



# How to be an Effective Advocate

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# Overview

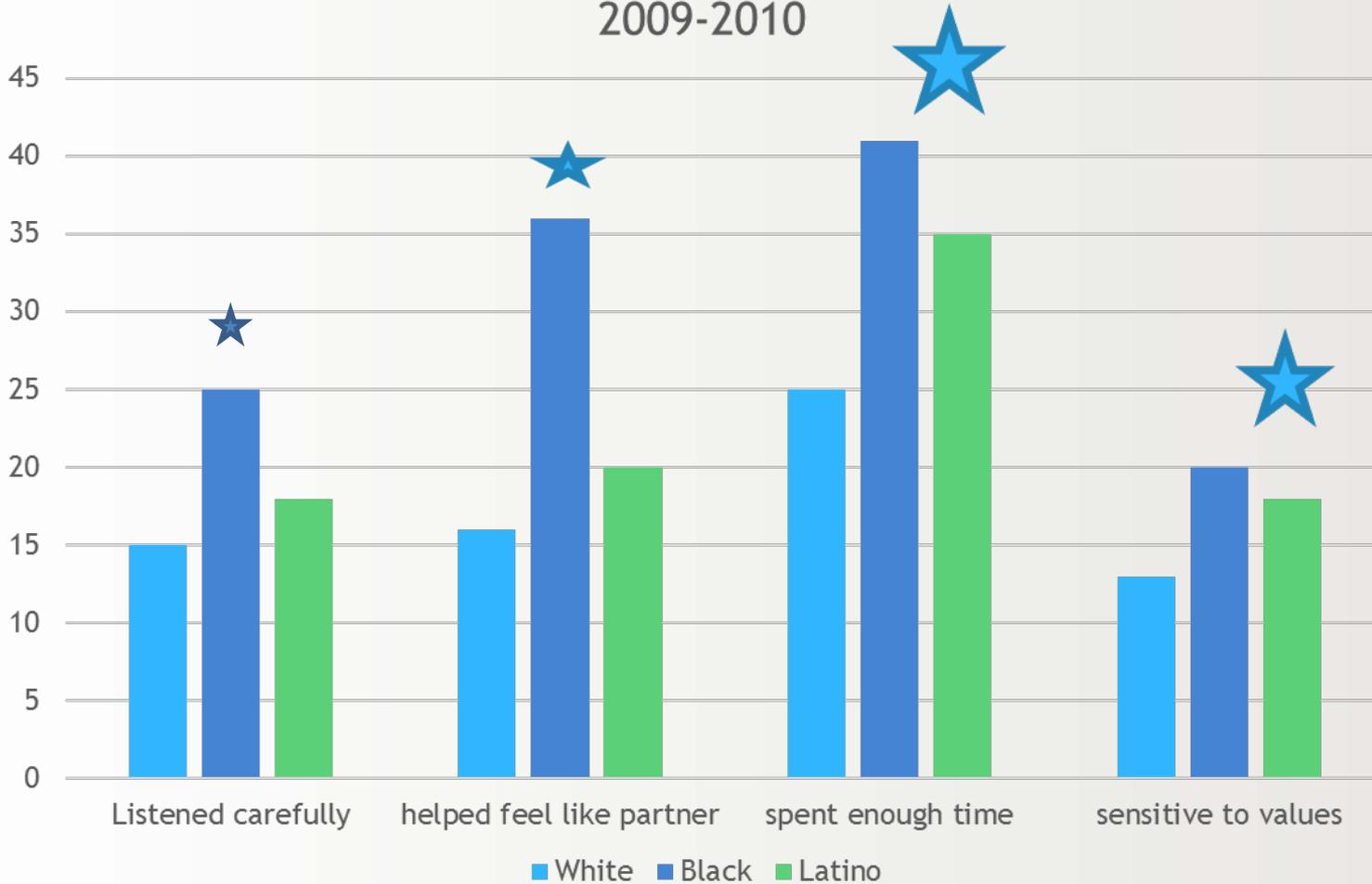
- Racial and ethnic disparities in diagnosis and services—why we need to advocate
- Learning about your child's disability and rights
- Getting organized and advocating in the community
- Advocating in the schools
- Parent perspectives for providers

# 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

