

Information for Family Support Personnel

Identifying, Understanding, and Accessing Evidence-Based Practices (EBPs): Supporting Families of Children with Autism Spectrum Disorder (ASD) and Other Developmental Disabilities



CAPTAIN (California Autism Professional Training and Information Network) is a multi-agency (Schools, Regional Centers, and Family Resource Centers) network developed to support the understanding and use of evidence-based practice for individuals with Autism Spectrum Disorder across the state.





Why is Family Participation So Important?

- Parent-professional collaboration, with active involvement of parents/caregivers, is not just an evidence-based practice in designing services for individuals with autism; it is also the law! (*Section 300.300 of the Code of Federal Regulations*)
- The family-centered model of service delivery acknowledges that interventions and supports for children with disabilities are most successful when the family's concerns, priorities, choices, and strengths are considered. (*Peterson & Speer, 2000*)

How Does Understanding Evidence-Based Practice Benefit Families?

- Families are the experts on their own children and their participation in intervention planning is vital. However, identifying effective interventions can be challenging.
- Many interventions now use the phrase "evidence-based practice" even when there is no scientifically sound research that supports their use. This can make it extremely difficult to know which interventions have research showing they are effective and which do not.
- Providing information, support, and resources helps parents recognize evidence-based practices. This knowledge can increase families' capacity and confidence as partners with children's service providers.

What Are Examples of Barriers Families May Face When Participating in Interventions and Service Decisions?

-  Time: Children with ASD are often involved with several different intervention activities that take tremendous amounts of the family's time and coordination of care.
-  Money: Decisions regarding interventions may have financial implication, including things like co-pays, medications, special diets, etc.
-  Emotional Stressors: Parents may feel overwhelmed as they decide how to allocate their attention and energy across family and professional obligations.
-  Information and Confidence: Parents may worry that they lack sufficient information about EBPs and may be more confident deferring to professionals to make treatment decisions.



How Can Family Support Professionals Assist Families in Learning About and Requesting EBPs?

- Encourage families to identify and share their preferences and values in the decision-making process.
 - Help families understand how to determine if a professional or organization has the capacity to provide EBPs.
 - Encourage families to trust themselves and their feelings about providers and their practices.
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Where Can Families Go to Learn More About EBPs

- **National Autism Center:** Provides information about EBPs and reliable resources for families and practitioners. Links to the National Standards Project report outlining Evidence Based Treatment for ASD (2009).
<https://www.nationalautismcenter.org/>
<https://www.nationalautismcenter.org/090605-2/>
- **National Professional Development Center on Autism Spectrum Disorder:** Provides free resources to families, teachers, professionals and technical assistance providers about EBPs.
<https://autismpdc.fpg.unc.edu/national-professional-development-center-autism-spectrum-disorder>
<https://autismpdc.fpg.unc.edu/evidence-based-practices>

Other Parent and Family Support Links:

- **CAPTAIN website:** Information about CAPTAIN, contact information for the CAPTAIN Cadre in each region and links to vetted resources. <http://www.captain.ca.gov/>
- **Learn the Signs Act Early:** Resources on early developmental milestones and monitoring. Free resources for families, providers and physicians including printables, apps, videos and online training modules.
<https://www.cdc.gov/ncbddd/actearly/index.html/>
<https://www.cdc.gov/ncbddd/childdevelopment/screening.html>
- **Autism Fact Sheets:** Free printable fact sheets about ASD in 14 different languages develop by the University of Southern California UCEDD. <https://www.cdc.gov/ncbddd/autism/facts.html>
<https://www.uscuedd.org/publications-resources/autism-pubs/autism-fact-sheets>
- **Autism Focused Intervention Resources & Modules (AFIRM):** Free online learning modules for the 27 EBPs identified by the NPDC-ASD. <https://afirm.fpg.unc.edu/afirm-modules>
- **Autism Distance Education Parent Training (ADEPT) Modules:** Free interactive, self-paced learning modules on skills teaching an positive behavior supports developed by the CEDD at the UC Davis MIND Institute.
<http://media.mindinstitute.org/education/ADEPT/Module1Menu.html>
https://health.ucdavis.edu/mindinstitute/centers/cedd/cedd_adept.html

