Advocacy: Telling Your Story

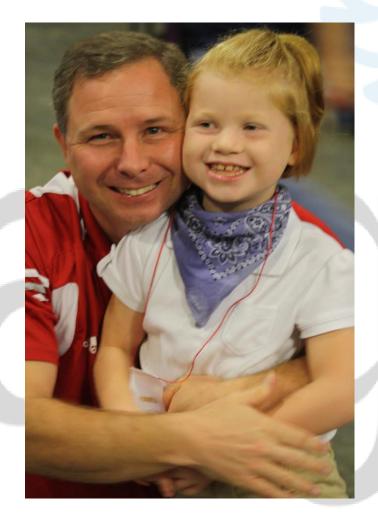
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SYNDROME FOUNDATION

Advocacy Defined

- Advocacy is speaking for or with others on their behalf.
- Advocacy involves A.CTION
- Advocacy involves C.OMMITMENT
- Advocacy involves T.IMELY CONVERSATION
- Advocacy involves I.NTERACTION
- Advocacy seeks O.UTCOMES
- Advocacy occurs N.OW
- Remember with A.C.T.I.O.N. DROME FOUNDATION

My Story (Education Inclusion)



- Elsie Madelynn Wright
- Needed 1 on 1 Aid to Facilitate Inclusion
- AAC Device was seen as to advanced for Elsie
- We involved our private speech therapist into meetings showing her level of competence
- Our resolve maintained and we received what we requested
- However, advocacy continues always

My Story (School Lunch Choice)



- Ella Christine Wright
- Adopted from Ukraine at 17 months
- Had a difficult time swallowing food
- School speech therapist wanted to limit her food to pureed only
- We had worked so hard for choice we would not allow this to happen
- We worked with Protection and Advocacy and Ella was able to eat a lunch she could choose

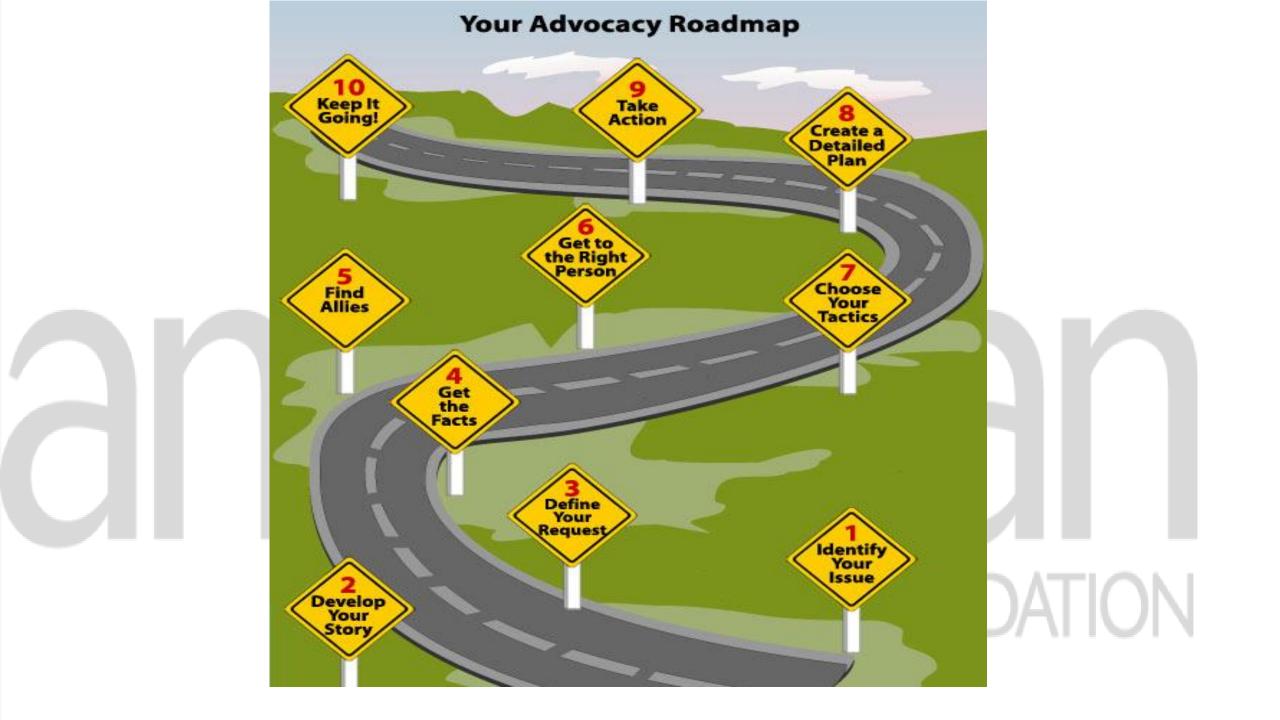


What is Your Story?

 Take a few minutes to discuss an advocacy issue with a friend in the audience

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- What happened?
- What was the story?
- What did you want?
- What were the facts?
- Did anyone help you?



Speechless Lesson

https://www.youtube.com/watch?v=eiBnuJEXumc

angeinan Syndrome Foundation

Master Advocacy Plan (MAP) Document Time

Master Advocacy Plan (MAP) Issue:					
Angelman Syndrome					
Advocacy Goal/Aim:					
Advocacy Objective:					
Activities	ACTION/	Target	Success	Schedule/	Resources
	Organizers	Audience	Indicators	Timeframe	Needed

Who Can Help Advocate?

- Planning is the key to success with advocacy
- Having others be part of your team is helpful
- Invite people to join you (i.e., IEPs, Therapy Visits, Doctors Appointments)
- Find community agencies/organizations (ARC, Protection and Advocacy) to help the advocacy process

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Connecting With Others: You Are NOT ALONE

- The Angelman Syndrome Foundation offers resource support (i.e., IEP Bank, Family Resource Team)
- Social Media plays a major role in modern day advocacy
 Angelman Protection and Rights Group
- Elected officials are important stakeholders to involve in advocacy
- Reaching out to others within your community in mentoring relationships (i.e., other parents, associations)

Go! Tell Your Story and Advocate Passionately

• Dollarhide, Clevenger, Dogan, & Edwards, 2014 found passionate commitment is the key to effective advocacy.





