



**MILITARY FAMILIES**  
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How Providers Can Support  
Advocacy & Leadership in  
Parents of Children with Disabilities

<https://learn.extension.org/events/3278>

U.S. DEPARTMENT OF DEFENSE      extension      USDA

This material is based upon work supported by the National Institute of Food and Agriculture, U.S. Department of Agriculture, and the Office of Military Family Readiness Policy, U.S. Department of Defense under Award Number 2015-48770-24.

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**COMMUNITY**

How Providers Can Support Advocacy & Leadership  
in Parents of Children with Disabilities

Sarah Taylor, MSW, Ph.D.  
Associate Professor, CSU East Bay Dept of Social Work

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### Today's Presenter

Sarah Taylor, MSW, Ph.D.  
Associate Professor of Social Work, California State University, East Bay



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### Acknowledgments

CSUEB Dept of Social Work  
Survey & Interview Participants  
Military Families Learning Network (MFLN)  
Co-Researcher Amy Conley Wright  
Zachary Drake & Quinn Drake Taylor  
Incredible network of support/hive mind



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### Who's Here? (Poll)

I am a (check all that apply):

- Social Service Provider or Administrator
- Medical professional
- Educator
- Family member of a person with a disability
- Person with a disability
- Researcher
- Other (please specify)

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- 99% of staff and clients have the best of intentions
- Systems are underfunded and under-resourced
- Sometimes it's hard to know whose job something is because of system fragmentation
- Collaboration is key
- Organizational change is slow...except when it isn't
- Better data is needed to inform practice...but figuring out how to get research messages to practitioners and families is difficult
- Partnerships and relationships are meaningful and important

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*I think my educational background has helped a lot. I have a degree in astrophysics, so I'm used to learning complicated stuff and trying to apply it to different problems. I'm a good problem solver.*

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## Most Important Things to Know About Quinn

- Incredible joie de vivre
- Excellent sense of humor
- Loves animals
- Curious nature
- Great helper at home and in school
- Good traveler
- Many interests: sports, music, cooking, play doh, appliances of all kinds, public transportation, water, technology, walks around the neighborhood, Ernie & Bert, Peppa Pig, and Daniel Tiger



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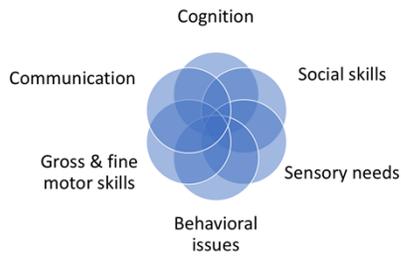
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## Challenges



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### Research Goals

- To learn about and share some of **the good stuff**.
- To understand how parents develop as effective advocates over the lifespan.
- To document the work that parents do to advocate for their children.
- To learn more about how parents do it. What skills, knowledge, and supports do they need to be effective advocates?
- To explore the relationships between coping, advocacy, and resilience.
- **To inform social work practice and related fields about how to support parents of kids with disabilities.**
- To support, build, and evaluate programs that help parents make a difference at individual, organizational, community, and policy levels.

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### Resilience

*...good outcomes in spite of serious threats to adaptation or development. Research on resilience aims to understand the processes that account for these good outcomes. (Masten, 2001, p. 228)*

*The great surprise of resilience research is the ordinariness of the phenomena. Resilience appears to be a common phenomenon that results in most cases from the operation of basic human adaptational systems. ... (Masten, 2001, p. 227)*

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### Building a Theoretical Model of Advocacy

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- I hope in your study you will discover that mothers of special kids are amazing and put themselves in front of any firing squad whether it be untrained schools, lame doctors, or penny pinching insurance companies to fight for their children.
- I never thought I would be capable of being such a strong advocate for anyone. Before having a child with special needs I was more soft-spoken and tended to go along with what others thought was best. I realized (very quickly) that this would not provide the best care or outcome for my child. In a world where we are supposed to trust the experts, I learned to trust myself. I am the expert when it comes to MY child.
- In an IEP meeting - my 3 year old with Down Syndrome was going to be placed in a classroom with Severely Handicapped Students because of lack of space in a different Special Needs classroom. My son is not Severely Handicapped & was not a good fit in that classroom - there would have been no motivation for him to grow. It was the answer to the problem in our school district to just get him placed. We would not sign the IEP. Called an additional meeting, took an attorney & a Down Syndrome Advocate. Ended up with the best classroom placement ever. I have learned to not take NO for an answer!

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### Advocacy Challenges (Poll)

What was your biggest advocacy challenge about, either as a provider, family member, or person with a disability?

- Establishing eligibility for services
- Getting access to appropriate and relevant services
- Increasing inclusion
- Raising public awareness and sensitivity
- Changing policy
- Something else (please specify)

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### Advocacy: Speaking Up, Speaking Out

Case Advocacy:  
On behalf of an individual or group

Cause Advocacy:  
Related to a social issue or category of people

Slide by Dr. Amy Conley Wright

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### Key Survey Findings

Parents advocate in a wide variety of settings.

Advocacy goals include obtaining access to appropriate services, increasing inclusion opportunities, raising public awareness about disability issues, and changing policies.

Advocacy work is time consuming and stressful for some (Many? Most?) parents.

**Over time, parents advocate in more community and political settings and they feel their impact is greater.**

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### Themes in “Anything you want to tell us” Responses – Parents of Young Children

Needs for support, knowledge, and skill.

- I think there needs to be more opportunities for parents to gather together to talk, share ideas, get support from one another. No one, unless you are another parent of a child with special needs, understands what it feels like, how difficult it is, what the challenges are. It can feel very isolating...*

Sharing frustrations.

- It is very challenging to advocate for your child and the school system fights you every step of the way. I naively felt they were there to help me and wish that someone would have told me that in fact their goal is to restrict services as much as possible. It is exhausting and frustrating.*

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### Themes in “Anything you want to tell us” Responses – Parents of Teens

Advice!

- Be educated about the subject and local process. Be assertive!*

Comments on mezzo and macro advocacy.

- It's all about the funding - we have to raise awareness in order to get the money to find better treatments and a cure.*

Declarative statements.

- Advocacy in schools is a giant rat maze...*

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## Core Case Advocacy Strategies

- Self-care
- Knowledge
- Networking and Social Support
- Persistence and Other Personal Characteristics
- Expertise, Authority, Teamwork, & Compassion

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## Self Care – Effective Advocacy Begins with a Well-Rested Advocate

- First priority – Always
  - Especially right after a diagnosis or major challenge
- Respite
- Support System
- Therapy/Support Groups
- Work-life balance
- Privacy
- Setting parenting priorities
  - Parent first, fun first
- Culture
- Sense of humor

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## Knowledge and Skills

Knowledge/Skill Area	Example Quotations
Special Education laws, policies, and norms, e.g. IEPs, accommodations, curriculum, 504 plans, and timelines	<i>I felt I was in control of that IEP. I knew exactly...this was the first time I can actually say to you, in all the years, I knew my daughter's present levels, I knew what she needed, I knew where she's going next year, I knew what her goals should be, I knew...and I actually understood everything single page of that IEP.</i>
Knowledge and skills they learned from employment and educational backgrounds e.g. law, medicine, nursing, social work, teaching, writing	<i>It just struck me that my whole professional career up to this point in some ways was a preparation for me to be an advocate. My professional background is as an editor and writer and marketing communications person. So, whether it's learning new material or getting the material out to people in a convincing way, it's really all about advocacy.</i>
Knowledge specific to their child's disability such as research on interventions and an understanding of the condition	<i>And then in terms of his medical treatment, it's kind of the same thing. You have to be, you have to learn how to advocate for what's best for him by doing the research on what are the latest treatments. What's going on in the world of treatment, not just for epilepsy, but for his underlying disorder to [disorder name removed for confidentiality], because it's a rare disease.</i>

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## Networking & Social Support

Conceptualization of support:

- Instrumental
- Emotional

Most frequently cited source of support was other parents of kids with disabilities.

Instrumental support from other parents includes referrals to programs and providers, advice about how to ask for services and who to ask, advice on helpful interventions, etc.

The main emotional support from other parents is that they "get it."

Parents connected with other parents in many ways:

- In person support groups
- Social media/online support groups
- Through therapist-led support groups
- Through centers that specialize in serving individuals with a specific disability

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## Examples of Support from Other Parents

*It's emotional and real practical suggestions. What other parents are doing, what other parents are trying, but mostly it's just validation that all of these things that I'm trying and feeling are being felt by other parents of these kids. It doesn't even matter what their special needs is. It doesn't even matter; we're all going through the same thing, which is very validating.*

*Because nobody else can really understand the fear that you feel when you're facing a surgery like that because everyone else around you seems to think, "Oh, well, the doctors will take care of it, and it will all be fine." But, actually the fear you experience pretty much actually at the level of trauma, that life threatening. **You have to have somebody there who can know what you're talking about.***

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## Other Findings on Support

- Support from family members and friends who do not have a child with a disability was highly variable. Some felt a great deal of support, and others none.
- The main thing provided by family members and friends was emotional support, but some helped by contributing financially and/or offering caregiving support.
- Providers offered more logistical support, but some also offered emotional support. These tended to be providers who went the extra mile and developed long-term relationships with families.

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## Other Findings on Support cont.

Families described some unexpected sources of support:

- Tennis coach who developed a special relationship with a child
- School that put the child's picture in the hallway
- Parents of other kids (kids without disabilities) keep an extra eye out for the kid with a disability, without the parent asking them to – this allows the child with a disability to participate more naturally in activities with other children.
- Church childcare program that just naturally accommodated a child with a disability with minimal prompting from the parents

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## Lack of Support

The main lack of support parents described from other family members and friends was others' "not getting it." Some described others as being dismissive of the parents' concerns or friends and family members who gave inappropriate advice.

Others described logistical problems with the family providing support, such as geographic distance or lack of knowledge or ability in caring for the child. These knowledge and ability areas tended to center around medical needs (e.g. g-tube) or behavioral issues (e.g. aggression).

The main lack of support parents described from professionals was being dismissive of the parents' expertise and experience. Parents also noted that some providers are more concerned about funding limitations than in providing assistance.

*Professionals who have decided that because they went to school for six years, they know more than I do. That's, I think that's the biggest hurdle, is, whether it's medical or educational or rights or anywhere. Your confrontation is in disagreement with anything that has to do with your child. The immediate response is, no, I know more than you do. I studied this, I went to school, I have my doctor's, blah, blah, blah. Rather than, you know your kid best, let's go ahead and look at that.*

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## Persistence & Other Personal Characteristics

- Parents described using distinct individual personal characteristics in their advocacy work – i.e. there is not one set of "best" characteristics for an advocate to have.
- Some parents utilized a team approach relying on complementary characteristics between them and their partner/spouse - e.g. "I'm the \_\_\_\_ one and she's the \_\_\_\_ one."

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### Persistence & Other Personal Characteristics cont.

- Some parents described a change in their personal characteristics as a result of the need to advocate.
  - *I had to become the person that I needed.*
- Most frequently noted characteristics include determination, commitment to the child, persistence, stubbornness, and tenaciousness.
  - *I'm the squeaky wheel. I'm the person that just never goes away. I'm the person that calls back again and again and again. I'm the person that just won't take no for an answer. "Okay, who else do I need to talk to? What other things can I try?"*

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### Expertise, Authority, Teamwork, & Compassion – Working with a Team of Professionals

- RCEB Social Worker
- Medical Insurance Staff
- OT
  - Fine motor
  - Feeding
- PT
- SLP
- School Psychologist
- Audiologist
- Pediatric Ophthalmologist
- Dentist
  - RCEB Dental Coordinator
  - Hospital-based general anesthesia for fillings
- Doctors
  - General Pediatrician
  - Developmental Pediatrician
  - Neurologist
  - Geneticist
  - Psychiatrist
  - ENT
- Special ed teacher, aides, and administrators
- Respite workers and babysitters
- Afterschool program director and staff
- Early intervention program/infant stimulation
- Service dog trainer

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### Other Case Advocacy Strategies

Please use the chat box to share some other kinds of strategies you have used in advocating for an individual child (as a parent or provider).

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## Final Note: A Plug for Cause Advocacy



(Presenter appears in the back center left of this photo.)

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## Selected Resources

- Providers located near a School of Social Work might want to partner with the school to get support in research and advocacy: <https://www.cswe.org/Accreditation/Directory-of-Accredited-Programs.aspx>
- Family Voices (policy-focused advocacy trainings for parents of children with disabilities): <http://www.familyvoices.org/>
- Boston Thrive in 5 (Trains parents to serve as developmental screeners for other families in their local communities): <http://thrivein5boston.org/>
- The Arc (public policy and legal advocacy for people with intellectual and developmental disabilities): <https://www.thearc.org/what-we-do/public-policy/policy-issues>
- Disability Rights Education and Defense Fund (DREDF): <https://dredf.org/>

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## Other Talks & Papers Based on this Research

### Peer-Reviewed Academic Papers

Taylor, S. and Corley Wright, A. (2017). The role of not-for-profit organizations in supporting advocacy and leadership in parents of children with disabilities: A cross-national perspective. *Third Sector Review*, 29(2), 81-107.

Corley Wright, A. & Taylor, S. (2014). Advocacy by parents of young children with special needs: Activities, processes, and perceived effectiveness. *Journal of Social Service Research*. Advance online publication. doi:10.1080/01488776.2014.896880

Taylor, S., Corley Wright, A., Pothier, H., Hill, C., & Rosenberg, M. (under review). It's like I have an advantage in all this: Experiences of advocacy by parents of children with disabilities from professional backgrounds.

### Essays

Taylor, S. (2017, March 28). [Commentary: How will AISD respond to landmark ruling for special education students?](#) Alameda Sun. (Local paper with circulation of over 20,000.)

Taylor, S. (2017, January 9). [Education for children with disabilities and the next attorney general](#). Blog on The Medium. (779 views between January-April 2017.)

### Selected Talks

Taylor, S. (2016, January). [How shouldn't have to be a rocket scientist to access services for kids with disabilities](#). National webinar for [Family Voices of California](#).

Taylor, S. & Wright, A. (2017, October). [Once upon a time in an IEP: Stories of educational advocacy by parents of children with disabilities](#). Sixty-minute breakfast session at the Annual Pacific Rim International Conference on Disability and Diversity, Honolulu, HI.

Taylor, S. & Wright, A. (2016, November). [The role of non-profit organizations in supporting the advocacy activities of parents of children with additional needs](#). Oral paper presentation at the Australian and New Zealand Third Sector Research Conference, University of Sydney, Australia.

Taylor, S. (2016, September, 2015, January & June). [Resilience, coffee, and community: How parents advocate for children with special needs](#). 2016, September: Noah's Shoalhaven, Parent Room Workshop Series, Noosa, Australia. In 2015, both presentations were with Family Voices of California, Parent Advocate Training Series, in two different formats: January, in-person: Oakland, CA, Family Education Resource Center; June, online: [YouTube](#), with over 60 participants from across the U.S.

Taylor, S. & Wright, A. (2016, April). [Advocacy activities by parents of children with disabilities: Exemplifying, empowering, and exhausting](#). Oral paper presentation at the annual Pacific Rim International Conference on Disability and Diversity, Honolulu, HI.

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**Contact**

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<https://www.csueastbay.edu/directory/profiles/sw/taylorsarah.html>

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**CEU Credit & Certificate**

- **One Survey, two different ways to receive a certificate.**
  1. MFLN Military Caregiving concentration area is offering 1.0 CEU credit from the UT School of Social Work to credentialed participants.
  2. MFLN Certificate of Completion for providers interested in receiving general training.
- **To receive a CEU credit OR certificate of completion, please complete the evaluation survey found at:**  
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**Upcoming Event**

- **Title:** 2018 TRICARE Changes Update
- **Time:** 11:00 a.m. Eastern
- **Date:** Wednesday, March 28, 2018
- **Location:** <https://learn.extension.org/events/3313>

For more information on MFLN Military Caregiving go to:  
<https://militaryfamilies.extension.org/military-caregiving/>

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Military Families Learning Network

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This material is based upon work supported by the National Institute of Food and Agriculture, U.S. Department of Agriculture, and the Office of Military Family Readiness Policy, U.S. Department of Defense under Award Number 2015-48770-24363.

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