Working the Room: Advocacy You Can Use

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Awareness

• Number One issue cited by X & Y patients and families as barriers to
  • Health care access
  • Educational Support
  • Legal and disability concerns
• The MOST Protected (withheld/hidden) information creates barriers

Can you hear me now?
Who? What? Why Should Anyone Care?
Communication is Bi-directional

Patients And Families

Doctors
Nurse Practitioners
Psychologists
Psychiatrists
Educators
Insurance Policy And More
Finding your Voice: Individually and Collectively

Nobody Knows

Is anybody else dealing with this?......

Who can I talk to?......

Is there any help at all?......

Why is this so hard?......

Am I alone?......
The X & Y Chromosome Community Must Be Heard

- Common Language
- Normalization
- Widespread Knowledge
- Accessible Education
- Advocacy in all forms
Advocacy in Its Many Forms

• Person to Person/People to People
  • Social Media Groups
  • In-Person Support Groups
  • National Advocacy group (AXYS)

• Person to Institution/People to Institution
  • School Districts/Schools
  • Vocational and Employment Settings
  • Legal and Law Enforcement
  • Judicial System

• Person to Systems/People to Systems
  • Insurance
  • Adjuvant Service Needs
  • Representation

It is LITERALLY, In our Hands
Impact of Advocacy

• Knowledge
• Actions based on Knowledge
• Network Knowledge Development
• Development of Familiar Language
• Awareness and Normalization
• Contagion of Awareness
• Patient-Centered Direction
• Patient-Centered Agency to affect Change

CHANGE!
From Invisible.............................. To Visible
Working the “Room”: Find someone who is involved already

• Attend another senate resolution and make a friend
• How to pull a senator to the ropes
• “I am one of your constituents”
• Specific to ask them: support funding for SPECIFIC
• Get used to being in the environment
• Get involved with other people in disability community
• Medicaid waivers; sometimes asking for the same thing
Organize Your Thoughts: Write out your story

• Support in school district
• Health insurance not covering medications or services
• Own personal story is powerful in a face-to-face
• Serendipitous introductions
• Kids might be able to page with legislators
• Kids can talk to their legislators
• Contagion of contact
• Find out what committees do your reps sit on?
• Who is important in making decisions in health care?
Legislators WANT to Hear From You

Footage with Senator Unterman
Making Contact

• Telephone appointment
• Get to know the legislative assistant
• Make specific requests:
  • Document/Photograph/Create News & Press Releases
    • To create a Proclamation
    • To request senator or representation to attend an event
    • Post to social media
Legislators are PEOPLE (just like us)

• Demonstrate kindness and respect
• Politely disagree, if required and then use this opportunity to MAKE THE CASE
• You can influence the way they think about things
• Thank them for their time and attention
• Leave an GOOD impression
Memorable BRANDING
Tools to Begin: Finding Your Legislators

• [https://www.senate.gov/senators/contact/]  

• [https://openstates.org]
Partners in Policy Making

- Partners in Policy Making: course (in every state) developmental disabilities

- [http://partnersonlinecourses.com](http://partnersonlinecourses.com)
SHOW UP!
Be in Strategic Pathways
In Session: Nerves and Hopefulness

- Singularity of Purpose
- Strength of Community
- Power of Combined Voices
Witnessing the Moment
There THEY are: Up Front and Center
Singular Mission Accomplished
All the Way to the TOP: 2016
All the Way to the Top: 2017
Advocacy Has to Come From the Inside

- How important is it to you?
- Avoid ”relying others”
- Nobody can tell your story better than you
- Be persistent, relentless and kind
- Keep showing up
- Reflect on your commitment: Value to the X & Y Chromosome community is based on each singular commitment

Step up and be Present