The health of mothers of school aged children with disabilities: Why should paediatric occupational therapists care?

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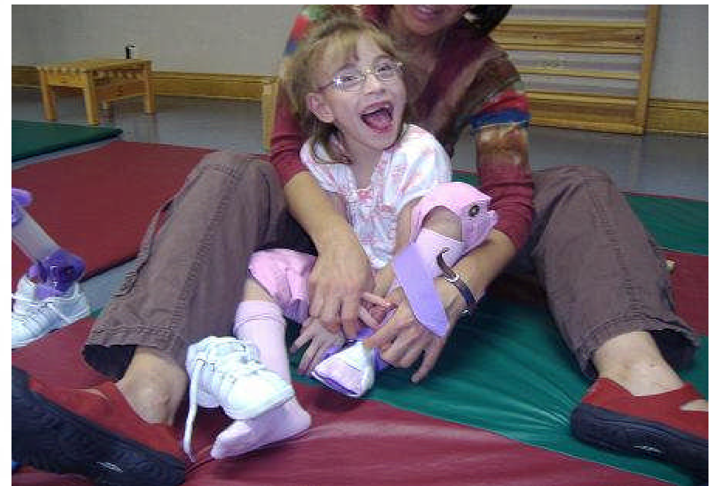
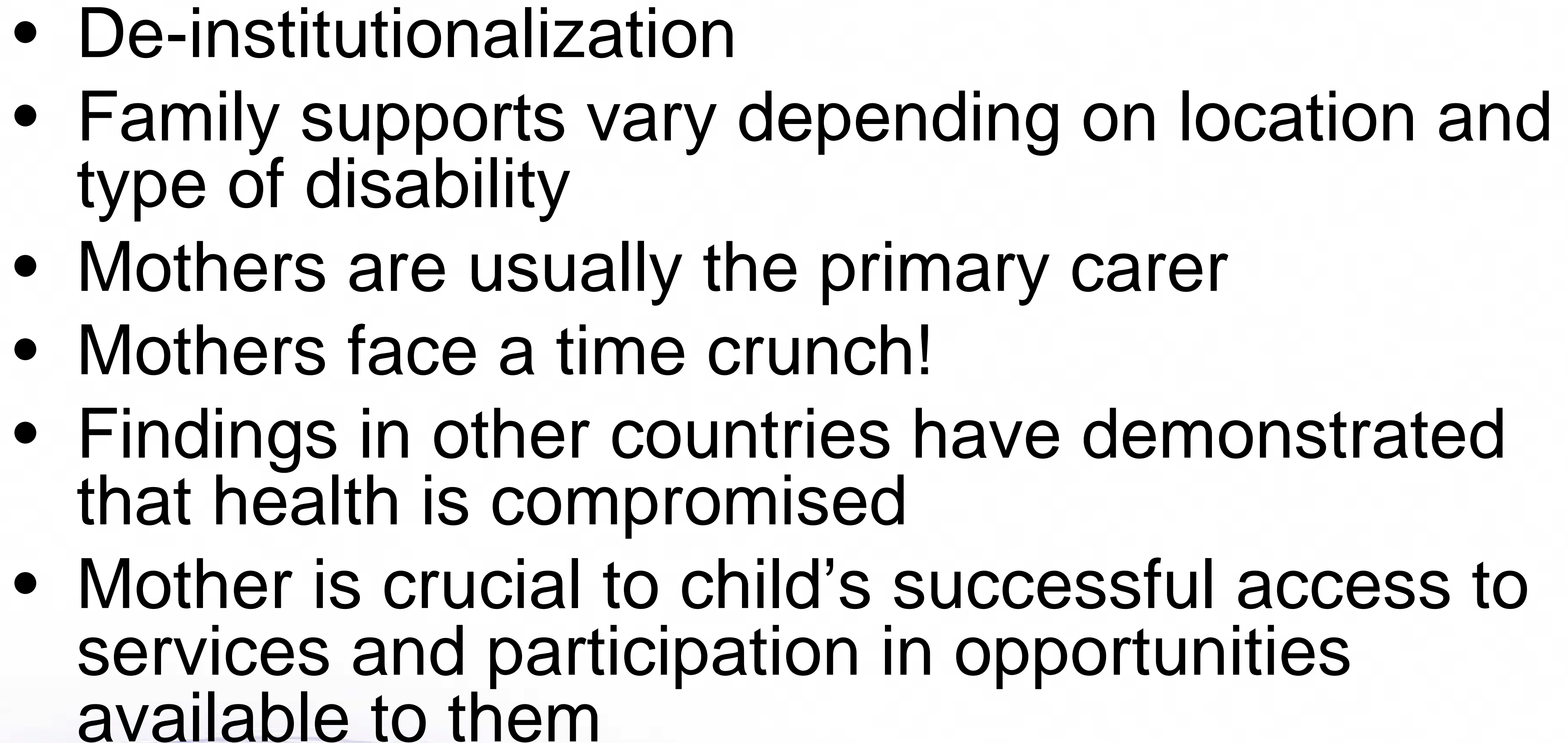
Aims of this presentation

- Introduce background
- Describe the research
- Present select findings
- Discuss the implications for OT's



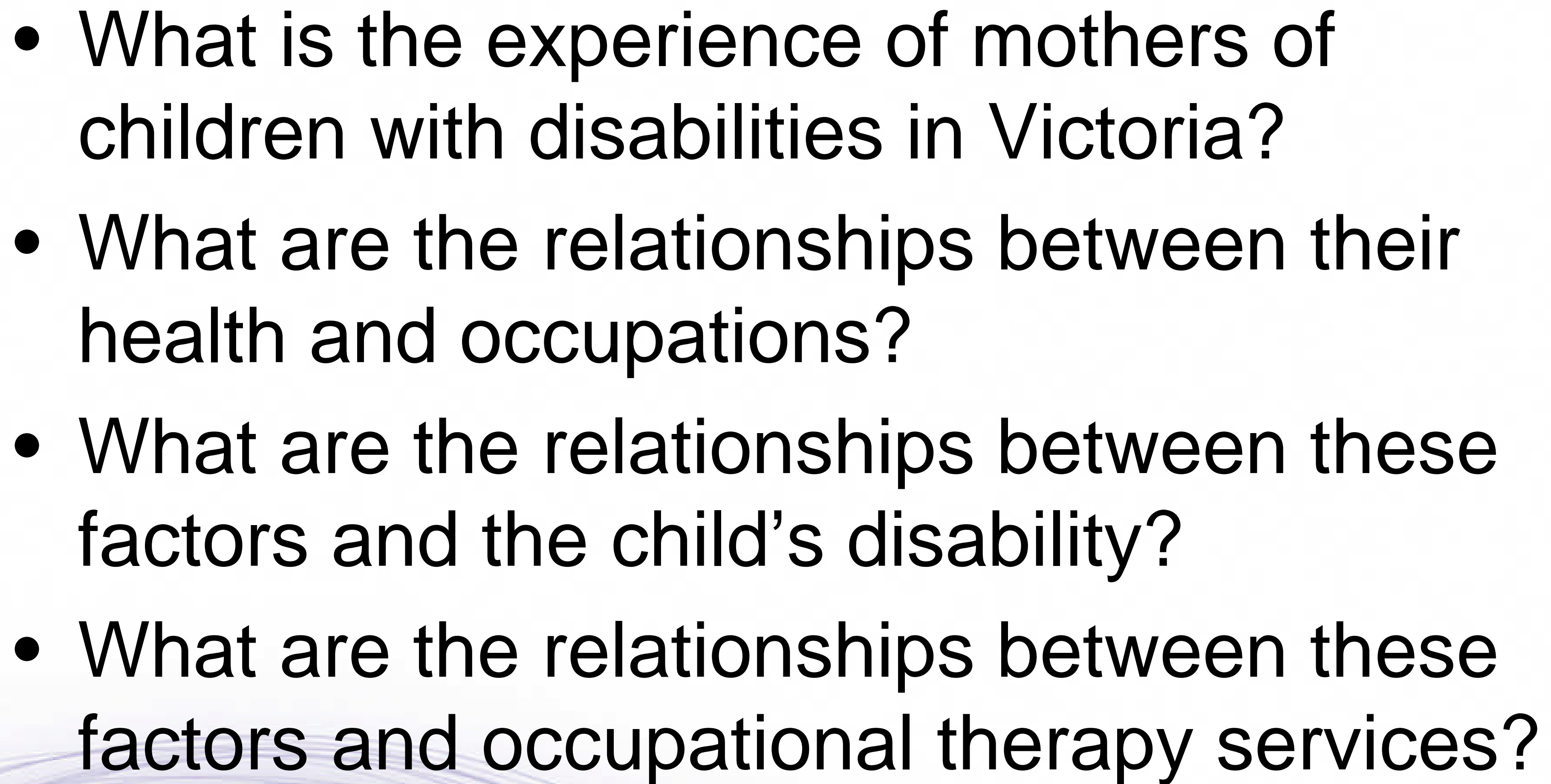
Background



- De-institutionalization
- Family supports vary depending on location and type of disability
- Mothers are usually the primary carer
- Mothers face a time crunch!
- Findings in other countries have demonstrated that health is compromised
- Mother is crucial to child's successful access to services and participation in opportunities available to them

Research questions:

- What is the experience of mothers of children with disabilities in Victoria?
- What are the relationships between their health and occupations?
- What are the relationships between these factors and the child's disability?
- What are the relationships between these factors and occupational therapy services?



The research was mixed method design

Step 1:
Qualitative study:
Experience of mothers of children with disabilities.
Lead to scale development (3) and selection of suitable tools.

Step 2:
Quantitative study:
Establish reliability and validity of scales (piloting)

Step 3:
(N=152)
1. Description of health and situation of mothers and analysis of relationships between variables
2. Evaluation of scales

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Mother and child measures

Variable	Measure
Mothers health status	SF-36
Mothers empowerment	Family empowerment scale
Extent caregiving ADL	PEDI caregiver scales
Extent assistance given to child during play/rec	Assistance to participate scale (APS)
Family cohesion	Family environment scale
Childs behaviour	Parent-child behaviour scale (PCBS)
Childs daily problems	PedsQl

Results: Characteristics of participants (n=152)

Age: 41.7 yrs (5.4)

Education status……………………………………Primary 2 (1%)
Secondary 65 (43%)
Post secondary/degree 54 (36%)
Postgraduate 31 (20%)

Relationship status………………….Married/De Facto 127 (84%)
Separated/divorced/widowed 15 (10%)
Single 6 (4%)

Work Status……………………………………..Full time 14 (9%)
Part time 69 (45%)
Study 21 (14%)

***128 (84%) women stated that they wanted and needed to work more*

***Reasons why they couldn't related to the child 71 (47%); themselves 72 (47%); and service limitations 101 (67%)*

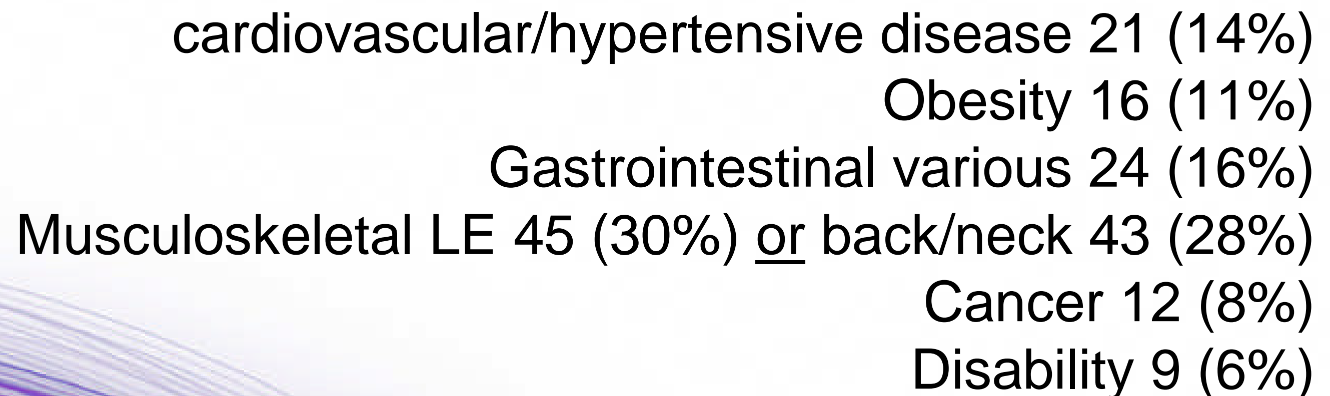
Self reported health conditions (n=127):

Mental health condition (n=75)

Depression 57 (38%)
Anxiety disorder 34 (22%)
Post traumatic stress disorder 4 (3%)
Obsessive compulsive disorder 2 (1%)
Anorexia Nervosa 2 (1%)
Post natal depression 8 (5%)
Bipolar mood disorder 3 (2%)

Physical health condition (n=127)

cardiovascular/hypertensive disease 21 (14%)
Obesity 16 (11%)
Gastrointestinal various 24 (16%)
Musculoskeletal LE 45 (30%) or back/neck 43 (28%)
Cancer 12 (8%)
Disability 9 (6%)



Children

*Child's age: 9.5yrs (3.7) range 5-18 yrs

*Child's schooling (67 Reg vs. 83 Seg)

Primary regular 56 (37%)

Secondary regular11 (7.2%)

Special schooling 75 (49.3%)

Mixed special and regular8 (5.3%)

Home2 (1.2%)

*Child's diagnosis per mother report (n=152)

Cerebral palsy 29 (19%)

Developmental delay 26 (17%)

Autism 67 (44%)

Asperger syndrome 25 (17%)

Intellectual disability 46 (30%)

Language disorder 15 (10%)

Epilepsy 20 (13%)

Sensory impairment (hearing/visual) 22 (15%)

Down syndrome 8 (5%)

Childhood psychiatric disorder: (n=30)

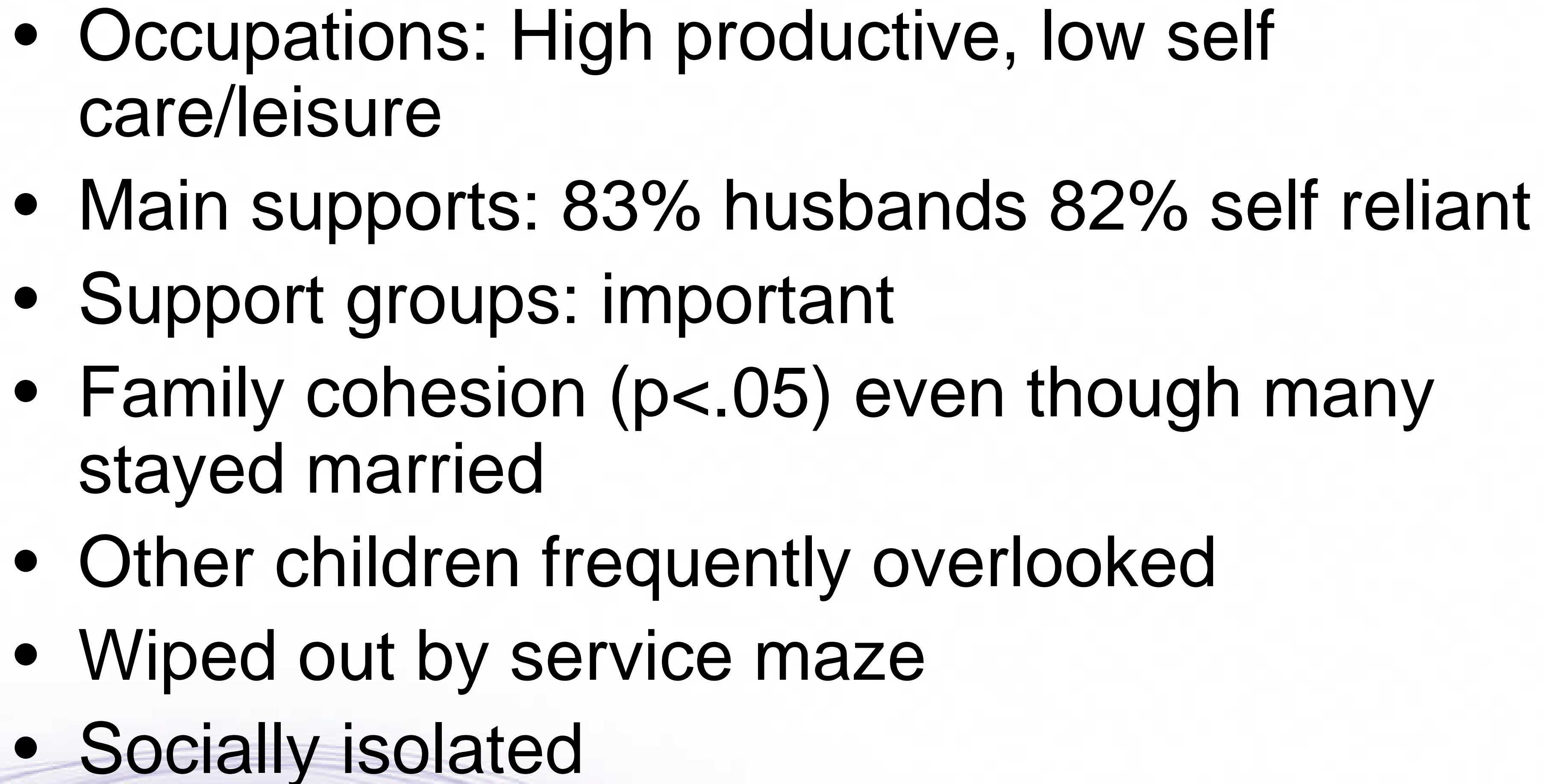
What types of services do children with disabilities receive?

Description of child's services:

School based therapy: OT 55%; PT 36%; SLP 62%
Integration aide: 51%
Private therapy: OT 22%; PT 13%; SLP 23%
Respite care: Range 0-120 hours
Average 16 hours month (SD=24hrs)

What did they need and not receive:
OT: school 32%; private 20%
PT: school 14%; private 9%
SLP: school 26%; private 23%
Integration aide: 14%

Mothers experience:



- Occupations: High productive, low self care/leisure
- Main supports: 83% husbands 82% self reliant
- Support groups: important
- Family cohesion ($p<.05$) even though many stayed married
- Other children frequently overlooked
- Wiped out by service maze
- Socially isolated

Relationships between mother's health and occupations:

- SF-36 and leisure occupations
  - Higher than r=.3 for 5 out of 8 sub scales (p<.001)
  - Strongest between mental health and leisure occupations r=.41, p<.001.
- SF-36 and self care
  - Vitality r=.36, p<.01
- SF-36 and health maintenance
  - Strongest for Vitality r=.48; General health r=.44; and mental health r=.45, (p<.004)

Relationships between health, occupations and child factors:

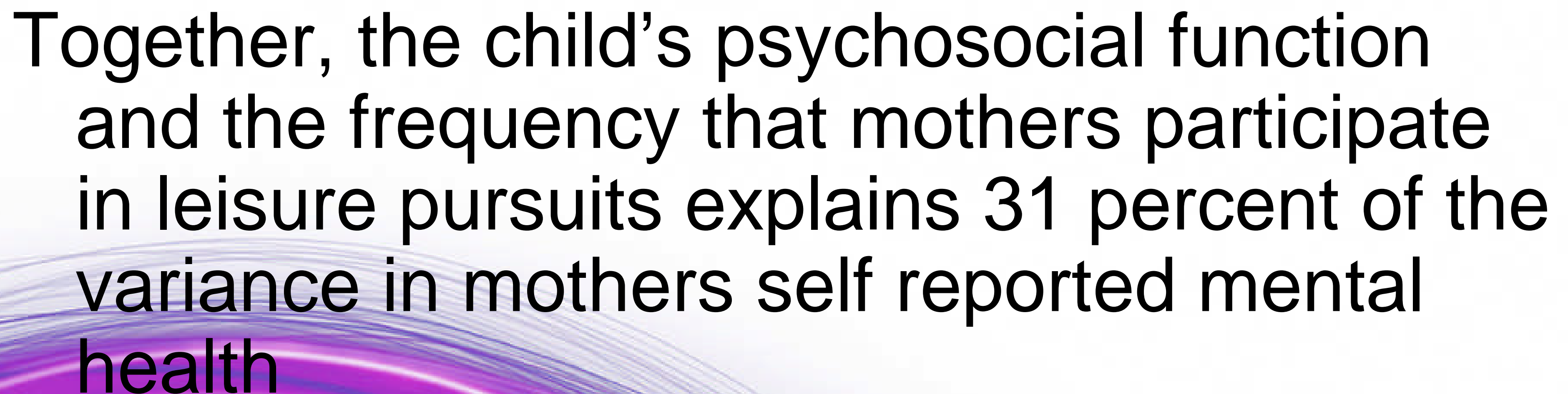
Correlations

- SF-36 and Peds QL
  - No correlation with child's physical QOL
  - Overall QOL r=.36 for mothers mental health
  - Psychosocial QOL r=.3 most areas and r=.477 for mothers mental health (p<.001)
- SF-36 and PEDI caregiver scales
- SF-36 and assistive devices

What has the strongest influence on the mothers self report mental health state?

Regression model explored contribution of mother factors, child factors and service factors to mothers mental health.

Together, the child's psychosocial function and the frequency that mothers participate in leisure pursuits explains 31 percent of the variance in mothers self reported mental health



Relationships between mothers health and child's services:

*Surprise finding:

High number of services did not correlate with the mothers health scores

Correlations were discovered between mothers health and the number of services the child did not receive. Correlations ranged from r=-.224 through r=-.344, p<.006. Strongest were for mothers general health (r=-.314) and Role emotional (r=-.344).

Conclusions about services

- Many children need Paediatric OT at school and privately and do not receive it
- Respite services are lean
- Service gap (home based respite, B/ASC and Holiday programs preventing mothers from working)
- Services need to be family centered
- Mothers are not necessarily able to advocate for their child, and lack of services might be detrimental to mothers health
- Seeking services causes *stress*

Implications for OT practice

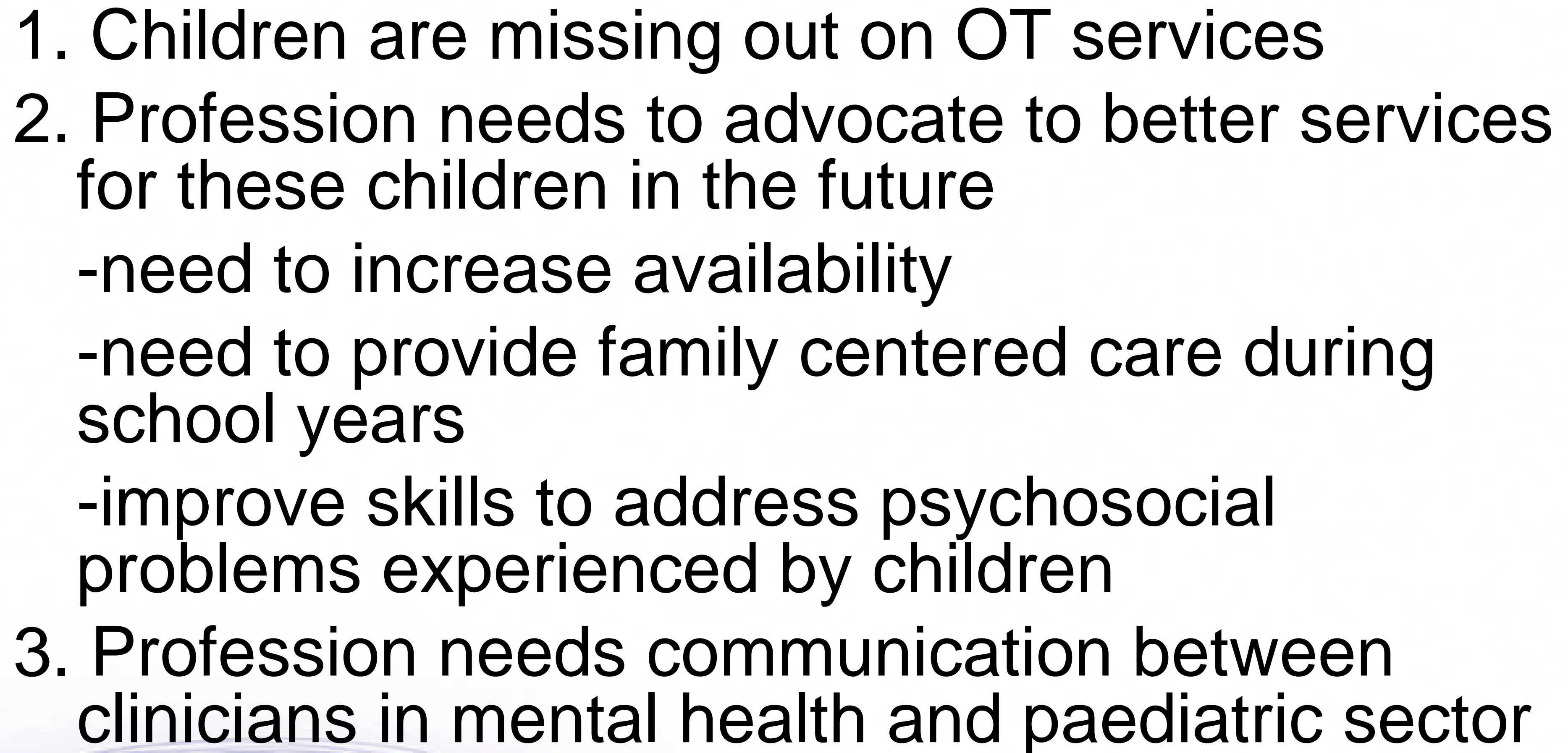
Why should OT'S care?

1. Children are missing out on OT services
2. Profession needs to advocate to better services for these children in the future

   -need to increase availability

   -need to provide family centered care during school years

   -improve skills to address psychosocial problems experienced by children
3. Profession needs communication between clinicians in mental health and paediatric sector



For reference list please contact

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Key message:

Behind this child sits a devoted mother who is involved for the long haul…

Occupational Therapists have a lot to offer such mums!