Seeking stakeholder input into strategic planning for future initiatives to advance the science, care and outcomes for children and youth with special health care needs and their families.

**Welcoming**
On June 21, 2018 from 2pm to 5pm the University of Minnesota School of Nursing’s Center for Children with Special Health Care Needs (CSHCN) welcomed key stakeholders to the Bentson Health Communities Innovation Center for the afternoon to share insights.

Ann Garwick and Wendy Looman, Center co-directors, provided a warm greeting, context, and shared that the Center is celebrating it’s 25th year having been initiated in 1993 by a nursing training grant from the Maternal and Child Health Bureau, Health Resources and Services Administration, and the Department of Health and Human Services. They then introduced the facilitator, Jen Mein, who guided the group through the afternoon discussions and other activities.

**Table Discussions**
Arranged at three tables, we explored the Center’s three strategic focus areas: essential competencies for providers, critical areas of future research, and quality improvement across systems. Everyone contributed in a process of sharing ideas and documenting discussions, filling up large sheets of paper with post-it notes with insights.

Across three rounds of table discussion, we brainstormed, considered what might be missing, and then identified possibilities in each area.
What competencies are essential for providers who care for children and youth with special health care needs and their families?

- Self-care, burnout, vicarious trauma, boundaries
- Focus on potential of all individuals, cultivate hope
- Child-centered, person-centered, family-centered care
- Cultivate curiosity
- Comprehensive knowledge of complexity - family, school, development changes, transitions, transportation
- Good interviewing skills including picking up on non-verbals
- Having experience, field work with families and communities
- Family systems training

What are the critical areas of future research to advance the care of CSHCN and their families?

- Include families from diverse backgrounds in research from the beginning
- Continue to focus on patient and family experience
- Develop new models to ensure continuity of care across systems, e.g. rural, case mapping using technology like tele-health, school nurses
- Utilizing big data methods to ensure quality care
- Coping and resilience for families with children with special health care needs
- Ensure access to meaningful research findings relevant to providers and families
- Focus on transitions - acute to chronic, city to rural, age

What are the priorities for quality improvement in the care of CSHCN and their families within and across systems e.g., hospitals, clinics, home, and school settings?

- Need sustainability and spread of quality improvement to have larger, positive impact
- Effective care coordination
- Streamline communication and documentation using technology, e.g. shared plans of care
- Use family-centered care model as foundation for quality improvement - culture, partnership, shared decision-making
- Families need to be involved from beginning of quality improvement/change - a member of the team
- Training workforce on what family-centered care means/is
- Collect and use data for both quality improvement and research
- Culture of quality improvement - need systems to have capacity for quality improvement and be ready to implement with full organizational support

Priority Setting

Next, in groups arranged by focus area, eight key insights/actions/possibilities were identified, written on post-it notes, and placed on a visual for all to see. Then, each person looked at the post-its across the three areas and positioned dot stickers by those items that they were energized by or they saw potential for significant impact. The dot stickers were color coded to show the variety of perspectives in the room: researcher, family member, community agency/organization representative, educator, provider. See outcomes below (bold items had the most dots):
Reflections
Once all the dots were counted, we stepped back and reflected upon the results. A rich discussion ensued and included the following points:

- Being family-focused, leveraging technology, ensuring continuity and sustainability were key mindsets that were represented across the three focus areas.
- The role of the Center was discussed as being a neutral hub; a convener; and a connector of learning, research, and expertise across boundaries.
- Learning opportunities offered by the Center go into the What and the How of care.
- Family voice, engagement, and shared decision-making is so important; participatory action research is an approach to consider.
- Diversity of cultures and perspectives to consider: race, ethnicity, geography, socio-economic, medical culture, environment, pediatric care vs. adult care

Stakeholder takeaways...

Feeling invigorated, validated, humbled, aligned, fortunate, hopeful, encouraged, grateful
Appreciating the passion, learning, synergy, opportunity, optimism, forward-looking
Anticipating next steps, movement

We would like to thank all who participated and also acknowledge the input we received from individuals who were unable to join us in person. Participants included family caregivers, health care professionals, and leaders from community and hospital based organizations in urban and rural settings.

Carolyn Allshouse  Megan Antolick  John Belew  Wendy Berghorst  Joan “Jody” Chrastek  Sarah Cox
Barb Dalbec  Naomi Goloff  Mary Kautto  Katie Martin  Jen Maytum  Anne McKechnie
Karen Peterson  Denise Post  Ann Seppelt  Barbara Beacham  Linda Lindeke

Center for Children with Special Health Care Needs