



Health Care Access Research
and Developmental Disabilities



Meeting the Health Needs of Adults with Down Syndrome: Lessons from Research and Clinical Practice


From Good to Great: Enhancing Quality of Life for People
with Down Syndrome

October 28, 2017

Presented by Rob Balogh and Bill Sullivan



1



Today

- H-CARDD Overview
 - Purpose
 - Rationale
 - Methods
- Results for Ontarians with Down syndrome
 - Contrasted to general population and those with developmental disabilities (DD)
 - Demographics
 - Health, health system use
 - Problematic health system outcomes

2



H-CARDD Purpose

- Determine health and health service related outcomes for adult Ontarians with developmental disabilities

3



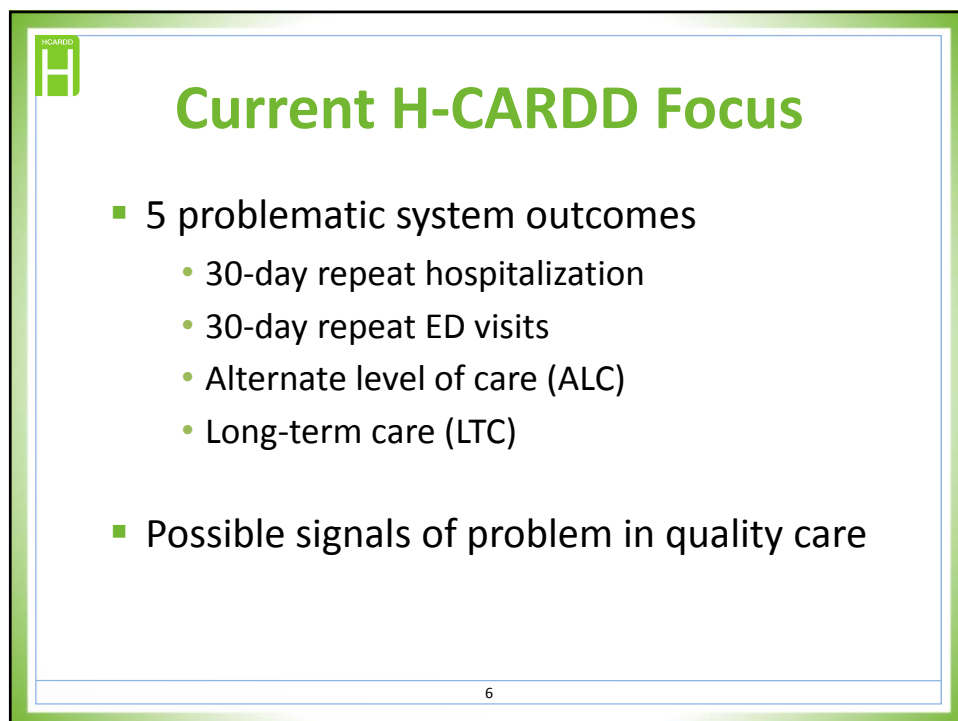
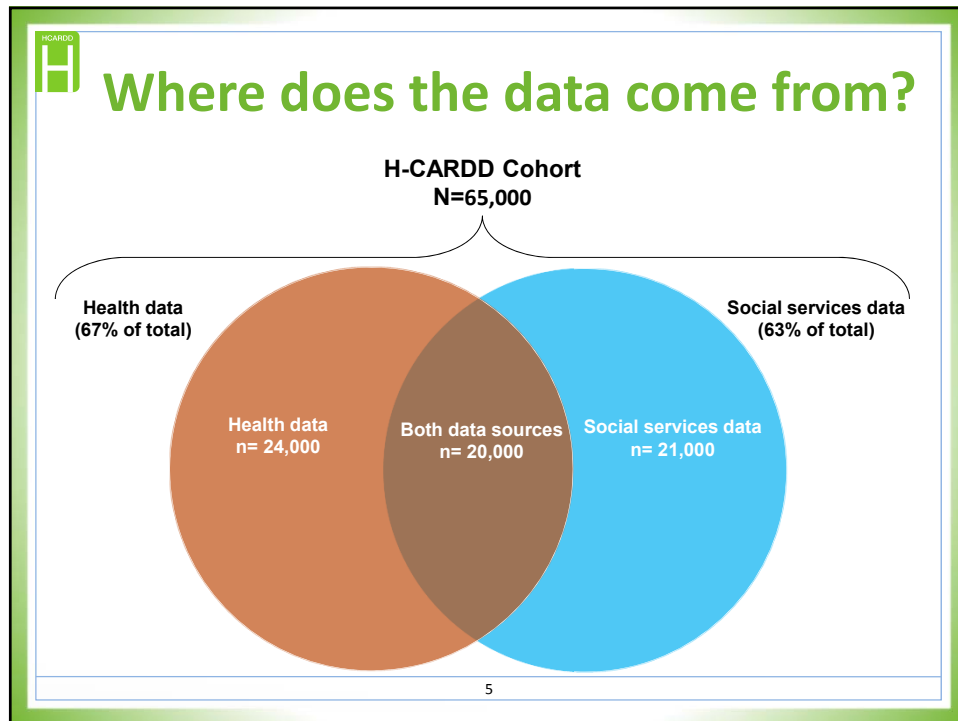
H-CARDD Rationale


- Compared to the general population, adults with DD (including those with Down syndrome) are at increased risk for experiencing:
 - Health problems
 - Problematic health system outcomes
- Lack of good data to understand situation in Canada

“lack of available, reliable data in almost every area of the developmental services sector”

Select Committee on Developmental Services (2014)

4






H-CARDD Groups

- Analytic groups:
 - **All H-CARDD** (Ontario adults, 19-65, with DD)
 - H-CARDD subgroups:
 - Down syndrome
 - **General Population**
 - Sample of adults without DD

7




H-CARDD and Down syndrome in Ontario

FY 2010, 19-65 years old

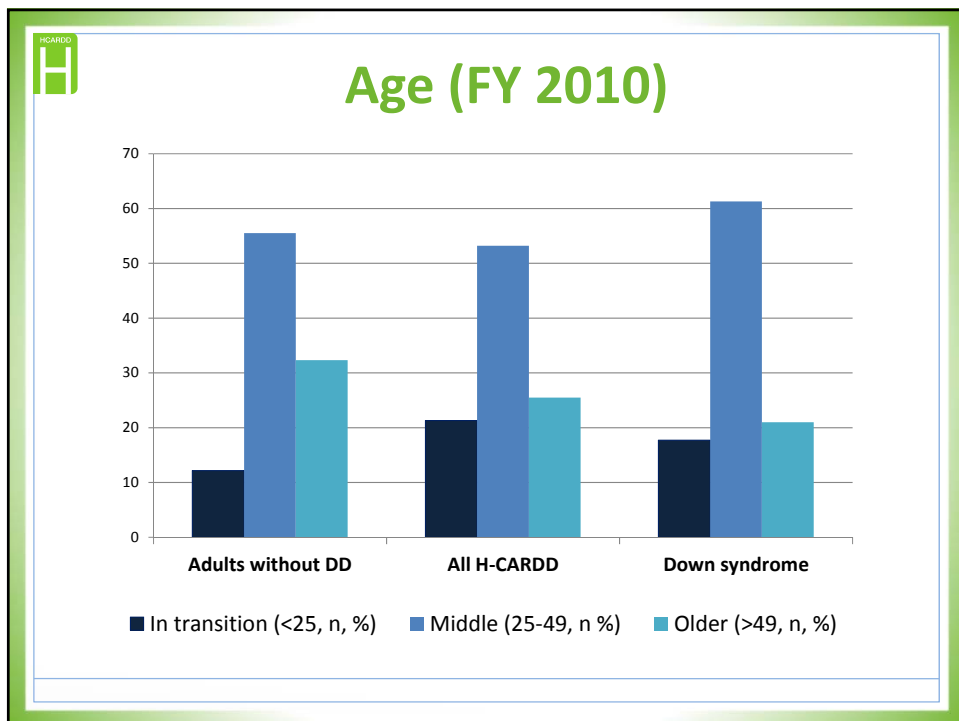
Group	N	% of H-CARDD
All H-CARDD	~65,000	100
Down syndrome	~5,500	8.4

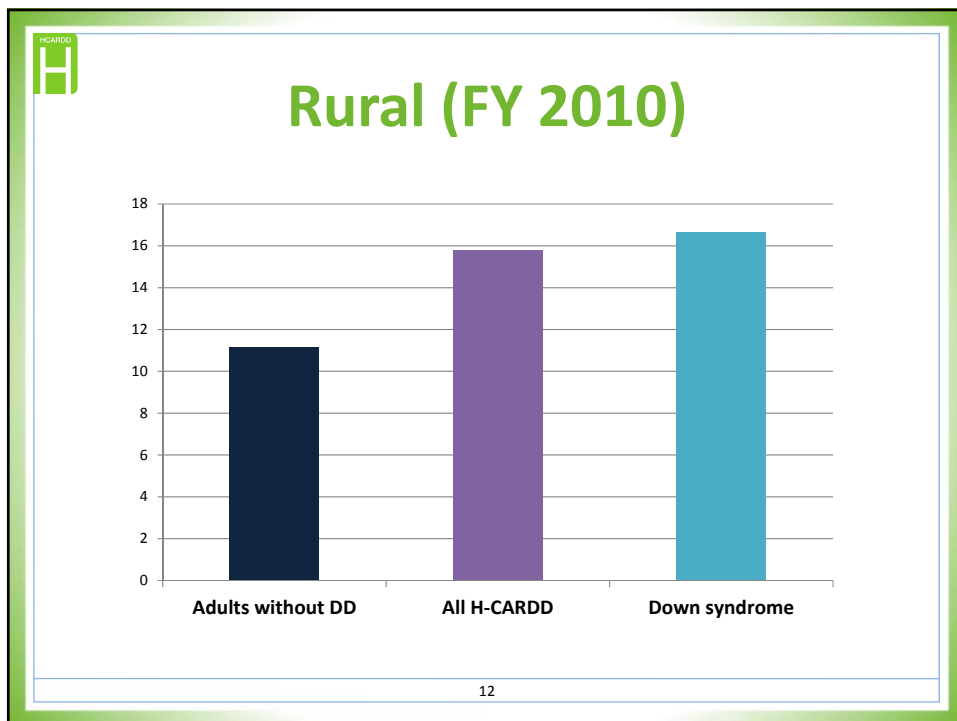
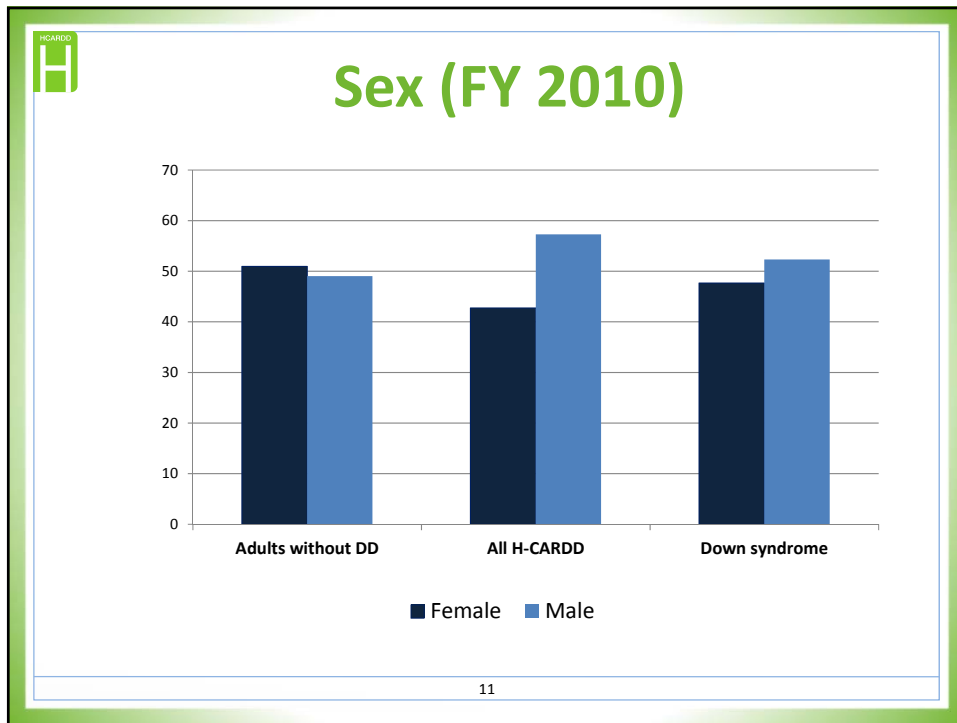
8

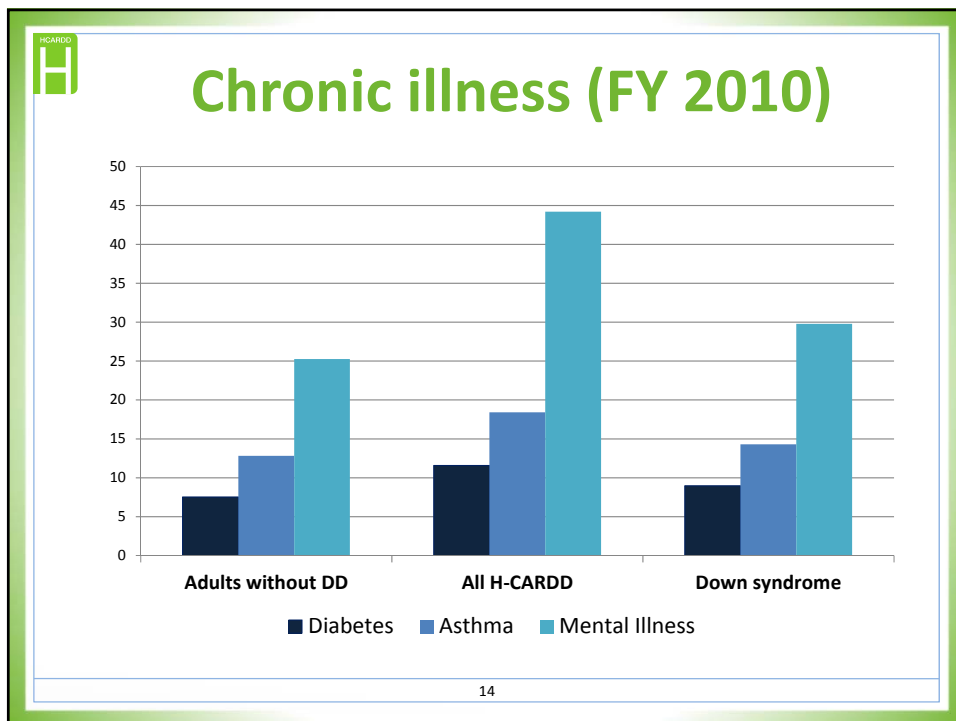
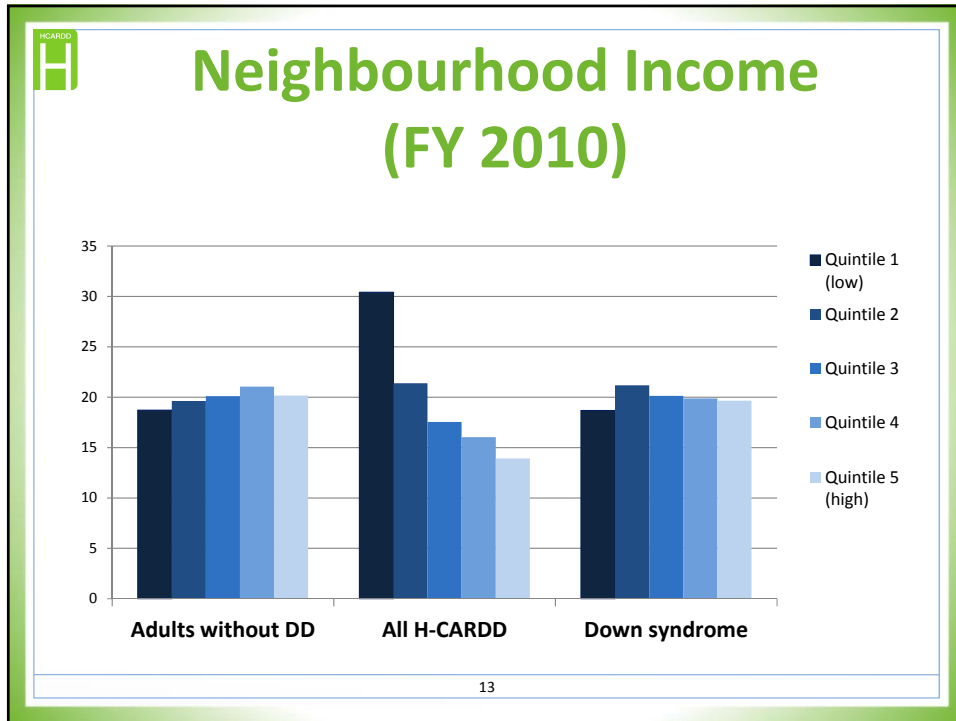


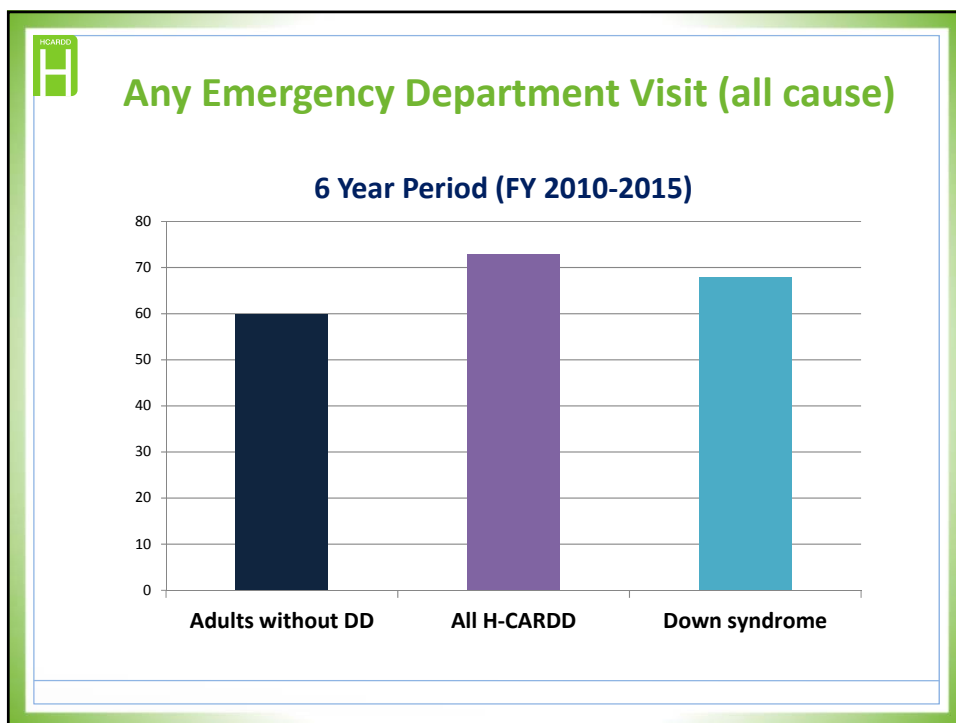
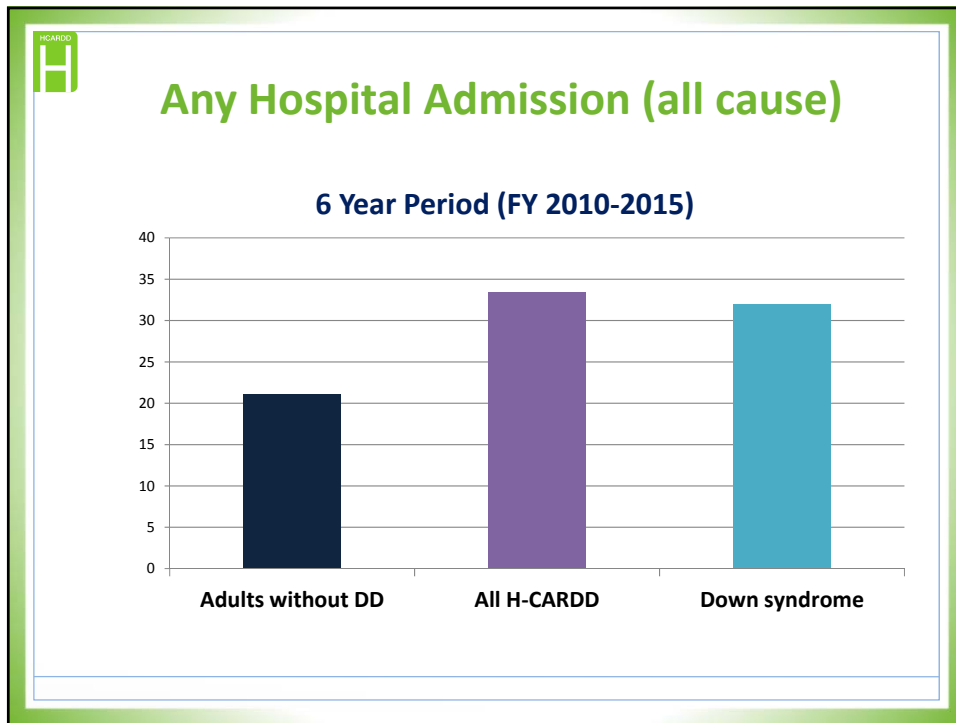
Results

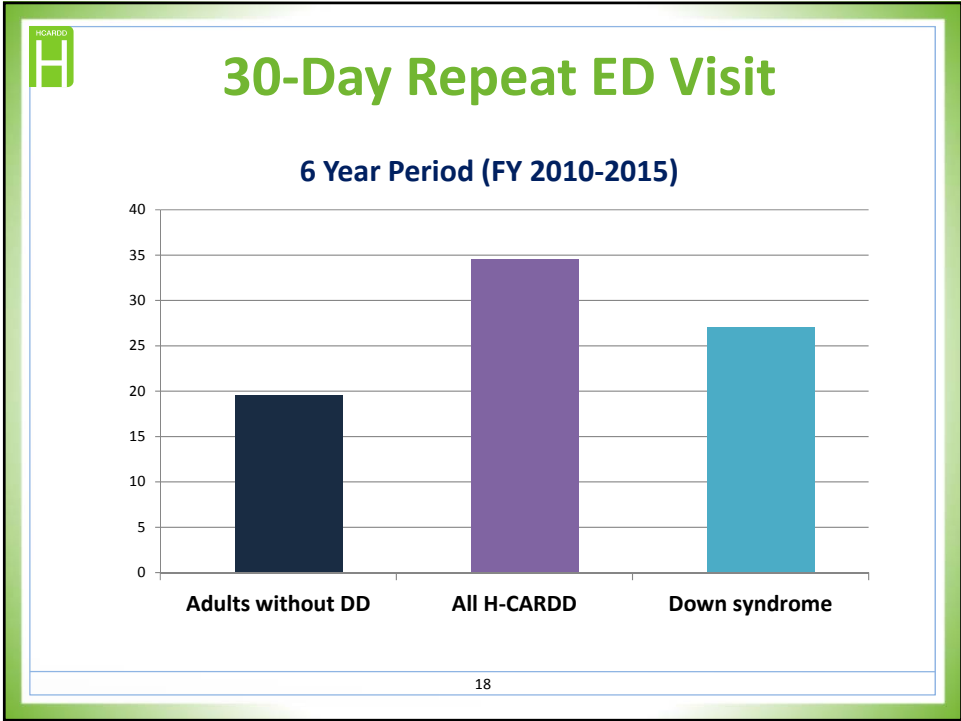
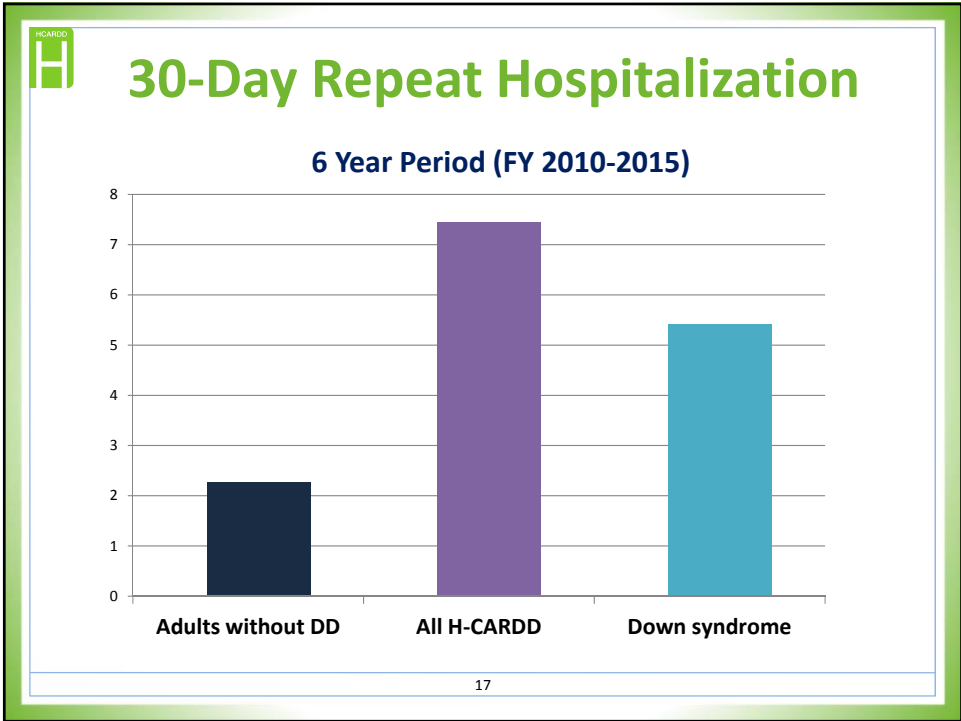
9

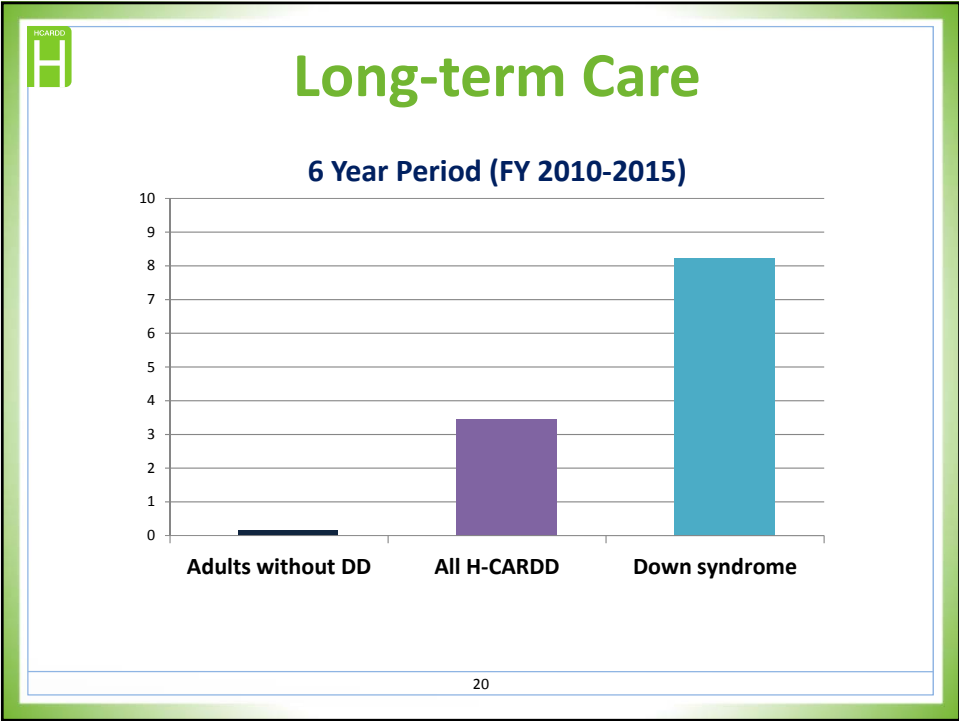
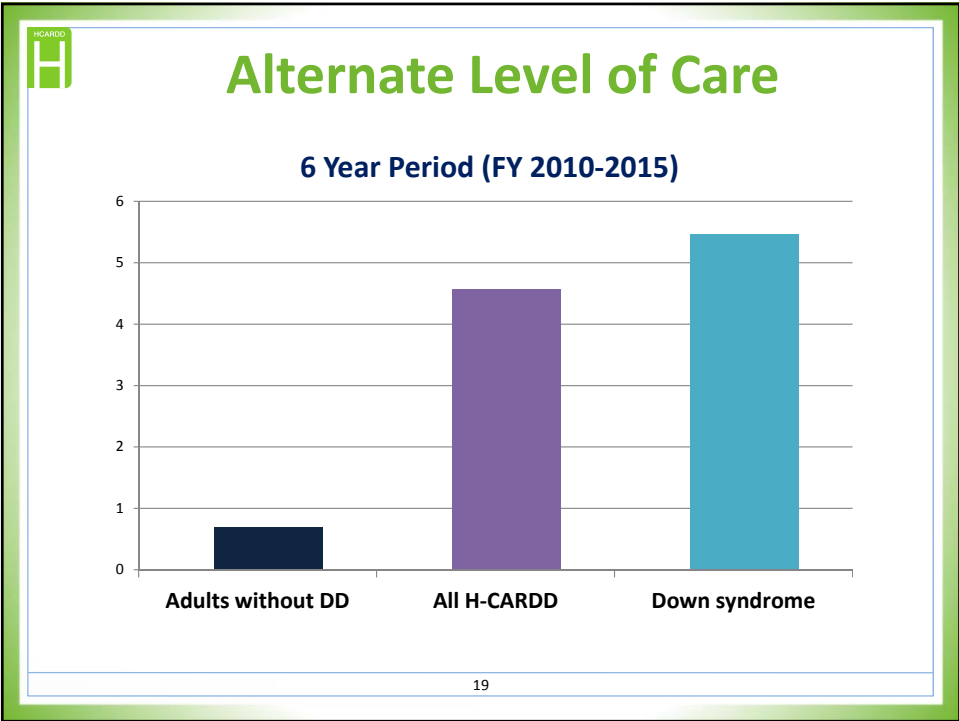














Summary

- 1st time in Canada: Population level data on health and health outcomes in people with Down syndrome
 - Approximately 5, 500 people with Down syndrome
- Demographics for people with Down syndrome: younger, %female = %male, income distribution not different from general population
- Health outcomes: overall slightly higher prevalence of chronic disease
- Health Service outcome:
 - Higher than those without developmental disabilities
 - Frequent admissions to long-term care facilities

21



Questions?
Implications?

22



Health Care Access Research
and Developmental Disabilities

Thank you!

Contact: Robert.Balogh@uoit.ca

H-CARDD is a research partnership to improve the health of Ontarians with developmental disabilities.

Visit our website to find health care tools for clinicians and patients, as well as to watch our health care practice videos.

Follow us on twitter for news and research updates. Please contact us for more information.



[@HCARDD](https://twitter.com/HCARDD)
[/HCARDD](https://www.facebook.com/HCARDD)
www.hcardd.ca



hcardd@camh.ca
(416) 535-8501 ext. 37813

23 www.hcardd.ca