

Thirteenth Family Research Network (FRN) Forum

*“Familial Caregivers and their Impact
on the
Resilience of Family Function”*

Monday, 27 April 2015
Auditorium, Level 1, Civil Service College

THIRTEENTH FAMILY RESEARCH NETWORK (FRN) FORUM:
“FAMILIAL CAREGIVERS AND THEIR IMPACT ON THE RESILIENCE OF FAMILY FUNCTION”
27 APRIL 2015

PRESENTATION IV

Needs Assessment on Respite Care for Caregivers of Persons with Disabilities

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Needs Assessment On Respite Care For Caregivers of Persons with Disabilities

by Dilys Tan, Manager, Service Planning & Development Group



**A Research By:
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National Council of Social Service**

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PICTURES

Woman charged with son's murder at West Coast

PUBLISHED ON JUN 3, 2013 10:02 AM

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Home > Singapore > Story >

Mother of seven-year-old boy found dead in Tampines arrested for alleged murder

PUBLISHED ON SEP 14, 2014 2:08 PM



Direct Effects:
 Mental breakdown/burn out
 Quitting of jobs
 Children/students with special needs unable to maximise potential
 Neglecting other children in the family w/o special needs

Focal Problem:
 Excessive psychological stress of caregivers of persons with disabilities

Direct Cause 1
 Difficulties in accessing information

Direct Cause 2
 Limited respite care options

Direct Cause 3
 No continuum of care

Direct Cause 4
 High cost of services required i.e. medical, therapy, specialised transport

Root Cause
 Information/source for caregivers to access

Root Cause
 Inability to process due to various sources

Root Cause
 Caregivers' lack of trust in FDWs and affordability

Root Cause
 Lack of extended family members to help

Root Cause
 High cost of existing childcare services

Root Cause
 Lack of trained manpower for existing services

Root Cause
 Lack of resources and capability in centres/schools to run longer hours and enrichment programmes

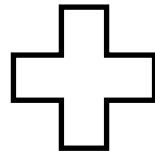
Root Cause
 Insufficient funding support

Root Cause
 Services are limited and specialised

Definition

Respite Care

- Temporary relief that caregivers get from their duties
- Paid or unpaid and provided by trained personnel, agencies, friends, other family members or other caregivers of PWDs



Psychological Support

- Support provided to caregivers in the form of counselling, support networks/groups



RESEARCH OBJECTIVE

- Profile of caregivers of persons with disabilities
- Respite care needs and service gaps
- Characteristics predicting use of respite care
 - Profiles of caregivers/child
 - Stress levels
- Implications for service planning and programme implementation

METHODOLOGY

Qualitative

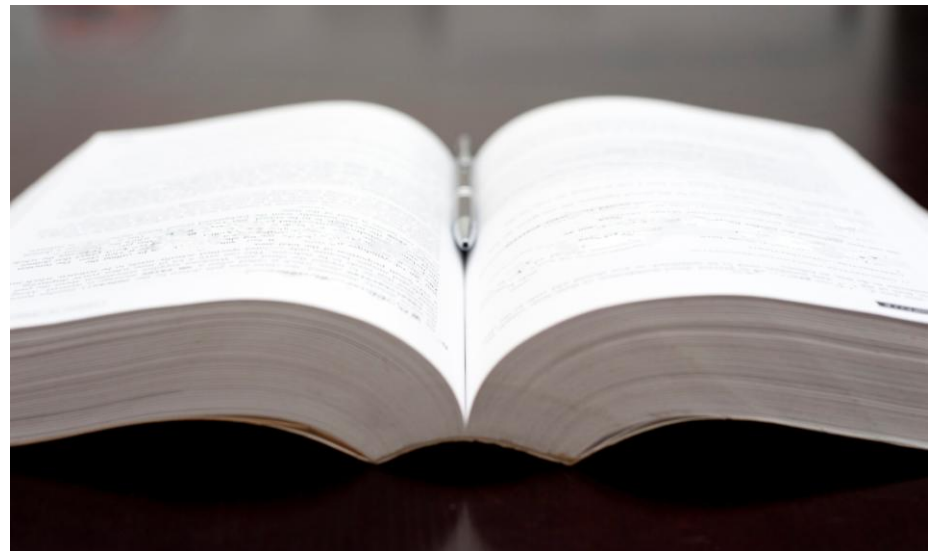
- 6 Focus Group Discussions (n=33)
- Capture ideas of what respite care meant, service gaps, and adequacy of services in meeting needs

Quantitative

- Stratified Sampling
- 1,600 anonymous surveys to EIPIC, SPED and Adult Services
- n=925

Instruments

- Caregiver Strain Index 12 (CSI)
- General Health Questionnaire 12 (GHQ)
- Kessler 6 (K6)



LIMITATIONS

- Cross-sectional survey – lack of contextual information
- Representation issues
 - No registry
 - Care recipients accessing services

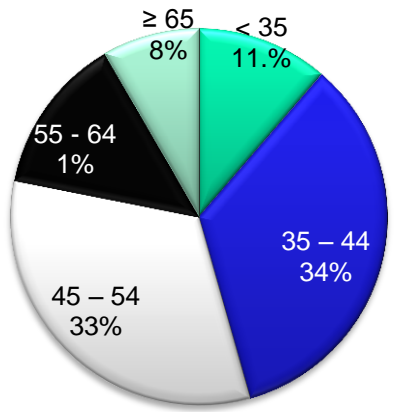
LITERATURE REVIEW

Substantial research showing

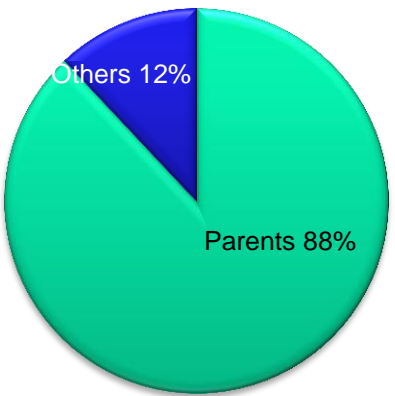
1. Parents of child with special needs experiencing higher levels of parenting stress
2. Positive effects of respite care
3. Variables affecting respite care use are
 - Severity of child disability
 - High level of stress
 - No. of people in family

Profile of Survey Respondents (n=925)

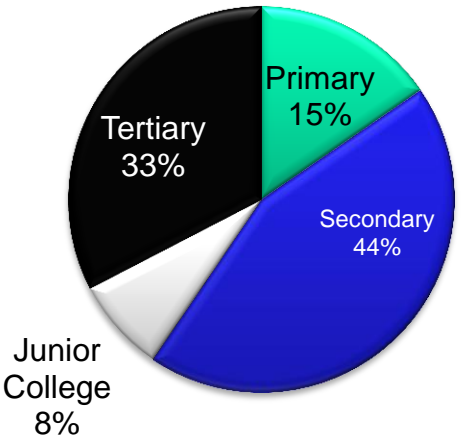
Age of Respondent (846)



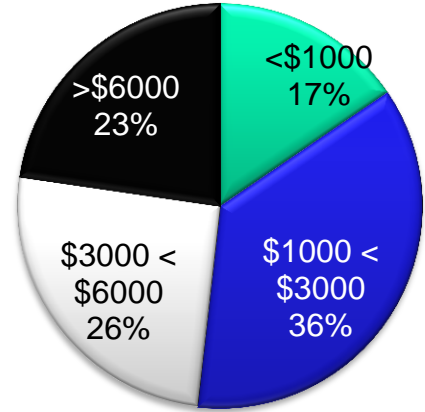
Relationship to Child (896)



Education level (925)

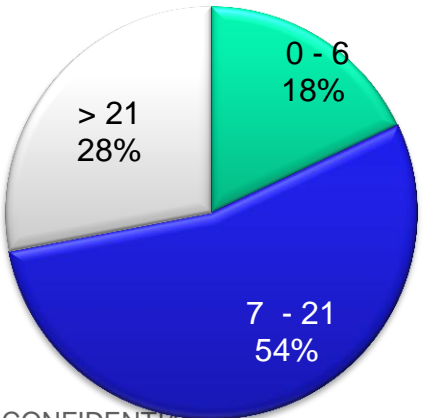


Household Income (886)

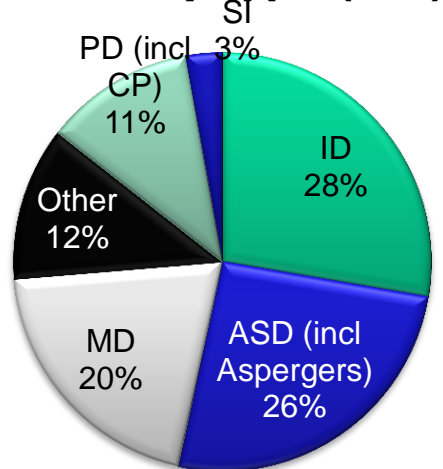


Profile of Child with Disability (n=925)

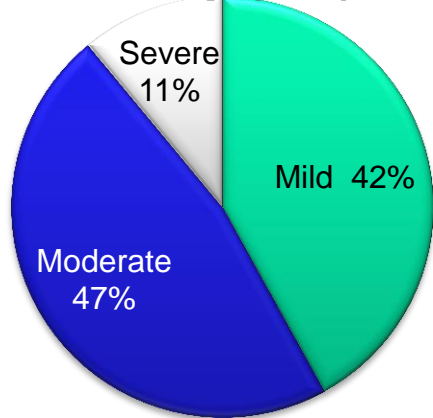
Age of child (821)



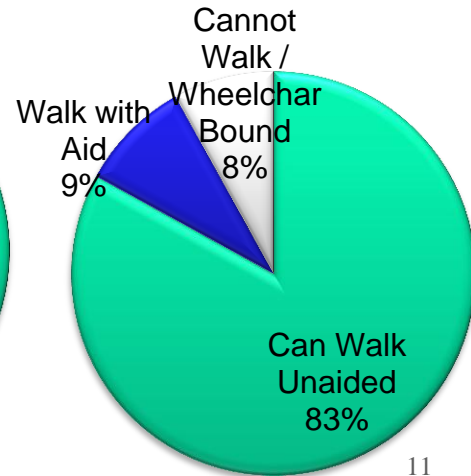
Disability Type (867)



Level of Disability (871)



Mobility of the Child (895)



FINDINGS

Awareness of Caregivers

- Basic understanding of Respite
- Majority learned of it from social services personnel

Important Factors in Respite Care Services

Important to Caregivers (In Order of Importance)	Important %
1. Child Safety	72%
2. Affordability	70%
3. Trained Personnel	59%
4. Home Security	39%
5. Support Services for Caregivers	39%
6. Convenience / Proximity	38%
7. Easy access to public transport	34%

Mode of Respite Care Services

Acceptable Mode of Respite Care to Caregivers	Acceptable %
1. Day care centre	86%
2. Residential Home	59%
3. Trained worker comes to your own home	49%
4. Someone else's' home (Friends/relatives/neighbours/another caregivers)	32%

Caregivers preferred Respite Carer Profiles	Preferred %
1. Trained/Social Workers	64%
2. Friends & Relatives	20%
3. Other Caregivers	16%

Situations Caregivers need Respite Care

Situations where Caregivers Need Respite Care	Need %
1. Feeling unwell physically	86%
2. Running out of energy / exhausted / burnt-out	80%
3. Care for another dependent who is ill	78%
4. Psychologically overwhelmed	78%
5. Crisis situation such as the death of a family member	77%
6. Short break / Breathing time	70%
7. Have overseas trip	61%
8. Holiday	55%
9. Change domestic worker	54%
10. Other situations	66%

Caregiver Stress & Psychological Well-Being

- Poor mental health among caregivers
 - 62.3% strained (by CSI average)
 - 36% psychologically distressed (by GHQ)
 - 10% (by K6 criteria)
- 65% indicated that the actual caregiving duty is heavy
- 63% indicated that they felt burdened



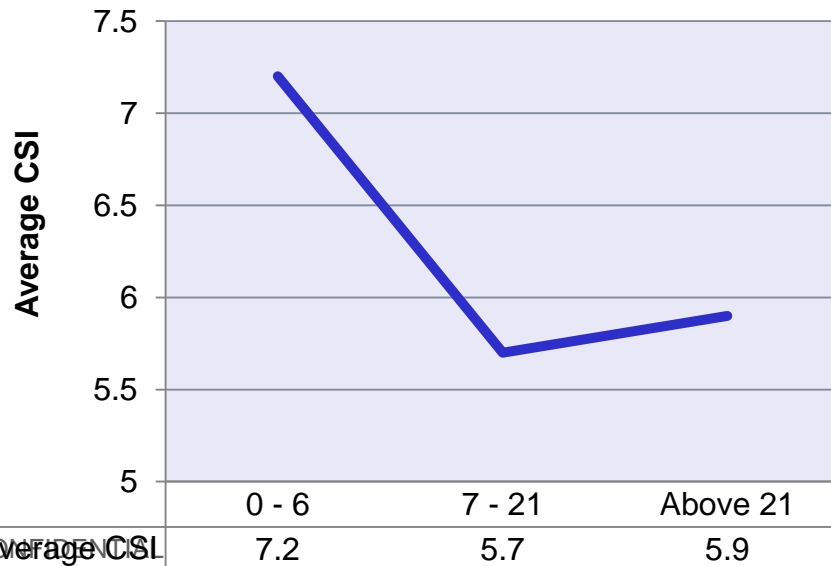
Factors Affecting Caregiver Stress & Psychological Well-Being

Age of Child

The younger the child the higher the stress index

"...I don't even know what is ASD! Maybe I was still in a denial stage, I cannot understand that he has this problem 'cause he looks so normal."

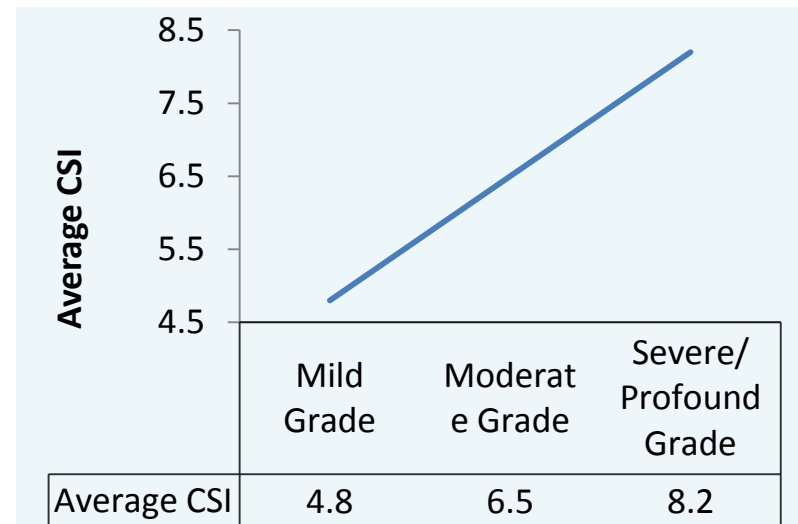
"So when it comes to my parents, my mom and my sis, it's very difficult to tell them...If I mention to them, they are more freak off than him. He is normal, they keep on insisting that he is normal, why am I so over worried, like put him into all these kind of programmes, seeing psychologist... why am I overdoing it..."



Level of Disability of Child

Higher severity higher stress index

"From young he was very violent. He bites, pinches, pulls my hair... I don't have energy to look after him anymore. He is very big very strong. If he gives me one push, I am finished and just fall..."



Factors Affecting Caregiver Stress & Psychological Well-Being

Type of Disability

ASD, MD associated with higher levels of stress

“...I’ve had a stressful episode where my son attacked me for about less than one minute; my whole day is wasted. Do you know what it feels like to be attacked by somebody bigger than you, someone you have been taking care of? Ah, he’s grabbing at you, kicking you, doing stuff like that? It only happened for less than a minute, but it will take a few days for me, for the scars to recover and every time I pick up my shirt or my handbag, it’s going to hurt my back because of the way he attacked me. Don’t talk about the trauma, don’t talk about the fear, don’t talk about anything else.”

Income and Education

Low Income and higher education higher stress index

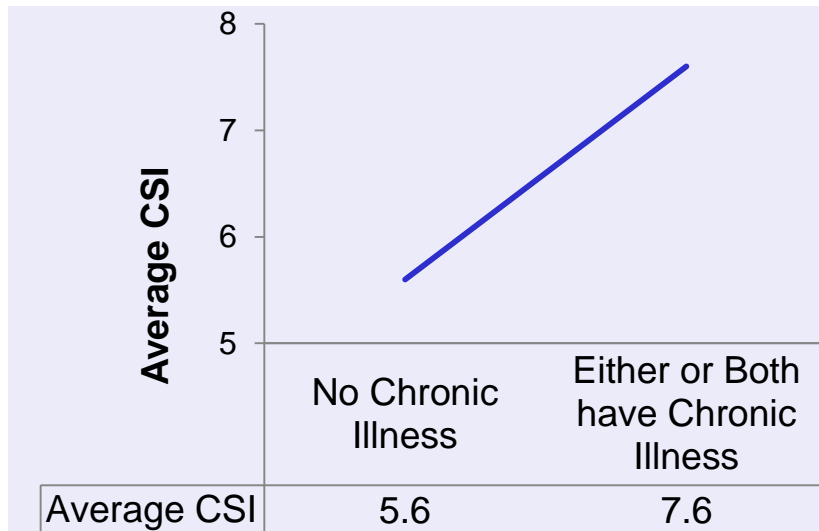
“The 1st year was difficult for me. ‘Cause he was my oldest son so when he came it was very idealistic...when we found out that he has Autism the world crumbled.”

Factors Affecting Caregiver Stress & Psychological Well-Being

Chronic Illness

Presence of chronic illness associated with higher stress index

“And she sees doctor every month, at least once. ‘Cause she sees for her eye, for her ear, she sees her paediatrician every year, various okay, various. So, imagine how much money is being involved..”

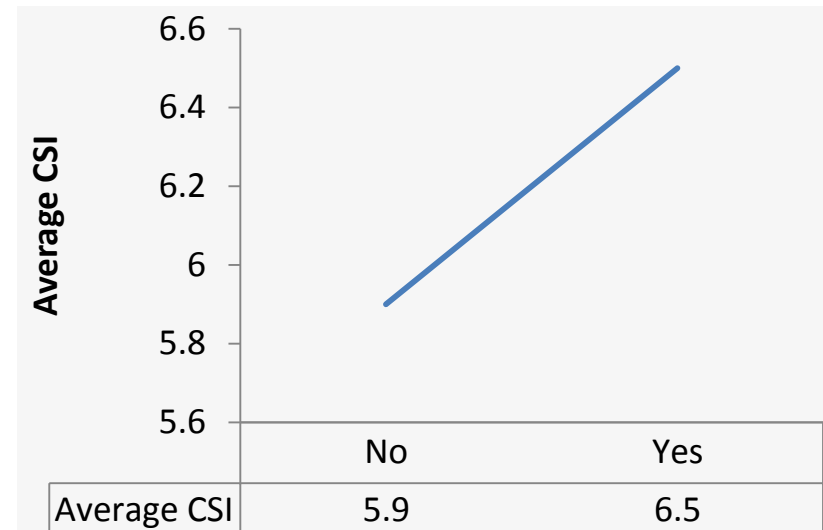


Foreign Domestic Worker

Caregivers with FDW had higher average stress index

“I am so tired of the maid. You know I wish not to have a maid. I (have) no choice so I tried for 2 years but I cannot carry on. It is very, very, tiring. Because I am working full-time you see.”

“I (am) scared after that I come home he call(s) her mother..”



Caregiver Stress and Need for Respite

- Caregiver stress predicts need for respite
- The need for respite care are mainly predicted by caregiver variables rather than child's
 - Respondent has chronic illness
 - Higher education
 - Foreign domestic workers



RECOMMENDATIONS

Areas to explore

Programmes
caregiver-
centric

Psychological
Support
Programmes

Emergency
situations

Support for
chronic illness

FDW

Support Post-
Diagnostic

Awareness: Be
Pro-active

Assessment ,
Intervention and
Screening

Further studies

Thank you