

# Oral health care experiences among individuals with IDD

Experiences from caregivers  
and self-advocates

January 31, 2020

Trenton, NJ

Presenter: Suma Setty, Senior  
Research Associate



COLUMBIA UNIVERSITY  
*College of Dental Medicine*



National Center for Children in Poverty  
Bank Street Graduate School of Education

# What is IDD?

- **Intellectual and developmental disabilities are disorders that usually present at birth.**
- **Intellectual disability:**
  - **developed before age 18**
  - **Is lifelong in nature**
  - **substantially limits the individual's intellectual functioning or intelligence, and/or adaptive behavior (e.g., social and life skills).**
- **Developmental disabilities**
  - **Broader category of lifelong disability that can be intellectual, physical or both**
- **Examples: cerebral palsy, down syndrome, fragile X syndrome, autism spectrum disorders**

# How does IDD affect oral health?

- Heightened sensitivity



# Main Themes



# Key Findings

Workers take leave for diverse and often disability-related reasons.

Workers want to maximize their time at work and benefit when they use paid leave in conjunction with other employment benefits.

Workers value the Family and Medical Leave Act (FMLA) and other leave options.

There are multiple barriers and gaps that limit workers' access to leave, including stigma against disabilities and fear of job loss.

# Multiple Barriers and Gaps Limit Workers' Access to Leave

Fear of job loss (including lack of employer support and stigma against disabilities)

“I’m always afraid they’ll let me go. I can’t take even two days off, because I worry about losing my job, because that’s my full-time job. I get the health insurance benefits for the whole family, so it makes me nervous to take off.”

New Jersey caregiver

Inadequate wage replacement

“I need to be paid 100% wages, not 60% wages in order to pay my bills.”

New Jersey caregiver

Inadequate coverage for self-employed and public workers

“Being self-employed was really the only option at this point because I can’t meet the criteria of a regular job. My son is high-school age and still needs a significant amount of support. Being able to show up on time and not have to call off work or be distracted because I can’t find enough support to meet his needs, that was a major factor in [becoming self-employed].”

New York caregiver with a disability and serious health condition

## Low awareness and understanding of the program

“Had I known that I could take leave to reset and also get paid, I would’ve done that. I had to instead work double to make up for what had happened rather than being able to rest and then come back restored and replenished.”

North Carolina caregiver with a disability and serious health condition

## Narrow or unclear covered reasons for leave

“it’s very hard to show that the needs of a person with a developmental disability and all of the things that go along with it, all of the therapies and appointments, are a medical condition.”

New York caregiver with two minor children with disabilities

## Bureaucracy that resulted in confusing information and a complex process

“The rules seem to be always changing. There’s different programs and they all sort of have similar names but they’re different. That’s complicated. Figuring out what’s federal and what’s state gets confusing, and if you don’t have a good person where you’re working whom you trust to help you through it, I’m not really sure how people do it.”

New York worker with disability

## Narrow definition of family

“Well, I remember reading about FMLA when I was trying to take this leave, and that’s when I read that it doesn’t cover siblings, that it’s just for parents and children and spouses.”

California caregiver, providing support for her younger brother with autism

## Contact Us

**Kavita Ahluwalia** [kpa3@cumc.columbia.edu](mailto:kpa3@cumc.columbia.edu)

**Heather Koball** [koball@nccp.org](mailto:koball@nccp.org)

**Suma Setty** [setty@nccp.org](mailto:setty@nccp.org)



COLUMBIA UNIVERSITY  
*College of Dental Medicine*



National Center for Children in Poverty  
Bank Street Graduate School of Education