The American Academy of Pediatrics (AAP) is recruiting up to nine (9) pediatric and adult provider practice team pairs to participate in a quality improvement project focusing on transition coordination from pediatric to adult focused care for patients with spina bifida. This project is funded through a cooperative agreement between the American Academy of Pediatrics and the Centers for Disease Control and Prevention’s National Center on Birth Defects and Developmental Disabilities (Grant # NU38OT000282). The project is being conducted in collaboration with the Spina Bifida Association and Got Transition; the technical assistance center for healthcare transition improvement.

Recent studies have revealed that the lack of continuity in preparing patients with spina bifida to transition into adult-centered care may have detrimental health consequences. A survey of over 30 spina bifida clinics indicated wide variances in what is offered to patients and families regarding transitional care services and formal transitional care programs. Overall clinics rate themselves as a 5/10 in their ability to provide services for their patients during transition. (Kelly et al, J Pediatr Rehabil Med, 2017)

Spina Bifida Quality Improvement Learning Collaborative

The spina bifida quality improvement learning collaborative will engage 9 teams consisting of a pediatric spina bifida clinic providers and an adult care provider(s). Teams will partner to improve transition coordination for patients with spina bifida consistent with the 2018 AAP/AAFP/ACP Clinical Report on Health Care Transitions, Guidelines for the Care of People with Spina Bifida, and Got Transitions Six Core Elements. The project will focus on:

- Implementation of a written policy or approach on transition for both pediatric and adult providers;
- Improvement in each practice’s score on the Current Assessment of Health Care Transition Activities for Transitioning Youth to Adult Health Care Providers (pediatric practice) and Integrating Young Adults into Adult Healthcare (adult practice) self-assessments;
- Development of a care plan that includes a transition plan for patients age 16-22; and
- Transfer to an adult provider such that a (1) a completed transfer package would be shared with the adult provider (2) an appointment scheduled with an adult provider within 6 months of the last pediatric visit.
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**Application Process** – Due Friday, July 26, 2019

Interested pediatric/adult practices should complete the [https://www.surveymonkey.com/r/SBQIApplication](https://www.surveymonkey.com/r/SBQIApplication) (only one form is needed per pediatric/adult clinic practice team pair). Applications will be reviewed by the interdisciplinary expert group. Practice teams will be notified of their acceptance/denial by late July/early August.

In preparation for the learning collaborative both the pediatric and adult practice/clinic should:

- **Gain buy-in/support from practice leadership, IT staff and other stakeholders.**
  Senior leaders and other stakeholders are in a position to enable the goals and long-term sustainability of improvements that are made over the course of the project. Support is needed to ensure dedicated time for both administrative support and clinical team members as well as to facilitate alignment with other strategic activities.

- **Gather a multidisciplinary team from for both the pediatric and adult practice/clinics.**
  Team members on both sides should include a lead physician and may include two or three additional members. These might be other physicians, nurse practitioners, nurses, parents/patients, care coordinators and/or office staff.

The American Academy of Pediatrics Institutional Review Board (AAP IRB) reviewed and determined, as authorized by 45 CFR 46.101, that the above-named protocol is exempt from federal regulations and meets at least one of the federal exemption categories. No identifiable protected health information will be collected for this project; therefore, HIPPA authorization will not be needed from patients in order to participate.

**Submit Applications by completing the online form:**
[https://www.surveymonkey.com/r/SBQIApplication](https://www.surveymonkey.com/r/SBQIApplication) (only one form is needed per pediatric/adult clinic practice team).

**Proposed High Level Timeline**

Project implementation will occur from August 2019 through July 2020. Pediatric/Adult practice teams selected to participate will do the following:

- **Prework (August – September 2019)**
  - Participate in one orientation webinar — August 14, 2019.
  - Participate in one project kick-off webinar — September 11, 2019.
  - Participate in one pre-implementation call with the quality improvement advisor — date to be determined per team.
  - Complete the Current Assessment of Health Care Transition Activities for Transitioning Youth to Adult Health Care Providers (pediatric practice) and Integrating Young Adults into Adult Healthcare (adult practice) self-assessments.
  - Draft/review/revise a process map for transition from pediatric to adult care (pediatric clinic).
  - Draft/review/revise a welcome and orientation process map for new adult patients with spina bifida (adult provider[s]).

- **Virtual learning session** (Wednesday, October 16, 2019 via videoconference)
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- **Action periods (October 2019 – June 2020)**
  - Maintain and submit de-identified quality improvement data (via Survey Monkey) based on established metrics for the project for all spina bifida patients age 16-22 in the practice. Anticipated due dates: September 13 (baseline), December 13, March 13 and June 12.
  - Participate on 3 action period webinars. Anticipated dates: January 8, April 8, July 8.
  - Monthly: implement Plan, Do, Study, Act (PDSA) cycles of change to implement iterative quality improvements for both pediatric and adult providers; tools and resources to support the PDSA cycles will be shared with the practices.
  - Monthly: complete and submit progress reports (via SurveyMonkey) regarding PDSA cycles of change for both pediatric and adult providers in the practice team.
  - As needed or applicable, participate in one-on-one coaching with the quality improvement advisor or a member of the project’s interdisciplinary expert group.
  - As needed or applicable, participate in office hours sessions held by the quality improvement advisor and/or members of the project’s interdisciplinary expert group.

- **Post action period (July 2020)**
  - Complete final data collection based on established metrics for the project.
  - Participate in one wrap-up webinar to 1) review all data, and 2) discuss sustainability as well as possible next steps.

The data collected over the course of the *transition from pediatric to adult centered care for youth living with spina bifida project* is intended to support learning and quality improvement both for your practice team and for all practices participating in this virtual learning collaborative. All data submissions are completely voluntary and will only be reported in aggregate.

Contact Nkem Chineme (nchineme@aap.org | 630-626-6342) OR Rachel Daskalov (rdaskalov@aap.org | 630-626-6063) for additional information about this project.