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# Living every day with a Neurological Condition: Results of the LINC study

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# The LINC Study

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## Acknowledgements

This study is part of the National Population Health Study of Neurological Conditions. We wish to acknowledge the Neurological Health Charities Canada and the Public Health Agency of Canada for their contribution to the success of this initiative.

Funding for the study was provided by the Public Health Agency of Canada. The opinions expressed in this publication are those of the authors/ researchers, and do not necessarily reflect the official views of the Public Health Agency of Canada.

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# **Impact on Health, Mental Health and Life Satisfaction**

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# How do Neurological Conditions Impact on Health, Mental Health and Life Satisfaction?

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**Compared to Canadians with other chronic conditions, *twice as many* LINC participants had poor:**

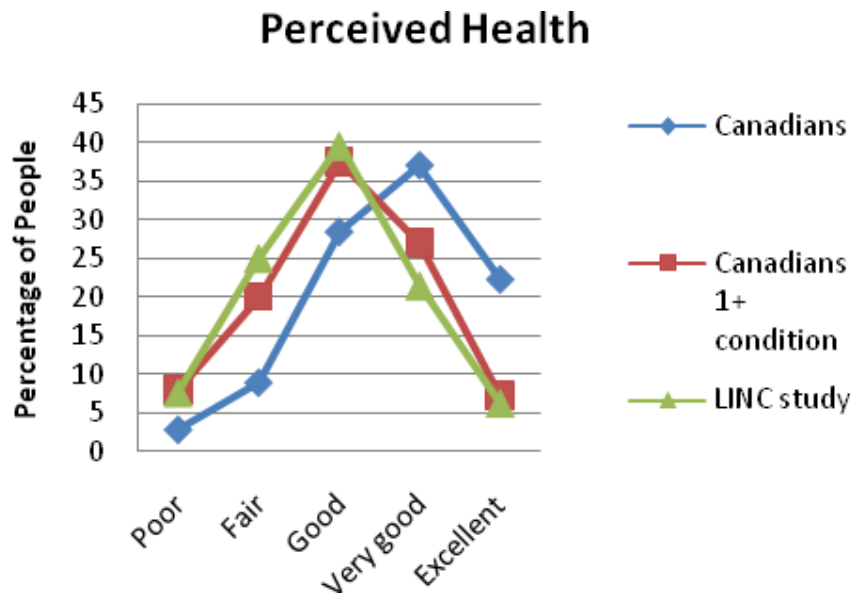
- perceived general health, mental health, and satisfaction with life in general.

## **How do we know?**

- The CCHS data is a sample of all Canadians, including people with no health problems.
  - We compared LINC adult participants to two age and sex matched groups: Canadians in general and Canadians with 2 or more non-neurological conditions.
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# Perceived Health:

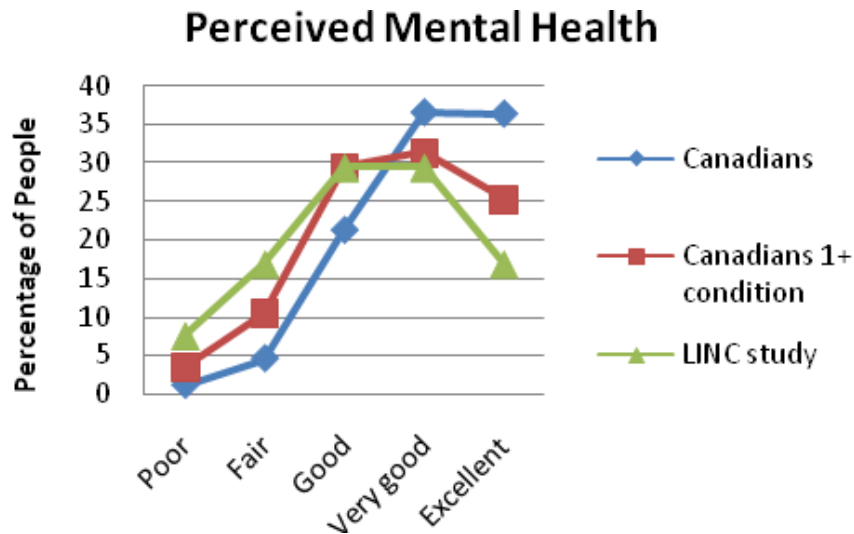
## LINC Participants Compared to other Canadians



- Almost 60% of Canadians report very good or excellent health.
- 34% of Canadians with two or more chronic condition report similar health.
- 28% of LINC participants report comparable health.

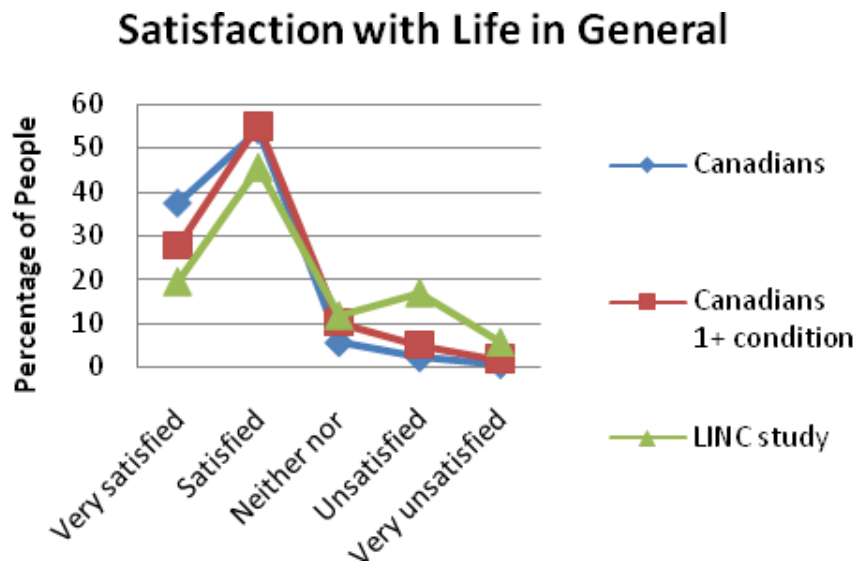
# Mental Health:

## LINC Participants Compared to other Canadians



- 36% of Canadians report very good or excellent mental health.
- 25% of Canadians with two or more chronic condition report similar health.
- 17% of LINC study participants reported excellent perceived mental health.

# Satisfaction with Life in General: LINC Participants Compared to other Canadians



- 22.9 % of LINC participants are unsatisfied with life in general compared to 2.9% of Canadians and 6.8% of people with two or more chronic conditions

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# **Impact on Health and Family Resources.**

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# What kind of supports and resources do people with neurological conditions use?

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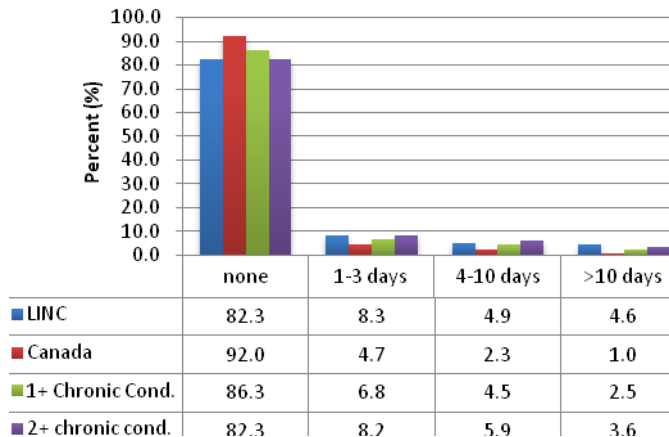
- **People with neurological conditions:**
  - Use more universally insured health services than the average Canadian with chronic health conditions.
  - Are heavy users of health care services not included in universally insured services.
  - Make extensive use of formal and informal caregiving.
  - Have out-of-pocket expenses even if they have medical insurance.

# Universally Insured Health Care

## Hospital Stay

### How do Persons with Neurologic Conditions Compare with other Canadians?

Distribution of Hospital Days: Age-Sex Standardized  
Comparison of Canada (CCHS) to LINC Sample

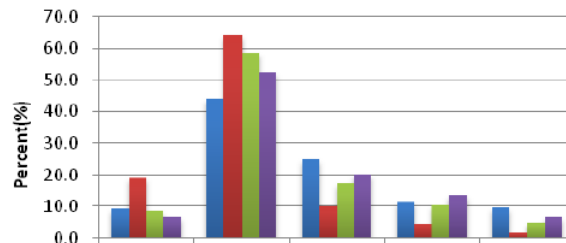


- Most LINC respondents (82.3%) did not have any days in hospital in the year before the survey.
- Use of hospital services by LINC respondents is similar to that of Canadian's with 2 or more chronic health conditions.

## Universally Insured Health Care

# GP and Specialist Visits

Distribution of General Practitioner Visits: Age-Sex Standardized Comparison of Canada (CCHS) to LINC Sample



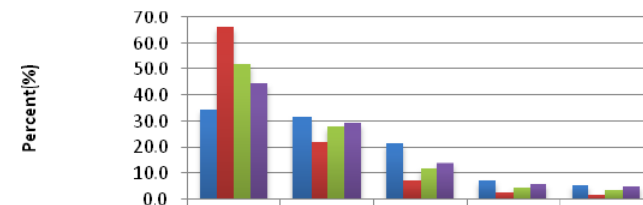
- More than 90% of LINC respondents had consultations with general practitioners in a year.

- LINC respondents used somewhat more general practitioner services than Canadians with one or more chronic conditions.

- Nearly 65% of LINC respondents had specialist consultations in the previous year - more than Canadians with two or more other chronic conditions.

- Participants also reported difficulty accessing specialist appointments.

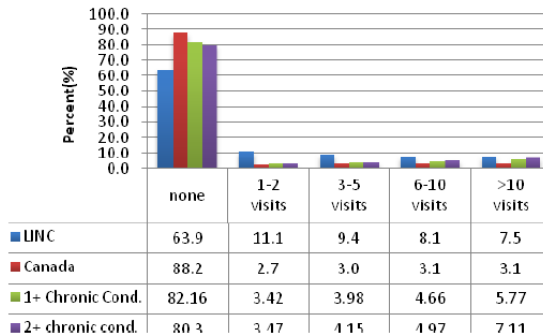
Distribution of Specialist Physician Visits: Age-Sex Standardized Comparison of Canada (CCHS) to LINC Sample



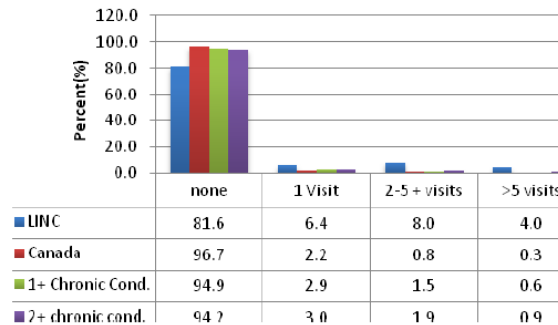
LINC	34.5	31.4	21.4	7.3	5.4
Canada	66.6	22.0	7.3	2.5	1.7
1+ Chronic Cond.	51.8	27.9	12.0	4.7	3.6
2+ chronic cond.	45.1	29.4	14.1	6.1	5.3

# Health Services not Universally Covered by Canadian Medicare: PT, OT, Speech, Social Work

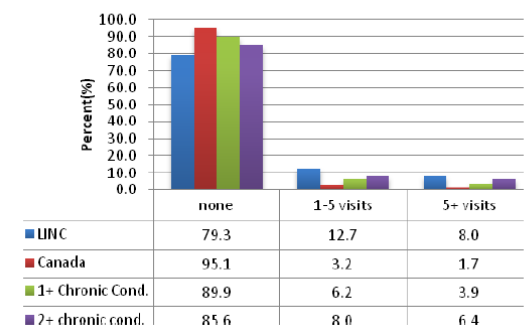
Distribution of Physiotherapist Visits: Age-Sex Standardized Comparison of Canada (CCHS) to LINC Sample



Distribution of Occupational Therapy, Audiology and Speech Therapy Consultations: Age-Sex Standardized Comparison of Canada (CCHS) to LINC Sample



Distribution of Social Work or Counsellor Consultations: Age-Sex Standardized Comparison of Canada (CCHS) to LINC Sample



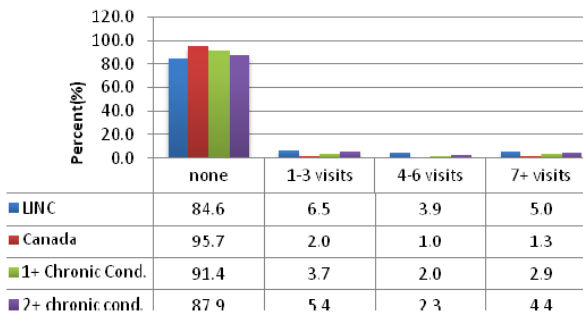
LINC participants used more:

- physiotherapy,
- social work,
- occupational therapy, audiology and speech therapy

than other Canadians –even those with two or more non-neurological chronic conditions.

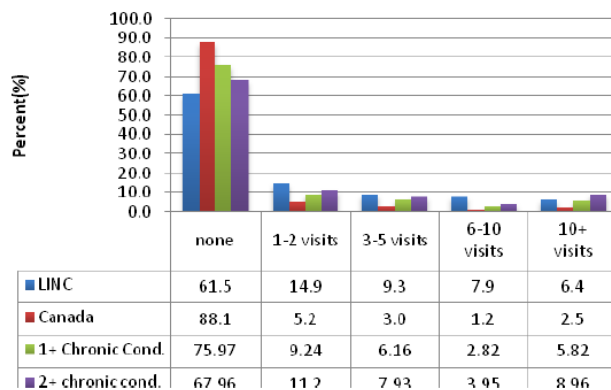
# Use of Other Health Services not Universally Covered by Canadian Medicare

Distribution of Psychologist Visits: Age-Sex Standardized Comparison of Canada (CCHS) to LINC Sample



- LINC participants were slightly more likely than their Canadian counterparts to receive psychological care.

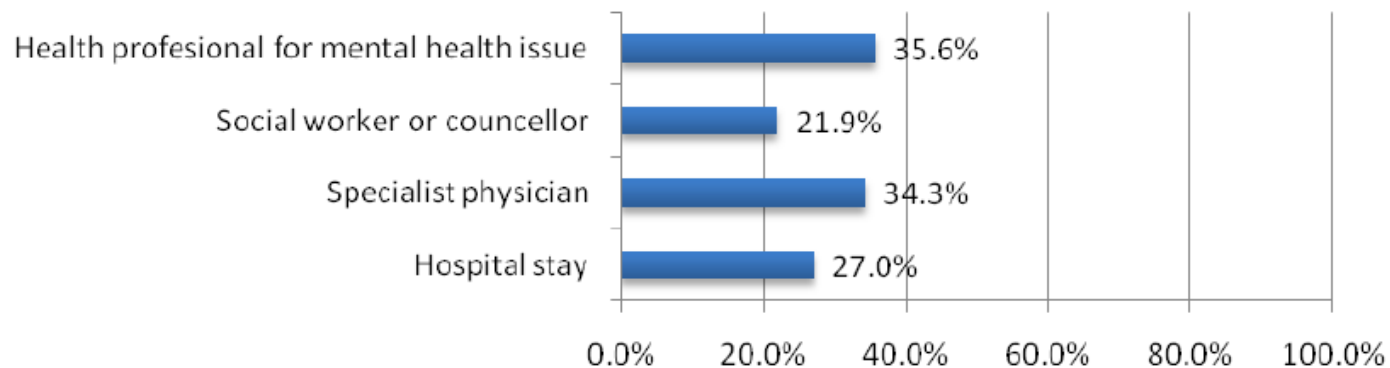
Distribution of Mental Health Care Consultations: Age-Sex Standardized Comparison of Canada (CCHS) to LINC Sample



- Nearly 40% of LINC respondents consulted a health professional about their emotional or mental health in the previous year.
- LINC respondents were more likely to have such consultations than other Canadian's, even those with two or more chronic conditions. Given that other chronic conditions include depressive and anxiety disorders, this is a striking finding.

# Use of Health Care Services by Parents of Children with Neurological Conditions

Percent of LINC Parents Reporting One or More Annual Conatcts With:



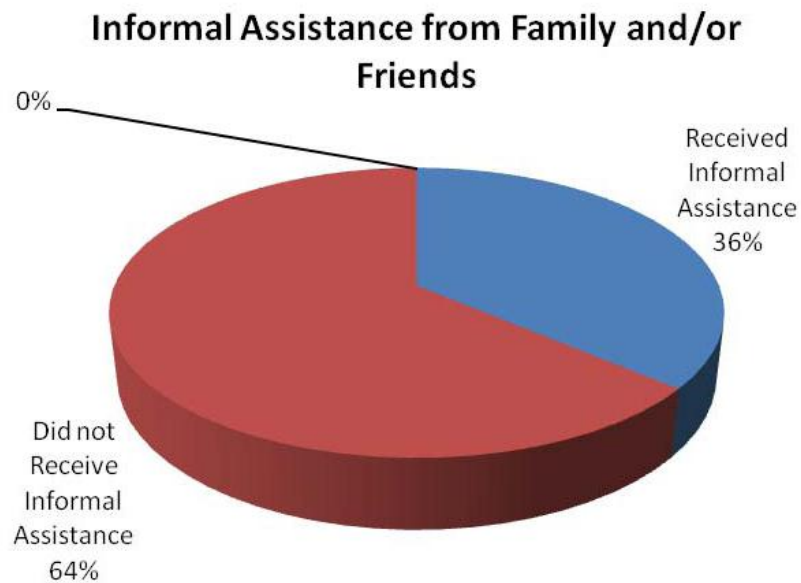
# Formal and Informal Care Received by Adults

Type of Assistance Received*	Formal Assistance (n=183)		Informal Assistance (n=180)	
	Number	Percent	Number	Percent
Housework, Home maintenance/yard work	113	61.75	210	62.87
Personal care (eating, dressing, bathing or toileting)	79	43.17	90	26.95
Transportation (trips to doctor or shopping)	64	34.97	164	49.1
Meal preparation or delivery	63	34.43	134	40.12
Medical care (medication, nursing care)	48	26.23	66	19.76
Making appointments or personal finances	27	14.75	71	21.26
Emotional Support (Informal Support Only)	N/A	N/A	164	49.1
* Some people received more than one service				

**25% of people received formal assistance; that is paid assistance**

**45% of people received informal assistance from family and/or friends**

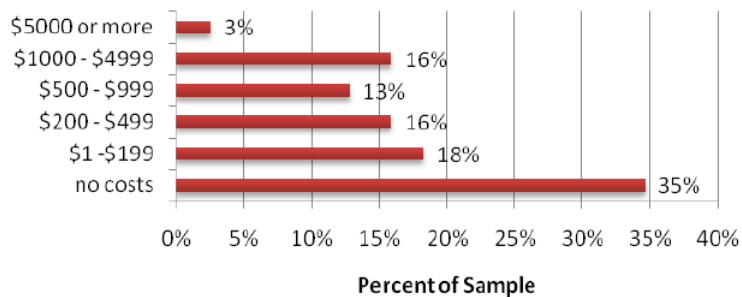
## Formal and Informal Care Received by Parents (Population Study), n=74





# Out of Pocket Health Care Costs

## Annual Out-of-Pocket Medication Costs



## FAMILIES

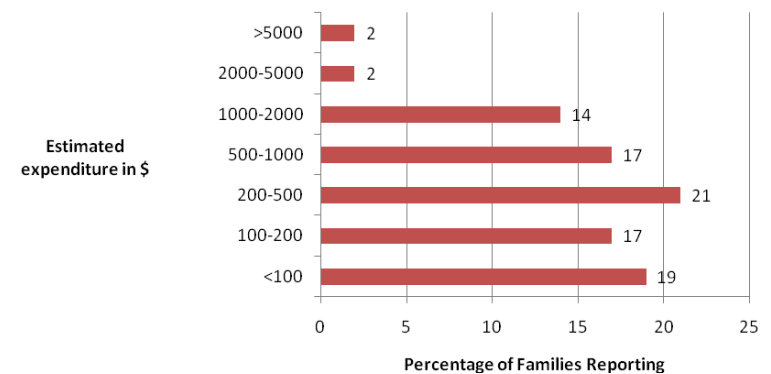
Some families had significant out-of-pocket costs for medications.

The most common out-of-pocket expenditures were for medications - 65% of the sample had out-of-pocket expenditures for medications.

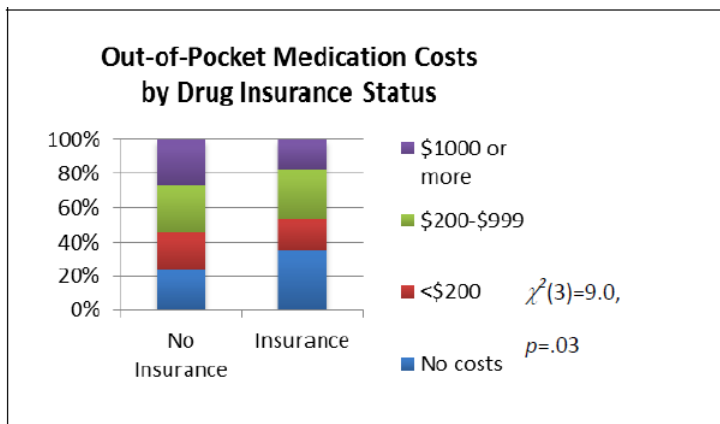
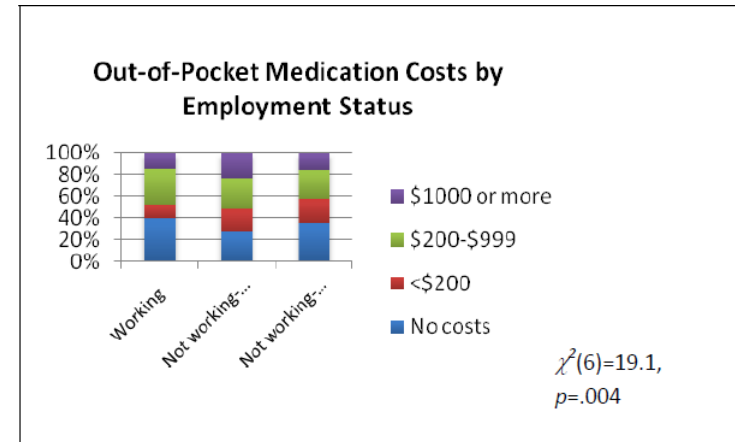
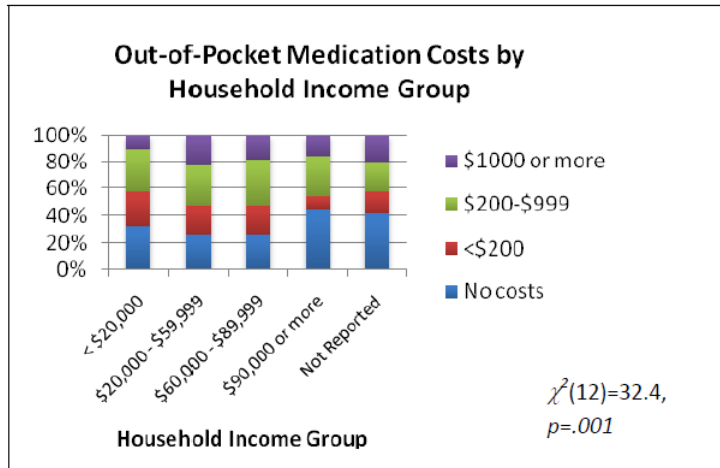
## ADULT PARTICIPANTS

19% had \$1000 or more in costs, and 32% had \$500 or more in costs.

## Annual Out-of-Pocket Costs for Medications (n=42)



# Out of Pocket Health Care Costs - Adults



Out-of-pocket medication costs are not equal across income groups.

- The highest and lowest income groups are the most likely to have low or no out-of-pocket costs.
- The two middle income groups are the most likely to have higher out-of-pocket costs.
- Similar costs present more significant financial challenges in the low-income group.

Persons who are not working for health reasons are more likely to have higher out of pocket drug costs.

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# Impact on Everyday Participation

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# What is the Impact on Everyday Life?

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- **The relationship between health and participation is complex and extends beyond the health care system and receipt of care.**
- **Participation is restricted due to physical barriers, stigma, lack of transportation.**
- **Employment matters – as income, for access to insurance and as a way to maintain social connectedness.**

## Adults' Community Participation (Population Survey)

**102 out of 754 participants (13.53%) consider themselves homebound**

Why do you consider yourself housebound?*	Number	%
Accessible transportation not available	29	28.34
Dependent on non-portable aids	11	10.78
Do not feel safe when leave home	31	38.39
No attendant or companion	37	36.27
Need assistance once arrive at destination	38	37.25
Condition aggravated by going out	34	33.33
Do not want to go out	30	29.41

\*Some people used more than 1 service

## Adults' Community Participation (Population Survey)

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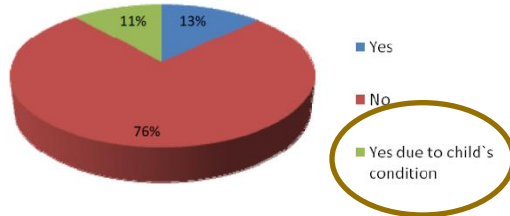
**Design and layout of buildings and places in the community made it difficult for 153 out of 754 participants (20.29%) to participate in leisure activities**

Impact	Number	Percent
Some difficulty	68	44.44
A lot of difficulty	42	27.45
Completely unable to participate	33	21.57
Not affected	5	3.27
Don't know	4	2.61
Do not wish to answer	1	0.65

# Life Events in Past 12 Months

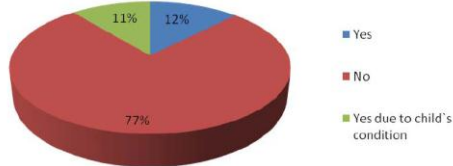
## Impacted by Child's Condition (Population Study) n=74

### Major Financial Crisis



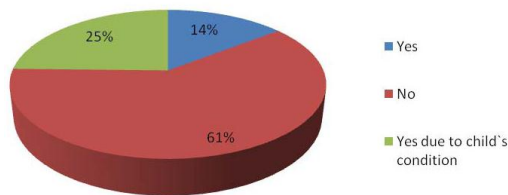
- 24% of parents indicated that their family had experienced a financial crisis in the past 12 months

### Demotion or Pay Cut for Either Parent



- 23% of parents told us that one parent had been demoted or received a cut in pay in the past 12 months

### Increased Arguments between Parents



- 39% of parents said they had increased frequency of arguments with their partner in the past 12 months

# Work Matters

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- **only 40% of working aged adults were employed, resulting in:**
  - Low family income
  - Less access to insurance, healthcare, resources
  - Less access to intangible benefits of work (social, personal, mental), health/mental health, engagement.



## Parent Employment (Population Study), n=74

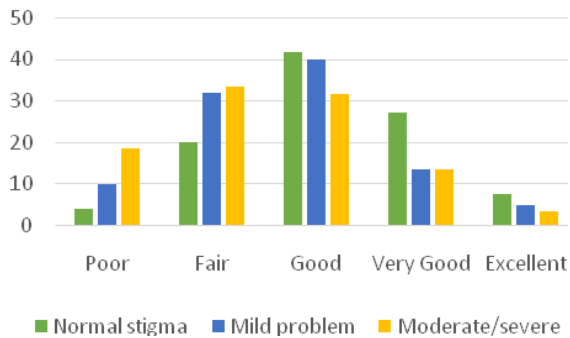
Parent Employment	Parent Report on Self Number(%)
<b>Employment Status in Past 3 months</b>	
Working	42(56.8)
Not working due to health reasons	2(2.7)
Not working due to other reasons	29(39)
<b>Average Numbers of hours worked per week</b>	33.61 hours (38 respondents)
<b>Absent from work in last week</b>	
Yes	1(1.0)
No	32(43)
N/A	40(54)
<b>Absent from work in past three months due to own health conditions</b>	
Yes	5(6.8) (Range 2-6 Days)
<b>Student</b>	
Full Time	4(6.1)
Part Time	1(1.0)
<b>Not working because caring for children</b>	
Yes	20(27)

- 56.8% working due to:
  - own health conditions
  - majority because they are caring for children.
- Qualitative data:
  - many parents cannot find child care for their child with a neurological condition.
  - When returning to the workforce after caring for their child, the transition to employment was difficult due to loss of skills and a less than desirable employment history.
- Flexibility in the workplace is needed.

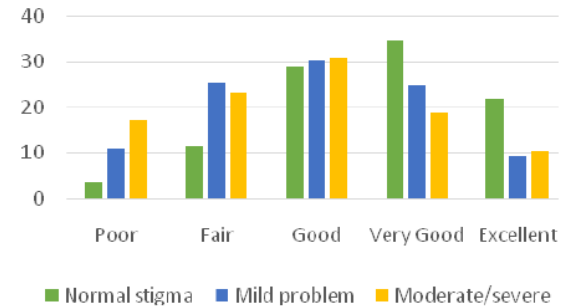
# Participation and Stigma

People experiencing more stigma have worse self-perceived health and mental health. They are also more likely to experience depression, as well as problems with upper and lower extremity function (as measured by Neuro-QOL subscales). Low participation leads to poorer health which leads to poorer participation.

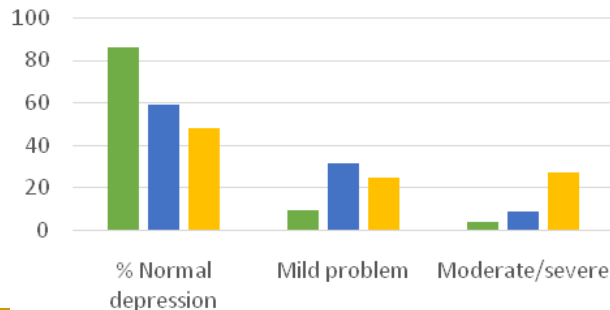
Self-perceived Health



Self-perceived Mental Health



Depression



Low participation



lower participation.

# Two short videos

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- **A first hand account**
- **More facts and figures**
  
- **<http://www.ccmrg.ca/linc/whatsnew.php>**

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