



Identifying the Gaps in Autism Services amongst Parents with Autistic Children



Patricia Mathelier, MBA^{1,2,3}, MSIV & S. Bazargan-Hejazi, PhD¹

1. Charles Drew University, 2. David Geffen School of Medicine at UCLA, 3. UCLA Anderson School of Management

Learning Objectives

- Uncover the struggles of parents of children with autism
- Brainstorm solutions that bridge the gap between parents' struggles and the services their children receive

Background

- 1 in 59 children (1.7%) in the US are diagnosed with Autism Spectrum Disorder (ASD), and this is a 15% increase since 2010.
- Empirical evidence have shown that caregivers of autistic children experience a higher rate of divorce and depression.
- Learning about parents' struggles can help tailor autism services to their needs

Methods

- **Study design:** Mixed-method study; survey & phone interview
- **Recruitment site:** Social media & word of mouth (2019-2020)
- **Eligibility criteria:** Parents of children with autism
- **Participants:** 24 phone interviews & 20 questionnaires

- **Sample Questions:**
 1. After initial suspicion of developmental delay, how long did it take your child to receive a diagnosis?
 2. What services were prescribed to your child vs. what services are they currently receiving?
 3. Where do you find your information about autism?
 4. Do you feel you have adequate support as a caregiver?

Results

Parent Reported Struggles (Interview)	
Navigating IEP/ services	63%
Burnout/ Overwhelm	58%
Tantrum/ Meltdown	46%
Lack of Support	38%
Routines	29%

Parenting Challenges (Survey)	
Missing Feelings of "Normalcy"	24%
Time Constraints	24%
Not Seeing Progress	19%
Feeling Connected to My Child	14%
Therapy is "too strict" or "harsh"	14%
Tracking Data	5%

Limitations

- Unknown socioeconomic and racial demographics of all participants
- Recall bias when answering questions
- Small sample size
- Lack of generalizability

Conclusions

- Parents of children with autism go through a spectrum of struggles
- Parents use digital media daily to fill in service gaps
- Our results suggests that parents of autistic children would benefit from an evidence-based digital solution for daily use
- Novel solutions are needed to make such digital solutions culturally and linguistically sensitive (ex: culture, language, parenting styles, etc.)