



# Perspectives on Disability Studies & Advocacy from Parents of Transition-Aged Youth with Autism Spectrum Disorder (ASD)

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## Introduction

- Young adults with ASD have difficulty after transition with post-secondary education, employment, independent living, and adult relationships.<sup>1</sup>
- Families and their youth with ASD deal with many barriers during and after transition, including the medical model of disability.<sup>2</sup>

## Disability Studies

- Proposed a program – **Re-Imagine Transition & Adult Success** for parents of transition-aged youth with ASD<sup>3</sup>
- Rooted in the Social Model of Disability
- Teach Social Model of Disability to inform decisions made by family with youth
- Hope to improve transition outcomes

## Methods

- 2 Listening sessions with ASD youths' parents in Oregon
- Each session 2 hours long
- Questions addressed parent advocacy during transition, child's adulthood outcomes, and thoughts on proposed program
- Thematic analysis of listening session

## Listening sessions with parents of transition-aged youth with ASD show:

- 1) Parents have long, challenging situations advocating for their youth.
- 2) They have many worries and some excitements for after their youth's transition.
- 3) They want programs to help them with transition but may already know about disability studies content.

"Advocacy is always a [gray area], because 'the personalities are so different that you have to deal with' you can't get comfortable, it's always a change, and your child is always changing too."

Parent Advocacy

"Just like any parent of a teen, they've had some life-long interests so I'm excited to see what they're going to do with that."

Excitements for Adulthood

"There are possibilities now, but a year ago it was terror. It's still terror."

Worry - Employment



SCAN ME

References + Plain Text

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## Participant Characteristics



7 mothers

2 female youth

2 gender non-binary youth



1 father

4 male youth



**Parents**

6 Caucasian  
1 mixed  
1 Hispanic

**Youth**

5 Caucasian  
2 mixed

**Age of Youth**

14- 19 years old

## Results - Themes

### Parents' Advocacy

- Ongoing process
- "Uphill battle"
- Search for appropriate resources for youth

### Parent Worries for Adulthood

- Youth having interpersonal adult relationships
- Youth's employment status
- Mental health resources as adult with ASD
- If parent dies what happens to youth

### Parent Excitements for Adulthood

- Seeing youth's interests in adulthood

### Program Feedback

- Disability Studies / social model already understood by parents who have transition-aged youth
- Parent programming for transition will be useful

## Discussion

- More research is needed about disability studies programs during transition for parents.
- Possibility of exploring content usefulness to youth
- May need to change program readings and content