MAPS
MULTIDIMENSIONAL ASSESSMENT
OF PROVIDERS AND SYSTEMS

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Listening to and learning from parents who are seeking developmental services for their adult children

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MCSS Speakers Series

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Agenda

- Project overview
- Final Phase 1 Results
  - Parents
  - Adult Children
  - Services requested
- Discussion
- Things to come: Phase 2 and 3
- Wrap-up

Overview of MAPS

- Research program 2010-2013
  - Inform assessment of services and supports for adults with intellectual/developmental disabilities.
  - Focus of enhanced social inclusion and choice
  - 5 projects to inform the selection of indicators

Please visit our website for more background information on MAPS: www.mapsresearch.ca

Parent Study Project Goals

1. Describe family profiles from MAPS and DSO data;
2. Identify variables that influence the parent decision to seek and receive different services;
3. Identify additional indicators of parent experiences that could be integrated in system monitoring.

Please visit our website for more background information on this study:
www.mapsresearch.ca

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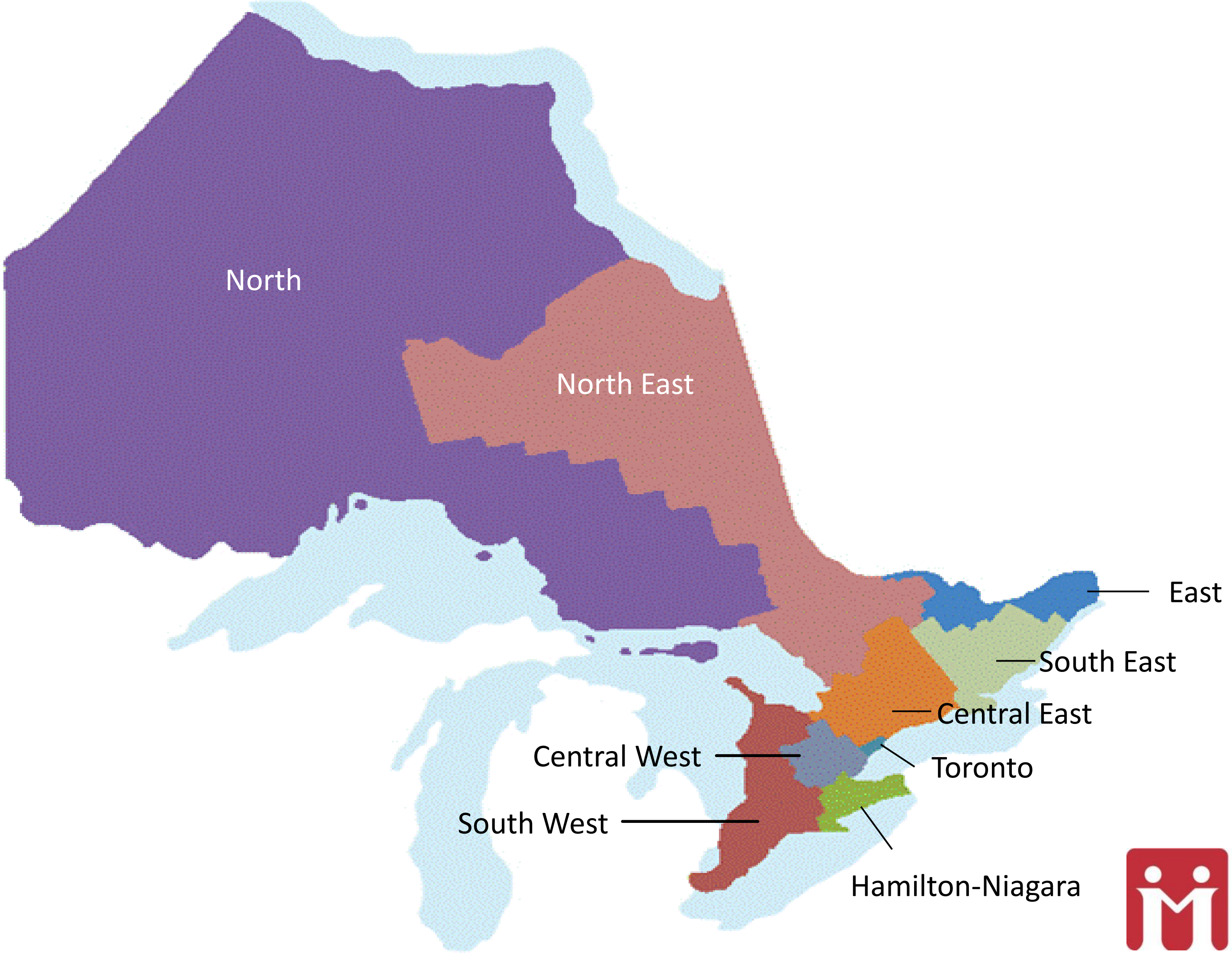
DSO Regions


North
North East
East
South East
Central East
Toronto
Central West
South West
Hamilton-Niagara

Review: Project Description

Phase (1): baseline phone interviews and surveys at time of service request

Phase (2): subgroup followed for 9 to 12 months

Phase (3) Select groups complete in-depth qualitative interviews

- Linkage of ministry collected data through Ontario's DSO's to MAPS interview and survey information

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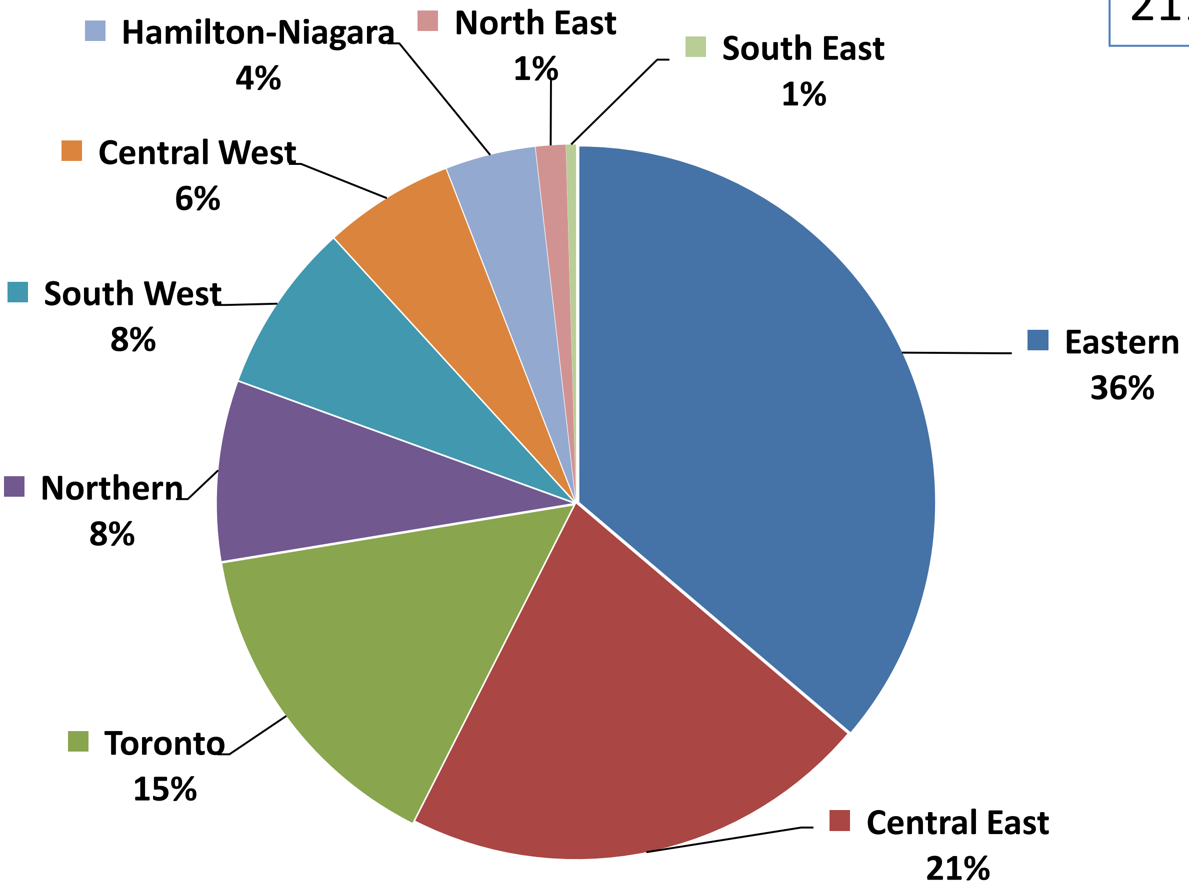
Recruitment

- 1720 recruitment forms sent to 9 DSOs
- ~69% of forms reached families

  (18.9% - 100%)
- ~21% of parents receiving the form requested more information (1% - 56%)
- ~84% of parents who received study details chose to participate (74% to 100%)

Participants by Region

Total:
211 Participants



Data collection

- Phase 1
  - 211 parents completed telephone interviews and/or mail surveys at time of service request.
- Phase 2
  - Ongoing: 181 parents agreed to be followed for up to a year with check-ins every 3 months.
- Phase 3
  - Ongoing: 6 families completed in-depth interviews in person, including 5 service provider; More scheduled in February for total of ~8 families.

Final Results
Phase 1

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Parent Demographics

- 85% mothers
- Majority aged 46-60 years old (range 38-91 years)
- 65% married to child's other parent; 25% separated/divorced; ~10% single/widowed
- 1/3 not currently working
- Half reported having at least one significant medical, physical or mental health condition*

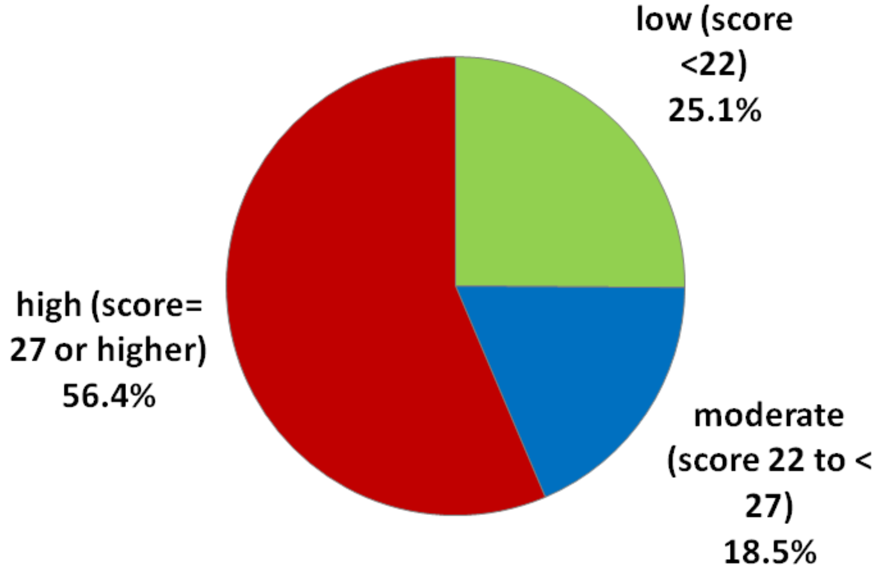
A closer look at the parents…

- 26% identified more than one household member with special needs
  - Other children with disabilities
  - spouse or other family members with mental health issues, medical, or physical conditions
  - Elderly parents of their own who require support

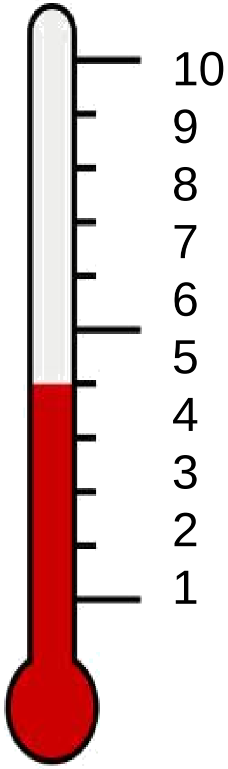
A closer look at the parents…

- **Mental Health**
  - Over half likely to be living with an emotional disorder

- **Perception of Burden**



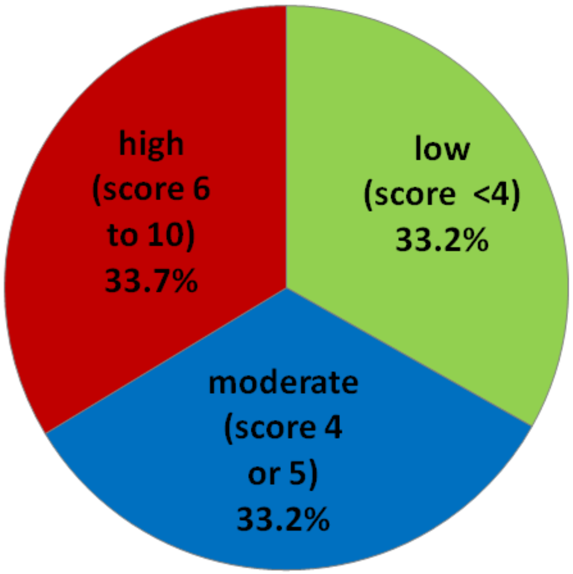
A closer look at the parents…



10: *“We are currently in crisis and it could not get any worse”*

1: *“Everything is fine, my family and I are not in crisis at all”*

Parents' Perceptions of Distress Around the Time they Made the Service Request (n=208)

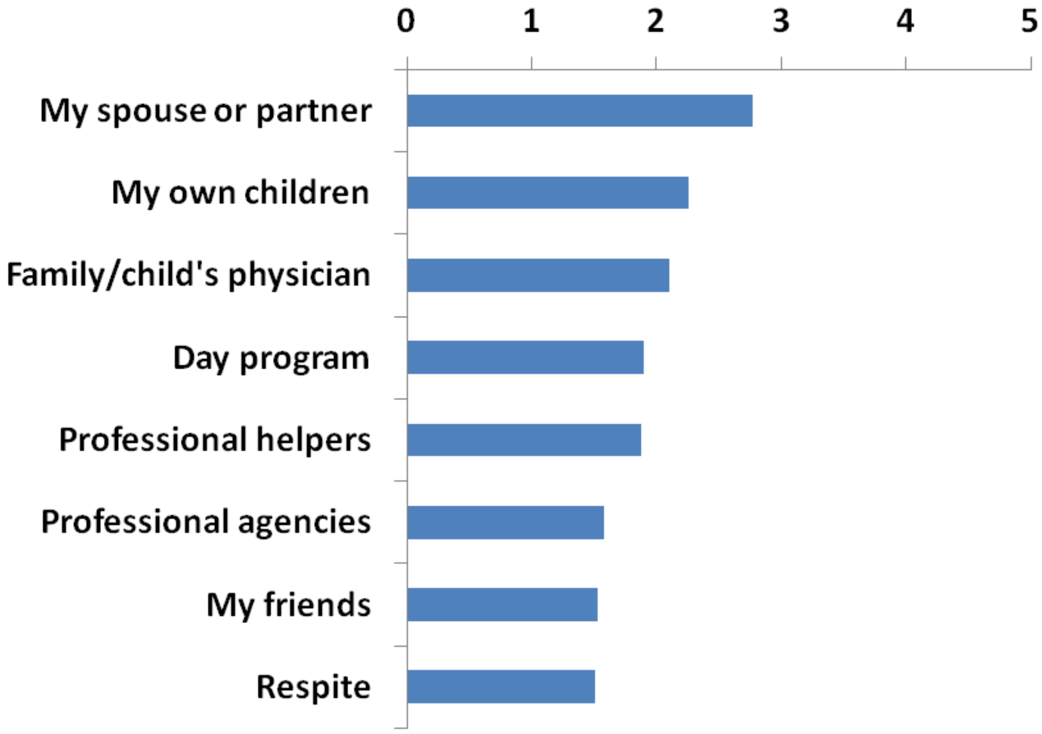


A closer look at the parents…

- **Perception of support**
  - – assessed using Family Support Scale (lists 20 sources of support and rate “helpfulness” from 1-5)
  - – Overall support scores varied from a low of 3 to a high of 60 (out of possible 100)
  - – On average, only 6 sources of support considered at least “somewhat helpful”
    - These were mostly informal supports

Parents' Perceptions of Sources of Supports Around the Time they Made the Service Request

***Supports Rated as "Helpful" on Average* (n=207)**



Supports Rates As "Absent" or"Unhelpful" on Average (<1.5)

- My relatives
- My parents
- Church members/minister
- My spouse/partner's relatives
- My spouse/partner's friends
- Coworkers
- My spouse/partner's parents
- Parent group members
- Other parents
- Cultural/linguistic groups
- Social groups/clubs

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A closer look at the parents…

- **Coping:**
  - As a group, the scores for compensating experience and mastery were higher than one might expect given the low support scores and the high report of burden.
  - Two dominant coping strategies were used: **acceptance** (emotion-focussed) and **problem-focussed** coping (active coping and planning)
  - Strategies that relied on other individuals for support were *less* commonly used.

Person with IDD: Demographics

- Majority under age 35 (47% under 20 years old and 44% between ages 21-34 years)
- 64% male
- Most born in Canada
  - Of the 6% born outside of Canada, only 1 was from an English-speaking country.

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Information *Not* Collected by DSOs

Individual with IDD—diagnosis:

- 33% identified as having Autism Spectrum Disorders
- 36% categorized as having Dual Diagnosis*

*Note: Dual Diagnosis is defined as having at least one of the following diagnoses – Drug or alcohol dependency/ addiction; Alzheimer disease or dementia; Psychiatric disorder/ mental illness; Behaviour disorder/ Serious behavior problems

Is diagnostic information relevant for service providers?

- Parents of individuals with ASD were more likely to request **caregiver respite.**
- Dual diagnosis status was associated with the request for **professional and specialized services**.
  - For individuals with a dual diagnosis, caregiver respite was less likely to be requested.

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What Supports are Parents Seeking?

Community Participation (n=142)

Agency Residential (n=92)

Caregiver Respite (n=67)

Professional and Specialized (n=20)

Activities of Daily Living (n=14)

PDP (n=6)

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What influences service requests?

- Parents requesting '**community participation supports**' were more likely to:
  - be younger,
  - have completed post secondary education, and
  - to be married to the individual's other parent.
- The individuals for whom supports were requested were more likely to:
  - be younger,
  - male, and
  - free of mobility impairments.

What influences service requests?

- Parents requesting ‘**agency residential support**’ were more likely to:
  - be older, and
  - report more caregiver burden.

- The individuals for whom supports were requested were more likely to:
  - be older.

What influences service requests?

- Parents requesting '**Respite**' were more likely to:
  - perceive higher levels of distress, approaching crisis.

- The individuals for whom supports were requested were more likely to:
  - have ASD

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A closer look at the individuals with IDD…

Are they socially included?

Are they socially included?

- When parents were asked about community connections for their son or daughter:
  - 1 in 5 parents said their child was NOT accepted and welcomed by community members.

> *“We have a child who was active and engaged during her years at school…left school at age 21 and has no day programs so is now home with her mother 24/7 and is becoming despondent and isolated. She has no purpose to her daily living and is totally dependent on her mother for stimulation.”*

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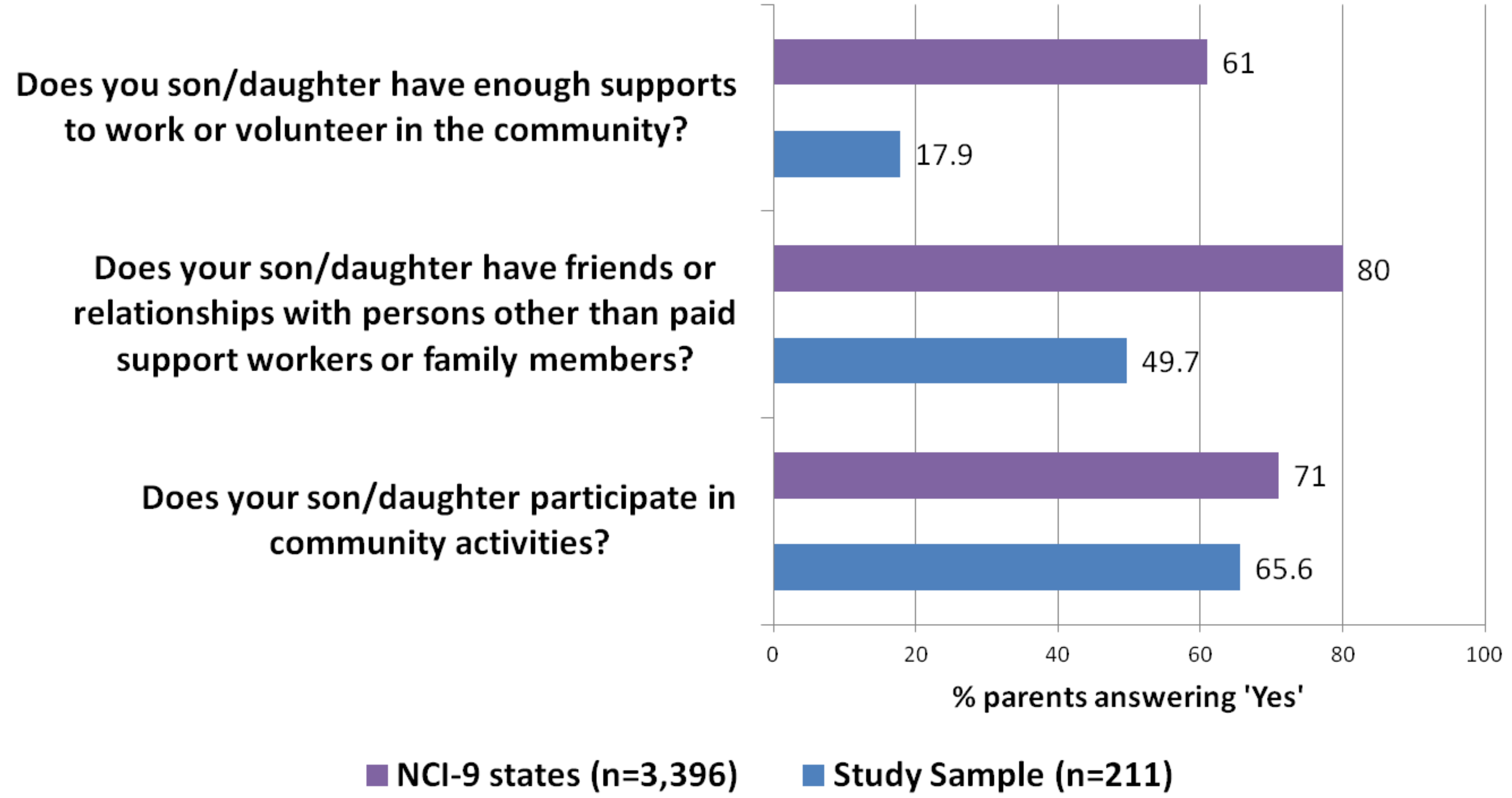
Are they socially included?



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Do they make choices?

- 40% of the children make their own choices about everyday activities (daily routines, what to spend money on, social activities, etc.)
- 42% of the children participate in discussions around future life decisions such as housing, finances and support staff providers.

*10.8% of parents responded N/A to these questions, suggesting they did not deem their child capable of making such decisions.

Do they have a plan?

- 24.1% had a personal life plan at time of applying for services. Of THOSE FAMILIES:
  - Only 55% indicated it included ALL the services and supports their son/daughter needed.
  - Only 60% of individuals with DD actually helped develop the plan*

*Note: this is comparable to the results of the NCI Family Survey of 9 states (58%) that included individuals in the planning process.

Wrapping up Phase 1

What did parents have to say?

- Found process confusing and difficult to navigate for information.
- Recognize the lack of available placements and overwhelming caseloads of agencies.
- General consensus that regardless of how stressed they were, they felt for other parents.
- Positive feedback towards study with hopes it will increase awareness towards individuals with DD and create more opportunities.

Limitations of Phase 1

- Participants limited to responding in written or oral English or French.
- Not representative across regions
  - Low response from South East, North East, Hamilton-Niagara, Central West
- only cross-section of individuals in Ontario
- Self-reported by parents

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Things to Come: Phase 2

What is it like waiting for services at 3 months follow-up?

- *“I have been very proactive and now am just waiting to see if the DSO comes up with anything additional that we need, because I know I will be put on wait lists. I hope DSO can help because I've always done everything on my own.”*

- *“I've been waiting for respite for 2.5 years. I'm sure I’m not the worst case out there so I'll have to just keep waiting and hope that it’s worth it in the end, but it is frustrating.”*

- *“We've applied for all kinds of things but there's waiting lists for things and most are years wait, not months.”*

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Things to Come: Phase 2

What is it like waiting for services at 6 months follow-up?

- *“I’ve given up asking for help.”*
- *“Our situation is always fluctuating and it's uncertain. Because of that, it doesn't matter how much planning we do, there's always a potential for a rip in our plans. Although it feels like the past 3 months have gone okay, I'm always very aware that the potential for disaster is present. I'm hoping the study will provide data to let people know what our situation is really like.”*
- *My appointment with the DSO was helpful… Even though the sense was that there is no money for supports, but at least I got the sense that some of my needs were being addressed.”*

Things to Come: Phase 2

What’s it like waiting at 9 and 12 months follow-up?

- *“We have had contact now with DSO and so we've done a lot of the preliminary work for that, and we have received some info from Community Living so they're going to start to see where we need things.”*
- *“my son's evaluation finally came back and I'm still not sure where he's situated on the priority list. They say it gets reported confidentially to the agencies but I think they should report back to the parents… So I'm not even bothering with them anymore. When I drop my son off on their doorstep, they can deal with it then.”*
- *“ A lot of people think you should feel sorry for us but that's the last thing we want, it makes us feel inadequate.. its better to just understand it. Don't feel sorry for me for having a child with Autism you know, just say hi to him, that's all they want.”*

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Things to Come: Phase 2

- We will also be looking at *who gets services*
  - What is different about them from those who do not?
- For whom do things seem to get better over time, and who gets worse?
- Overlapping ADSS and SIS information with MAPS data
  - Exploring associations
  - Anything important we are collecting that could be collected through ADSS

Things to Come: Phase 3 Sneak Peak

- Looking at innovating practices families are doing while they wait for services
- Families engage in a diverse range of practices including:
  - Taking part in a “homegrown” day program
  - Use of a long term care facility
  - Balancing tasks between a mother and her 21 year old son while the father is out of the country for work
  - Advocating to seek special permission to receive day program and respite services through a desired agency

Phase 3 Sneak Peak

- Positively evaluated engagement with developmental services tends to involve:
  - substantial effort and resources on the part of families

"I had to work my butt off and dip into our RRSP's"

  - A "champion" service provider who often helps families navigate the "system" and/or blurs the lines between formal and informal care

"They don't just tell you oh that's over my job I can't do it. No, he just thinks What can I do for you?"

Questions and Comments?

Thank you!

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What are we learning?

- Parents want to tell their story and be agents of change
- Routinely collected data can be used for research, with some tweaks
- We may need to consider some additional questions about the parent experience
- Understanding families better should lead to a more responsive system of supports