

# **CANADIAN MODELS OF FAMILY- AND PERSON-DIRECTED RESPITE**

**Canadian Respite Network**

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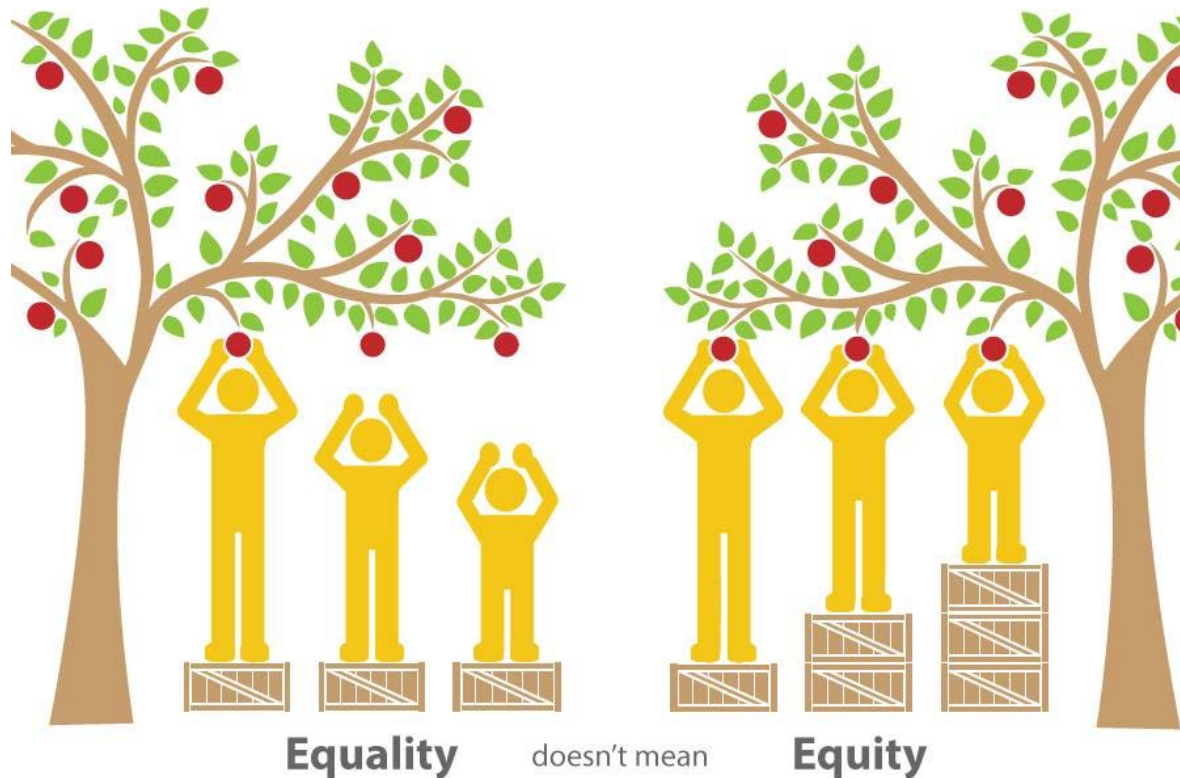
# LEARNING OBJECTIVES

1. Define respite and its importance to full citizenship
2. Introduce the Canadian Respite Network and survey goals
3. Describe respite service variations in Canada
4. Detail the types of respite services that promote full citizenship
5. Develop a fuller understanding of the types of respite supports available across Canada to enable us to create federal policy ensuring adequate supports for individuals and their families.

# Why is Respite Important?

Parents said they had an urgent need for respite support but it had to meet the needs of their children/adult family members. If it didn't then it wasn't a break (Hutchinson et al, 2010).

Respite services should be a way to achieve equity!



# Respite promotes Full Citizenship

- Re-define respite as a support for individuals to participate in the community (Full Citizenship) vs. a need for families to have a break.

Provides equitable opportunities to:

Participate in activities that everyone has a right to participate in.

Give families a similar quality of life to other families

- **Not a Break from life, but a Change in quality of life!**

# Canadian Respite Network

Network formed as result of the International Short Break Conference held in Toronto, Ontario in 2012.

Canadian respite service providers came together to share knowledge and resources.

<https://www.facebook.com/canadianrespitenetwork>

Access to respite varies based on the capacity of service providers, funding, and geography (Hutchinson et al., 2010) but how does it vary across Canada?

# Method: Survey Design

## Survey Questionnaire

- Network members formulated questions
  - structured- and open-ended questions
- Respondents were contacted through members' contacts and community (note: no Canadian directory of respite service providers).

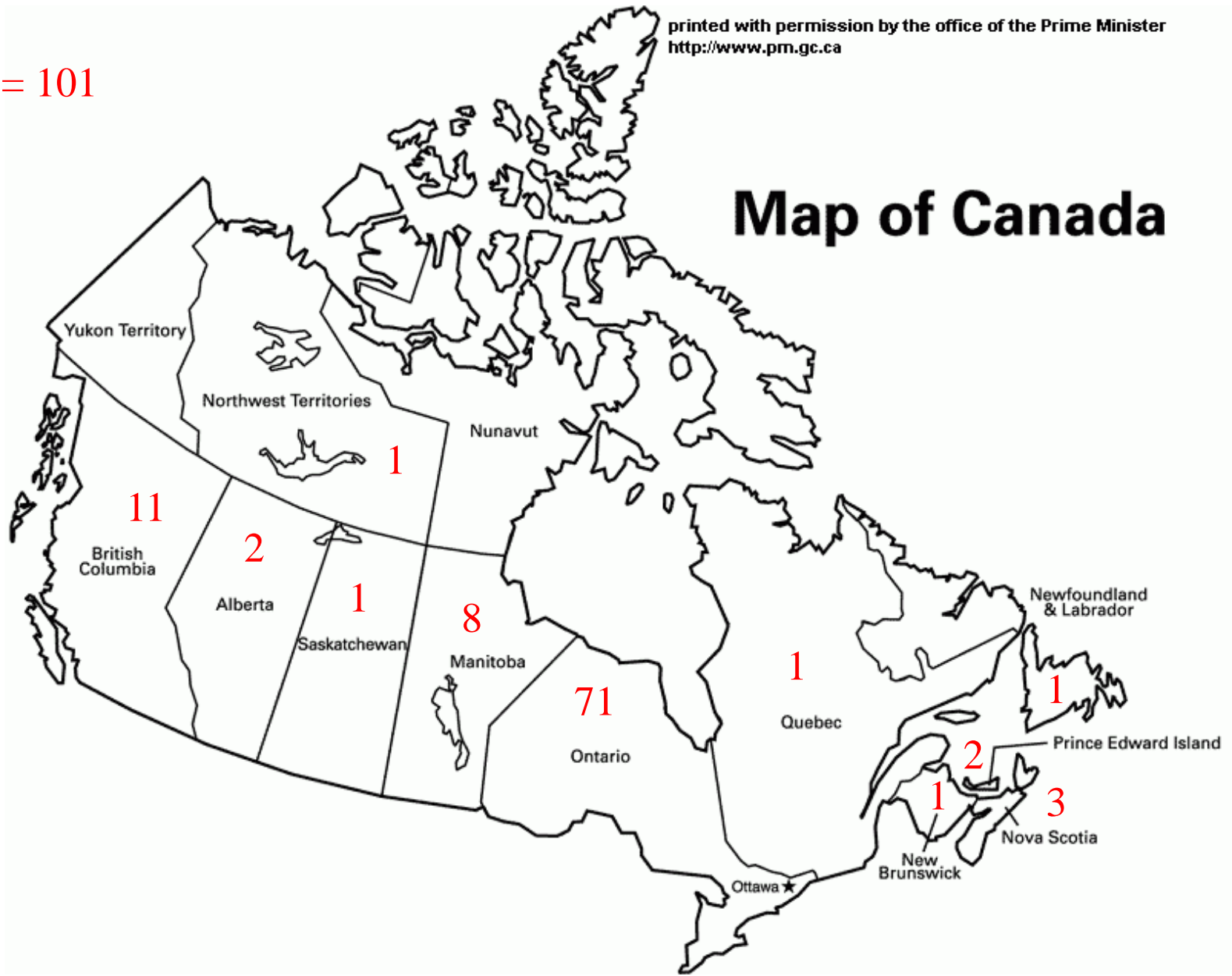
Advantages: standardized questions – everyone answers the same questions

Limitations: self-reporting and possibly bias recall

# Survey Respondents

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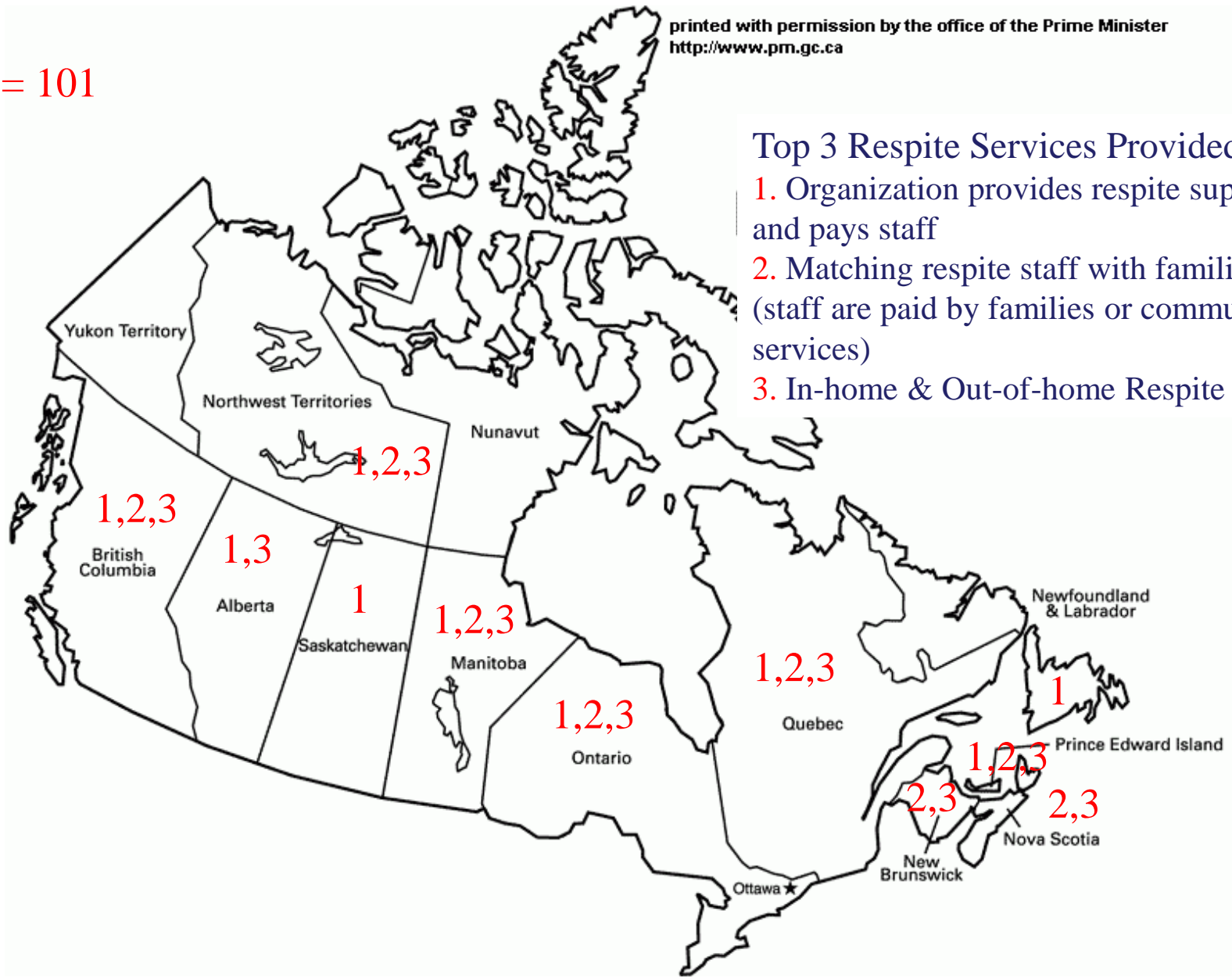
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# Top 3 Respite Services Provided

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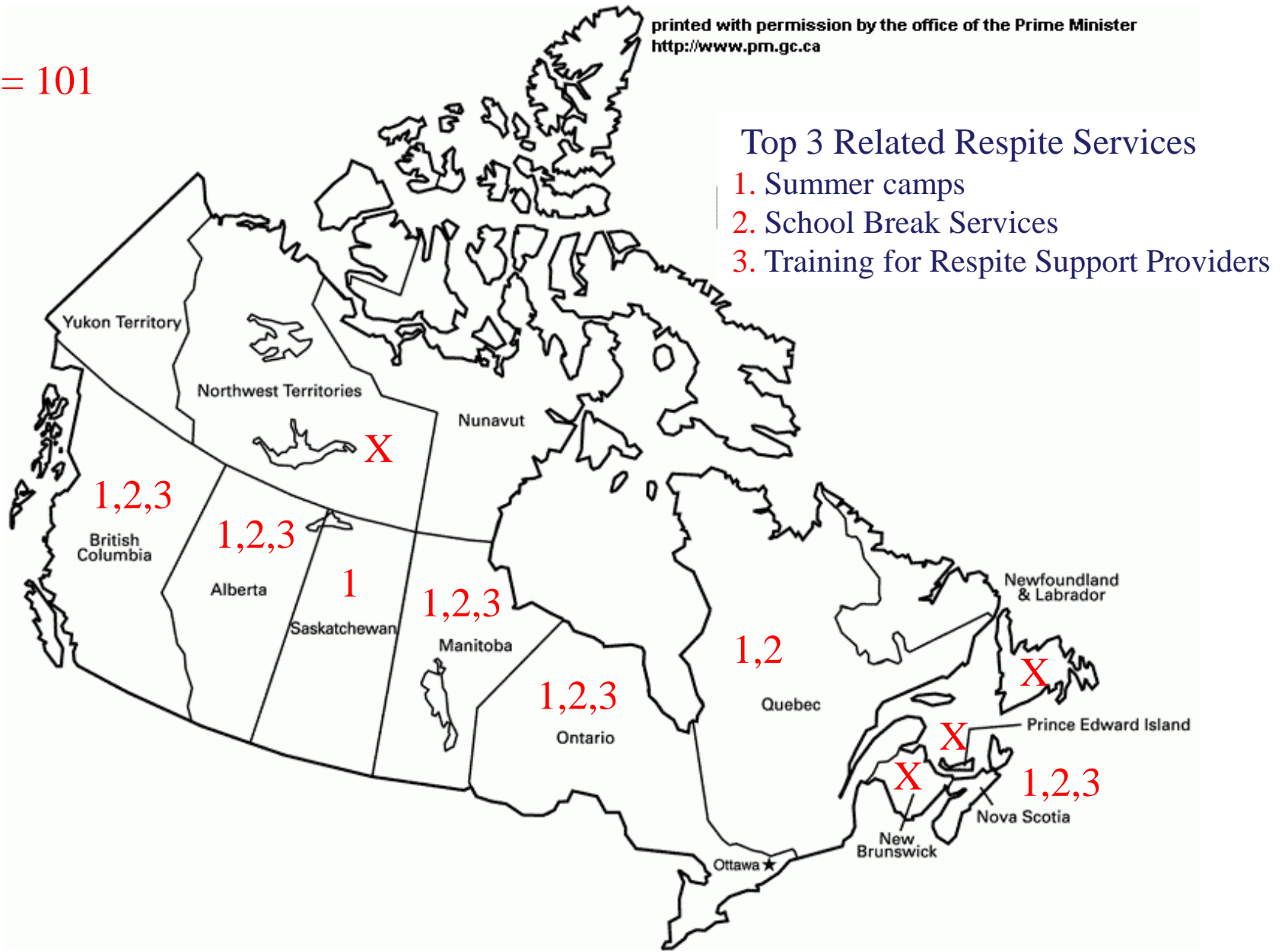
- ### Top 3 Respite Services Provided
1. Organization provides respite support and pays staff
  2. Matching respite staff with families (staff are paid by families or community services)
  3. In-home & Out-of-home Respite



# Top 3 Related Respite Services Provided

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# Models: How are Respite Services Provided?

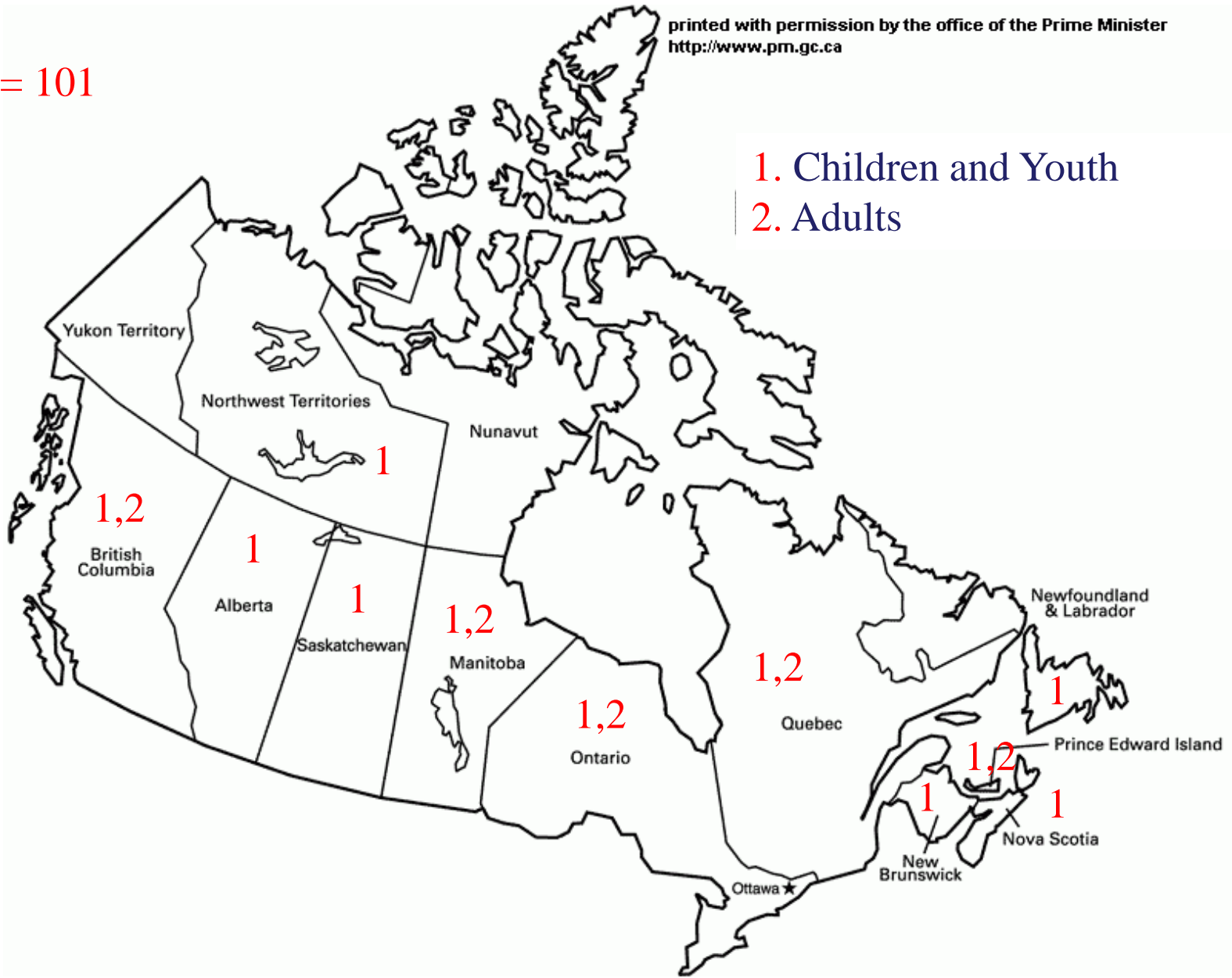
- Negotiated with families- some Provinces provide funds but no services
- Other provinces have more “traditional” style services and supports. E.g.
  - Respite apartment
  - Respite bed in licenced group home
  - Selected day program locations
- Some provinces have blended models
- Many are volunteer or low pay/stipend models
  
- Regardless of the model, how can we use individualized resources to assist in moving to authentic relationships?

# Ages Served

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- 1. Children and Youth
- 2. Adults

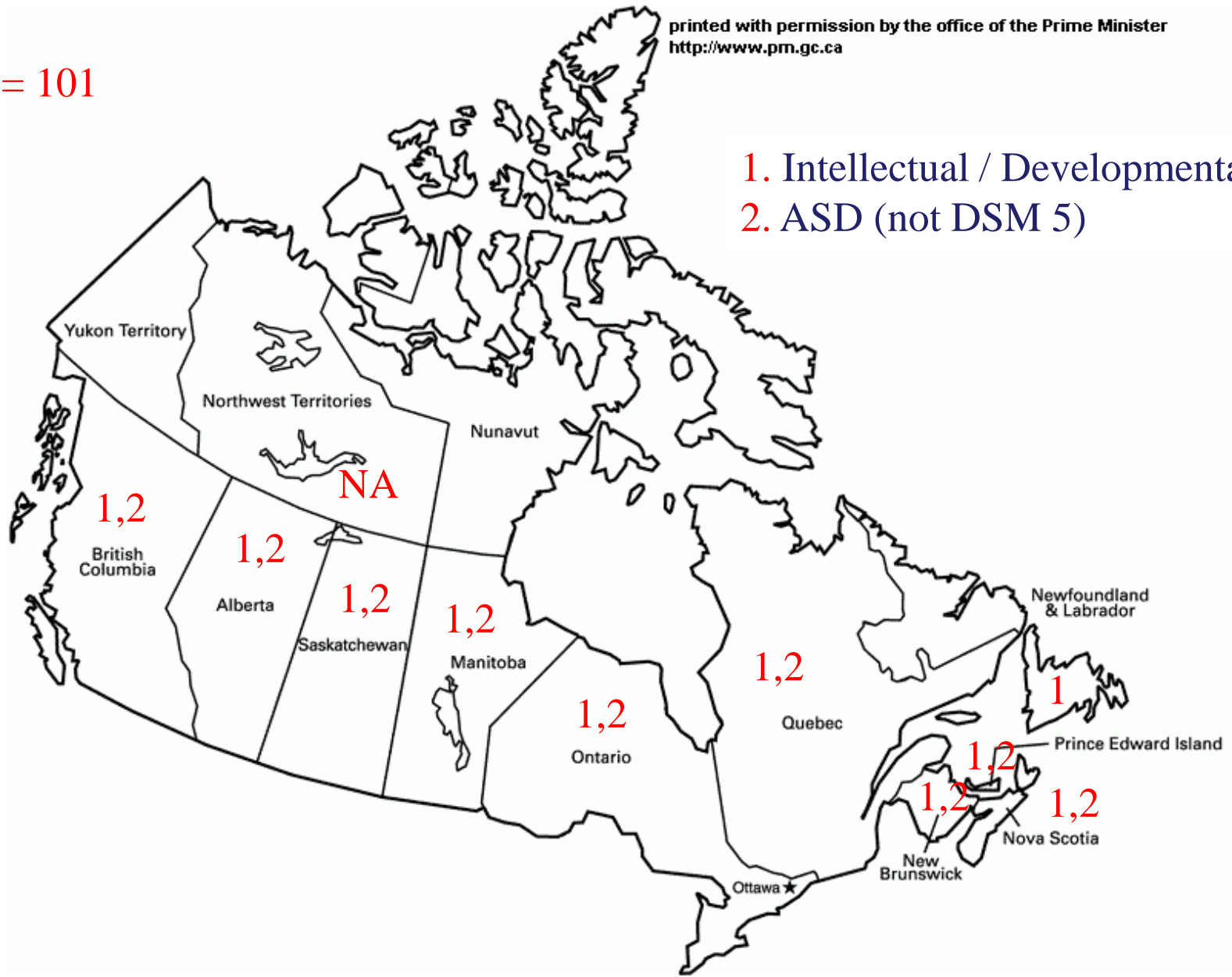


# Specific Criteria: Primary Diagnosis

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1. Intellectual / Developmental
2. ASD (not DSM 5)



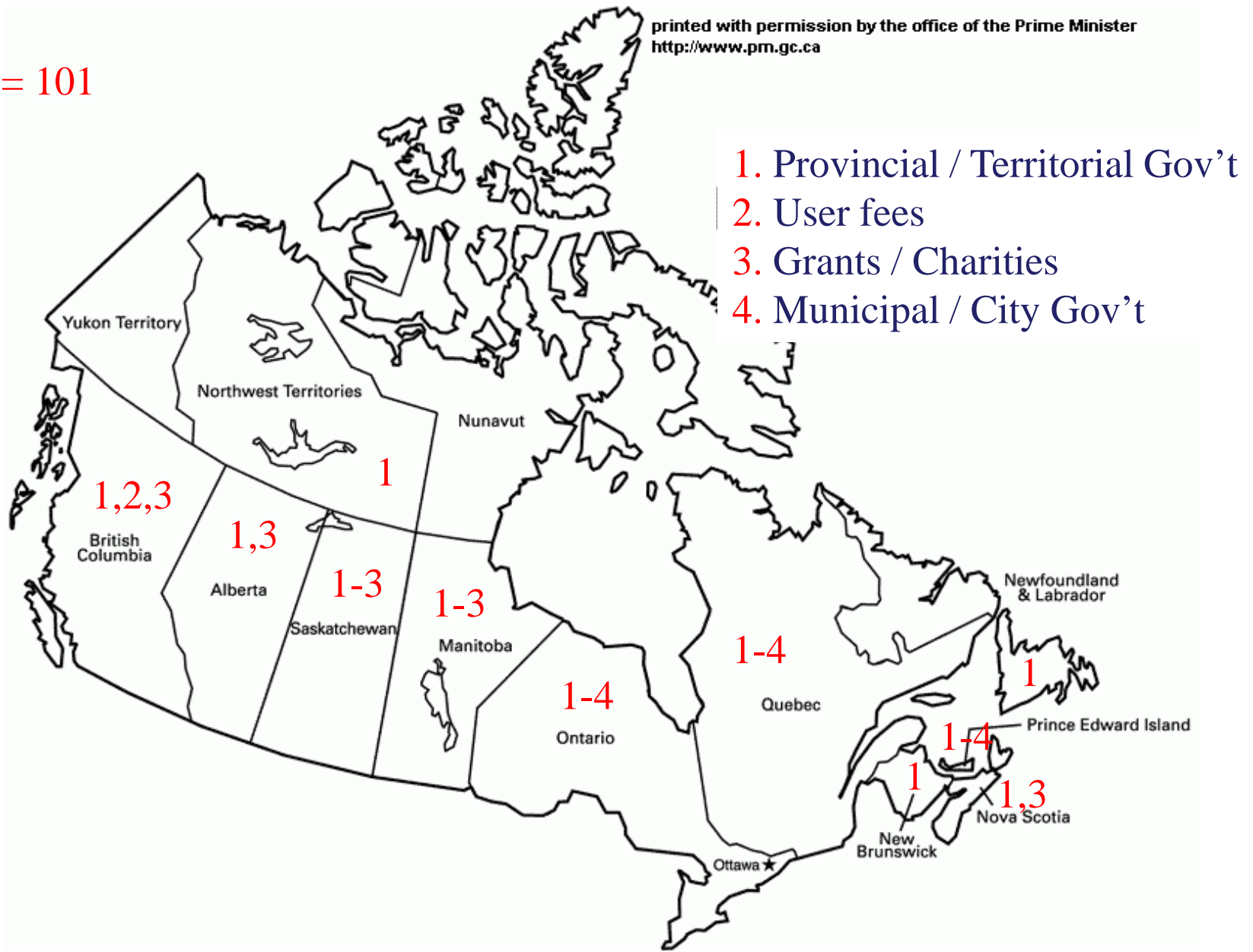
# Secondary Criteria

- Some programs had secondary criteria based on individual diagnosis or need
- Families also report that it is important for services to be truly responsive and individualized. Respite provider has to have the specific skills needed to support their family member e.g. positive behavioural support, first aid, able to provide personal care, able to respond to a crisis situation, able to provide medical care.
- Most importantly... the skills to build a trusting relationship. E.g., specific communication skills or strategies.

# Funding Sources

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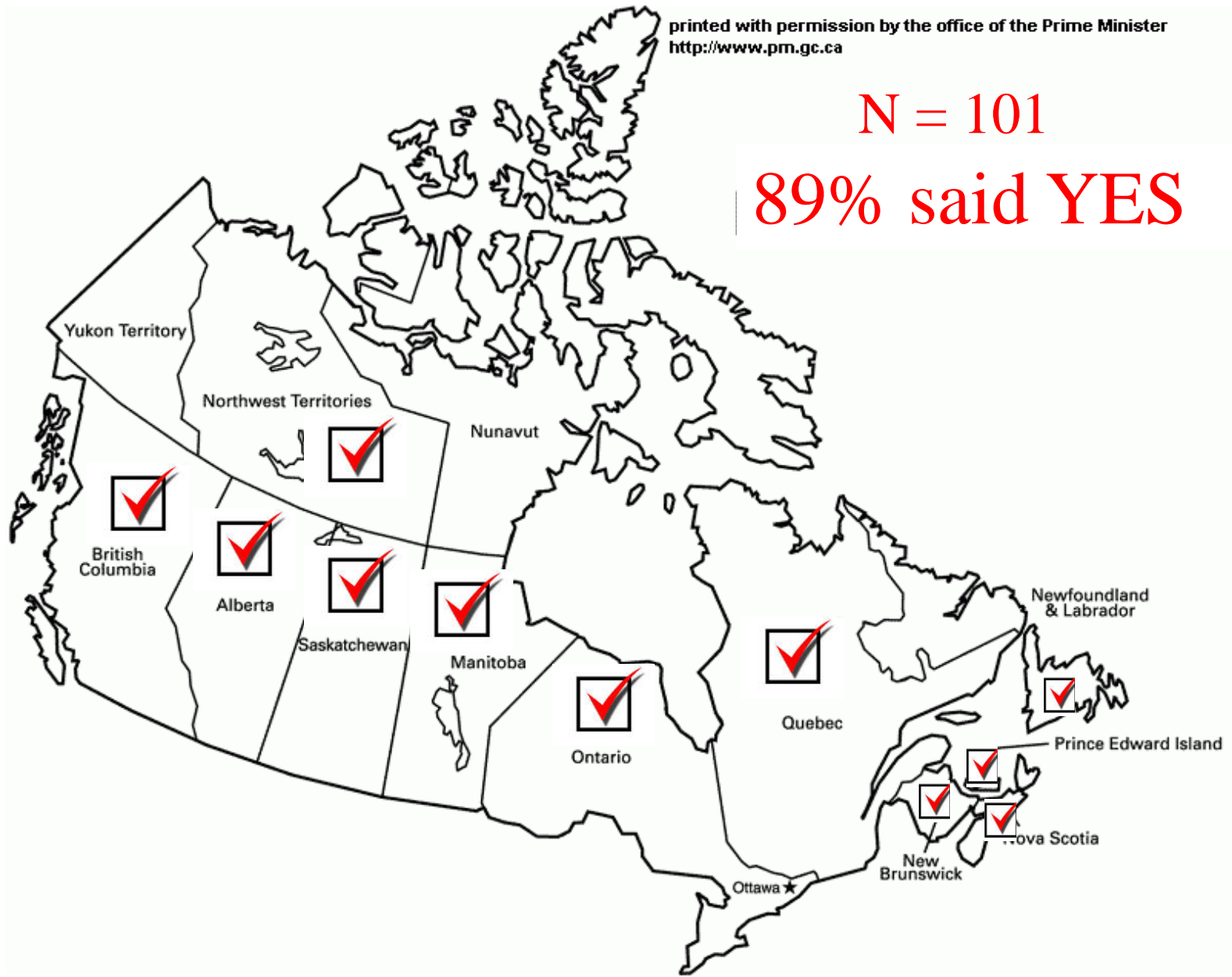


# Do you want to join the National Respite Network?

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89% said YES





# Do you want to share information?

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100% said YES





# Intentional Use of Respite Resources

- Respite or Short break services can play an important role in helping people develop meaningful roles, nurturing relationships and having a good life in community. However, it means that everyone has to use the resources very intentionally.



# Why is this conversation important?

- Moving the needle to have a national strategy for individualized support means looking at the needs of individuals and their families.
- Respite is one way to recognize this need and encourage government action
- There is an urgent need for support for adults and their family members to strengthen and sustain important support and relationship.
- Paradigm shift to person-directed respite support – “I’m not a diagnosis!” “Respite should be more than a break!”

# Call for Action in Canada

- No universal system: inequity across Canada
- Calling for a National Respite Strategy
- Many other countries have rights in legislation for individualized supports and family support.
- We hope that by building on our knowledge, advocacy and resources we can encourage and advocate for a national acceptance of responsibility, legislation and funding.

# We can all contribute



- We work hard with our sons and daughters to create lives that will be fulfilling and where they are valued and have meaningful roles in their family, neighbourhood and community.
- It takes even more intention to achieve this, but attitudes are shifting.
- Respite/short break services can inspire, provide support and encourage relationships, skills and opportunities.

# References

## References

Canadian Association for Community Living (2008) Real respite for the whole family : a resource guide for organizing and delivering a family workshop on respite for individuals with an intellectual disability and their families, Ottawa, Ontario.

Hutchinson, Paula , with Bryson, S., Harvey, V., LeBlanc, D., MacRae, A. and McFadyen, S. (2010) Creating Respite Solutions for Nova Scotia Families of Children and Adult Children with Chronically High Needs. Dalhousie University, Halifax, NS.