Empowering Individuals and Families as Advocates

The Advocacy ATLAS

Accessible Tools for Leadership and Advocacy Success

September 23, 2013
Background

- National Coordinating Center (NCC)
  - Administered by ACMG
  - 3 year grant from Genetics Services Branch, HRSA
  - June 2012-May 2015

- Goal:
  - Form a collaborative network of partnerships/tools
  - Improve consumers’ access to, knowledge about and quality of genetic services
What Do We Mean By “Consumer”? 

- Individuals who utilize genetic services and their families 
  - Diagnosed with genetic condition 
  - At risk for genetic condition
Program Objectives

1. Support consumers and engage consumer groups
2. Improve access to information, services, and resources
3. Promote genetics education through new linkages
4. Disseminate resources and services information
5. Ensure activities are consumer directed
Empowering Individuals

- Connecting individuals with services and support
- Making information and tools easily accessible
- Compiling quality tools on communication skills and leadership to help in everyday situations and improve access
Life Happens
= Advocacy Happens
Top Three E’s of Advocacy

- Empowerment
- Effective
- Engaged
Key Tools and Skills in ATLAS

- Communication
- Leadership
- Support
Advocacy ATLAS

...Accessible Tools for Leadership and Advocacy Success

- Access to Healthcare
- Accessible Communities
- Legislation & Political Action
- Education Services & Supports
- Communicating About Your Health
- Steps to Employment Success
- Transition to Adulthood
- Youth Leadership
- Advocacy & Leadership Skills
- Insurance & Financial Assistance

Was this helpful for you? Submit Feedback
Scenario 1: Marilyn

• My son Enio was 2 ½ years old, undergoing dental surgery, he was given anesthesia, after 35 minutes into the surgery his heart stopped twice, he was in a coma after that for a little over a month, when he came out of coma he had;
  • Seizures
  • Cortically Blind
  • Developmental Delay (2 years)
  • Fine motor skills not developed
  • Gross motor skills not developed
Scenario 1 continued

• As a parent I was totally desperate, lonely, fearful and blaming myself. I had gone through all the emotions every parent could go through.
• Then I started to look for resources, information, attended my first conference ever.
• Started to talk to other parents, to find out they were going through some of the things we had just experience.
• We started the first Family Support group, in a very small rural town, we were told that the support group would not last, we are still meeting to this day.
• My son Enio is a college graduate...
Potential Resources from ATLAS

• Advocacy and Leadership Skills
  • Getting Involved as a Parent
    • You Are An Advocate for Your Child with Special Healthcare Needs- Family Voices
    • Building a Family Network- Statewide Parent Advocacy Network
    • Parents as Collaborative Leaders- University of Vermont and PACER Center
      • Effective Meeting Strategies
      • Defining Parent Leadership
      • Tips for Leading Effective Meetings

• Advocacy Basics
  • Tools for Advocacy- Family Voices of California
Scenario 2: Alexa

- 1\textsuperscript{st} day of Kindergarten, separate mini bus pulls into driveway. Alexa should be able to ride to school with her sister and neighborhood friend on the regular bus, as they are all going to same school anyway!

- Barrier – How to convince school administrators and board to add lift to regular bus.
Steps Involved

• Created our story about why this should be done
• Researched decision-makers and built relationships
• Strategized around changing attitudes
• Researched laws
• Researched costs
• Organized all materials and kept detailed notes
• Practiced presenting
Potential Resources from ATLAS

Education Services and Supports

• Organizing Information & Creating an IEP (slides 13 – 15)
• The Art of Negotiation (slide 17)
• The Art of Collaboration and Negotiation
• Creating Agreement/Conflict Resolution/Collaborative Problem-Solving (slide 11)
• Link to Wrights Law
• Advocating Through Letter Writing
Potential Resources from ATLAS

Legislation & Political Action

- Guide to Effectively Educating State and Local Policymakers
- Action Plans to Educate Policymakers
Potential Resources from ATLAS

Advocacy & Leadership Skills

• Getting Involved as a Parent
  • Parents as Presenters
  Workshop Participant Guide
Advocacy Success!
Wheelchair Lift on Regular Bus
Scenario 3: Jamie

- Fun loving 8 year old boy with special healthcare needs, wants to attend the local summer camp his sister attended

- **Barriers:**
  - Program Director expresses that CSHCN do not belong at camp
  - Camp counselors receiving negative messages about CSHCN
Steps Involved

- Discover fears/concerns of program director
- Share information about Jamie’s needs
- Brainstorm how best to support Jamie at camp
- Set up regular check-ins with staff
- Support aide

Resources on choosing a camp
- ACA Accredited Camps- American Camp Association [http://www.camppparents.org/funsafety](http://www.camppparents.org/funsafety)
Resources

• **Accessible communities:**
  - Discover Camp
  - Communicating with and about people with disabilities

• **Advocacy and Leadership skills:**
  - The Art of Collaboration and Negotiation
  - Creating Agreement, Conflict Resolution, and Collaborative Problem Solving
  - You Are an Advocate for Your Child with Special Health Care Needs
  - Parent Leadership 101
Advocacy Success!

**Solutions:**
- Learn concerns and provide accurate info
- Yearly in-service to camp counselors about inclusion of all children
Parent to Parent USA

- **Vision:** All children with disabilities and special health care needs grow up in a family who supports them to lead full and happy lives in their communities.

- **Mission:** P2PUSA promotes excellence in P2P programs across the nation. There is hope, strength, and power in connecting parents of children with disabilities or special health care needs.

- **We believe...**
  - that every parent’s journey has value.
  - in the strength and resiliency of parents.
  - in the power of parents supporting one another.
  - that support should be available to parents and families throughout the lifespan.
Parent to Parent Basics

• Parent to parent support, promoted by Parent to Parent USA, is the intentional matching of an experienced, prepared, Support Parent with a parent seeking peer support.

• Parent to Parent USA Alliance Members are statewide organizations providing support and information to families with children who have special health care needs or disabilities, most notably through parent to parent support.
Connect or Collaborate with an Existing P2P Alliance Member

1. Go to [www.p2pusa.org](http://www.p2pusa.org)
2. Click on “Looking for Support”
3. On the US map, click on your state for all contact information

Or...contact Kathy Brill at (717) 503-8992 or [ksbrill@p2pusa.org](mailto:ksbrill@p2pusa.org) to further discuss your needs and plans
Family Voices

• **We are** ... a national family-run non-profit organization founded (1992) by families of CYSHCN to activate family roles in health care

• **Our mission is** ... to achieve family-centered care for all children and youth with special health care needs and/or disabilities
Family Voices

➢ Through our work, we . . .

• Provide families with **tools to make informed decisions**

• Encourage **self advocacy/empowerment in youth/young people** with disabilities

• **Build partnerships** among families and professionals

• **Advocate** for improved public and private policies

• Serve as a **trusted resource on health care**

www.familyvoices.org  www.fv-ncfpp.org
National Center for Family Professional Partnerships (FV-NCFPP)

FV-NCFPP is the National Center dedicated to the MCHB outcome measure: families will partner in healthcare decision-making for CYSHCN at all levels. We

• Created the concept of F2F HICs and pushed for their funding
• Provide peer mentoring, support, training, TA to family leaders in every state
• Promote partnerships between families and professionals by providing tools, opportunities, and mentorship

www.fv-ncfpp.org  www.fvkasa.org
www.familyvoices.org
Questions?

Kathy Brill
Executive Director, Parent to Parent USA
ksbrill@p2pusa.org

Beverly Baker
Co-Director, National Center for Family Professional Partnerships (NCFPP)
Family Voices, Inc.
bbaker@familyvoices.org

Gina Pola-Money, Director, Utah Family Voices
gina.ufv@gmail.com

Marilyn Ruiz, Program Director, Family STAR Family Network on Disabilities
marilyn@fndfl.org

Sharon Romelczyk, Program Manager, NGECN
sromelczyk@geneticalliance.org
Stay Tuned!

- **Webinar 2: Advocacy Through the Transition Years and Beyond**
  October 15, 2013, 2 pm EST

- **Webinar 3: Resources on Access, Support and Advocacy in the Health and Insurance Worlds**
  November 13, 2013, 2 pm EST
Thank You!

This webinar is an activity of the National Genetics Education and Consumer Network (NGECN), part of the National Coordinating Center for Regional Genetic Services Collaboratives grant no. U22MC04100, funded by the Health Resource and Service Administration (HRSA).