

# SUPPORTING MOTHERS AND FAMILIES OF CHILDREN AND YOUNG PEOPLE WITH DISABILITIES: WHAT DO EDUCATORS NEED TO KNOW?

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# MOTHERING IN THE CONTEXT OF DISABILITY IS DIFFERENT

WHY STUDY MOTHERS?

PHASES COMMON TO MANY MOTHERS

MATERNAL STRESS AND HEALTH

WHAT DO MOTHERS SAY ABOUT SCHOOLS AND  
SCHOOL SUPPORT?

MAKING A DIFFERENCE IN SCHOOLS: 5 STRATEGIES

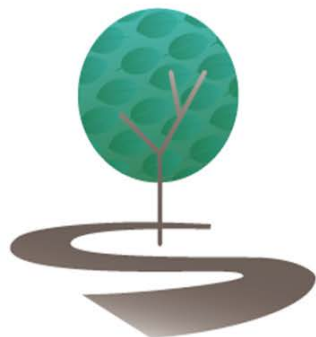


# WHY STUDY MOTHERS?

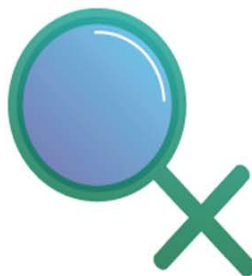
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Mothers are very important people!

# HEALTHY MOTHERS HEALTHY FAMILIES: A PROGRAM FOR MOTHERS



Journey of Mothers



Health and Research Findings



What Mothers say about Stress



Healthy Mind,  
Healthy Mum



Active, Healthy Mum



Managing and Staying Strong



# WHAT DO WE KNOW ABOUT MOTHERING A CHILD WITH A DISABILITY?

- Mothers are primary caregivers in 95% of families (Brehaut, 2004; Nelson, 2002; ABS, 2014).
- Financial impact is high (Powers, 2002)
- Parents miss out on lifestyle choices, work and health (Bourke-Taylor, 2014)
- Mothers experience predictable phases (Bourke-Taylor et al., 2010, Green, 2001)
- Many mothers have high stress and health issues (Brehaut, 2005; Raina et al., 2004; Singer, 2006; Bourke-Taylor et al., 2012)



# PRIMARY CAREGIVER TASKS: IDENTIFIED BY MOTHERS

- Direct care during the day and night.
- Indirect care in the absence of the child.
- Teacher/therapist responsibilities for child's learning, development and maintain/improve health.
- Advocacy—child; other children; service advocacy and political advocacy.
- Organizing the service system around the child.
- Managing people within those service systems—school, community, health and medical systems.
- Financial responsibilities.
- Coordinating and meeting the needs of other family members as influenced by disability.



# FINANCIAL IMPACT IS DOUBLE PRONGED

- Cannot participate in paid work to capacity (Powers 2006, Bourke-Taylor 2011)
- Costs of raising a child up to 20 fold typically developing children (Brehaut et al., 2015; Raina et al., 2004)
- Study with CPEC, 29 families raising a child to 6 years
  - (Bourke-Taylor, Cotter, Stephan, 2014).
    - Home—0-\$107,600
    - Vehicle—0-\$100,000
    - Seating--0-\$37,700
  - Therapy/medical--0-\$259,000
    - Communication--\$22,240

# PARENTS MISS OUT

- Study of parents of children with CP under 6 years
  - Entertainment together
  - Gifts within family
  - Medical or dental services for mum and dad
  - Recreation
  - Activities and items for other children
- Parent may reduce or alter work/professional career aspirations.



# PHASES COMMON TO MANY MOTHERS

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# Initial shock, disbelief, and grief phase

- **Phillipa:** “He was banging his head on walls, he was tippy toeing, he was laughing hysterically for no reason. He was very obviously autistic, and I didn’t have a clue in the world ... My journey was one of total shock, loss, and I was just totally grief stricken.”
- **Alana:** “Andrew and the oxygen tank and that went on for 12 months ... those times are a real blur ... it was just survival ... just one day into another sleepless night The worst time is in the early days, probably the first five years.”

# Seekership

- Mothers describe “staying up until 2 am just searching for ...interventions on the internet”, or trying a doctor or therapist, quitting, and locating another and another until the ‘right person’ is found.

**Amanda:** “In the early days it was about never doing enough for Peter. That was. . .before I knew where he’d end up on the scale of disability. When I was really putting in the hard yards and trying to make that first milestone with the movement or whatever and I chased around all the different therapies, gave everything a go.”

# Disability focused

- High contact with service systems: education, therapy and medical system.
- Parents need to know how to peruse the available services and options that offer their child health and progress.
- Family income can be compromised if parents aren't aware of what are realistic outcomes for their child.

**Phillipa** felt like she was just going around and around:

“It’s just like Autism, autism, autism!”

**Jane:** “We sold our car, our family car, so that Lucas could undergo hyperbaric oxygen. It cost \$30,000...he seemed to be weaker afterwards...that was the only real change.”



# Balanced

- Mothers know when they are in the balanced phase

**Rebecca:** “I've been more open with people about when I need help. I'm able to communicate that more, knowing I need to do that to be able to look after myself and to relieve some of the pressure and burden.”

**Ahn:** “I have been thinking a lot about my own health. I realise how important it is to look after myself. I have finally given myself permission to take time out, relax and express my own needs.”

**Thalia:** “To me the most important light bulb moment was when I realised the importance of social support and friendships to my health. I don't think that I had really made that link before. I realised that I need to prioritise time with friends a little bit more.”



# MATERNAL STRESS AND HEALTH

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In 2009, prominent Australian scientist Professor Elizabeth Blackburn became the first Australian woman to be awarded a Nobel prize.

- Landmark molecular biological study
- Compared mothers with a child with a disability and high stress to other mothers
- Cellular aging, and with it, early onset of age-related diseases.
- Mothers caring for a child with a disability (N=39), who reported the highest levels of perceived stress, also demonstrated cellular aging at the equivalent of women *a decade older*

# STRESS AND LONGEVITY

- Western Australian study (Fairthorne, et al., 2014)
- Suggested early mortality of mothers of children with disability
- Calculated hazard ratios for mothers of children with ID and ASD
- Determined risk of death and cause
  - Twice risk of death (not DS)
  - 40% higher risk cancer
  - 150% higher risk cardiovascular disease
  - 200% higher risk misadventure



# INVESTIGATED MENTAL HEALTH AND ASSOCIATED FACTORS

## Child factors

- Extent of disability
- Type of disability
- Aspects of child's needs influence mother's health

## Service factors

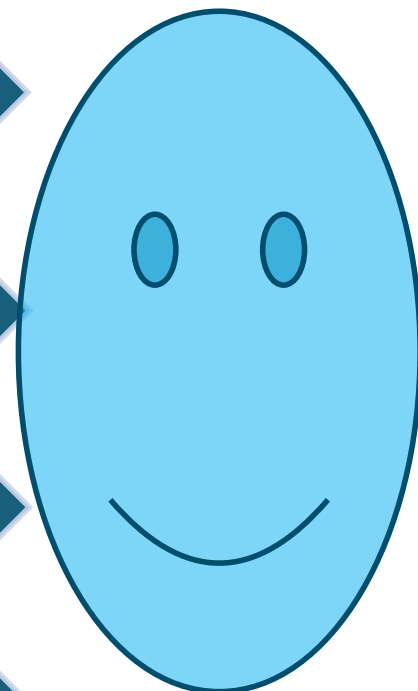
- Respite care
- Professional services (availability/competency)
- School support

## Mother factors

- Health
- Education
- Self empowerment

## Family factors

- Income
- Parental situation
- Other children



# Many child-related and responsibility type questions...

- Lifts, manual assistance
- Amount of assistance child required in play, self care, mobility, social function, as well as equipment to participate
- Medication refusal
- Challenging behaviour
- Sleep behaviour
- Child's quality of life and daily challenges
- Supports and services at home, school and community
- Supports that child needed but did not have.

# MOTHERS IN THIS RESEARCH

Mothers age: 41.7 (5.4 years) range 29-57

Education Status:

Secondary 67 (44%)

Post Secondary 32 (21%)

Degree/s 53 (35%)

Relationship status:

Married/partnered 127 (84%)

Separated/widowed 15 (10%)

Single 6 (4%)

Family constellation

One child 36 (24%)

Two children 71 (47%)

Three children 33 (22%)

Four or more children 11 (7%)

Children with a disability

One 117 (77%)

Two 31 (20%)

Three 4 (3%)

# CHILDREN IN THIS RESEARCH

Child's age:	9.5yrs (3.7) range 5-18 yrs
Child's schooling	(67 Local mainstream; 83 Specialized)
	Primary local 56 (37%)
	Secondary local 11 (7.2%)
	Mixed 83 (55%)
	Home 2 (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%)
	Epilepsy 20 (13%)
	Sensory impairment (hearing/visual) 22 (15%)
	Down syndrome 8 (5%)
	Childhood psychiatric disorder (ADHD=19) 30 (12%)

# MENTAL HEALTH

75 (49%) of mothers had  
been diagnosed with  
a MH condition since  
the birth of their child

The vast majority of mothers had been  
diagnosed with Depression  
and/or Anxiety

# FACTORS THAT DID NOT INFLUENCE MATERNAL MENTAL HEALTH

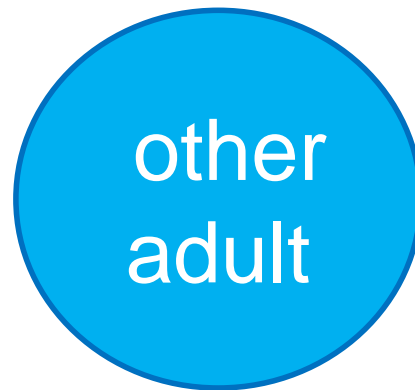
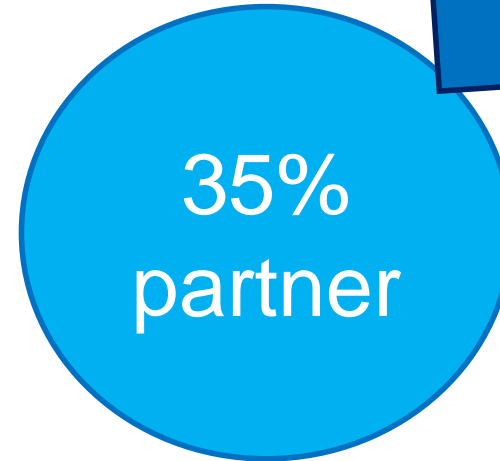
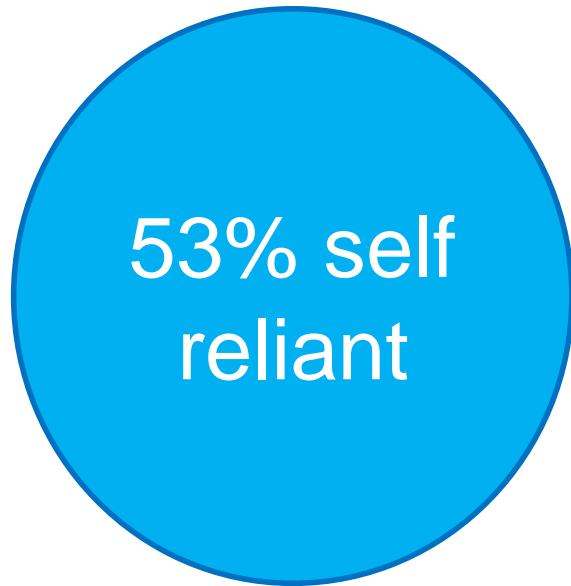
- Extent of disability (play, self care, mobility, psychosocial function).
- Lifting or physically supporting child.
- Number or type of assistive devices.
- Number of services that the child needed.
- Education level of mother.
- Whether mother was partnered or not.
- Income of family.
- Type of school

# FACTORS THAT DID INFLUENCE MATERNAL MENTAL HEALTH

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**Ten significant factors**

# 1. Identified life supports






## 2. Age & number of children.



Preschool  
aged child



More than  
one child  
with a  
disability

# 3. Autism

- Mothers did report higher stress than other mothers.
- Mothers did have higher rates of diagnosed mental health conditions

## 4. Paid work

55 percent of mothers worked for pay (best health).

82 percent wanted and needed to work more

Why not?

- Mother-related reasons— (28% of reasons)
- Child related reasons— (29% of reasons)
- Service limitations— (43% of reasons)

# 5. Sleep



Sleep almost every night 52%

Up most nights, once/night 24%

Up most nights, More than twice 24%

## 6. Challenging behaviour

- Is associated with strain on both parents and family
- Involves a range of persistent behaviours over time that cause distress to the child and family.
- Challenging behaviour correlated with maternal mental health and family cohesion.
- Children with ASD or additional childhood psychiatric conditions may behave in challenging ways with higher frequency.

Refusal of  
other carers

Persistent unhappiness or  
discontent state

Violence

Reliance on  
routine

Resistance to routine

Aggression

Aggravating others

Uncooperative behaviour

## 7. Emotional well being

worried

afraid

Trouble sleeping

scared

sad

angry

## 8. Empowerment around disability

- Understanding their child's disability
- Managing their child's needs within family and daily life
- Coping with problems
- Finding information
- Knowing how to help their child
- Knowing that they could manage problems and find solutions
- Having family life under control.



## 9. Unmet service needs

- The average number of services required and used by a child: **nearly 8 services.**
- The average number of unmet services: **3 services.**
- What were the services?
  - School based and or private speech pathologist
  - School based and or private occupational therapist
  - School based psychologist
  - Tutor
  - Case manager



# 10. Participation in healthy, social, active leisure pursuits

- Measure of how often mothers participated in:
  - Healthy active pursuits with others/alone
  - Passive leisure pursuits with others/alone
  - Time out
  - Time with socially supportive others
  - Spiritual time



## Other mothers?

Are all mothers time poor and unable to attend to their own health and recreational needs?

To find out I surveyed 263 Victorian mothers of typically developing children and compared participation to 152 Victorian mothers of a child with a disability

>weekly

With Without

Time in self care/health planning	46%	71%
Time in active pursuits alone	16%	75%
Time in active pursuits with others	22%	51%
Time with socially supportive others	23%	49%
Time out	16%	35%
Time in passive pursuits alone	22%	38%
Time in passive pursuits with others	8%	42%



# Factors associated with higher stress

- Having a preschool aged in family
- More than one child with a disability
- Lack of sleep/sleep interruption
- Inability to work as desired and needed
- Child with ASD
- Child described as having poor emotional wellbeing
- Lack of supportive other
- Challenging behaviour
- Inability to take time to care for self and participate in leisure
- Poor empowerment and sense of control over family life
- High number of unmet service needs
- Belief that health affected caregiving



# WHAT DO MOTHERS SAY ABOUT SCHOOLS AND SUPPORT?

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“For schools to be proactive rather than reactive.”

“Strategies to help kids at home because this will empower parents to support their kids!”

“Take the parents mental health seriously”

“Work as a team. Understand that we know our child best”

“Maybe have an appointed person to liaise with so that you don’t feel like you are taking up so much of the teachers time.”

“Acknowledge the ‘individualness’ of each child AND each family.”

“Let OTs and psychologists into classrooms and listen to their professional advice. Be open to strategies to help kids at school.”

“Sometimes I think schools should have a third party available to parents of special needs students to assist in difficult times where stress is on both parents and teachers.”

“With issues like kids getting hit by another kid. It will be helpful if teachers give skills to kids on how not to get hit.”

“Communication, openness, sense of partnership.”

“Encourage socialisation of parents and children.”

“Our school is great at encouraging parents as they get that the best approach is everyone being on the same page. My experience with mainstream schools was ‘Yes, you are an overprotective mum. We have dealt with more children. We know best. You are wrong.’ It diminishes us as parents until we realise that we have other options. We don’t need schools or people like that in our lives.”



# MAKING A DIFFERENCE IN SCHOOLS: 5 STRATEGIES

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# SCHOOLS MAKING A DIFFERENCE

## 1. Examine your school's health and wellbeing culture

**The smallest change can make a big difference.**

Walking group

Fruit bowl at reception

Greeting herbal teas

Health magazines at reception

Mum and Dad's fitness fundraising

Artists in residence

Musical events

Parent pod

Newsletter items about health and wellbeing

# SCHOOLS MAKING A DIFFERENCE

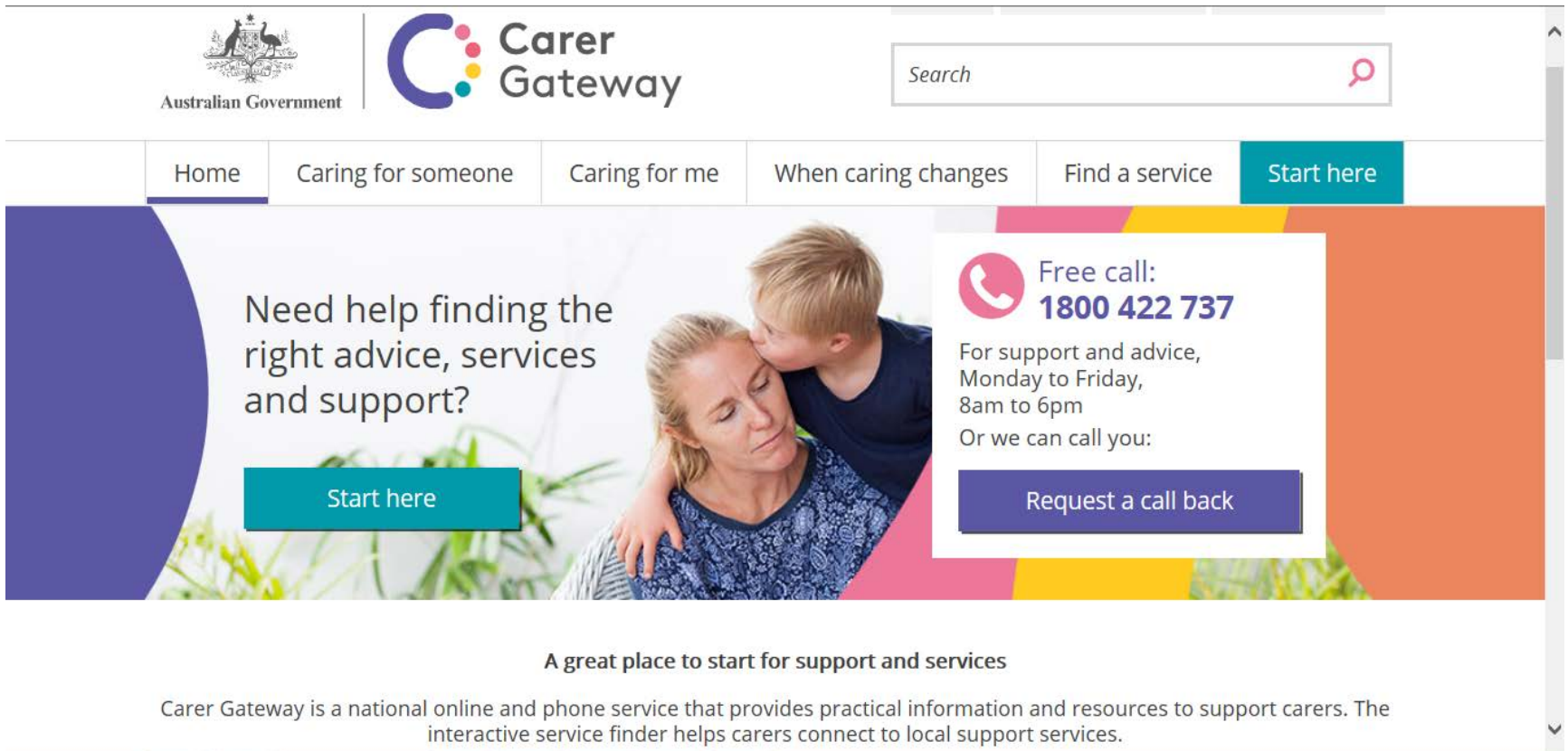
## 2. Identify carer champions

Mental Health Australia has identified Carer Champions--  
People in an organisation charged with thinking, planning and acting in the carers interest.

- Make the positions rotational and open
- National Carer Strategy promotes this view.
- Identifying and understanding of the carer role.
- Carer programs (sleep, child anxiety/parent anxiety)

# Carer Gateway:

<https://www.carergateway.gov.au>



The screenshot shows the Carer Gateway website homepage. At the top left is the Australian Government logo. Next to it is the Carer Gateway logo, which consists of a stylized 'C' made of colored dots followed by the text 'Carer Gateway'. To the right is a search bar with the placeholder text 'Search' and a magnifying glass icon. Below the search bar is a navigation menu with six items: 'Home', 'Caring for someone', 'Caring for me', 'When caring changes', 'Find a service', and 'Start here'. The 'Start here' item is highlighted with a teal background. Below the navigation menu is a large banner image featuring a woman and a young boy. The woman has her eyes closed and a slightly distressed expression, and the boy is kissing her on the cheek. Overlaid on the banner is a white box with a pink telephone icon and the text 'Free call: 1800 422 737'. Below this is the text 'For support and advice, Monday to Friday, 8am to 6pm' and 'Or we can call you:'. At the bottom of the white box is a purple button that says 'Request a call back'. To the left of the white box is a teal button that says 'Start here'. Below the banner is the text 'A great place to start for support and services'. At the bottom of the page is a paragraph of text: 'Carer Gateway is a national online and phone service that provides practical information and resources to support carers. The interactive service finder helps carers connect to local support services.'

Australian Government

Carer Gateway

Search

Home Caring for someone Caring for me When caring changes Find a service **Start here**

Need help finding the right advice, services and support?

**Start here**

**Free call: 1800 422 737**

For support and advice, Monday to Friday, 8am to 6pm  
Or we can call you:

**Request a call back**

**A great place to start for support and services**

Carer Gateway is a national online and phone service that provides practical information and resources to support carers. The interactive service finder helps carers connect to local support services.

# An information and navigation site:

## A great place to start for support and services

Carer Gateway is a national online and phone service that provides practical information and resources to support carers. The interactive service finder helps carers connect to local support services.



Am I a carer?



Types of carers



Planning for  
an emergency  
situation



Connecting  
with other  
carers



Payments for  
carers



Health and  
wellbeing

# SCHOOLS MAKING A DIFFERENCE

## 3. Empathise *and* assist parents to develop help seeking behaviours.

- Develop resources and systems in the school.
- Organise formal pathways to debrief and support staff.

<https://www.google.com.au/#q=brene+brown+empathy>



# SCHOOLS MAKING A DIFFERENCE

## **4. Celebrate the child, value fun, friendships and family.**

Focus on achievements

Focus on child's emotional wellbeing at school

Focus on individuality of child and family

Overtly encourage connectedness



# SCHOOLS MAKING A DIFFERENCE

## 5. Looking after yourself!

Identify boundaries and rules of engagement

Empathise without getting compassion fatigue

*Seek support*

*Seek advice*

*Debrief*

*Accept help*

*Ensure someone is safe and then self-check*



# FULL REFERENCE LIST AVAILABLE

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**SINCERE THANKS TO ALL MOTHERS,  
PARTICIPANTS IN STUDIES AND COLLEAGUES.**