



How to be an Effective Advocate

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Overview

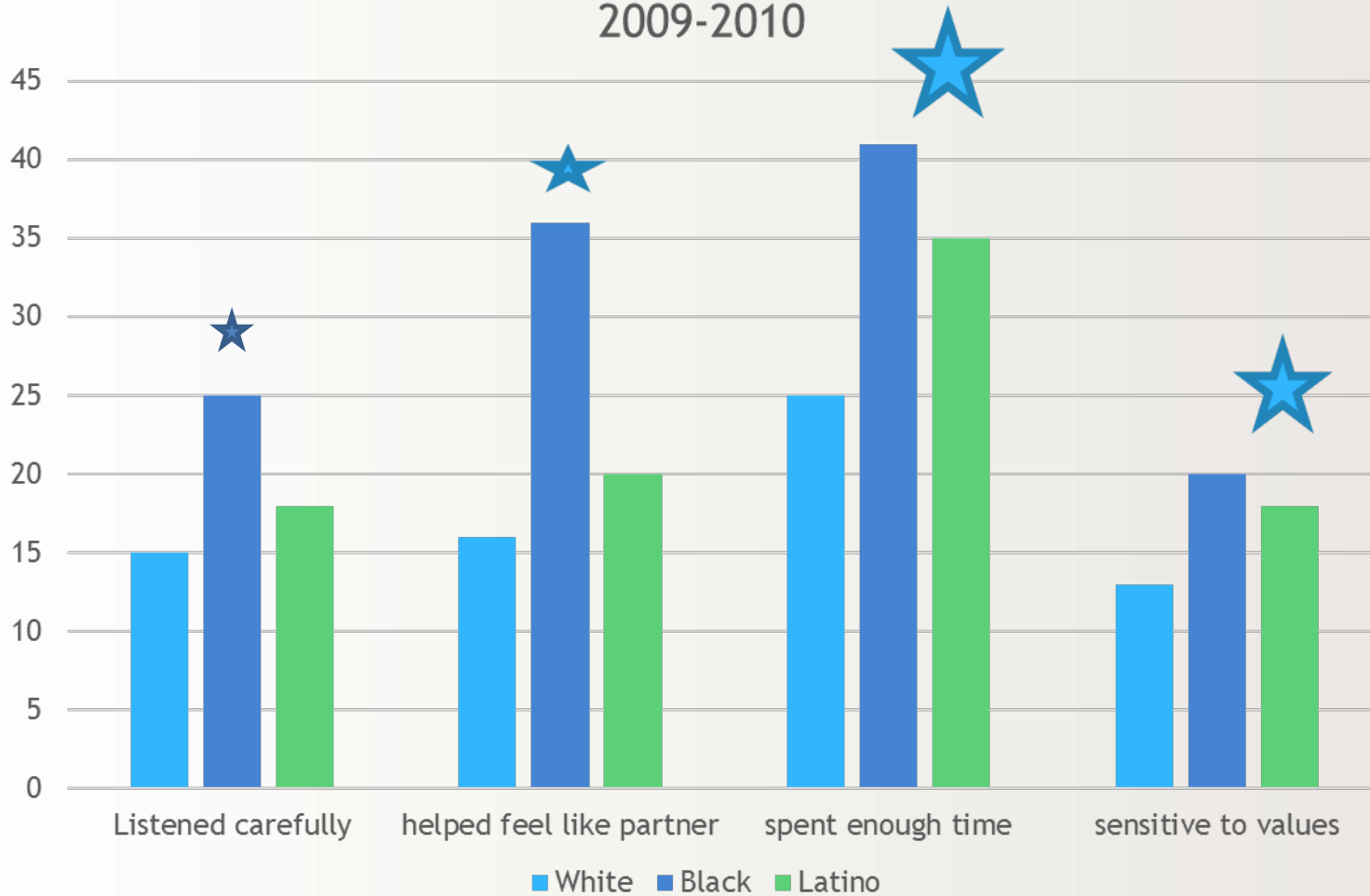
- Racial and ethnic disparities in diagnosis and services—why we need to advocate
- Learning about your child's disability and rights
- Getting organized and advocating in the community
- Advocating in the schools
- Parent perspectives for providers

Racial and Ethnic Disparities for children with IDD

- Black and Latino children might be under represented or overrepresented in diagnosis and services
 - Black and Latino children are underrepresented in the diagnosis and treatment of autism
 - Overrepresented in special education programs in the schools
- There may be differences in how they and their parents are treated by providers

Quality of care

2009-2010



How do we make sure our children receive appropriate diagnosis and services?

- Understanding your child and what he/she needs
- Advocating for you child is key

What is advocacy?

- Working and even fighting to get what your child needs
- You are your child's best advocate because you know your child better than anyone
- You are an ideal and capable person to help your child access resource he/she needs

Knowing your child's disability

- Felicia's story
- Important to know not only child's diagnosis, but her/his specific needs
 - Does she need help communicating?
 - Does she need to pace back and forth when she's stressed?
 - Does she learn better sitting in the front?
 - Will she need extra time to complete in class work?

Know what services and supports to ask for

- What services in the community or school are appropriate for your child?
- Find out about specific interventions and accommodations that will benefit your child
- Connect with others to learn more, support groups, conferences like this one

Know the key players

- It is most effective to talk to the people who have the authority to make decisions
 - Who is the director or person that decides on services?
 - Who is in charge of the programs you are advocating for
 - Who is the supervisor of this person?
 - Good to know the chain of command

Knowing your rights and responsibilities

- Learn about policies that apply to your child—for example the IDEA Act
- How are services funded and by what agencies?
- Can learn about these things from
 - Websites, joining a group or organization, talking to other parents
- Example, integral care services (handout)

Get organized

- It can be hard to keep on top of all of the meetings, phone calls and appointments
 - Use files or binders to keep important records and reports safe and in one place
 - Put everything in writing including your requests, concerns and responses you get
 - Keep a phone log of the dates, times and people you talk to
 - Take notes at meetings, or ask someone to. You can ask whether you can digitally record the meeting

Use clear and effective communication

- Remember you are an equal partner
 - Focus on the needs of the child
 - Work together to find solutions
 - Speak clearly and directly
 - Avoid making people feel defensive
 - Turn negatives into positives
 - Summarize at the end to be sure all have same understanding

Know how to resolve disagreements

- Don't have to take no for an answer
 - Informal processes for disagreements
 - Face to face conversations
 - Written communication
 - Facilitated ARD meeting (you can request this)
 - Formal processes
 - Mediation
 - Complaints
 - appeals

Key terms for school services

- [The Admission, Review and Dismissal \(ARD\) Meeting](#) is a meeting in which teachers and other support staff bring their expertise on education, and parents bring their expertise on their child –needs, abilities, and desires, and parent expectations.
- Together, you write the [Individualized Education Program \(IEP\)](#). This is a full program of services to help your child.

More key terms

- **Free and Appropriate Public Education (FAPE)**
 - Special education and related services are provided to the child at no cost and are mandated by law
- **Individual with Disabilities Education Act (IDEA)**
 - Federal law that grants equal access to students with disabilities through the IEP process
- **Least Restrictive Environment (LRE)**
 - Your child has the right to be educated with typically developing peers to the extent possible

Tips for ARD meetings

1. Know that you are the expert on your child
2. The ARD is about meeting your child's educational needs—what is interfering with his/her learning
 1. Request services that will address the needs
 2. Prepare a list of concerns in advance, can give it to the case manager before the meeting
 3. Speak up when you disagree

- 4. Speak up when you disagree
- Read over the IEP document before signing
 - Signing doc doesn't mean you agree with everything, but that you were present
- 5. Indicate where you disagree
 - There is a way to indicate parts you agree with and parts you don't
 - Services can start on parts you agree on while resolving disagreements
- 6. No service can be removed or discontinued without your permission
 - There is a separate place to sign for changes, consider this carefully
 - Your child has the protection of “stay put” meaning remaining in place until disagreements are resolved

- 7. You have the right to visit any proposed placement before making a decision to place your child there
- 8. Accurate assessments are the basis of all planning and can help define some of your child's needs
 - If you feel the district testing did not reveal your child's needs you can request an independent evaluation (at the district's expense)

Supporting diverse families in their advocacy efforts

- Historically advocating has been complicated
- Time means different things to different cultures
- Education Levels
- Socioeconomic status
- Institutional racism

Guidelines for Providers

- Listen
- Each family is an individual
- Provide culturally sensitive and appropriate responses.
- Connection to community and resources

Additional Guidelines

- ABC's
 - Alternate arrangements
 - Being flexible
 - Creating opportunities for partnerships
- Reflection

One TEAM

