Advocacy Strategies & Opportunities

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California’s Family to Family Health Information Center (*there’s one in every state!*)

- The voice of families
- The vision of quality health care
- The future for children and youth with special health care needs
From the Frying Pan...into to the Fire

Conflicting situations
- Crisis decision making
- Competing demands

A pivotal moment
- A lot at risk
- Managing accountability

Opportunity knocks
- Flexible mindset
- More empathy
Questions
1. What is the policy?
2. Are there directives, guidelines?
3. What’s the plan for …?
4. How can we …?
5. Why/why not?
6. Who can help?

Contacts
- Teacher & district
- Advisory Committees
- School Board

Approaches
- Assume good intentions
- Identify priorities
- Focus your efforts
- Ask
- Craft a powerful story
- Enlist allies/ask for help
- Engage with decisionmakers
- Hold them accountable
- Avoid threats
## Things to Consider

**Concern: Toby is losing speech and social skills without therapy.**

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<td><strong>1. Purpose</strong></td>
<td>• Stop regression of speech and social skills.</td>
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<td><strong>2. Desired outcome</strong></td>
<td>• Virtual speech sessions</td>
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<td><strong>3. The problem</strong></td>
<td>• The consultative model doesn’t address needs, goals, services in IEP</td>
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| **4. Examples** | • Speech has become unintelligible.  
| | • SLP sends group email with videos, worksheets.  
| | • Doesn’t address speech, social skills.  |
| **5. Visual aide, creative wording or “hooks”** | • Went from joyful chatterbox to sad and withdrawn.  
| | • He’s mostly unintelligible.  
| | • So frustrated he’s avoiding talking with us.  |
| **6. Solutions/suggestions** | • Schedule a Zoom meeting to brainstorm solutions |
| **7. Don’t forget...** | • Stay on point, keep records, copy myself on emails |
| **8. My Plan/Steps** | • Review records, correspondence  
| | • Find out if there is a policy/plan  
| | • Draft my story  
| | • Send request  
| | • Share my story with SELPA CAC – Ask them to get info from others  
| | • Comment at school board meeting |
I’m now experiencing things I didn’t really understand before.

Advocates are not reaching out as much. *We NEED to hear from you to know what’s working/not working.*

Social media is very important but it’s not the most direct way to contact [policy] staff.

It’s helpful to get specific priorities [from groups and individuals].

Go to the right level [of government].

- Don’t be afraid to reach out!
- More time for constituents
- Compressed timelines, fewer hearings = less public input

Where do I start?

- What brought you to policy work?
- How has your work changed?
- How can I weigh in?
- Systems level change may reduce the need for situational advocacy
- The results can be significant
- It’s not as hard or time consuming as you think!

**Powerful Advocacy Strategies**

- Serve on a board or committee: 3-5 hours
- Meet with a decisionmaker: 1 hour
- Ask decisionmaker for help: 15-30 min
- Respond to action alert: 1-5 min
  - Social media
  - Email
  - Call

Family Voices of California – Project Leadership 2020 (California)
Advocacy Resources

Updates

- Family Voices of California: www.familyvoicesofca.org
- Family Voices (national) – find your state’s chapter https://familyvoices.org
- Professional societies, school districts, health systems, elected official newsletters, social media

Policies Affecting People with Disabilities

- The Arc CA: thearcca.org
- American Association of People with Disabilities: https://www.aapd.com
- Disability Rights Education and Defense fund: https://dredf.org
- National Down Syndrome Congress: https://www.ndsccenter.org
- TASH: https://tash.org

Resources

- A Day in Our Shoes: https://adayinourshoes.com
- Council of Parent Attorneys & Advocates: https://www.copaa.org
Thank you!

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bit.ly/ProjectLeadershipUS-2020

www.familyvoicesofca.org