Youth Leadership Toolkit: Adding Youth Voices and Perspectives

Complete Abstract:
I. Introduction:
Doctors, did you ever wonder what your young-adult patients really wanted from you and your medical home when they came in for a visit? Parents, did you ever want to know how your teenagers felt as they struggled with their transition to adulthood? Youth and young adults, did you ever wonder if you were the only one that felt like your parents did not let you have the freedom that you wanted? Teachers, did you ever want to have a panel of young adults with disabilities visit your class and talk to your students about how they overcame their struggles to become more independent? Trainers, are you looking for fresh content, new formats, and ideas straight from people with disabilities to make your next training event memorable?

Well, the Youth Leadership Toolkit may be just what you need. http://blt.cpd.usu.edu/Leadership_Toolkit.html

See the videos for youth and young adults, by youth and young adults. Listen to what young adults in Utah and Nebraska have to say about leadership, advocacy, medical care, transportation, independent living, and changing the world. Find out how youth and young adults are learning about leadership and self-advocacy by getting out and speaking at local, state, and national events.

II. Presentation Goals:
Watch video clips where the young adults with disabilities are the stars and what they have to say is better than anything you will see in theaters this year. Share your ideas about how the videos and guide book can be used for future training and how the next set of videos can be even better.

III. Reviews:
“The personal stories taught me that it's okay to try new things.” (young adult)
“I liked listening to what the people had to say about their own experiences.” (young adult)
I liked knowing that “I can get a job with my disability.” (young adult)
“I enjoyed hearing the Child/Adult's point of view.” (parent)
“Real people talking about real challenges.” (parent)
“Honest info from the patient.” (medical staff)
“A wonderful tool.” (medical staff)
“Dispelling so many myths and stereotypes.” (medical staff)
“Each vignette is a kernel and nugget of gold.” (medical staff)
“New toolkit brings young adults with disabilities into the conversation.” (CPD Blog)

IV. Why We Make Videos:
A long time ago in a conference room far, far away, we videotaped a panel of young adults talking to doctors about how they could improve their medical home services for youth and young adults with disabilities. With funding from a grant, we made a video, called “Respecting the Young Adult Patient,” and put it on YouTube when we kept getting requests for it. We showed it at meetings and training events to add to presentations by young adults or to share the
voices of young adults when they could not attend the events due to work, school, or family schedules. The young adults, part of our Young Adult Advisory Committee (YAC) for our Medical Home – Integrated Services Grant, really liked being a part of making the video and were eager to do more videos.

When we received our Youth Information, Training and Resource Center grant and supplemental funding from the Centers for Medicare & Medicaid Service, we gathered new ideas from our expanded group of young adults and set out to make more videos. We drove to the far reaches of Utah to interview young adults during a snow storm. We did interviews during dinner parties and at libraries. We also asked our friends in Nebraska to help us by interviewing some of their young adults. We cut and clipped footage until the floor was covered with videotape (not really, it’s all digital) and found the best clips for our nearly two-hour DVD with sections for healthcare providers, families, youth, and disability organizations. We also made a guide book that goes with the DVD to give suggestions for using the Toolkit including key points, suggested discussion questions, and ideas for where to show the DVD. It was a busy several months, but it was fun.

We wanted to share what the young adults had to say about their lives, their medical care, their interactions with service providers, their struggles to move out, their adventures on public transportation, their experiences in college, and their experiences learning to be more independent. Even though we did not get a chance to talk to people with every different disability, we found that the young adults that we talked to had some common experiences that all teenagers face as they become adults. They all had great stories, different and similar, funny and sad.

We now have the opportunity to share those stories at training events with other youth and young adults; during conferences for healthcare and service providers; at meetings with advocacy and community organizations; and even in the homes of families of youth with disabilities. We shared the Toolkits with Family-to-Family Health Information Centers; Family Voices Network members; Association of University Disability Centers members; Youth Information, Training and Resource Centers; local medical homes; and other organizations. We look forward to sharing more Toolkits and DVDs with more organizations and families.

What’s next for us? We’ll be editing the bloopers for the special features, of course. We’ll also be getting ideas for making more videos. We hope you can join our session and give us your feedback and ideas.

V. Our Supporters:
The Youth Leadership Toolkit was developed with support from and in partnership with the Centers for Medicare & Medicaid Service; the Independent Living Research Utilization program; the Utah State University Center for Persons with Disabilities, Utah Regional Leadership Education and Neurodevelopmental Disabilities Program; Utah Family Voices Health Information Center; the Becoming Leaders for Tomorrow, a Youth Information, Training and Resource Center from the Administration on Developmental Disabilities; local organizations; and, most importantly, youth and young adults.