Family Support is the Missing Ingredient to Success:
Findings from the Colorado Parent Mentorship Program
Public Health Burden

- 1 in 68 ASD prevalence
  - $1.4-2.4 million per individual lifetime
  - $40,000-$60,000 per year behavioral treatments
  - Annual medical costs 6X no ASD
Complex systems of care

- Long wait-lists
- Lack of providers
- Lack of funding
- 5 months to first service
Complex systems of care

- Uncertainty about effectiveness
  - 100+ available treatments
  - 2 with “modest” evidence base (AHRQ)
  - Many with little to no clear evidence
    - Some harmful (e.g., chelation)
  - 4.5 treatments tried/yr
Family Burden

- Quality of life
- Unpredictable outcomes
- Complex Systems of care
- Reduced community interaction/Isolation

- Family challenges
- Mental health concerns
- Earning potential
- Long term care
- Experience more ACE’s
Assumptions

1. Raising children is hard...
   - ...Autism can make it harder
     - Service systems
     - Siblings/spouses, work, etc.
     - behaviors
Protective Factors

- social support predicts well-being and adjustment among parents raising a child with ASD
- maternal perceptions of social support
  - increased sense of competency and decreased depression
Assumptions

1. Raising children is hard...
   - ...Autism can make it harder
2. We all want to help children with autism
   - Clinicians, parents, systems, schools, etc.
3. “Help” means different things to different
“Help” in the medical model

- Evidence based practices
  - Behavioral intervention;
  - Social skills trainings;
  - Pt/ot/speech, psych, etc/

- All EXTREMELY important

- But Maslow’s Hammer:
  - “If they only tool you have is a hammer, you tend to see every problem as a nail.”
Colorado Parent Mentoring Program

- Provide parents with skills necessary to coordinate child’s care
  - Informational support
  - Emotional support
Colorado Parent Mentoring

- Individualized action planning
- Navigation training
- Parent-to-parent mentoring
Individualized action planning

**Challenges**

1. Toilet training
2. Eye contact
3. Stimming
4. 
5. 

**Goals**

1. Alert mom when wet
2. Look when called by name
3. Reduce negative reaction to stopping

**Resources**

- Psychologists/nanny
- Speech
- Persistent husband/OT

**Action Steps**

- Consult with psych/make plan with nanny
- Ask SLP to incorporate into Tx
- Have husband work with OT and child

**Family**

1. Sibs left out
2. No time with spouse
3. In-laws don’t agree with Dx/Act like I caused it

**Notes:**

- Reduce comments about how this was because of my choice
- To vaccinate

**Options:**

- One date per month/Get away
- Vacation prize/
- Best friend/science

**Activities:**

- Cousins/YMCA with pool down street
- Big kid only trip to YMCA
- Find babysitter/Ask if kids can stay with Grandma
- Let husband know how I feel/Find strategy to find common ground
Individualized action planning

Components of Effective Intervention
The National Academy of Sciences, *Educating Children with Autism*

- Young kids need lots of learning opportunities (active engagement in intensive instructional program)
- Active plan for generalization
- Time with typically developing peers
- Emphasis on communication, imitation and play
- Require direct, active instruction
- Intervention should be systematic, goal focused and planful
- Needs family involvement, parent training
Navigation Training

- Very complex systems of care
- Focus on individual needs/resources
Module 2: Navigating School Systems

Using the Colorado Parent Mentoring Program Online Modules

Module 1: Overview of Systems Navigation
Module 2: Navigating School Systems
Module 3: Navigating Community Centered Boards
Module 4: Navigating Insurance
Mentor training

TRAINING DAY ONE
- Systems navigation
- Types of interventions
- Confidentiality and safety

TRAINING DAY TWO
- Role of grief
- Art of mentoring
  - Video examples
  - Role playing
- Pre-post knowledge test
- Mentor certification
The Matching process

- Child characteristics
  - Child Impact Questionnaire
  - Social Responsiveness Scale
- Geographic location
- Race, ethnicity
- Gender (parent or child)
- Spiritual values
- Parenting style
Mentoring

- Meet at least monthly
- Any medium
- Monitoring form
Design

- Recruitment: 3 local clinics
- Active intervention vs waitlist control
- Intervention + 6 months mentor follow-up

Measures
- FACES
- PSOC
- FQOL
- FIQ
- Qualitative interview
Mentee demographics

- Gender:
  - Female: 59
  - Male: 7

- Ethnicity:
  - Non-Hispanic: 55
  - Hispanic: 8
  - Not Reported: 3

- Race (choice checked):
  - American Indian or Alaska Native: 2
  - Asian: 1
  - African America: 1
  - Native Hawaiian or Other Pacific Islander: 0
  - Caucasian: 54
  - Hispanic or Latino: 8
  - Other: 2
  - Not Reported: 1
Consort figure

162 Screened

21 ineligible

33 active

34 waitlist

74 lost to follow up before randomization

4 lost to follow up

2 lost to follow up
Findings

- Satisfaction with program high
- No change in stress or family impact
- Service utilization
  - Heavy reliance on IDEA funded services
  - Speech/OT
  - Drops in summer
Findings: *Family Quality of Life Scale (FQOL)*

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Findings:
*Family Adaptability & Cohesion Evaluation Scale – IV (FACES-IV)*

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**Stratified by Study Group (Active)**

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**Stratified by Study Group (Waitlist)**

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Qualitative findings

Emotional support

- “Support from other parents is the greatest benefit. You can feel so isolated. It’s helpful to know so many other have gone through the same thing. I felt validated.”
- “Good to talk with other parents in the same position. Good to know that we are not alone.”
- “Program gave me hope. It can be done. Pointed us in the right direction.”
Qualitative findings

Informational support

- “I am much better equipped to navigate the system on my child’s behalf.”
- “I am more confident in my ability to help my son.”
- “The number one thing is that it put me in touch with the right people and gave me the knowledge to figure out where to go next.”
Conclusions

- Enhances satisfaction with care
- Prevents/reduces family rigidity
- Improves emotional quality of life
- Sense of competence in navigating systems of care
- Not about amount or type of care
- Life remains stressful
So what?

- Not about direct care to children
  - Or parents
- Supporting families has measurable impact on outcomes that matter to parents and families
  - Triple Aim
- Family support is a missing element from many clinical services
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