20, 22, 24, 26, and 28). These additional slides provide the name, main focus areas, and potential system partners needed to address the standards within a particular Domain. Organizations/teams using these slides should customize the “Relevant Systems Partners”, when appropriate, to name specific agencies and/or organizations within their state.
- An “ultra-detailed” orientation/discussion uses all the slides in the deck (Slides 1-29). The additional slides included use the detailed language contained within the standards, organized by the potential relevant system partners needed to address the standards within a particular Domain. It is important to note that (1) the numbers before the standards on these slides correspond to the numbered standards in the original National Standards for Systems of Care for CYSHCN document; and (2) organizations/teams using these slides should customize the “Relevant Systems Partners”, when appropriate, to name specific agencies and/or organizations within their state.

Ways to Use the Tool
Your organization/team can use this Standards Presentation Tool in multiple ways, including but not limited to:

- Orient your organization and staff to the standards.
- Orient your partners and other CYSHCN stakeholders to the standards.
- Use them in conjunction with National Standards assessment tools to orient CYSHCN stakeholders to the standards and assess systems of care for CYSHCN in your state.

¹ To request this and other National Standards assessment tools, please email Meredith Pyle at The Association of Maternal and Child Health Programs (AMCHP) at mpyle@amchp.org
A Note About Modifying/Customizing Slides
The graphics on these PowerPoint slides were made using Smart Art Graphics (a tool available in the PowerPoint software. Formatting Smart Art can be tricky at times. If you find that you are having trouble maintaining the current formatting (text size, graphic shapes color, etc.) of the Presentation Slides as you customize them for your organization/state, please refer to the following tips and links:

Tips:
- If you have trouble with the colors of the Smart Art shapes, change the color design to something simpler. To do this, select the Smart Art shape on the slide by clicking on it so that the selection box appears around the entire graphic. Then from the top menu, choose “Design” (next to “Format”) and select a simpler color template with no background fill:

Helpful Links:
- “Learn More About Smart Art graphics” article at https://support.office.com/client/SmartArt-graphic-91d1bf9b-8c06-4e21-ad31-f2c21af7d53b
- PowerPoint 2007 Smart Art Tutorial from UPenn at http://gethelp.library.upenn.edu/workshops/biomed/ppt07/smartart07.html
- “How to Edit PowerPoint 2007 Smart Art Text For Dummies” article at http://www.dummies.com/how-to/content/how-to-edit-powerpoint-2007-smartart-text.html