



## Background

- Approximately 1 out of every 6 children (17%) born in the US has a developmental disability (IDD); this proportion is on the increase<sup>1</sup>
- Most individuals with IDD lack a dental provider when they reach adulthood<sup>2</sup>
- Currently **only 32% of general dentists see individuals with IDD**, compared to 89% of pediatric dentists<sup>1</sup>
- Little qualitative literature exists regarding dental care transition; evidence emanates from survey-based studies<sup>3</sup>

## Methods & Participants

### Specific Aims:

To better understand challenges that families face when attempting to transition to an adult dental provider

To better understand barriers seen and faced by pediatric and general dentists in taking care of and transitioning of this population

Gain more understanding of systemic issues affecting the care of this population

### Methods:

- Recorded semi-structured interviews with key stakeholders: **families** with an individual with developmental disability (n= 19), **pediatric and general dentists** (n=9), state and national level **experts and policy makers** (n=3)
- Families recruited using email and social media postings on national recruiting services
- Interviews transcribed and analyzed using MAXQDA™ 2022. Inductive coding process used to identify emerging themes

## Results: Major Emerging Themes

### Theme 1: Medicaid acceptance and reimbursement rates provide significant barrier:

"I've exhausted [myself] trying to find a dentist that'll take Medicaid in Charlotte, even though there's dentists that are on every corner. I don't know if there's a dental school that's here. There is no [dental] school here in Charlotte"  
- Family

"I think there's much greater willingness to serve Medicaid population and those with special needs, but they have to be reimbursed. They have to be able to keep their lights on"  
- Policymaker

"So, the cost of rendering care to those patients is a barrier. Even if the dentist knows how to handle and work with patients who have special healthcare needs, they may not do it, because they don't think they're reimbursed at the level."  
- Policymaker

### Theme 2: Providers lack education, comfort, and office structure for treating patients with IDD:

"They don't receive adequate training to see patients with special healthcare needs. And some of them do pick up either CE courses or some training, but it doesn't prepare them to see a wide range of special care patients"  
- General dentist

"Students are not getting enough experience and they're not getting enough guided experience with those patients to feel totally comfortable when they come out of school."  
- General dentist

"There's just not many people who do it, who say they do it. And I don't mean this in a bad way, but I just get the feeling that nobody has any [significant] training to deal with people with autism [and other special needs]."  
- Family

"The idea that you may have a person with autism in a waiting room and they may be rearranging the furniture or they may be acting different and they're mixing with patients that may not understand that it affects the whole practice."  
- Family

"I've had parents tell me that they tried to bring their child to a general dentist and they brought the child in the room and immediately the dentist said, "Yeah, no, I'm not going to be able to do an exam today," and just right off the bat without even meeting them or getting to know the child."  
- Pediatric Dentist

### Theme 3: Offices exhibit discriminatory practices of accepting patients:

"We [called] five offices. " We call, we make an appointment, we say that we have Medicaid. "Oh yes, we'll take." And then after, say, "Oh no, we don't." I'm like, "We did it. You say new patient, I mean, which kind of new patient you take?"  
- Family

"They're protected under the ADA, Americans with Disabilities Act. You can't say you're not going to treat the population. 90 to 95% of this population can be treated in a community practice...But to turn away that 95, just because of the assumption of the diagnosis, is absolutely ridiculous."  
- Policymaker

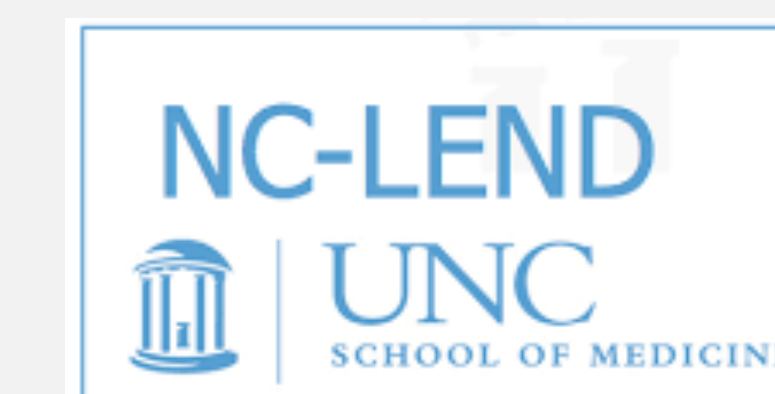
"I know that it happens...I know that sometimes they'll say, "Along the autism spectrum, we'll see these patients, but we won't see these patients. I don't want that group of patients treated in the practice ... And yes, there are some sort of tricks that are being played."  
- Policymaker

## Conclusions

1. Families with **IDD face significant barriers to successful transition of care**, including lack of provider education/comfort, Medicaid acceptance, and ill-equipped offices for care of individuals with IDD.
2. Results suggest increased emphasis on dental school education and increases in Medicaid reimbursement as areas of improvement to facilitate transition.
3. Further improvements are necessary to ensure discriminatory practices of accepting patients are eliminated.

## Acknowledgement & References

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