

# The Influence of Parent Experience: Investigating the Association between Parent Experiences and Parent-Reported Behaviours of their Autistic Child

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### Introduction

- Aspects contributing to Parent Stress:
- impaired social communication skills<sup>3</sup>
- isolation from friends and family<sup>1</sup>
- problem behaviours<sup>4</sup>
- financial requirements and access to care<sup>4</sup>
- Parents with an autistic child report higher levels of burden → this is associated with perceived parenting self-efficacy<sup>5</sup>
- Few studies to date have assessed the family's experience quantitatively → this has been addressed with the recent development of the Autism Family Experience Questionnaire (AFEQ)²

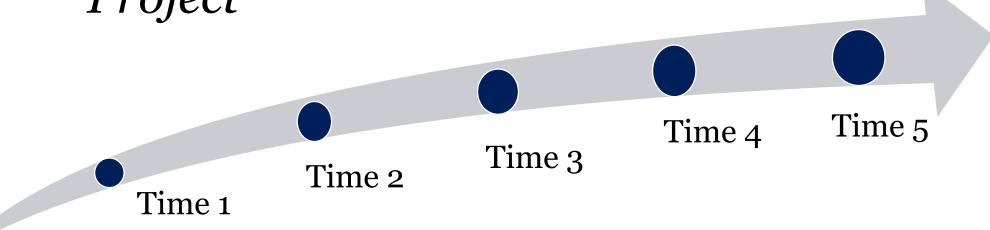
## Research Objectives

Hypothesis: We hypothesized that lower parental experience scores, representing a more negative perceived experience, would be associated with lower scores in parent-reported child development.

#### Methods

Participants: 91 autistic children (76 boys) with a mean age at enrollment of 49.01 months (SD=9.23)

- Data obtained from the pilot phase of the Pediatric Autism Research Cohort Project



Analysis: Correlation analysis was conducted, followed by Fisher's z transformation to assess differences between timepoints.

Results suggest a possible association between how parents feel about their parenting experience and parent-reported development in their autistic child; however, it may not be evident until the child is slightly older and/or has carried their ASD diagnosis for more than 2 years.



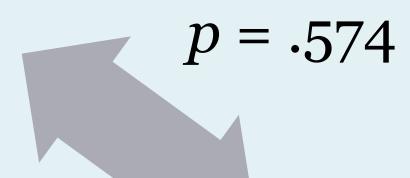


Parenting Experience (AFEQ1)

Time 4 = <. 001
Time 5 = .022

Child Development (AFEQ3)

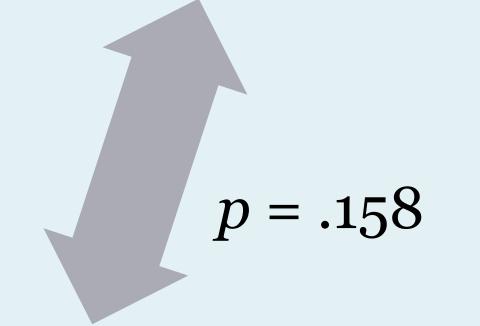
Time 1



Time 5







Time 4



p < .001

Time 3

## Discussion

- The significant difference between time 3 & 4 may indicate an important time period in the relationship between parent's perceived family experience and their autistic child's development → or at least their perception of this development.
- Results from this study will:

   a) inform the continuation of the full-phase PARC study when full data samples have been collected
- b) may help us to further understand the relationship between family experiences of having an autistic child and the autistic child's development as perceived by their parents
- This may be influential, and therefore important to consider, when adapting or developing support systems for these families and their autistic child.

#### References

1) Gorlin, E. I., McAlpine, C. P., Garwick, A., Wieling, E. (2016). Severe childhood autism: The family lived experience. *Journal of Pediatric Nursing*, *31*(6), 580-597. doi:10.1016/j.pedn.2016.09.002

2) Leadbitter, K., Macdonald, W., Taylor, C., Buckle, K. L., & PACT Consortium. (2020). Parent perceptions of participation in a parent-mediated communication focussed intervention with their young child with autism spectrum disorder. *Autism*, *24*(8), 2129-2141. doi:10.1177/1362361320936394

3) Russel, S. & McCloskey, C. R., (2016). Parent perceptions of care received by children with an autism spectrum disorder. *Journal of Pediatric Nursing*, *31*(1), 21-31. doi:10.1016/j.pedn.2015.11.002

4) Shepherd, D., Landon, J., Taylor, S., & Goedeke, S. (2018). Coping and care-related stress in parents of a child with autism spectrum disorder. *Anxiety, Stress, & Coping.* 31(3), 277-290. doi:10.1080/10615806.2018.1442614

5) Weiss, J.A., Tint, A., Paquette-Smith, M., & Lunsky, Y. (2016). Perceived self-efficacy in parents of adolescents and adults with autism spectrum disorder. *Autism*, *20*(4), pp. 425-

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