Children’s Hospital and Health System
Patient Care Policy and Procedure

This policy applies to the following entity(s):
☒ Children’s Hospital and Health System

SUBJECT: Transition Planning for Youth with Special Health Care Needs (YSHCN) to Adult Health Care Setting

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DEFINITIONS:

Transition

The purposeful planned movement of adolescents and young adults with chronic health conditions from child-centered care to adult health care.

Transfer of Care

The physical transfer of information and care from a child-centered to an adult health care environment.

Transition Planning

The active process of engaging and supporting the youth and family in managing their health care condition or disability as independently as possible. Further support will be offered as appropriate in regards to guardianship, future education, work plans, living arrangements and finances.

Transition Checklist
Provides a place to document (as available in EHR) ongoing assessment and teaching needs focused on self-management skills. The transition checklist serves as a guide to optimize communication and integration across the system.

Transition Summary
A personalized plan of care developed for each young adult. The document will provide a comprehensive summary of the youth's medical, surgical, social-emotional and developmental history including personal/family goals.

Transition Coordinator
The primary care provider or member of the care team who will take on the responsibility of coordinating transition services to adult health care. The transition coordinator is ultimately responsible for providing an updated transition care plan to the youth, adult provider and family as appropriate.

POLICY

Children's Hospital of Wisconsin is committed to helping all youth make a smooth transition from pediatric to adult health care. This process requires working with youth and families to plan and prepare for transition starting around the 12th birthday. Youth with Special Health Care Needs (YSHCN) should participate in the transition process that is developmentally appropriate and meaningful for them regardless of when they transfer care to an adult provider. The preferences of the youth and family regarding the transfer of care to an adult care provider occurs with a discussion with primary providers to determine the best health interests of the youth and family.

Transition tends to occur between the ages of 18-22 years of age. Individual specialty situations may arise in the course of transition for certain youth and certain patient populations. There are YSHCN who will continue to require the assistance of another adult to make health care decisions. In this situation, the guardian of the YSHCN will assist in the process to facilitate the transition to the adult health care setting. As much as possible and appropriate the YSHCN should be involved in the planning and decision making for transition. The goal of transition for YSHCN is to maximize lifelong functioning and potential through the provision of high quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood.

PROCEDURE

I. General Expectations

A. “TRANSITION” should be listed in the problem list at age 12 years for YSHCN in conjunction with documentation of discussion with the youth and guardian.
B. When appropriate, the youth that is being transitioned should be given the opportunity to talk with their health care provider independent of their family.
C. Documentation should be evidenced by a progress note or by the transition checklist.
D. Members of the care team should use the transition checklist, where available, to guide conversations and goal setting that promotes independence and transition to adult health care. Although it is recognized that specialty organizations may support the use of diagnostic specific transition recommendations. The use of any specialty transition document should be evident in the electronic health record. Additionally, it is recognized that certain youth will be unable to manage their own health care and therefore their guardian should be prepared for the transition process.
E. When available, a copy of the checklist should be printed out and shared with the youth and/or family over time.
F. A final transition summary should be provided to the youth, family and adult provider when the transfer of care from pediatric to adult health care occurs.
G. In collaboration with youth/family and the health care team assist in setting developmentally appropriate goals that promote independence based on results of the self-assessment.
H. The health care team will provide opportunities for youth to independently participate in visits, medical decision-making and their transition plan.
I. Health care teams will partner with youth, parents, guardians and community organizations to maximize the youth’s autonomy and role in his/her transition plan.

II. Recommended Transition Team Roles:

A. The primary care provider most often serves as the transition coordinator unless another care team member has identified themselves as the transition coordinator.

III. Specialty Providers

A. Transition should be added to the problem list at age 12 as appropriate.
B. In collaboration with the care team, the specialty provider should also prepare a transition summary at the time of the transfer of care.

C. Prepare patients and their families for the adult health care model including legal changes in decision-making, privacy, consent, self-advocacy and access to information.

IV. Registered Nurses and/or Social Workers:

A. Assess youth and family in self-management skills that will promote independence.
B. Support youth and family in developing skills for self-efficacy to promote, maintain, or restore health such as: managing medical condition, managing medication, managing equipment/supplies, adult decision making, adult services, finance, education, employment, transportation, and recreation.
C. Works with family to complete an initial self-assessment utilizing a transition checklist (as available) to determine transition readiness and determine goals. Discusses these results with the family and health care team. Updates the transition checklist as appropriate (or as available in the EHR).
D. Document transition planning in patient education when appropriate.

V. Documentation

The Transition Checklist, where available, is located in the flowsheets in the EHR, titled Transition Checklist. Any health care provider who has provided guidance in self-management skills and transition issues with the youth and family should review the specific topic in the Transition Checklist and document as appropriate in the corresponding section.

VI. Supporting Documents

Family Education Documents –Teaching Sheets:

Transition to adulthood checklist 1491

Transition to adulthood: Resource directory 1359
Transition to adulthood: Resource directory (Spanish)

Transition to adulthood: Education after high school 1375
Transition to adulthood: Education after high school (Spanish)

Transition to adulthood: Adult guardianship 1372

Transition to adulthood: Adult guardianship (Spanish)

Transition to adulthood: Insurance 1374
Transition to adulthood: Insurance (Spanish)

Transition to adulthood: Having an active social life 1376
Transition to adulthood: Having a social life (Spanish)

Transition to adulthood: Employment (work) 1373
Transition to adulthood: Employment (work) (Spanish)

Transition to adulthood: Finding the right doctor (1358)

Transition to adulthood Housing and independent living (Spanish)
Transition to adulthood: Housing and independent living 1371

VII. REFERENCES

AAP, AAFP, ACP-ASIM (2002) A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics* 110(6-Pt 2), 1304-1306

AAP, AAFP, ACP (2011) Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home. *Pediatrics* 128; 182.2.

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Role of Internists in the Transition From Pediatric to Adult Health Care. *Annals of internal medicine*, *167*(5), 362.

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Approved by the Joint Clinical Practice Council February 19, 2018