

Science of Broadening Participation of Women in Science and Education
Fields and the Workforce

At Ito Campus, Kyushu University (November 16, 2015)

Mothers of Children with Disabilities and Care for Such Mothers

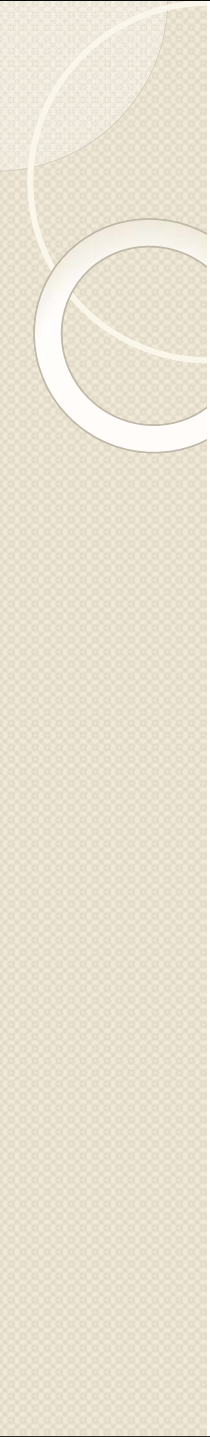
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“All referenced material used for this presentation
were translated from Japanese”



Self Introduction

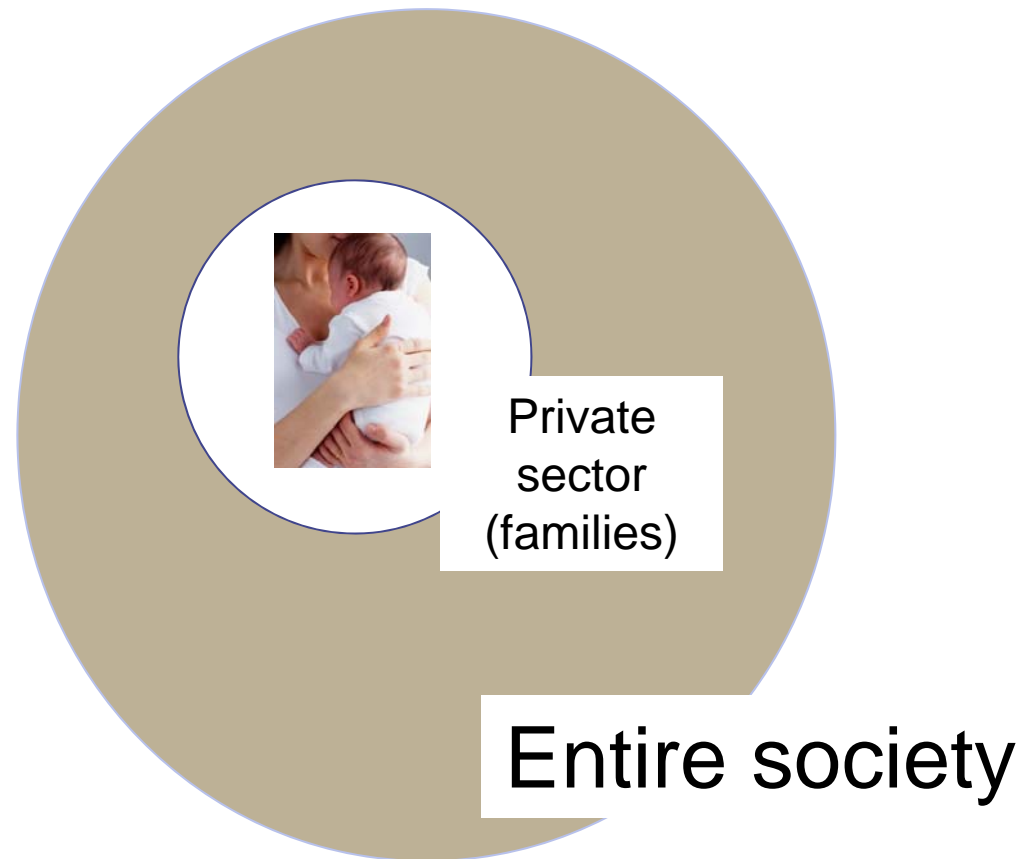
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- Specialty: Sociology
(Family sociology/welfare sociology/
local community sociology)
 - Research themes :
Research on family welfare problems
and local community support
 - * Care for senior citizens/parenting/
rearing of children with disabilities

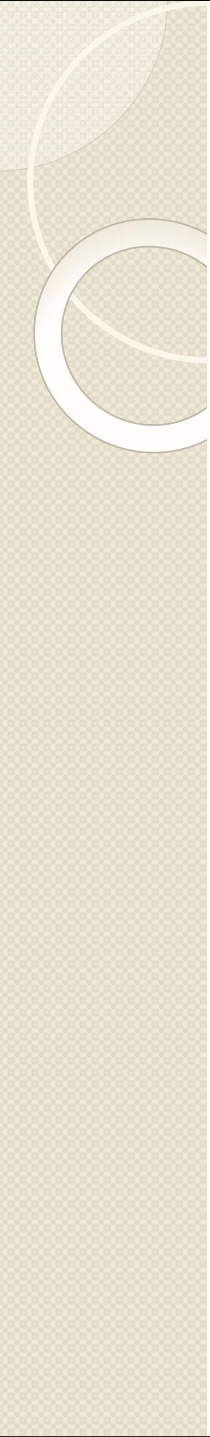


Families of Children with Disabilities

Progress in the Socialization of Parenting

- Who plays the main role in parenting?



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- Socialization of parenting
 - Measurement from 2 angles: Socialization of “parenting work”, and Reallocation of “parenting costs” (Funabashi, 2006, p. 36)
 - High level achievement of socialization of “parenting work”
 - Public sector . . . Quantitative expansion
(political agenda)
Diverse services
 - Private sector . . . Diverse parties involved
Diverse services

- However, some families get left behind the trend of socializing parenting.



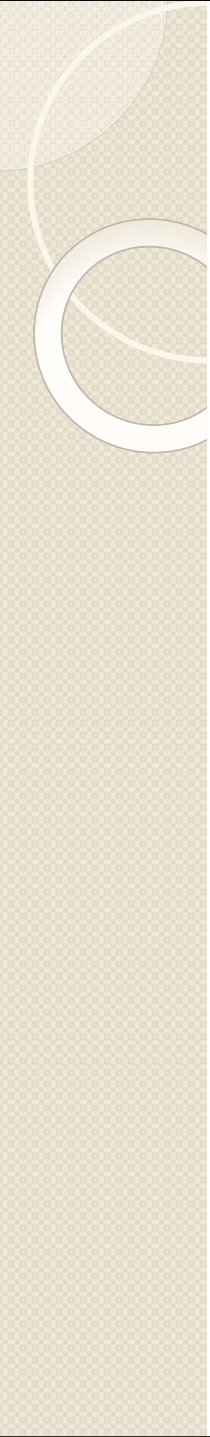
Families of children with
disabilities/diseases

- What has made me aware of problems faced by families of children with disabilities/diseases?



- Encounter with an organization of children with disabilities
- My daughter's disease (eating disorder)



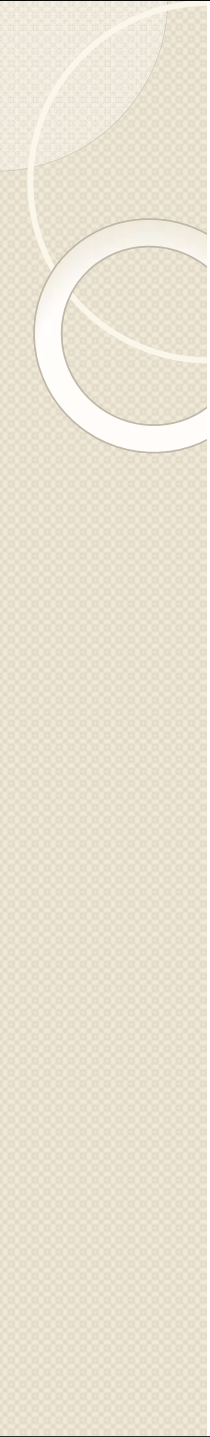


Families of Children with Disabilities Missing Out in the Trend of Parenting Socialization

- Public sector --- It cannot be assumed that families of children with disabilities are also included as eligible receivers of parenting support. (Yamashita, 2012a)
- Private sector --- Few support programs give sufficient consideration for families of children with disabilities. (Yamashita, 2012b)
- Social norms --- Pressure to fulfill the role of achieving the wellbeing of children with disabilities (Fujiwara, 2006)



Research on Mothers of Children with developmental disorders

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- Research target . . . Families of children with developmental disorders
 - Research contents . . .
 - Analyses of actual situations of families of children with disabilities
 - Analysis of living difficulties faced by mothers (Yamashita & Kawano, 2013)
 - Analysis of social support for mothers (Yamashita, 2014)
 - Analysis of actions taken by mothers to solve problems (Yamashita, 2013)
 - Analysis of mothers' social participation and living difficulties (Yamashita, 2015)
 - Examination of support measures for families of children with disabilities
 - Analysis of actual situations of public support (Yamashita, 2012a)
 - Analysis of parenting support organizations run on residents' own initiative (Yamashita, 2012b)

Findings from Analysis of Living Difficulties

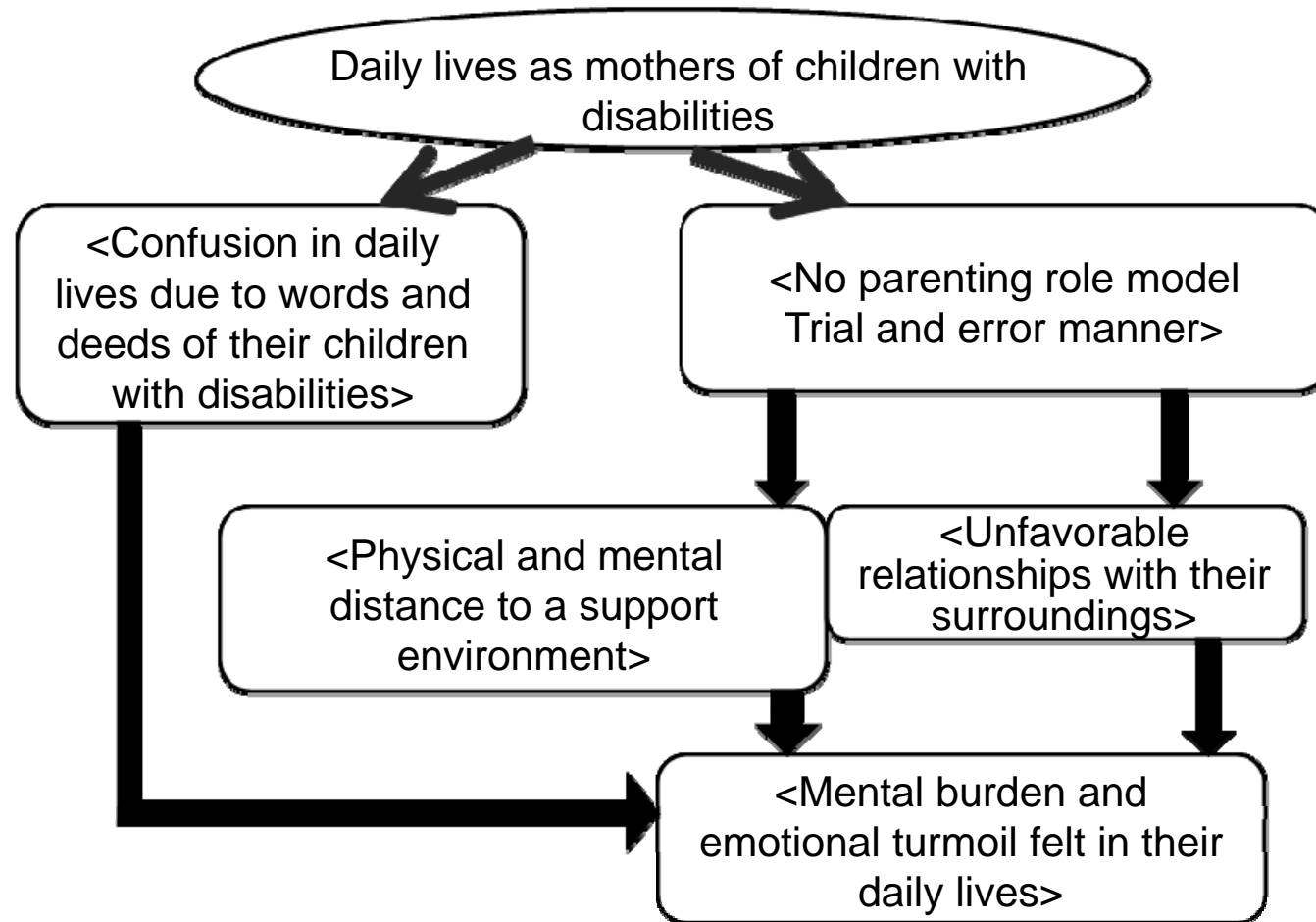
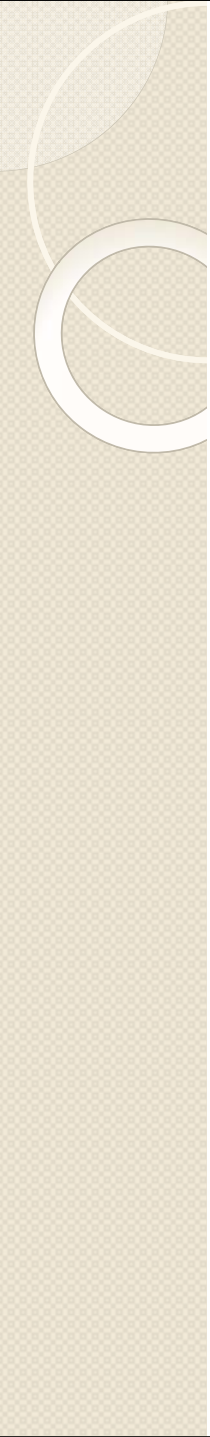


Fig. 1. Conceptual model: Mutual relationships of living difficulties

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- Although mothers are asking for parenting support, they cannot receive it.
 - Even though mothers themselves feel living difficulties, they tend to put priority on taking care of their children.

<Violence/Panic>

- <Children breaking things at home>

My child broke an electric fan and other household electric appliances... He also shouted for me to die. (E: August 9, 2011)

My child screamed, shouted, and went into a wild rage. He yelled at me, "Shut up!" and "You, idiot!" He also broke some windows and doors. (A: August 9, 2011)

- <Children acting violently toward their mothers>
- <Children feeling panic>

<Physical and Mental Health>

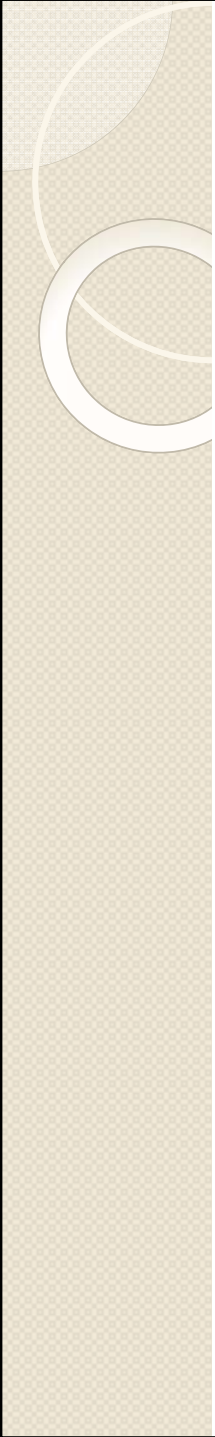
- <Poor physical condition>
(Since keeping unusual hours,) I'm totally exhausted. (N: August 9, 2011)
- <Poor mental condition>
I feel like I'm losing my mind. (C: July 8, 2011)
Oh, me too. (Her child doesn't sleep at night, either.) So I had to go to the hospital. (B: July 8, 2011)



Findings from Analysis of Social Support

- Variety of support sources is narrow. Does this mean that such support is effective only to parents in similar situations?
- Support contents are limited. (Emotional support in most cases)

(Mothers manage to cope with their situations, receiving only emotional support from those in similar situations (e.g. parents' association))

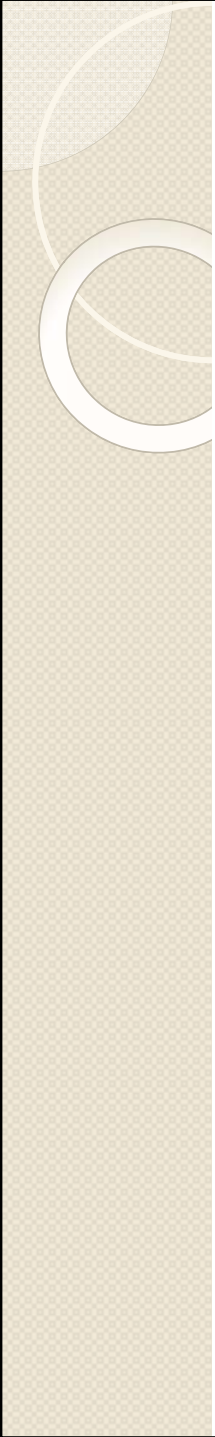
- 
- Parents' association (making mothers feel that their feelings are understood [that they are receiving sympathy, and that they are not alone])

Although this may sound strange, I'm really happy that I can meet those with whom we can share our feelings so much. I've never experienced this before. (Y: July 13, 2012)



Mothers' Situations Identified by Two Research Projects

- Extreme Isolation
 - Even though mothers are asking for parenting support, they cannot receive it, which only causes them more stress.
 - Mothers' own difficulties tend to become latent, as if there were no such difficulties.
 - Mothers manage to cope with their situations, receiving only emotional support from those in similar situations.



In the U.K., an advanced country
regarding support for carers, do
mothers experience similar
difficulties?

(According to 2013 research)

- Excellent programs and political measures for supporting carers (public sector)
- Excellent organizations for supporting carers (private sector)
 - Policy recommendation, awareness programs, surveys & research
 - Diverse, excellent, practical services

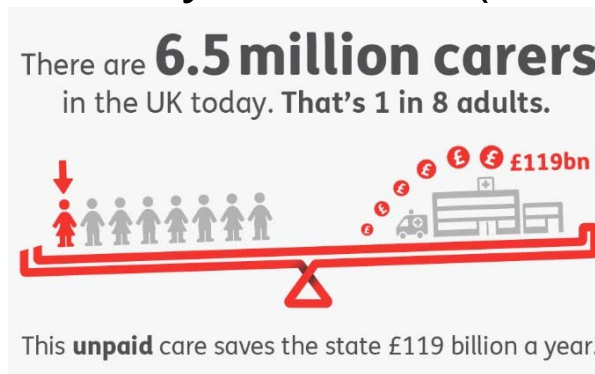


- Do carers still experience difficulties (despite such diverse, excellent programs and services)?

- Group meetings for mutual self-help group
- Comparison with an association of mothers of children with disabilities in Miyakonojo City, Miyazaki
 - Differences (clear demands)
 - Clearly demanding what they need as carers
 - Similarities (difficulties)
 - Little support from experts
 - Children's problems (violence, smoking, drugs)
 - Isolation
 - (Feeling like fighting anytime and anywhere)
 - (Only parents' associations are a lifesaving place.)



- Similarities between Countries Developing a Policy for Providing Carers with Advanced Support
 - The rationale for providing public support for carers is based on their contribution toward reducing public costs. There is an evaluation and recognition that a large part of the original burdens borne by public expenses is covered by carers' voluntary actions. (Kinoshita, 2013)



<http://www.carersuk.org/>

- Does the problem lie in the recognition that care is the family's responsibility?



Conclusion



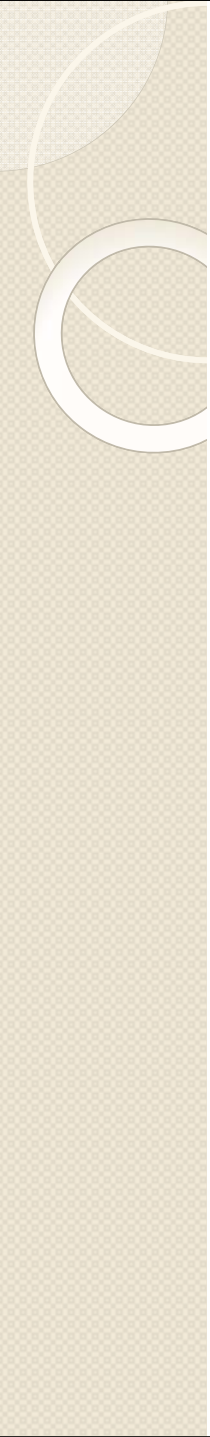
Mothers of Children with developmental disorders

- Lack of social support . . . People seriously affected by such a lack

Until I participated in the parents' association, I had not been able to shed any tears. The group enabled me to display my emotions.

Until I participated in the parents' association, I had not been able to share my feelings with anyone, I was very happy about it.

Do the above statements mean that all they can obtain is just mutual support from/to those in similar situations?

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- What has caused this lack of support?
 - (1) Societal pressure given to the role of achieving the wellbeing of children with disabilities (Fujiwara, 2006)
 - (2) Social norms and structure in which it is taken for granted that mothers are responsible for children's care (gender structure)



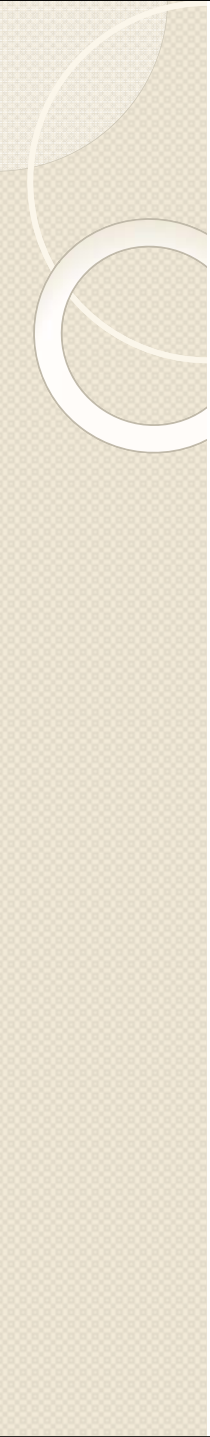
(3) Characteristic properties of developmental disorders

- In case of children with a developmental disorders that does not involve mental retardation, they are often regarded as merely mischievous or selfish based on their actions. Many such children are scolded very much. (Negoro, 2011, p. 334)
- Since development disability itself is difficult to identify, problems of children with such disability are often shifted to those of upbringing and disciplining, causing peculiar parenting difficulties. (Ishizaki, 2010)



Toward Addressing the Lack of Social Support

- (1) Necessity of socialization of care for carers

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- “We are always in a mesh of relationships; we are never fully independent and self-sufficient, but we always stand in relationships of dependence and interdependence.” (Kittay, 2011, p. 47)
 - “The equal importance of dependent and dependency worker (individual who provides care for a dependent) is demanded by an ethic of care itself.” (Kittay, 2011, p. 50)
 - There is a need to find measures for social sharing of care. (Nakane, 2005, p. 61)

- (2) Women's participation



- In terms of discussion and implementation of measures for women's participation, more progress has been made in the public sector than in the private sector.
- It's necessary to ensure that problems in the private sector are considered simultaneously.



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