

**Advocacy through Storytelling:
Uniting the Unique Voices of
Advocates to Influence Legislators
and Professionals**

Presented By:

<p>Stephanie Meredith Author of "Understanding a Down Syndrome Diagnosis" and Co-Author of "Diagnosis to Delivery: A Pregnant Mother's Guide to Down Syndrome" Andy's Mom</p>	<p>Jawanda Mast Past Executive Director of the Down Syndrome Association of Memphis and The Mid-South Board Member of KCDSG TN Partners in Policymaking Institute Graduate Rachel's Mom</p>
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Unique Voices

• **The Power of YOU**

- The Parent Movement
- The Self Advocacy Movement

Historical Perspective

- How does a 1971 case in Pennsylvania impact my child today?
- Have you heard of Mills versus Board of Education?
- What is the significance of Section 504 of the Rehabilitation Act in 1973?
- Have you heard of IDEA?

Areas of Government and Other Professionals

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- National
- Regional
- State
- Local (eg. School District)
- Healthcare professionals
- Educators
- Others



National Advocacy

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Individuals with Disabilities Education Act (1975):
Profile of Madeleine Will
NDSS National Policy Center
GACS (Governmental Affairs Committee)
Team Captains



State Advocacy

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Georgia Katie Beckett Medicaid Waiver:
Profile of Heidi Moore

- Email/Letter campaign
- State Capitol "Rally for the Children"
- Presentations at disability events
- Participation in Governor's Council
- Positive relationships with legislators



State Advocacy Examples

Missouri GAC started in 2009
Two Major Accomplishments:

Restraint & Seclusion - GAC members worked with Missouri Families against Restraint and Seclusion (NOMO Seclusion) to effect this policy change. Now, all school districts in Missouri must adopt a policy on Restraint and Seclusion based on minimum standards set by DESE.



State Advocacy Examples

Missouri GAC started in 2009
Two Major Accomplishments continued:

Early Childhood Special Education - In an attempt to help decrease and balance the budget several MO legislators wanted to introduce legislation that would discontinue state funding of ECSE (3 – 5 year old) programs and make the local school districts fund these programs if they wanted them. GAC partnered with agencies across the state to send letters to our MO legislators and DESE. As yet, no legislation has been introduced regarding the repeal of funding for our ECSE programs in MO.

Local Advocacy

**Cherokee County School Board:
Profile of Kathy Dillon and Stephanie Meredith**

- Email/Letter campaign
- Organize meeting of parents
- Coordinate speeches to the school board
- Engage local media
- Organize advocacy group: real and virtual

“Professional” examples

- Memphis Obstetrics & Gynecology example
 - Presented information resources to doctors/staff
 - Distributed materials about Down Syndrome Walk
 - Sent holiday picture card annually
 - Result:
 - ◊ Contacted when baby with Down syndrome born
 - ◊ Volunteered at walk
 - ◊ Donated holiday honorarium to DSAM
- Atlanta Educators example
 - Invited educators to extra-curricular events
 - Made videotapes to share with educators
 - Result:
 - Used extra-curricular interests as motivators in the classroom

Current National Issues

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- ABLE Act of 2011
- 21 Research Act
- Keeping All Students Safe Act

Where to find more info:

- NDSS Policy Center Action Alerts
- NDSC Action Alerts

*One page summaries will be distributed

Current State Issues: Kansas

- KanCare

This plan calls for the 'outsourcing' of all Medicaid funds in Kansas - nearly \$3 billion dollars - to out-of-state, for-profit insurance companies. With this proposal long-term care services for persons with intellectual and developmental disabilities -- the HCBS waiver -- will be under the control of these insurance companies.



Current State Issues: Missouri

- Prevent premature, costly out-of-home placement by funding individual and family supports, through expansion of the Partnership for Hope.
- Increase the number of Lopez Waiver slots to 400 (increase of 200) to serve children under the age of 18 who have a permanent and total disability.
- Continue to mandate and appropriately fund Early Childhood Special Education for all eligible children ages 3-5, based on individual needs.

More Information: Kansas

Interhab of Kansas <http://interhab.org/main/>

Invisible Kansans <http://invisiblekansans.org>

Local CDDO (Community Development Organization).

✦ Email Lurena.Mead@jocogov.org to be added to Monday Morning Update distribution.

Families Together - <http://www.familiestogetherinc.org/>

More Information - Missouri

MACDDS <http://macdds.org/>

MACDDS legislative issues page:
<http://macdds.org/resources/legislative-issues/>

ARC of Missouri <http://www.arcofmissouri.org/index.htm>

Legislative page <http://www.arcofmissouri.org/act-arc-of-missouri-2.htm>

Finding Your Elected Officials

National:

<http://votesmart.org>

<http://capwiz.com/ndss/home/>

State – Kansas

<http://www.ipsr.ku.edu/ksda/vote/> or

<http://www.invisiblekansans.org>

State – Missouri

<http://capwiz.com/thearc/home/>



Current Local Issues

• Vary by district

- Peer mentoring programs
- Funding
- KC MO: Non-Accreditation and Options

• To find out more & local officials:

- County government website
- Local school district website, email distributions



Crafting a Story

- How would the legislation personally impact your family?
- Examples: Craig Blackburn, Katie Beckett Waiver, and ABLE Act
- Write a 2-3 paragraph summary. Include photos.
- Send a letter/email, make a call, or visit.

You are the only one who can offer your personal perspective to enlighten your Representative about an issue that concerns you.

Forming connections

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- Action Alerts
- Google Alerts
- Twitter
- Facebook
- Listservs
- “Coffee Shop” Local Advocacy



Develop lawmakers and professionals as allies

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- Invite legislators to join Down Syndrome caucuses
- Invite legislators to organized events and rallies
- Invite lawmakers to your home
- Meet with lawmakers in their offices
- Call and email your representatives.
- Introduce lawmakers to self-advocates.



- Invite professionals to your child's events
- Send holiday cards and thank you notes
- Give updates about your child at annual visits
- Invite professionals to participate on advisory committees

Advocacy Profiles

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Advocacy Lite

- Sign up for action alerts.
- Phone calls/emails upon request.

SMALL INVESTMENT = SIGNIFICANT IMPACT

Advocacy Engaged

- Attend rallies
- Meet with your legislator in person

Advocacy Pumped

- Organize rallies
- Participate in committees
- Share testimony
- Form advocacy groups

Legislator/Professional Advocacy Tips

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- 1 email represents 100 people; 1 call or letter represents 500 people; and 1 visit represents 1000 people.
- Always be positive, courteous, and appreciative.
- Find the number/address/email for your legislators.
- Write a story with a personal angle when sending a letter or email.
- Write and practice a script before meeting your legislator in person. Always send a "thank you" note afterward.
- Send holiday or other picture cards including your letter or a personal letters to important people. Sign them up for the DSG newsletter. Take newsletters, articles, books to appointments & IEP meetings. Forward interesting studies, articles, etc. via email

More Tips to Advocate with Anyone

Educate and be educated Shameless promotion

- Serve on Site Council, School Board, Committees, Task Forces
- PTO/PTA participation
- Room parent
- Down syndrome Awareness Month & World Down Syndrome Day
- Proclamations with city, county, state government
- Observe at school, church, community organizations
- Step Up For Down Syndrome Walk & Dress Down for Down Syndrome
