

## Leadership Education in Neurodevelopmental and related Disabilities (LEND) Program

Division of Developmental and Behavioral Pediatrics  
Cincinnati Children's Hospital Medical Center  
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### *Project Abstract*

#### **Disability Identity and Attitudes towards Prenatal Testing in the Osteogenesis Imperfecta Community**

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Little is known about disability identity, which is an individual's view of themselves, their disability, and their connection with the disability community and the larger world. Fewer studies still have explored the complexity of disability identity within the context of preparing for parenthood. In the osteogenesis imperfecta (OI) community, no studies have explored either of these concepts. Similarly, studies have yet to look into the OI community's attitudes surrounding prenatal diagnostic testing (PDT) for OI. In this study we aim to quantify both disability identity and attitudes towards PDT within the OI community, as well as evaluate the relationship between these two characteristics. Using a cross-sectional questionnaire, we surveyed biological parents who have OI themselves or who do not have OI, but have a child with OI. We used the Questionnaire on Disability Identity and Opportunity (QDIO) to assess disability identity which looks at four factors of disability identity: pride, exclusion, social model, and medical model. We also assessed attitude regarding personal and population use of PDT for OI. Finally, we allowed for optional comments.

One hundred fifty-nine parents completed the survey including, 74 parents with OI and 85 parents without OI. We found that disability identity did not differ significantly between parents with and without OI. Parents endorsed disability pride over disability exclusion, ( $p < 0.0001$ ) and endorsed the social model of disability over the medical model of disability ( $p < 0.0001$ ). We also found that 54 percent of respondents agreed that they would personally want to use PDT for OI, and that respondents without OI indicated a stronger agreement (63.5%) than respondents with OI (41.9%) ( $p = 0.0064$ ). Respondents who endorsed the social model of disability were more likely to endorse PDT for personal use. Forty-two percent of respondents agreed that population-based PDT for OI should be available. There was no significant difference in agreement between respondents without OI (35.3%) and respondents with OI (48.7%) ( $p = 0.0883$ ). Respondents who endorsed disability pride were more likely to agree with population-based PDT. Parent comments covered many subjects including many descriptions of why they agree or disagree with PDT.

Our study raises many more questions than it answers, especially as it crosses several domains of research. From a disability studies perspective, more empirical data is needed to define disability identity, including the role of disability identity among nondisabled family members and caregivers. From a prenatal counseling perspective, we need a greater understanding of why individuals within a disability community support or oppose PDT. We are hopeful that our research will reveal answers for the OI community and spur further research. Our findings, will inform medical professionals, community organizations providing care and services to parents with OI, and general OI community at large.