

# An evaluation of the experiences of Parkinson Society Saskatchewan members and their caregivers


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# Outline

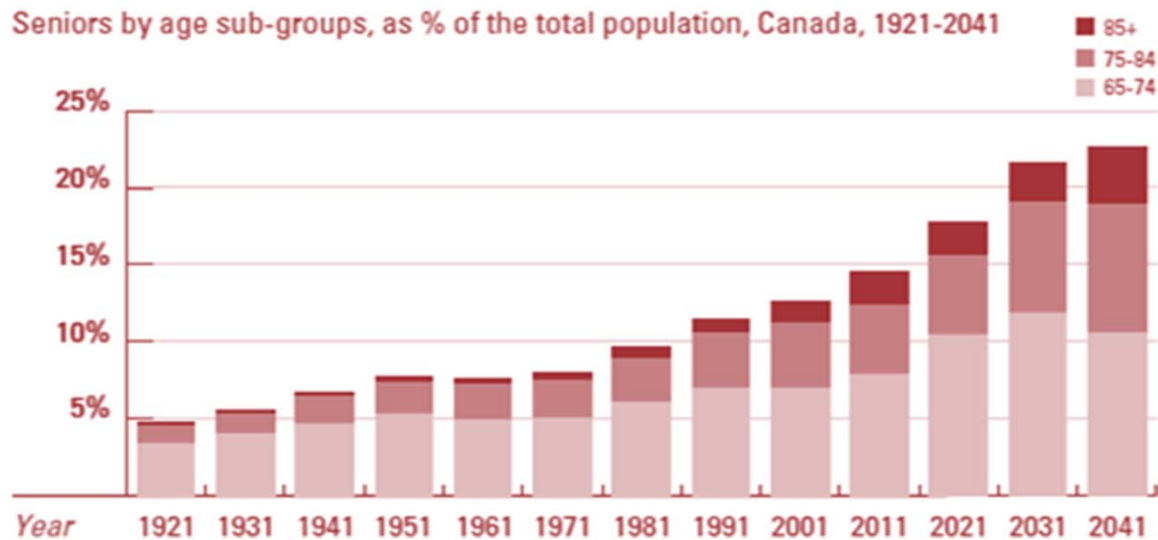
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- **Background**
  - **Objectives**
  - **Methodology**
  - **Findings**
  - **Recommendations**
  - **Conclusion**
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# What is Parkinson's Disease?

Parkinson's is a degenerative brain disease that mostly affects older people. It is more common in developed countries where people's life span is longer.

Currently, over 100,000 people in Canada live with Parkinson's.

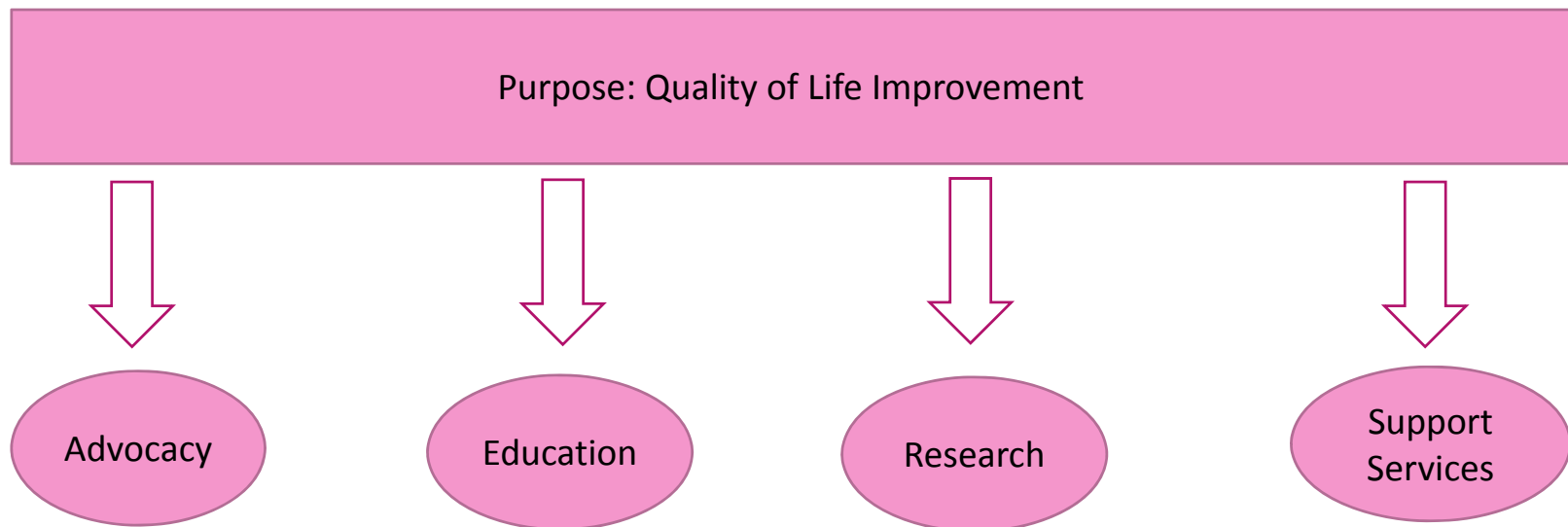


Source: Health Canada in collaboration with the Interdepartmental Committee on Aging and Seniors Issues, *Canada's Aging Population* (Ottawa: Public Works and Government Services Canada, 2002), p. 3.

# What is Parkinson Society Saskatchewan?

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Parkinson Society Saskatchewan (PSS) is one of the regional partners of the Parkinson Society Canada. It is the voice of people living with Parkinson's (PWP) in Saskatchewan.



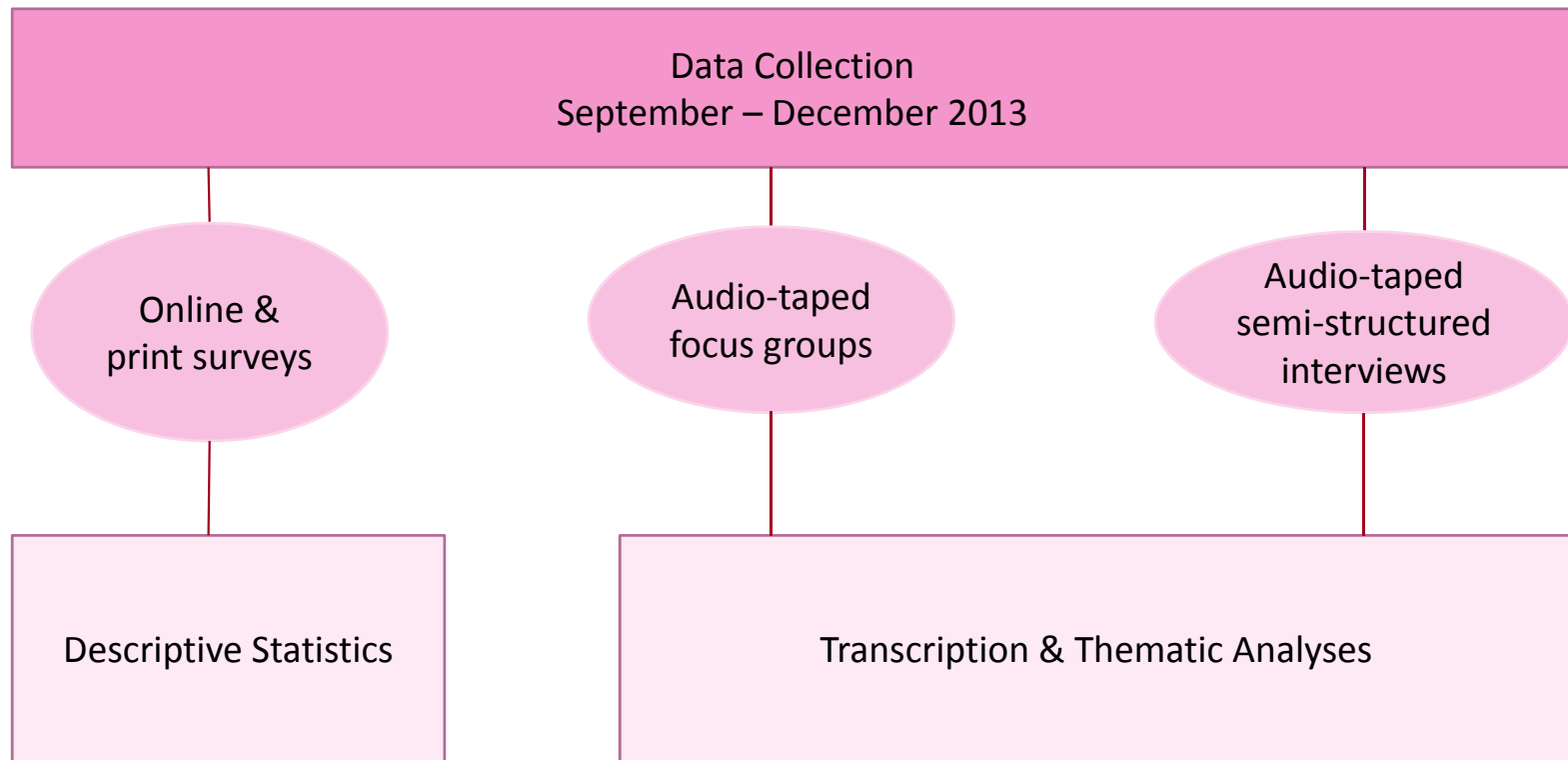
# Research Objectives

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- To determine if PSS is meeting its mandate by evaluating its current programming offered to people with Parkinson's (PWP) and their caregivers in Saskatchewan
  
- To identify member needs and service delivery gaps

# Method

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# Participants

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Surveys	Focus groups	In depth interviews
40	4	4
23 PWP 17 caregivers	2 in urban communities 2 in rural communities 52 PWP & caregivers	Key informants with direct involvement in organization

# Challenges with Diagnosis

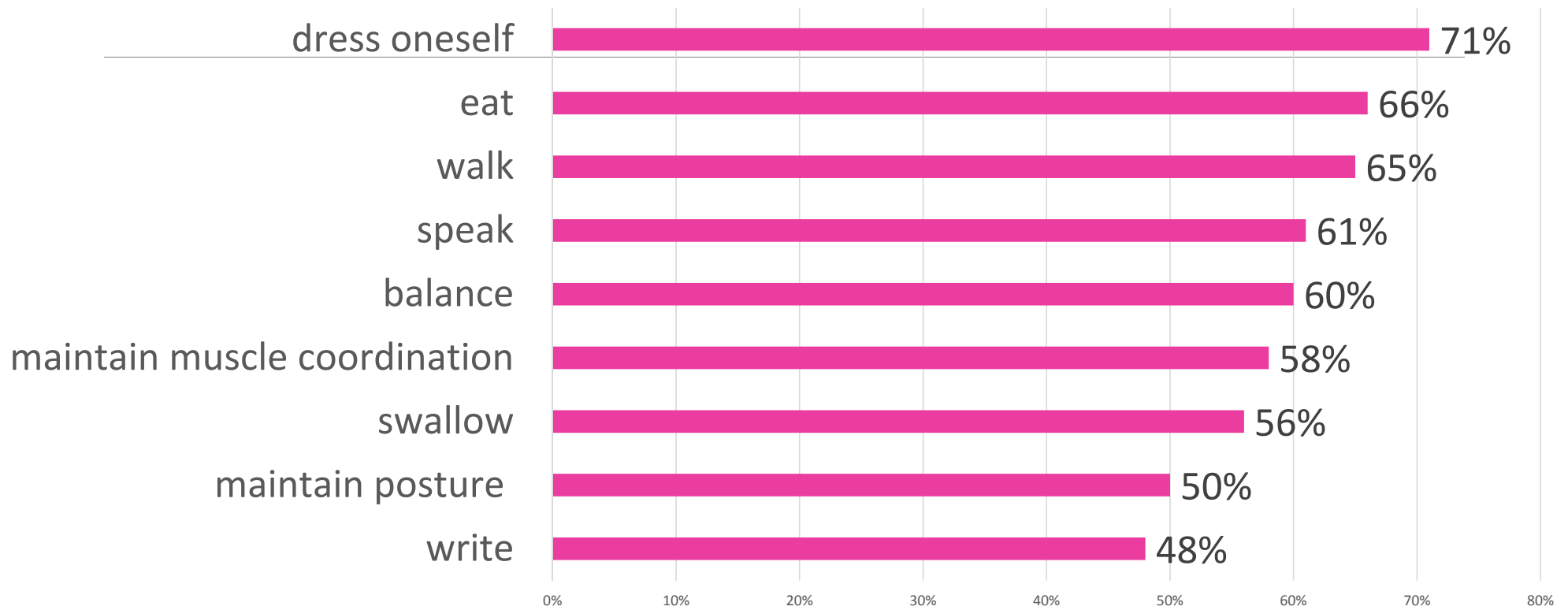
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“I thought I had a physical problem, other than that they didn’t seem to know, kept sending me back.”

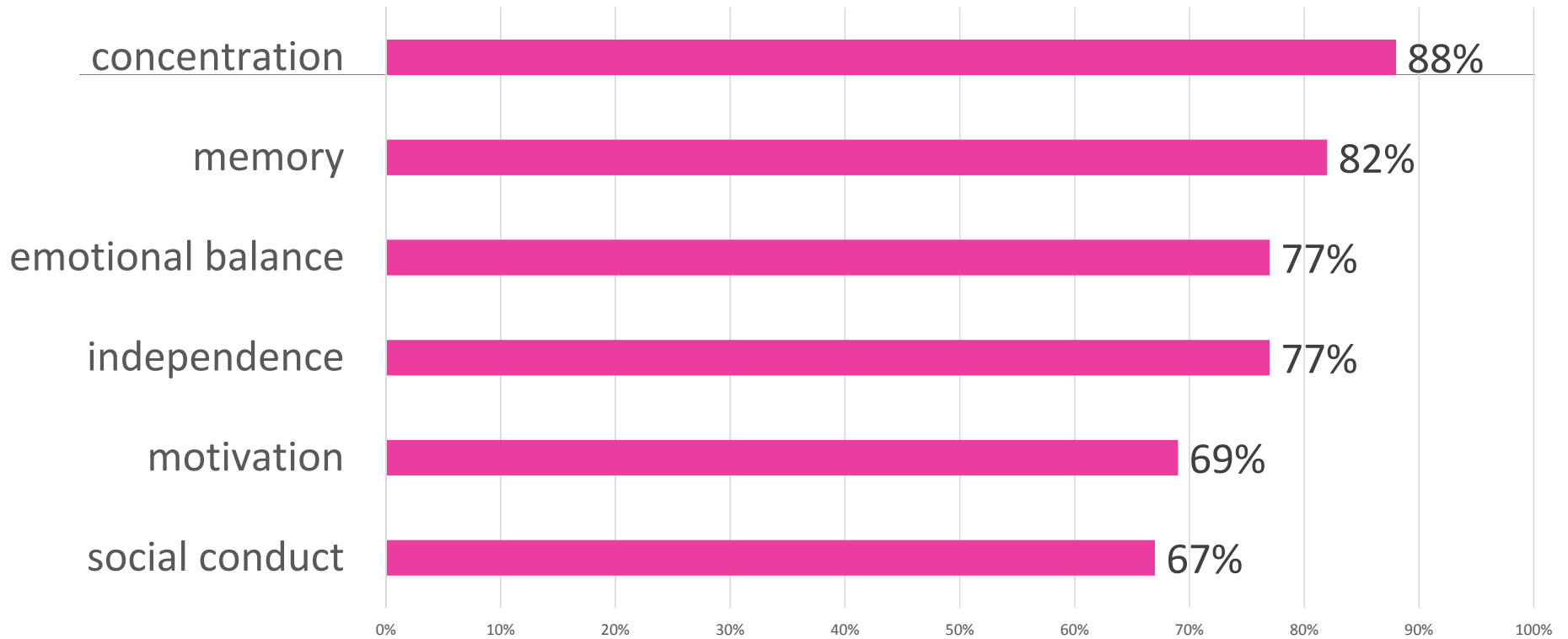
“First time I went for a diagnosis, they said, well, we know one thing, you don’t have Parkinson’s. The following year I was diagnosed with it.”



# Motor Challenges of PWP



# Non-motor Challenges of PWP



# Medications & Care in Facilities

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“It’s a fight, you literally feel like you’re fighting with them...”

“They were doing a whole bunch of tests and the doctor said it doesn’t matter if you don’t take your meds for two days.”

“I don’t think they think it’s that important. In the hospital they were understaffed, they were running slow.”

# Delays in Appointments with Neurologists

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“...haven’t heard for an appointment yet either and I’m thinking if I don’t hear pretty soon, I’m going to phone...over a year, the last three times, I had to phone.”

“As far as we know, how many neurologists do we have in Saskatchewan?”

# Access to Parkinson's-specific Services

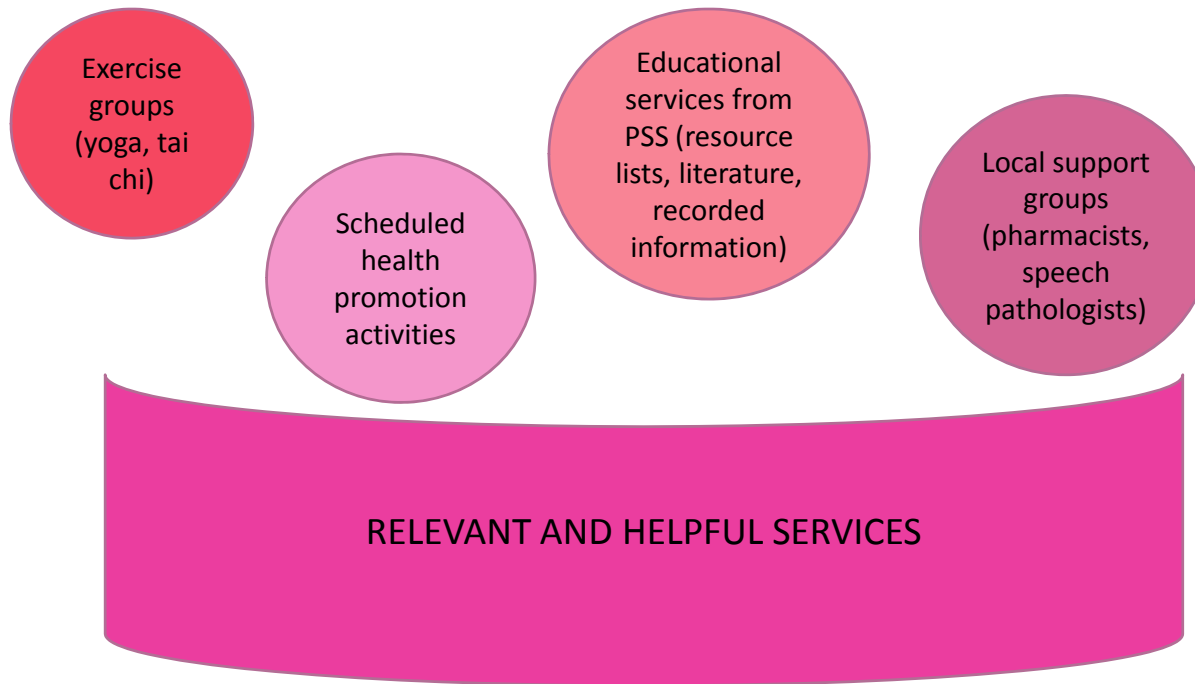
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**Especially scarce in rural areas:**

“I don't think there are any out here. There could be home care but I'm not sure...”

# Available Services

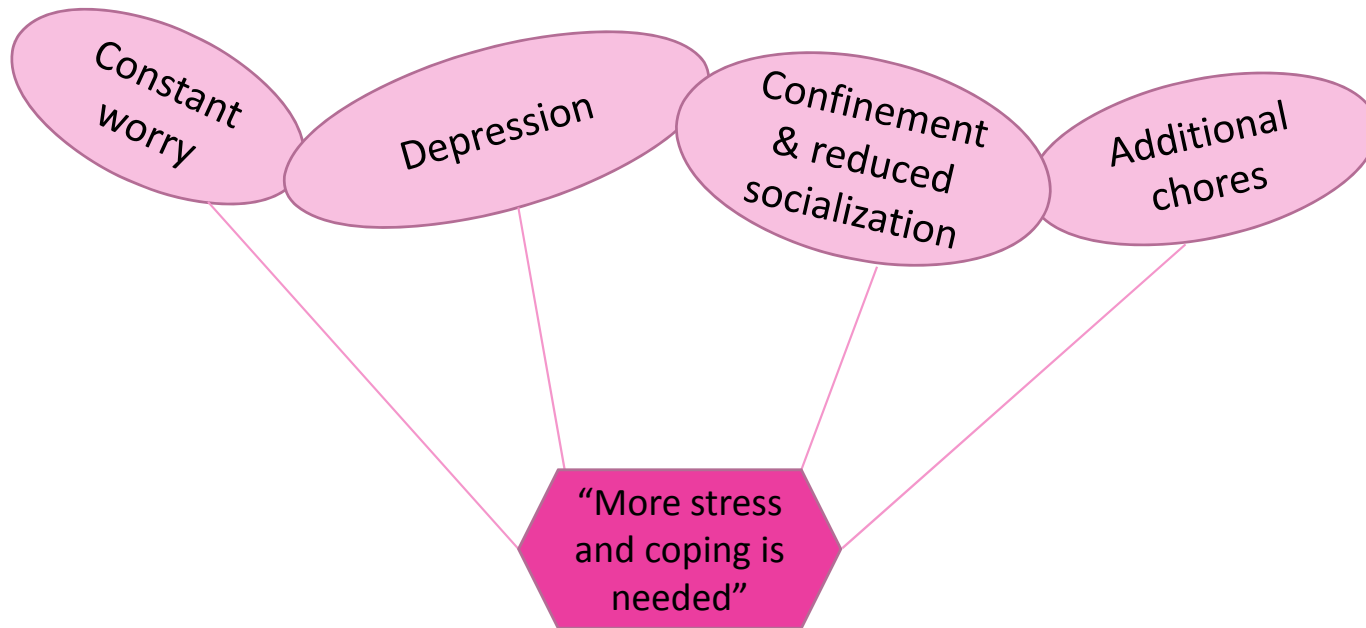
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# Effect of Parkinson's on Caregivers

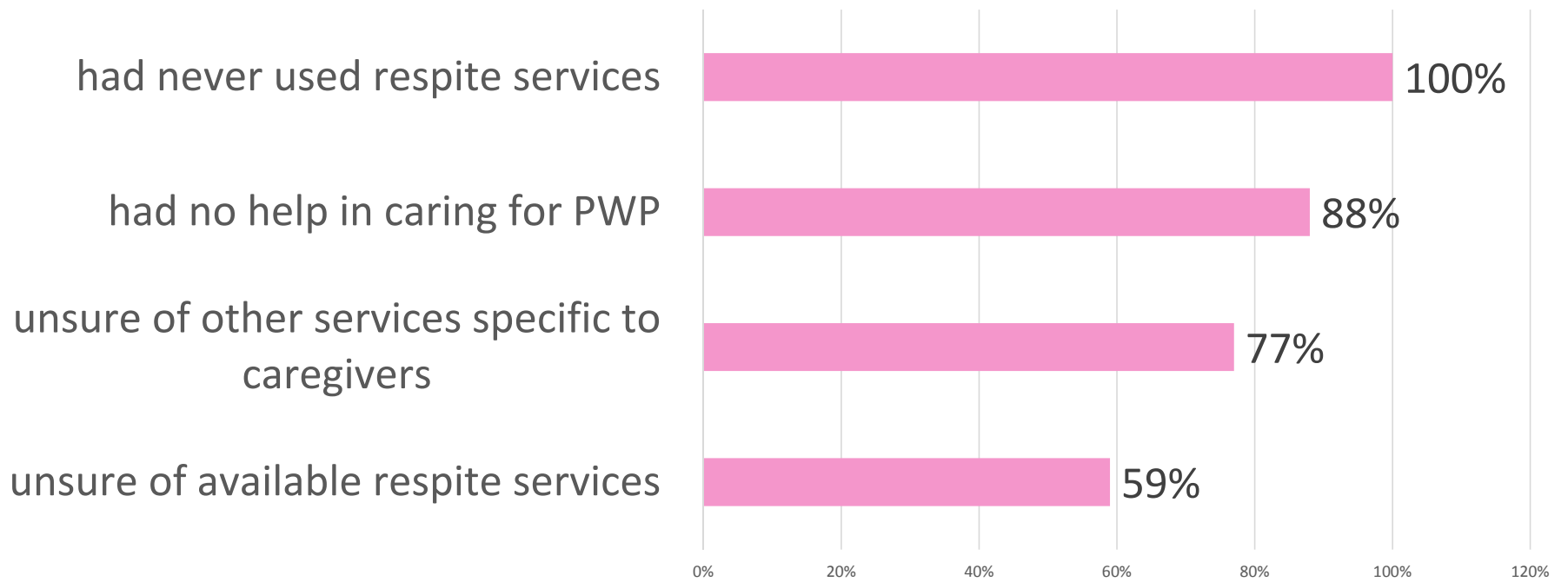
41%

Mental & Physical Health affected



# Caregivers & Respite Services

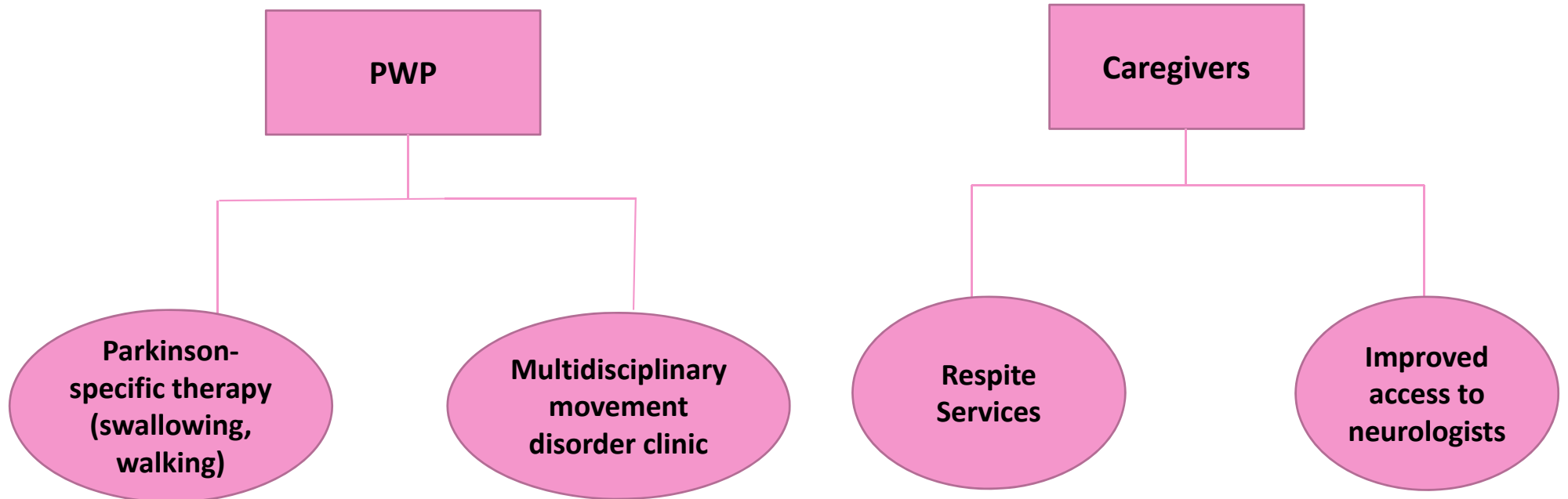
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# Greatest Needs

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# Service Improvement Themes

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“We need specialized services. We come from a small town and we don’t have any services about anything.”

- Expansion of services for highly progressed patients
- Enhancing advocacy for increased neurologists and dissemination of research findings
- Care support
- Additional support groups and formal facilitation
- Increased collaboration among health professionals

# Conclusion

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There are a number of opportunities for expanding and improving care to PWP and caregivers in Saskatchewan:

- ❑ **Establishing** networks of allied health care professionals specializing in care and management of PWP
- ❑ **Disseminating** information on successful treatment innovations
- ❑ **Engaging** health ministries on behalf of PWP for long-term care support

# Final Statement of PWP

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*There's a pile of information out there. I don't think there's a lack of information. What I would like to see is health professionals—doctors, nurses and so on, more knowledgeable about Parkinson's and I would like to see therapy where we could go for specialized care specific to the symptoms. I think that would be a very big thing in controlling and keeping Parkinson's at bay for longer.*

# Acknowledgements

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