

# SURVEY SAYS



Parents Tell Us  
How We Can Engage Them

## WHAT MAKES PARENTS FEEL ENGAGED?

- Feeling Heard
- Having a Say In Decisions
- Individualized Planning
- Understanding, Not Blaming
- Complete List of Resources
- Access to Quality Care for My Child



**FAMILIES TELL US  
WHAT THEY NEED**

## HOW CAN PROFESSIONALS BE WELCOMING?

**WELCOME**

**THE KEY IS TO ASK**

- ASK what we need
- ASK what we have tried
- ASK what barriers we face
- ASK how we are doing
- ASK how you can support
- Respect our unique situation
- Explain how treatments will help

## WHAT DISENGAGES PARENTS?

- Decisions Made Without Me
- Feeling Judged
- Not Being Heard
- Not Considering My Whole Family
- Not Taking My Concerns Seriously
- Showing Up Late/Changing Appointments
- Not Remembering Our Family's Story
- Making Assumptions/Being Condescending



**WHAT NOT TO DO**



**WHAT HELPS BUILD  
ENGAGEMENT**

## WHAT ADVICE DO PARENTS OFFER?

- Offer Hope/Resources/Guidance
- Recognize How Tough This Is For Me
- Be a Caring and Trustworthy Advocate
- Write Factual, Not Emotional Reports
- Compliment and Celebrate Progress
- Encourage Self-Efficacy
- Expect Setbacks & Support Us
- Know We Are Thankful