

## 18th Annual Chronic Illness and Disability Conference: Transition from Pediatric to Adult-based Care

Youth Panel – Youth Experiences

October 6, 2017

Sarah Graham, MPH, CCRP

*Pediatrics*

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### Objectives

- Better understand the purpose and importance of establishing a youth advisory board
- Identify key steps and best practices in establishing a youth advisory board
- Understand the youth perspective of serving on an advisory board

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### “Voice of TCH”- Recruitment

- Patient and Family Services Department
- Provider recommendations
- Flyer on TCH social media accounts

**YOUTH ADVISORY BOARD**

The Health Care Transition Program at Texas Children's Hospital is looking for youth to serve on its Youth Advisory Board. The Health Care Transition Program helps support young adults on their transition from pediatric to adult-based care through peer support, education and skill-building.

<p><b>We Are Looking For You!</b></p> <ul style="list-style-type: none"> <li>→ Youth ages 18-21 with inflammatory bowel disease, hypertension, chronic kidney disease, kidney transplant, systemic lupus erythematosus, juvenile dermatomyositis, juvenile idiopathic arthritis, weight struggle or a mental health diagnosis (eg. depression, anxiety, eating disorder)</li> <li>→ Someone who is enthusiastic about leadership and advocacy</li> <li>→ Individuals who are interested in learning more about health care transition, rights and rights</li> <li>→ Someone who is willing to commit to 6 months or more</li> </ul> <p><b>When?</b></p> <ul style="list-style-type: none"> <li>• Monthly in-person meetings</li> <li>• Occasional email correspondence and meetings by Skype or other form of telecommunication</li> </ul>	<p><b>Why Join?</b></p> <ul style="list-style-type: none"> <li>• Make a difference in your community</li> <li>• Have your voice heard</li> <li>• Build leadership skills through training and hands on experience</li> <li>• Network with other leaders in the medical field</li> <li>• Earn community service hours</li> <li>• Help improve health care transition for patients at Texas Children's Hospital</li> </ul>
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**Contact Sarah at (832) 822-0603 or [sarahg@bcm.edu](mailto:sarahg@bcm.edu) to ask questions and complete an application.**

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### “Voice of TCH”- Training

- Orientation and training
  - Video on the history of TCH
  - HIPAA/confidentiality
  - Patient-centered care
  - Background on Health Care Transition
- Background checks on those 18+
- Official hospital volunteers

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### “Voice of TCH”- Operations

- Leadership team coordinates monthly meetings
  - Space
  - Materials
  - Snacks
  - Compensation (\$25 gift card per meeting)
  - Agendas (with board input)
  - Lead meetings
  - Minutes

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### “Voice of TCH”- Operations Continued

- Board members picked the meeting day and time
- Collected detailed contact information, emergency contact information and dietary restrictions
- Board members identified gift card preference (Amazon) and snack suggestions



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### “Voice of TCH”- Barriers & Solutions

- Location & parking
  - Off-campus TCH building with free parking
- Member attendance
  - Save the Date email 1 month in advance
  - Reminder and RSVP email 3 days in advance
    - Include brief description of the agenda
  - Copy caregivers of minors on all correspondence
  - Invite members to help create the next agenda and specific projects
  - Provide evidence of how their feedback has been applied

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### “Voice of TCH”- Barriers & Solutions Continued

- Member turnover
  - Ask members to commit to at least 6 months
  - Touch base regularly regarding the meeting schedule
  - Tap into the talents and interests of your members
  - Recruit new members year around
    - Invite members to recommend other patients they know
    - Host a fun event to welcome new members (e.g., ice cream social)
  - Consider teleconference option once established (haven't tried this yet)

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### “Voice of TCH”- Barriers & Solutions Continued

- Staff Attendance
  - Have 2 staff members present to help facilitate small group work, to be there in case of an emergency, or even just to make an even number on pair activities
  - Keep the staff/member ratio in mind...don't have more staff than members.
- Popularity within your institution
  - Be ready for others wanting to tap into your group!
  - Focus on the original objectives of the board, but allow for guests when time permits

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## Meeting Facilitation Best Practices

- Use agendas to keep everyone on track
- Icebreakers!
- Develop ground rules
- Use a variety of methods/activities to collect feedback and ideas
- Have your group create their name and logo
- Tap into member talents and interests
- Provide a sneak peek of the next meeting
- Reflect, reflect, reflect



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## Youth Panel

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## Acknowledgements

### Youth Panel

#### My Team

- Albert Hergenroeder, MD
- Blanca Sanchez-Fournier
- Connie Wiemann, PhD

#### Collaborators

- Alma Martinez
- Beth Garland, PhD
- Emily Wei, MPH
- Tamara Thrasher-Cateni

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Questions??



**Thank you!!**

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