The Caregiver Perspective: Examining the Healthcare Transition from Pediatric to Adult Services for Individuals with Down Syndrome in Nova Scotia

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BACKGROUND

Down syndrome:

- Is the most common genetic condition and one of the only conditions diagnosed at birth.
- Has a variety of congenital abnormalities and acquired conditions that are associated with it
  - Intellectual disability, thyroid disease, hearing impairments, osteoporosis, sleep apnea, cardiac anomalies, dementia, and obesity[2,3]

Nova Scotia has the highest rate of disability in Canada at 37.9%[1]

Despite the presence of clinical guidelines, individuals with disabilities, including those with Down syndrome, **experience significant health care disparities**.

PRELIMINARY RESULTS

Themes emerging from preliminary interviews:

Lack of **communication** about the transition process

Confusion regarding **how** the transition process works

Inconsistency in **age** of transition

Parental awareness that specialized care for individuals with intellectual disability is **necessary**

No formal transition process identifiable by parents

OBJECTIVES/AIMS

Purpose of the study: Explore transitioning from pediatric to adult health care services for individuals with Down syndrome who live in Nova Scotia.

Research aims: To identify **advocacy**, **policy reform**, **inclusive service provisions** in healthcare and **overall lived experiences** of accessing healthcare programming and services for children and youth with Down syndrome as they transition into adult care.

RESEARCH QUESTION

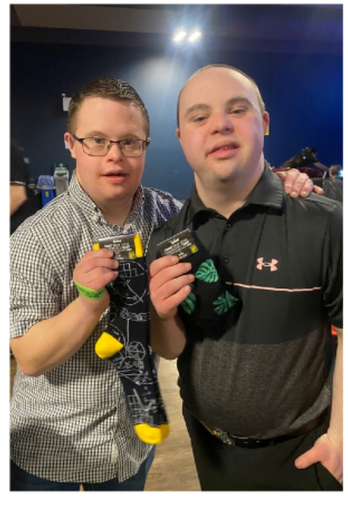
What are the **experiences** of **individuals with Down syndrome** as they **transition from pediatric to adult healthcare services** in Nova Scotia, **from the perspective of their parent/caregiver(s)?**

CONCLUSIONS

This research is still in the data collection phase, and the results are preliminary.

Final conclusions will aid in:

- **Advancing transitioning processes** for families and patients in Nova Scotia
- **Expanding knowledge** about medical conditions, system gaps, barriers and care planning required to **improve health outcomes** for those with **Down syndrome**
- Lending opportunities to **support patients and families in advocating** for continuity of healthcare services.



DESIGN/METHODS

Participants must fulfill the following criteria:
1) Participant is a caregiver or parent of an individual with Down syndrome; **2)** The individual with Down syndrome is currently between the ages of 17-30 years; **3)** The individual and parent/caregiver reside within the province of Nova Scotia

Data Collection: 30-45 minute interviews will take place between the parent/caregiver and the researcher. Microsoft Teams and the Voice Memos application will be used to audio record the interview, which will then be transcribed. 9-17 interviews will allow for data saturation[4].

Data Analysis: The data will be analyzed using a **thematic analysis** approach, where interviews will be reviewed to find **common themes among and within interviewee's responses.** This will allow the researchers to **identify the main feelings, emotions, and experiences** associated with the transition from pediatric to adult care, and how this has specifically affected the experience and health outcomes for individuals with Down syndrome.

REFERENCES

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NEXT STEPS

Summer 2026

- **Data collection**
- **Interview 8-10 participants**

Fall 2026

Sharing results provincially, and within Cape Breton University

End of Summer

Data collection and results finalized

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