



Friday's Child



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“I Can Learn From You, You Can Learn From Me” - Involving Youth in Program and Policy

How do you convince a group of adults to bring youth into the conversation in a meaningful way?

How do you ensure that the voice of youth is heard and not merely brushed aside?

Organizations are seeking youth involvement to fulfill grant requirements—but not really knowing how to make the best use of such involvement once they get it.

These are issues that Mallory Cyr, a Kids As Self Advocates (KASA) consultant and former member of KASA's National Advisory Board, frequently addresses. It's not just a matter of getting the youth to the table but also of creating equal partnerships in which youth and adults understand and appreciate what each has to offer.

“It's important to be transparent—let youth understand why you want to involve them and what you hope to gain from each other,” Mallory explains. “The challenges are deeply rooted as to how to listen to youth. Adults might say, ‘Here's what I think they would say, but it is just easier if I do it myself.’” Not only does that kind of attitude underestimate the youth perspective, but it also removes an important dimension from the discussion.

It is important that youth understand the issues on the table. “The question is how to make things accessible without oversimplifying and losing the context or making the youth feel like you are talking down to them—making them ‘youth-friendly.’”

Mallory recently conducted a focus group with her state youth advisory to assist with the upcoming Title V Needs Assessment. “It



was eye-opening to see how little the youth understand about ‘the system.’ They are not at fault—the system is confusing!” She adds, “The more information youth are given, the more they can contribute.”

“I've done a lot of work encouraging states to get youth involvement. I'm often asked is ‘Is it worth the investment to arrange this group, work on a Saturday—all the things it takes to involve youth in the professional world—is it really worth it?’ And then they meet one youth whose story touches them. They see what youth have to offer, and their thinking changes to, ‘This is a great idea—it's added new energy to our discussions—we need to keep doing it!’”

KASA is a youth-led project of Family Voices offering guidance on what it means to be a youth-led organization, how to make meetings and materials accessible, and how to achieve valuable youth participation. “All the work done that is generally youth-led and youth-created is inspiring and proof that it is possible if you are willing to put in the effort,” Mallory explains.



Welcome Family Voices' Newest Staff Member: Connie Johnson!

Connie joins the Lexington, Massachusetts, Family Voices staff as the NCFPP Program Assistant. As a member of the NCFPP team, Connie will provide administrative and project support and contribute to program activities. In addition to an impressive professional background, Connie's first-hand knowledge of family issues and systems navigation stems from finding services for her son who was diagnosed with Asperger's Syndrome. Connie looks forward to helping Family Voices translate complex ideas into more understandable language.

Please help us welcome Connie! Her email address is

cjohnson@familyvoices.org.



MCH-Public Health Leadership Institute: Looking for Leaders to Change Maternal and Child Health in the 21st Century!

Are you a mid-to senior level agency or family leader with experience at Title V, an agency, or a family advocacy organization—like Family Voices? This executive education program is designed to “significantly expand self-awareness and quickly build practical skills for effectively leading, managing people, and building partnerships, to advocate for and create the MCH systems of tomorrow.” The two-year Leadership Institute combines three intensive onsite retreats at the University of North Carolina at Chapel Hill, NC, with distance-based learning, including conference calls, webinars, and one-on-one coaching with experts in the field. The Institute is funded by a HRSA/MCHB grant in partnership with AMCHP, UNC Gillings Global School of Public Health, CityMatCH, National Center for Cultural Competence, and Family Voices. Generous travel scholarships are available to Fellows this first year. Applications for Fellows are being accepted through February 15th. Don't delay! For more information contact Karen Anzola kanzola@familyvoices.org or see: <http://www.mchphli.org>.

KASA also helps train adults to be allies working with youth. Allies learn to ask “how can I support you in this?” and ask guiding questions, thus allowing youth to move forward, either on their own or as a valuable group member.

Mallory sums it up, “Meaningful [youth and adult] relationships and involvement stems from honesty and communication and the willingness to make the commitment to be educated about what youth involvement means. Don't resort to tokenism [such as including one youth to represent all youth] —just for the sake of having youth. I can learn from you, and you can learn from me!”

KASA Resources: Written For and By Youth Advocates



The KASA website has over 60 free YOUTH-CREATED resources on Advocacy, Education, Health, Dating and Relationships, and much more at: <http://www.fvkasa.org/resources/index.html>. See especially the following:

- KASA's Pocket Guide for Youth on How to be Involved in a Board or Council: Roles and Responsibilities. Found at: <http://www.fvkasa.org> [lower right side of the page]
- KASA's Youth As Leaders: A “How To” Manual on Including Youth as Leaders in Your Organization, Agency, or Project. Found at: <http://www.fvkasa.org/about/whatsnew.html>

Paving the Way for Others:

Micah Fialka-Feldman



Micah Fialka-Feldman is no stranger to Family Voices. You may recall his story of traveling alone for the first time to the KASA Board meeting in Washington, DC, in the June issue of *Friday's Child*. Micah's latest claim to fame is winning a court battle for the right to live in a dorm at Oakland University 20 miles from his home in Huntingdon Woods, Michigan. As a part-time student who pays tuition and is in a program designed especially for students with intellectual disabilities, he wanted the “full college experience” and live independently in a dorm. The school refused, based on his part-time status in a special program. Micah sued, and recently won his case—in time to move in for the start of the new semester.

“It's exciting. I've been waiting two years for this,” explained Micah. “I'm so happy that the judge made his decision so quick. I'm happy to have the full college life.” In addition to dorm life, Micah's full college life includes classes this semester in Persuasion and Public Speaking, and he's in “tons of clubs”—the Jewish Club, and Alpha Phi Omega, a community service organization, to name a few.

Winning this civil rights case, Micah is an inspiration for all of us to stand up and fight for something we believe in. A poster on his dorm wall underscores up Micah's quest for change: “A community that excludes one member is not a community at all.”

Friday's Child is a monthly e-newsletter providing news and resources from the Family Voices network and the broader community of families and friends of children and youth with special health care needs/disabilities. Subscribe at: <http://www.familyvoices.org/pub/fc/>.

News From Our Partners



AAP

SSI for Children and Youth with Disabilities Policy Statement:

This new AAP policy statement describes updated SSI medical and financial eligibility criteria and the disability-determination process as ways pediatricians can help children and youth apply for the SSI benefits.

<http://aappolicy.aappublications.org/cgi/content/abstract/pediatrics;124/6/1702?rss=1>

New Immunization Website

Families and pediatricians will find information on vaccine-preventable diseases, vaccine safety information, and other helpful resources here.

<http://www.aap.org/immunization/>

Healthy & Ready to Work

Topical Call #13: Community Supports for Transition:

The latest in HRTW's series of conference calls addressed community supports that help youth transition to leading healthy, productive adult lives, including in-home supports and/or personal care services, employment, transportation, and recreation supports. Archives of these calls are available on the "HRTW University" web pages at

<http://www.hrtw.org/hrtwu/>

AMCHP

Innovation Station:

A new AMCHP database helps locate new, promising, and best practices across the US. Searchable by state or region, practice category, primary topic, national performance measure, year, and keyword, you'll also find resources to help evaluate public health programs. Check it out at:

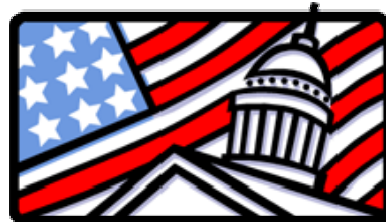
<http://www.amchp.org/AboutAMCHP/BestPractices/InnovationStation/Pages/default.aspx>



Family Leaders Participate in Jumpstart Quality Improvement

Family Voices and F2F HIC leaders Christy Blakely and Eileen Forlenza from Colorado, Molly Cole and Nanfi Nagenda-Lubogo from Connecticut, Josie Thomas and Kelly Meissner from Maryland, Nina Baker from Nebraska, Jodi Thornley and Nicole Schomberg from Nevada, Donene Feist from North Dakota, and Joan Badger from Pennsylvania joined staff from their Title V programs and other state leaders in an innovative, interactive learning collaborative – a "Jumpstart" Quality Improvement Training. Led by NICHQ staff and consultants, including Carolyn Allshouse of Family Voices of Minnesota, participant teams learned and practiced applying key improvement concepts from the world of business to their work as MCHB Integrated Systems grantees in their states.

The two-day training was packed with information and practice activities such as: developing concrete "aim" statements of what you are trying to accomplish; identifying "changes" to progress toward your goal, using "Plan, Do, Study, Act" cycles to quickly evaluate whether steps result in improvement and therefore should be "adapted"; and developing an "improvement measures" strategy to determine relatively quickly if your changes will lead to progress toward your ultimate goal. Teams will begin to put the tools they learned to work back in their home states. Ongoing feedback through conference calls and consultations with NICHQ will help grantees put these exciting techniques to work.



Legislative Corner

Health Care Reform

Until the recent Massachusetts election to fill the seat of the late Senator Edward Kennedy, negotiations were taking place to resolve the differences between the health care reform bills passed by the House and Senate. A respite has allowed congressional leaders to figure out how to proceed. Their problem: with the election of Republican Scott Brown to the Massachusetts seat, Democrats have lost the magical 60th vote needed to advance legislation in the Senate. At this time, the most viable course to health care reform is for the House to pass the Senate bill. Subsequent legislation could address some of the concerns of House members. As of this writing, however, House Speaker Nancy Pelosi has indicated that she cannot get a majority of the House Members to vote for the Senate bill.

Both Senate and House bills have outlined positive changes for youth and young adults with special health care needs. Although the bills differ on the particulars, the following are included in both bills and therefore likely to be in some form in any final legislation:

MORE NEWS YOU CAN USE

☑ National Survey of Children and CSHNCH Data Resources 2007 National Survey of Children's Health Data Available

HRSA and MCHB have announced the release of [The Health and Well-Being of Children: A Portrait of States and the Nation 2007](#), a report of the results of the 2007 National Survey of Children's Health (NSCH), representing national and state information on oral, physical, and mental health of 91,642 children from birth to age 17. The report is available at <http://www.childhealthdata.org>. Request a hard copy by contacting the HRSA Information Center toll-free at 1-888-ASK-HRSA or 703-442-9051 (or at <http://ask.hrsa.gov/>).

☑ AAP Releases *Pediatrics* Supplement Highlighting Findings from the 2005-2006 National Survey of Children with Special Health Care Needs (NS-CSHCN)

Conducted on alternate years from the NSCH, the NS-CSHCN is the subject of the AAP's [December 2009 supplement issue](#) to *Pediatrics*. Fifteen articles describe how this important data on more than 40,000 children nationwide can be used to inform policy and practice. The 2005-2006 NS-CSHCN is accessible at: <http://www.cdc.gov/nchs/slaits/cshcn.htm>.

☑ National Council on Disability: New Report on Affordable, Accessible, and Appropriate Housing for People with Disabilities

The State of Housing in America in the 21st Century: A Disability Perspective, a new report from the National Council on Disabilities, provides a status update on housing for people with disabilities and includes housing opportunity improvement recommendations. Download the report at: <http://www.ncd.gov/>

- A requirement to **allow dependents to remain on their parents' health insurance plans for a longer period** -- through age 26 in the House bill (effective 1/1/10) and through age 25 in the Senate bill (effective 6 months after the bill's enactment).
- **A temporary a high-risk insurance pool** for individuals unable to get insurance due to pre-existing conditions, to be established in 2010.
- **Expansion of the Medicaid program.** Both the House and Senate bills expand Medicaid to cover *all* individuals in families with incomes under certain thresholds -- 150% of the federal poverty level (FPL) in the House bill (as of 2013), and 133% of the FPL in the Senate bill (as of 2014).
- **Elimination of lifetime benefit caps** (effective 2010) and **annual benefit caps** (effective 2013/2014).
- **Elimination of pre-existing condition exclusions; prohibition on premium variations based on health status.** (Effective 2013 in the House bill; 2014 in the Senate bill.)

For more detailed information on these and other provisions, visit the Kaiser Family Foundation website, at <http://www.kff.org/healthreform/sidebyside.cfm>. For information on how to get involved, please visit the Family Voices website at www.familyvoices.org.

If you have any questions about these or other federal issues, please feel free to contact the Public Policy Team -- Brooke Lehmann (blehmann@familyvoices.org) and Janis Guerney (jguerney@familyvoices.org).



NEWS YOU CAN USE

- ☑ **Disability.gov: Self-Advocacy Resources for Teens**
Check out tools to help teens actively participate in their Individualized Education Program (IEP) meetings. http://www.disability.gov/education/student_resources/self-advocacy
- ☑ **Office of Minority Health's National Plan for Action - Public Comments**
OMH's National Plan describes the status of minority health disparities in the US, and suggests 20 improvement strategies. Comments can be made until February 12, 2010. <http://minorityhealth.hhs.gov/npa/templates/browse.aspx?vl=1&vlID=31>
- ☑ **New Magazine from League for People with Disabilities: I.D.E.A.L.**
I.D.E.A.L. (Individuals with Disabilities Express About Life) is a new magazine designed to "create a new and positive image for young people with disabilities" and eliminate disability stereotypes, according to *I.D.E.A.L.*'s CEO and Founder, Zarifa Roberson. Topics will include education, careers, sexuality, relationships, family, and policies. <http://www.leagueforpeople.org/>
- ☑ **New MCH Library Knowledge Path: EPSDT**
The latest in the continuing series of updated Knowledge Paths from the Maternal and Child Health Library at Georgetown University includes guidelines for health-promotion and disease-prevention services for infants, children, and youth. http://www.mchlibrary.info/KnowledgePaths/kp_EPSDT.html
- ☑ **Diversity Rx Webinar: Health Literacy in Primary Care: Using a Self-Assessment Tool to Guide Quality Improvement in Primary Care**
This free webinar, scheduled for Thursday, February 4, 2010, from 3:00-4:15pm, addresses making health information accessible and understandable to lead to better informed health care decisions. To register, go to: <https://www2.gotomeeting.com/register/657849523> (space is limited)