

HCARDD: Health Care Access Research & Developmental Disabilities, A Partnerships for Health Improvement Project

E. Lin, D. Simeonov, H. Diepstra, B.
Isaacs, D. Butterill, and Y. Lunsky

CAHSPR, Vancouver, May 30, 2013

Overview

- Background
- Results
- Integrated Knowledge Translation
- Conclusions and next steps

Background: HCARDD

- Health Care Access Research & Developmental Disabilities
- 3-year CIHR PHSI grant
- Objectives
 - **Create & evaluate Ontario DD datasets (ODSP and health admin data)**
 - Describe primary care use of adults with IDD
 - Evaluate provision of guideline-recommended primary care to adults with DD

Background: DD

- Why important?
 - DD pop has greater health risks/issues.
 - Good health care planning requires better estimates of DD pop and information on their health care needs.
- Definition based on:
 - Based on *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008*

Background: DD Conditions

- Conditions characterized by:
 - Life-long limitations in cognitive & adaptive functioning
 - Originate before age 18
 - Not based on etiology or IQ level
- Examples:
 - Mental retardation, Down syndrome, Fragile x, Autism-spectrum disorders, Fetal alcohol syndrome, Others

Background: Problems identifying DD

- Population survey + clinical assessment
 - Very few assess all respondents
- Registries or service/support recipients
 - Accept registry or service evaluation at face value
- Administrative data
 - capture 8% ¹ to 38% ² unique cases outside of registries
 - But still incomplete

¹ Westerinen, et al., 2007

² van Schroyen Stein Lantman-deValk, et al., 2006

Background: HCARDD solution

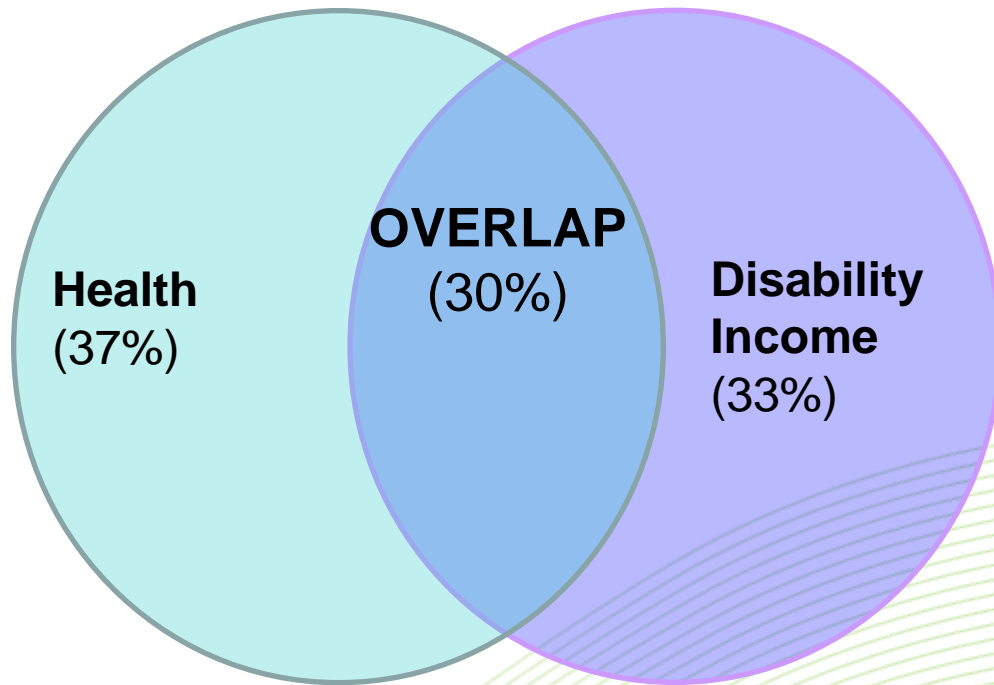
Link health administrative and disability income support data

- Need to identify variables for linking information
- Need to identify how privacy would be protected
- Need to plan for safe transfer of information

Background: Data linkage process

- Privacy Impact Assessment completed Spring 2011 by consultants (10 months)
- Data Sharing Agreement between holders of these data signed December 2011 (18 months)
- Transfer of disability income support data to holder of health administrative data done January 2012
- Final linkage completed June 2012 (2 years)

Results: Linked datasets



Prevalence

Health: 0.52

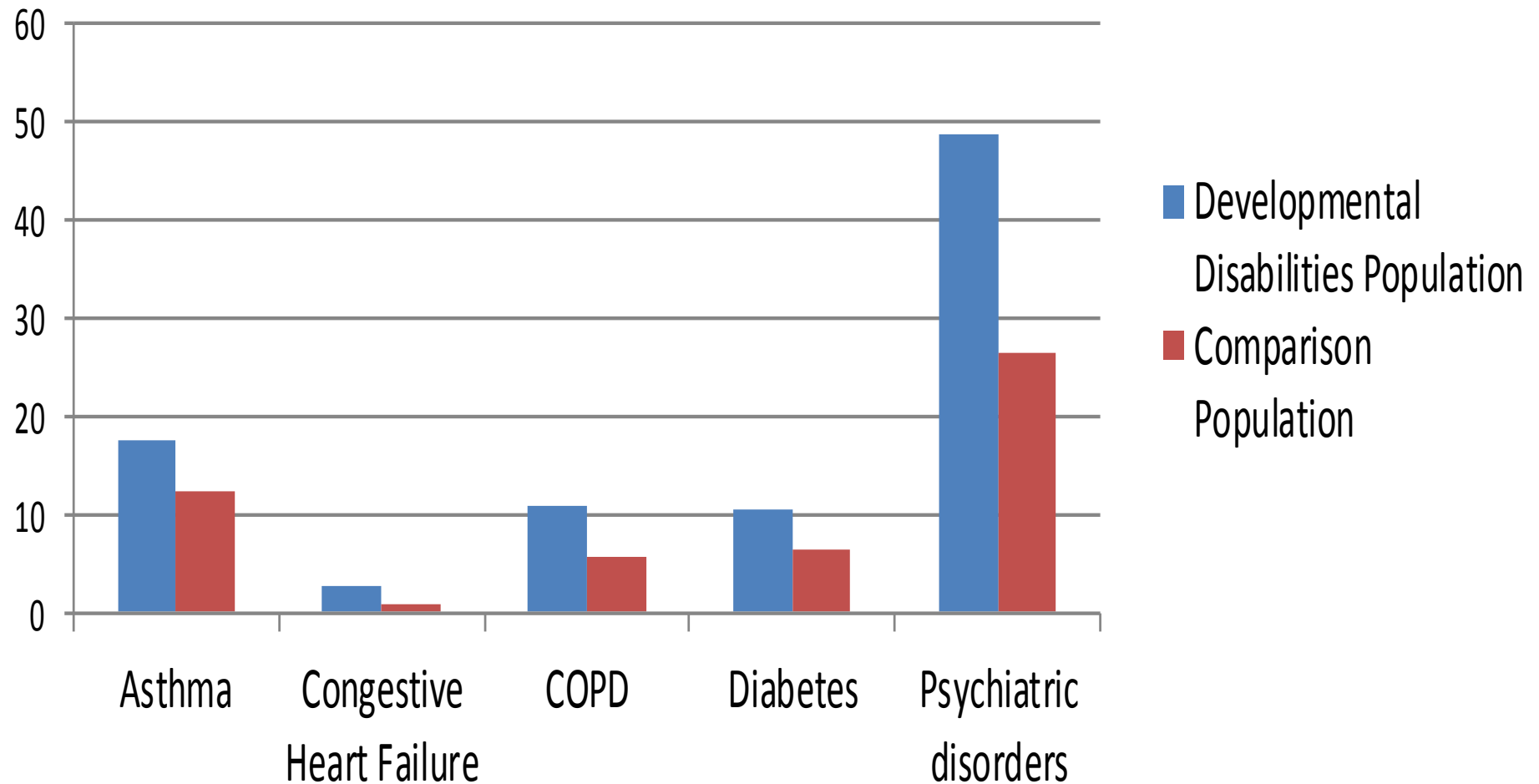
Disability
Income: 0.49

MERGED: 0.78
(n = 66,000+)

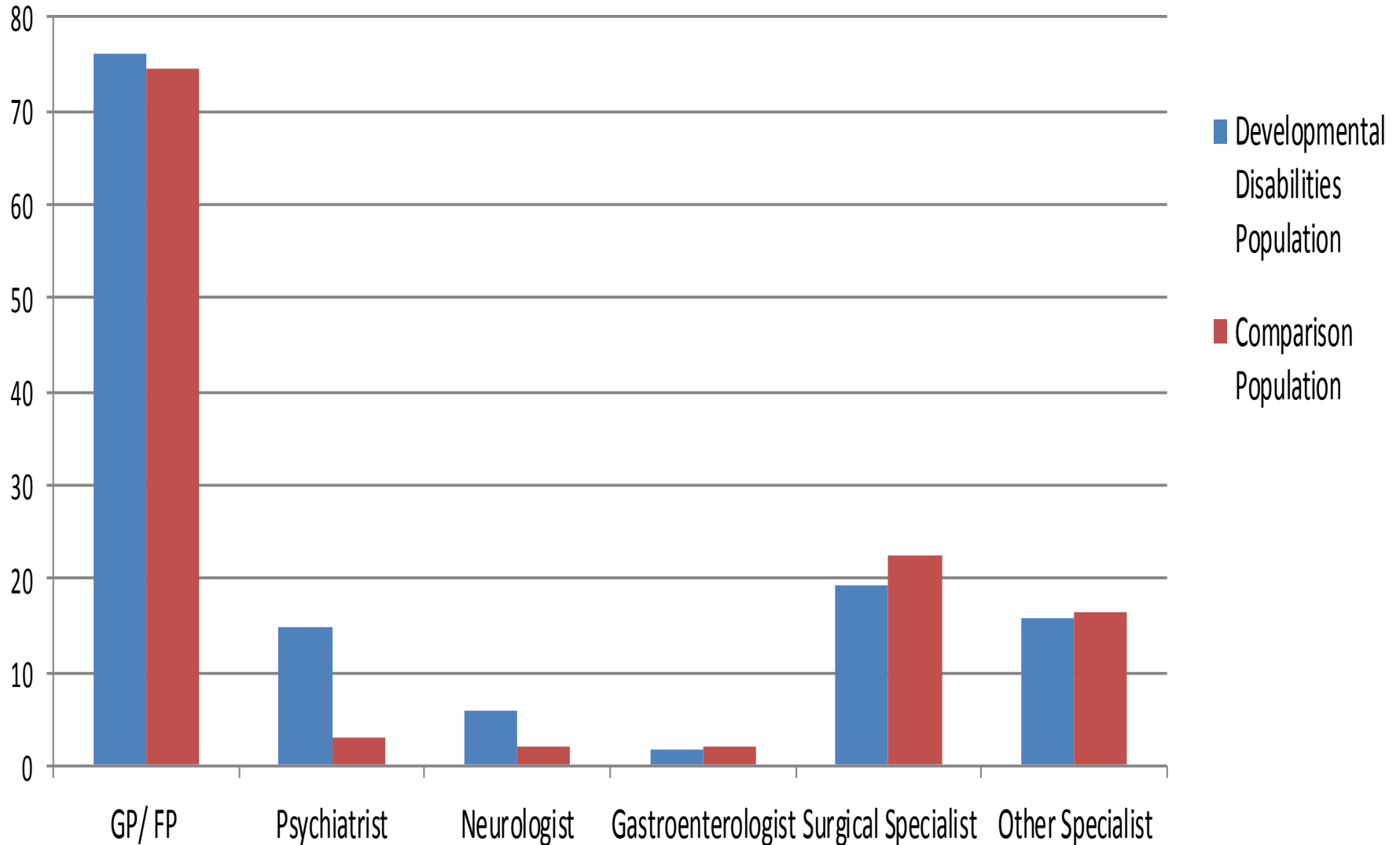
DD vs. comparison cohorts

	DD	Comparison
% males	57.3	49.1
% rural	15.6	11.0
% high income neighbourhood	13.9	19.8

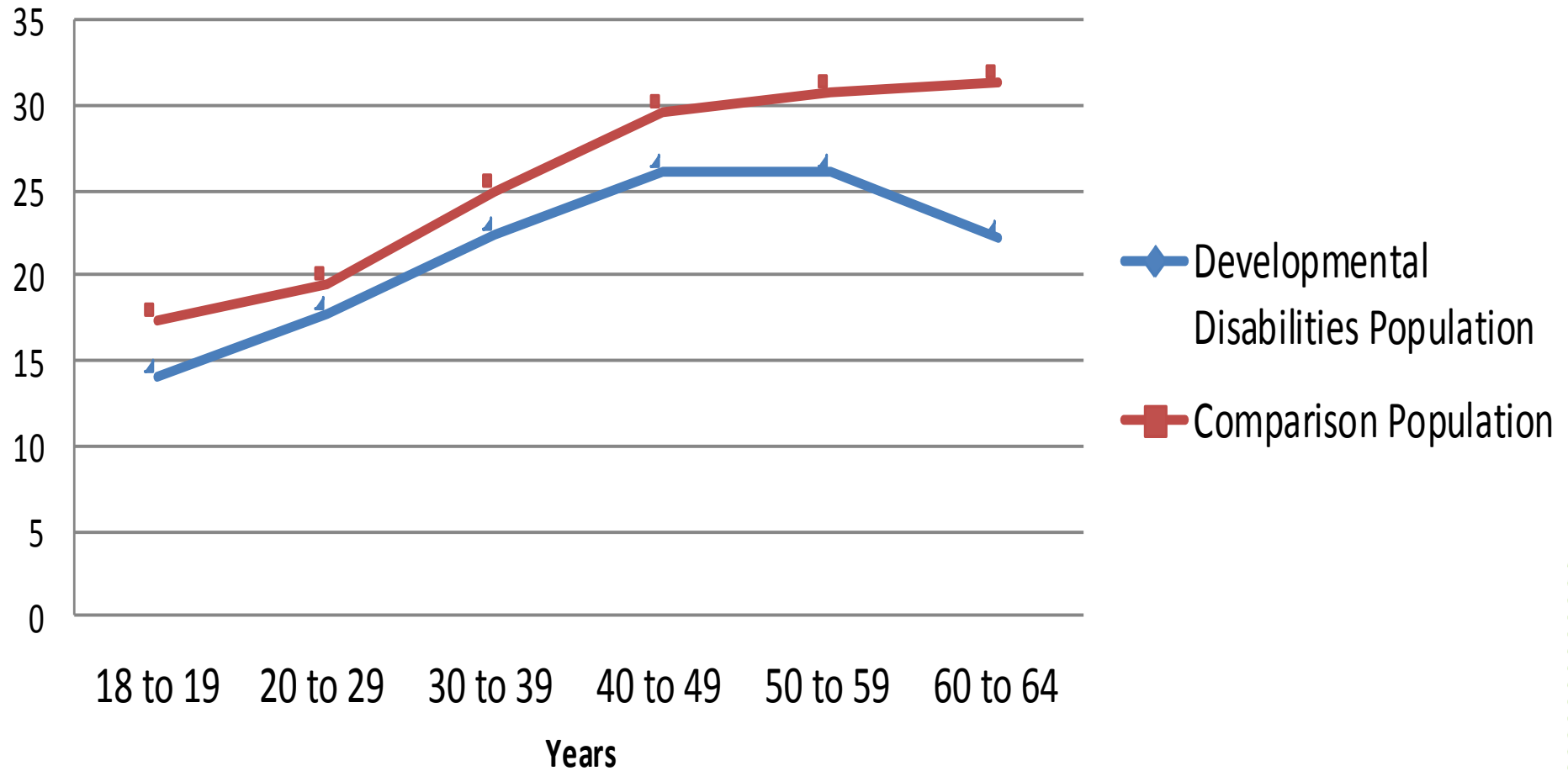
Chronic conditions in adults with and without developmental disabilities



Patterns of Health Care Utilization in adults with and without developmental disability



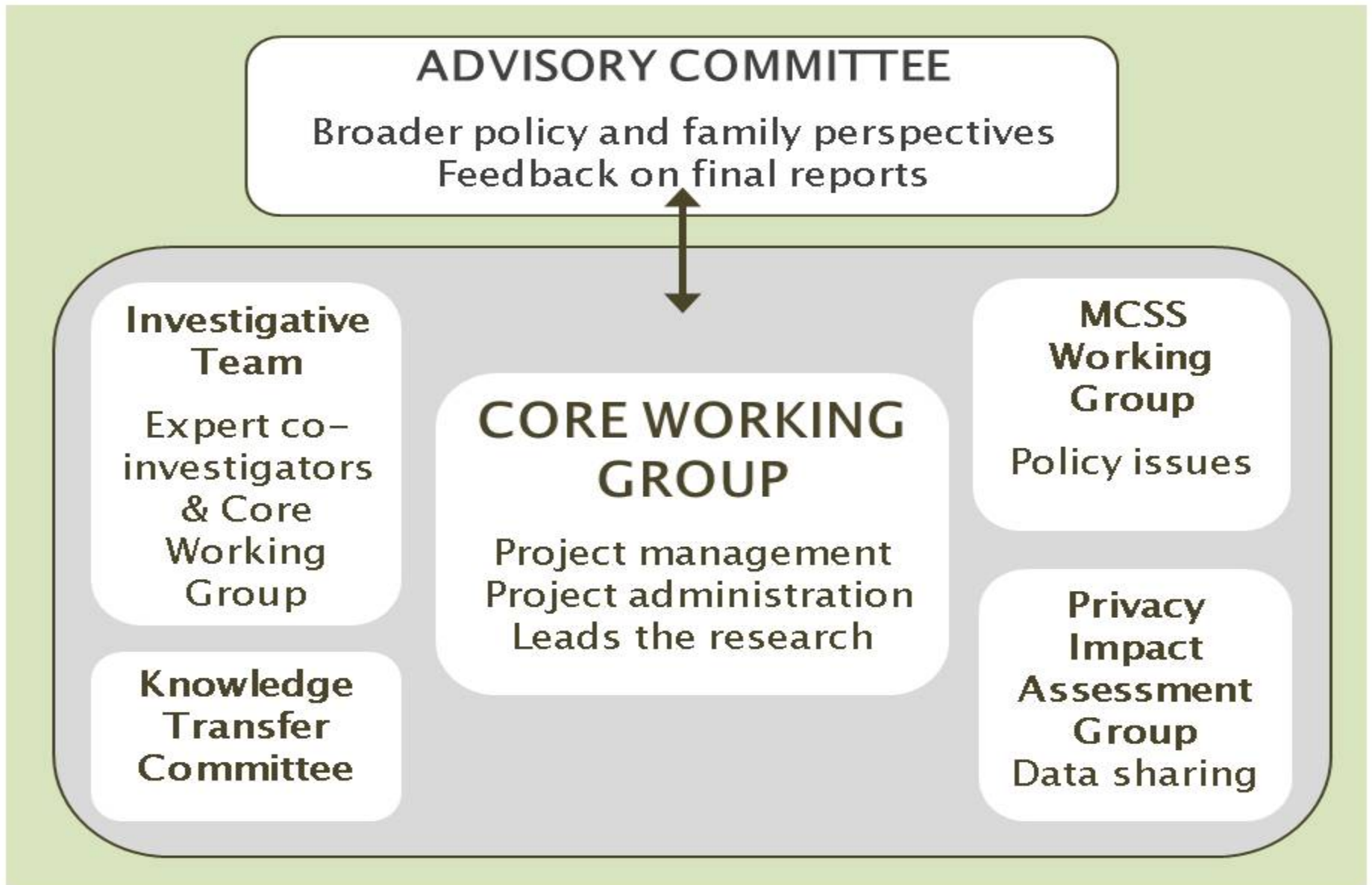
Proportion of adults who received at least one annual health exam by age



Knowledge Translation: Two Strategies



Integrated Knowledge Translation-iKT



Integrated Knowledge Translation-iKT

ADVISORY COMMITTEE

2 research
7 ministry, 5 providers, 1 parent



Investigative Team

11 research
3 ministry
1 regional
1 provider

Knowledge Transfer

6 research
1 ministry
1 regional
1 provider

CORE WORKING GROUP

6 research
2 ministry

MCSS Working Group

5 ministry

Privacy Impact Assessment

6 research
4 ministry

Integrated Knowledge Translation-iKT



	Year 1				Year 2				Year 3				Year 4	
	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2
DECISION MAKING														
ADVISORY (POLICY/USER)			●			●				●				●
INVESTIGATIVE TEAM (RESEARCH)			●	●		●		●	●	●		●	●	
CORE WORKING GROUP (BOTH)		●	●	●	●	●	●	●	●	●	●	●	●	●
DISSEMINATION														
POLICY/USER AUDIENCE						3	1	2	2	1				
RESEARCH AUDIENCE							3					1	2	4
BOTH							3			3	7			3

Intermittent/End-of Grant KT strategies

- Newsletter* (3x per year)
- Social Media (Twitter@HCARDD)
 - 87 followers
 - 30% advocates, 28% ‘individuals’
 - 15% researchers, 13% providers)
- Website (www.hcardd.ca)
- ATLAS report forthcoming in Fall 2013
- Ongoing presentations and peer-reviewed publications

*to subscribe email: HCARDD@surreyplace.on.ca

Summary and next steps

- Linked health administrative and disability income support data → largest cohort of adults with DD.
- Found health and health services disparities for adults with DD in Ontario.
- KT strategies guided entire project and are facilitating translation of results into policy and planning decisions.
- KT also key in gaining new \$\$ (2013-2016) to implement changes in emergency and primary care and do more analyses of linked data

Thank you!

