Building a Teen Advisory Council
Objectives

- Determine if there is a need for a youth advisory at your hospital
- Mission of the committee
- How to get membership
- Funding
- Requirements of the members
- Potential tasks/projects
- Lessons learned
- Tips for success
What is your youth population?

- How many teens or youth does your facility serve?
- Will their voice be helpful in hospital decision making – food services, linens, entertainment, overall policy?
- Would youth perspective and support be helpful for programming goals?
- Does your facility have staff that can allocate time to supervise and support an advisory program?

% of Adolescent Patients Receiving Care at BCH includes both inpatient and outpatient setting
Getting Started

• Institutional Support
  – Written proposal
    • At BCH, proposal sent to the CNO
  – Working Mission Statement
    • Finalize mission statement with council members
Serve as a forum to explore areas of interest to teen patients and their siblings

Make recommendations and suggestions of ways to enhance the quality and quantity of programs and practice that affect the teen patient population through self-advocacy

Inform the hospital administration, clinicians and other hospital employees of the work of the committee

Provide teens with leadership experience, practice writing proposals, and public speaking opportunities
• Approximate cost/year is $8500.
• Boston Children’s Hospital League has generously funded this program.
• Costs incurred include:
  – Parking
  – Dinner
  – Activities
  – End of year celebration for graduates
Funding Considerations

• Determine expenses
  - Food (event v. meeting)
  - Parking
  - Art/Marketing supplies
  - Gifts
  - Decorations
  - Equipment
  - Entertainment (DJ’s, performers)

• Potential funding sources
  - In kind donations
  - Grants
  - Adolescent Medicine or Family Services budgets
  - Further assistance from your development office
### Membership

**Considerations**

- How many members
- Age range
- Gender
- Patients? Siblings? Both?
- Well teens or current patients?
- Are cultural or socioeconomic measures relevant?
- Application/referral?

**BCH**

- 26 members (patients and 2 siblings)
- Ages 14-21 years old
- Variety of diagnoses, cultures and socioeconomic status
- Diagnosis is relevant to the group in being accepted but not once they are participating — i.e. only 1 CF patient at a time, minimal psychosocial diagnoses at the same time
Recruitment

Considerations

- How will you get the teens/youth?
- Do you have a hospital intranet?
- Can you develop a committee website?
- Is there a hospital mailing or flyers?
- Do work closely with teen providers? NP’s, MD’s, SW, Psych

BCH

- Initially: word of mouth, provider suggestions
- Presentation to providers by TAC
- Website: [http://www.childrenshospital.org/patientsfamilies/Site1393/mainpageS1393P405.html](http://www.childrenshospital.org/patientsfamilies/Site1393/mainpageS1393P405.html)
- Now: Self referral and provider referrals
Application process

**Considerations**

- What information do you need to know about the applicant?
- Do you want referral letters?
- What are the requirements for participation?
- Do you have them sign a contract?
- Parent permission

**BCH**

- Application/Consent to participate
- Interview: Facilitator and TAC co-chair
- Letter of support from a clinician
- Commitment contract
  - Attendance
  - Respect
  - Cellphones
  - Duties/Requirements

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Boston Children's Hospital

Until every child is well.
Structure of Committee

- Frequency and length of meetings
- Number of members
- Co-chairs
- Agenda and minutes
- Communication with members
  - HIPAA concerns
  - Social networking
Facilitators

- Have a multidisciplinary team of facilitators – RN, CLS, SW, AA, Public Affairs, etc...
- Appoint one main facilitator
  - Communication (emails/phone calls)
  - Record keeping
  - Financials/Budget
  - Mediator for teens and staff
  - Work with adolescent co-chairs
- Understanding of developmental stages and chronic illness status
- Know and have access to hospital resources
  - Funding
  - Catering
  - Parking
  - Conference Rooms
  - Hospital staff/contacts
Staff Facilitators (continued)

• **facilitators need to remember that they are there to facilitate the council by supporting the adolescents.....this is the teens council**
Co-Chairs

- At BCH, 2 teen co-chairs
- Paid position
- Develop agenda and write minutes
- Meet with facilitators
- Assist with interviewing/orienting new members and summer interviews
Meeting structure

Tips:

- Pick a time that works for everyone, usually after school
- Allow time for teens to socialize, unwind, eat, etc...
- Keep meetings to 2.5 hours or less
- Determine if you want to designate a teen to lead the meeting or a staff facilitator
- Send out the agenda ahead of time if possible
- Include elements of fun and work in every meeting

Agenda

- 3/31/11
- 5:00 - 5:30 dinner (updates: funding, party)
- 5:30 - 5:45 small groups decide the format for their group (individual responses, small group discussion, narrator interview etc)
- 5:45 - 6:15 decide the script and practice
- 6:15 - 7:00 videotape.
Projects

• Social programs for adolescent patients
  – Teen cart
  – Teen parties

• Quality Improvement projects
  – Health Care Communication Project
  – Identification of barriers regarding transition from pediatric care to adult health care providers. This includes strategies to manage the identified barriers.
• Government Relations
  – Working with the government relations staff to:
    • support bills that impact pediatric health care
    • meeting with State Representatives
    • attending the State House Legislative breakfast
    • testifying at Legislative hearings in support of a mental health bill.
  – Three teens and their families went to Washington DC with Federal Government Relations staff to meet with their congressmen regarding bills that affect pediatric health care.
Projects (continued)

- Creation of videos for adolescent patients
  - What to bring for an inpatient admission
  - What to bring to an outpatient appointment
  - Importance of self advocacy during doctor appointments.

- The videos are on YouTube and the hospital’s web site.
Projects (continued)

Focus Groups

- Social networking policies
- Appeal of teen inpatient rooms
- Feedback to a variety of clinical programs regarding tools for adolescent programs

Advisory Opportunities

- Hospital VP’s
- Media and Marketing/Public Affairs
- Food Services
- Environmental Services
- Creative Arts Program
- Social Work
- Family Advisory
- Web team
- Ethics Team
- Family Centered Rounds
Projects (continued)

- Hospital wide committees
  - Patient Portal

- Other committees
  - Health Care Research Fellowship Advisory Committee
  - Input to National Pediatric Discharge Checklist
Projects (continued)

- Presentations
  - 2\textsuperscript{nd} International Patient and Family Centered Care Conference (2005) ~ \textit{The Power of Empowering Teens} (1 teen, 2 staff)
  - Presentation to hospital administrators and clinical staff (2007, 2009) ~ Proposal and Outcomes of \textit{The Adolescent Health Care Communication Project} (all teens)
– 5th International Conference On Patient-And Family-Centered Care, Partnerships for Quality and Safety (2012) ~ *Evolution of the Teen Advisory Committee (TAC), Boston Children’s Hospital: Review of a Decade of Work* (4 teens, 2 staff facilitators)
Lessons learned Adolescents

- Building a sense of empowerment
  - Punctuality and communication
  - Leadership and public speaking
  - Benefits of teamwork
  - Advocacy and role-modeling
  - Service to the community
  - Compassion and empathy for others
Lessons learned facilitators

- Adolescents can effectively take the lead on setting and maintaining boundaries
- Structured recruitment, application and interview processes are necessary
- Importance of one-to-one confidential facilitator/teen meetings
- Role of developmental stage and chronic illness status
- Rituals as an important component
- Involvement of healthy siblings of teens with chronic illness
- Short term projects work best
- Multidisciplinary staff facilitators provide a broad skill set to their work with the adolescent population
- Preparation of staff presenters and visitors
Lessons learned by hospital staff & administration:

- TAC represents the voice of all teens at the hospital.
- Teens have the capacity to advise staff and providers.
- Teens can function as advocates for their own needs.
- TAC provides a forum for the teens’ concerns to be addressed on a hospital-wide basis.
- Adolescents embrace opportunities to partner and collaborate with hospital staff.
- Adolescents have a strong desire to “give back” to their providers and hospital community.
Tips for Developing a Teen Council

- Start small and grow over time
- Remember that teens developmentally need a balance of support and independence
- Let the council drive the agenda....ask what is most important to work on from an adolescent perspective
- Facilitators are to facilitate and not take over
- Teens have lots of great ideas; they just need a forum in which to express them.
- Build in an element of FUN!