Managing the Wait for Autism Spectrum Disorder Services in Newfoundland and Labrador:
A Grounded Theory Study

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Overview

- Background
- Study Objectives
- Findings
- Conclusions
- Questions

Background

- CDC: 1/68
- Canada: 1/94
- Wait times
- Financial Implications

Study Objectives

- To determine the process parents of children and adolescents diagnosed with ASD go through to access diagnostic and treatment services for their children throughout the life course of their disease
- To explore whether parents' SES affected this process

Core Category

Managing the Wait

Process Model

Child exhibits concerning behaviors

Phase 1 **Watchful waiting**

Noticing suspected behaviors
Searching for assessment and diagnosis

Phase 2 **Informed waiting**

Receiving the diagnosis
Facing challenges in accessing treatment services
Realizing the impact of an ASD diagnosis

Phase 3 **Contemplative waiting**

Pondering the future
Reflecting on the past and making recommendations

Phase 1: Watchful waiting

- 1.1 Noticing suspected behaviors
- 1.2 Searching for assessment and diagnosis

1.1 Noticing suspected behaviors

“He was different probably just before he turned 3 years old, like he’d get really latched on to things, like really concentrate and just couldn’t break that boredom cycle and had these really strange kind of hand gestures that he would be doing all the time and there were the sounds he’d make – odd noises at certain times and you know, they might last for 30 minutes…he didn’t interact socially.”

1.2 Searching for assessment and diagnosis

"[We] waited 8 months to get into speech…the speech language pathologist was the one that even hinted that there could be something. She suggested that we go to get tested for autism…it was 19 months [on the wait list] from the time we started; [it] was 36 months when he got his diagnosis."

Phase 2: Informed waiting

- 2.1 Receiving the diagnosis
- 2.2 Facing challenges in accessing treatment services
- 2.3 Realizing the impact of an ASD diagnosis

2.1 Receiving the diagnosis

“Within like 30 minutes he [pediatrician] came out and he said, ‘You know, sorry your son has autism.’ After being given the diagnosis, I was like a mess for two days. I couldn’t even talk. How did it happen? Why did it happen? Am I responsible for this?”

2.2 Facing challenges in accessing treatment services

"When you hear the word, 'autism' you're introduced to the fact there's a 12-18 month wait. So that's 12-18 months wasted. Then OT took us 2 years to get in, speech took us 6 months. It's unacceptable from my perspective. That's precious time wasted…Applied behavioral analysis (ABA) we were put on a wait list – it was a good 6 or 7 months…We applied for [autism service dog]…it took 3 years to get him."

2.3 Realizing the impact of an ASD diagnosis

“We stayed married for financial reasons. So it was either file for bankruptcy or live on the welfare system…So he [husband] has a room in the house and my son and I have the rest of the house. We share a residence and he sees his son when he wants to. When he doesn’t choose to, well we go on with our day unfortunately. It’s not easy. We’re trying our damnest to make it work…the divorce rate is high.”

Phase 3: Contemplative waiting

- 3.1 Pondering the future
- 3.2 Reflecting on the past and making recommendations

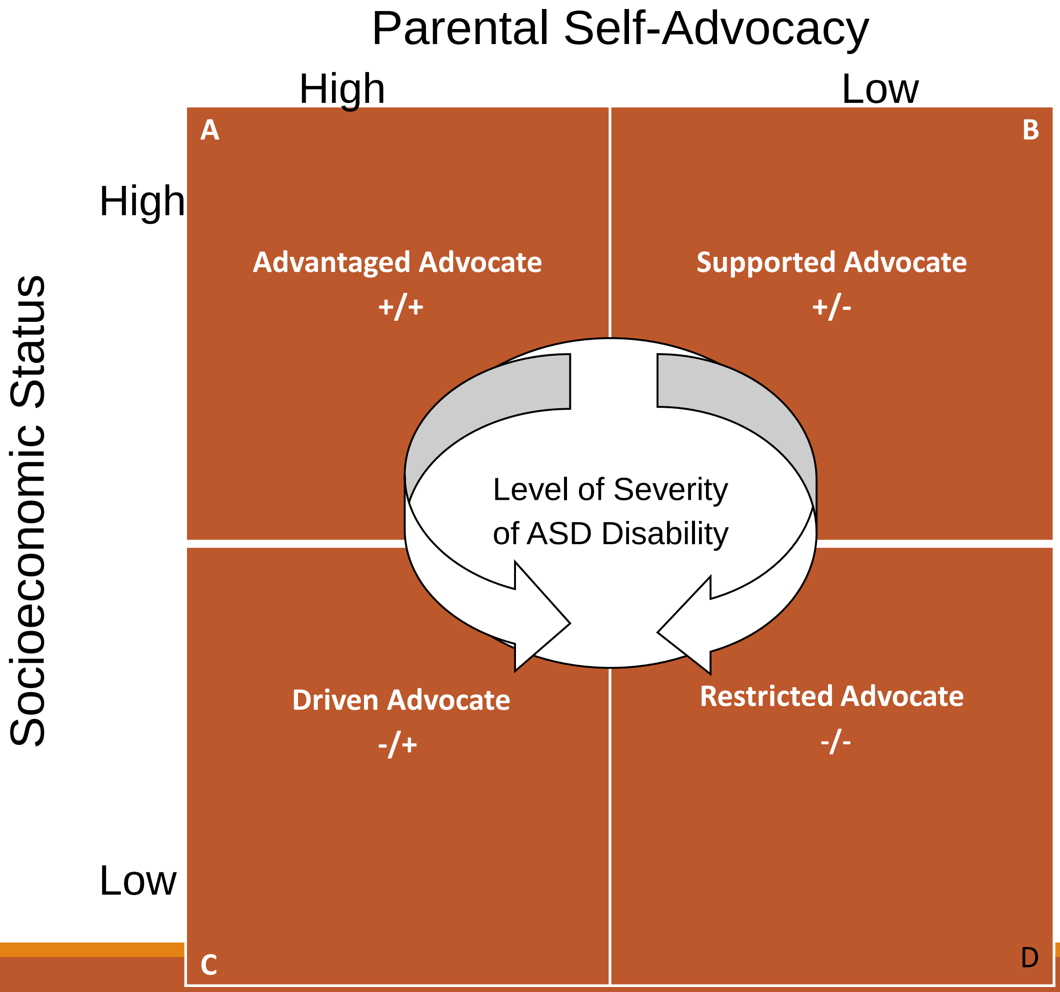
3.1 Pondering the future

“Is he going to have any friends? Is he going to be able to talk? Am I ever going to have any kind of parent-child communication in the regular sense with this kid? Will he grow up to be somebody who has a job and is able to support himself and have friends and a certain level of happiness…a happy, healthy life?”

3.2 Reflecting on the past and making recommendations

"The earlier the diagnosis the earlier you get started on this. I feel like when any parent gets a diagnosis there should be a list like this is what you do. You go here. These are the steps. It would be nice to give a card to a family that's going through it to say, you can call here and they will give you support – kind of like a helpline."

Parental strategies in the process of ‘Managing the Wait’



Parental Self-Advocacy

High

Low

Socioeconomic Status

High

Low

A

Advantaged Advocate

+/+

B

Supported Advocate

+/-

Level of Severity
of ASD Disability

Driven Advocate

-/+

Restricted Advocate

-/-

C

D

Conclusions

- Wait times and access to services
- Support and information
- Impact on families
- Socioeconomic factors

I'm not misbehaving

I have Autism

Please be understanding

Questions