

# Family, Care, and Independent Living: A Study of Gender Perspective

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Session 2 (Family and

Independent Living of Persons with Disabilities in the Community)



# Outline

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1. Frequency of Independent Living in the Community
2. The Situation of People with Disabilities and their Family
  - (1) Living Situation
  - (2) Income
  - (3) Family and Care
  - (4) Life Changes Caused by the Coronavirus Disease 2019 Pandemic
3. Support Obligation
4. Conclusion

# 1. Frequency of Independent Living in the Community

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In recent years, there have been more examples of people with severe intellectual disabilities and those in need of medical care, as well as those with physical disabilities, living independently in the community.

Teramoto (2008), (2015)

Ebihara (2015)

Hiramoto (2017)

Movies:

“Michikusa” (2019) <https://michikusa-movie.com/>

“Independent Living” (2020) <https://bunbunfilms.com/filmil/>



## However...

- A question arises: "Why do you want to live an independent life when you have a family?"
- In reality, many people with disabilities live with and are financially dependent on their families and personally dependent on their mothers.
- The phrase "after the death of a parent" indicates an understanding of the areas which a parent should care for and support. It also expresses the parent's determination to take care of the child as much as possible, but to admit the child to the facility when they are unable to take on that care.
- Behind this is the existence of a legal system that presupposes that the family cares for and supports the individuals with disabilities.

## 2. Situation for People with Disabilities and Their Families

### (1) Living Situation (Where do they live)



#### Detailed Data Number of Persons with Disabilities (estimate)

		Total	Persons living at home	Persons accommodated in facilities
Children/adults with physical disabilities	Younger than 18	72,000	68,000	4,000
	18 or older	4,195,000	4,125,000	70,000
	Unknown age	93,000	93,000	-
	Total	4,360,000 (34)	4,287,000 (34)	73,000 (1)
Children/adults with intellectual disabilities	Younger than 18	225,000	214,000	11,000
	18 or older	851,000	729,000	122,000
	Unknown age	18,000	18,000	-
	Total	1,094,000 (9)	962,000 (8)	132,000 (1)

		Total	Outpatient	Inpatient
Persons with mental disorders	Younger than 20	276,000	273,000	3,000
	20 or older	3,916,000	3,618,000	298,000
	Unknown age	7,000	7,000	0
	Total	4,193,000 (33)	3,891,000 (31)	302,000 (2)

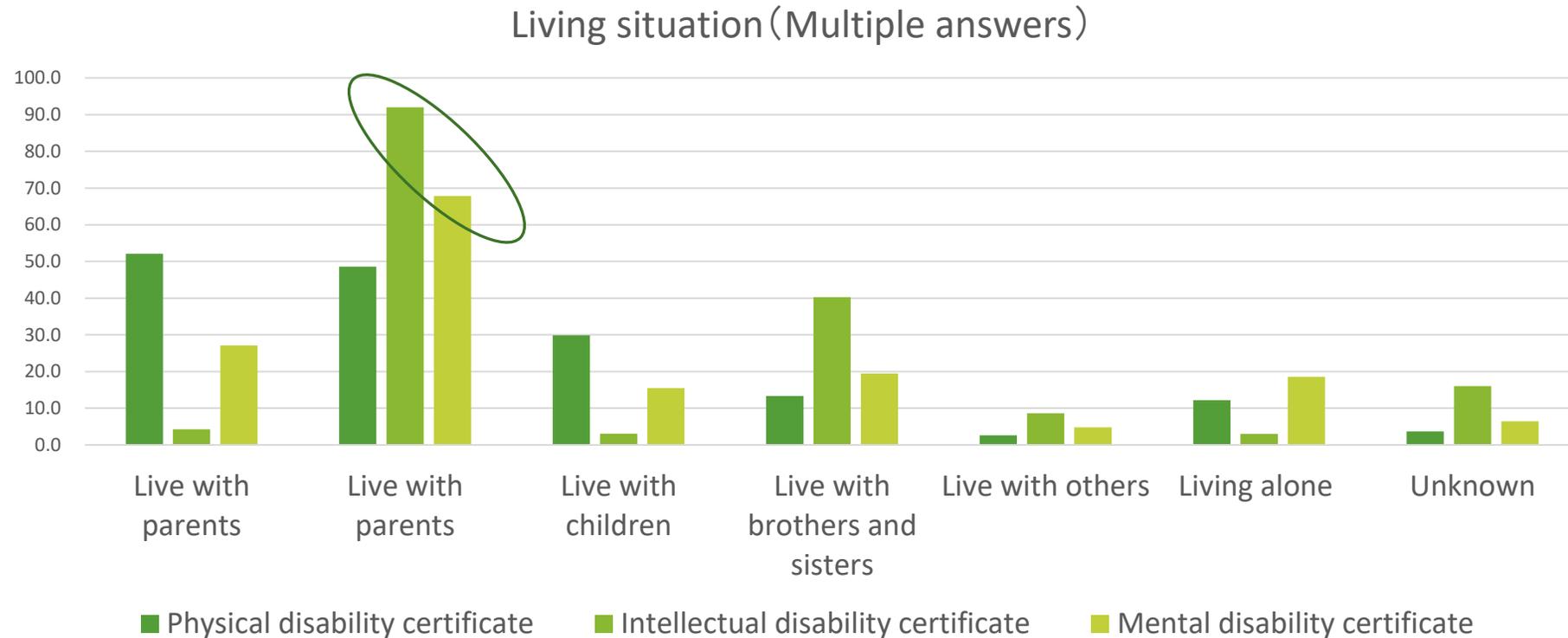
# (1) Living Situation (Where do they live )

	People with physical disabilities (18 or Order)	People with intellectual disabilities (18 or Order)	People with mental disorders (20 or Order)
Persons accommodated in facilities/Inpatient <sup>1</sup>	1.6% (accommodated in facilities)	14.3% (accommodated in facilities)	7.6% (Inpatient)
Persons living at home	98.4%	85.7%	92.4%
Persons living at a group home <sup>2</sup> (among those living at home)	2.4%	14.9%	4.4%

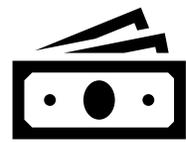
<sup>1</sup>Ministry of Health, Labour and Welfare (2020a) <https://www.mhlw.go.jp/english/wp/wp-hw13/dl/09e.pdf>

<sup>2</sup>Ministry of Health, Labour and Welfare (2018) [https://www.mhlw.go.jp/toukei/list/dl/seikatsu\\_chousa\\_c\\_h28.pdf](https://www.mhlw.go.jp/toukei/list/dl/seikatsu_chousa_c_h28.pdf)

# (1) Living Situation (Who do they live with?)



# (2) Income



Average income (per one month) of disability certificate (age 18~64)



Ministry of Health, Labour and Welfare (2018) [https://www.mhlw.go.jp/toukei/list/dl/seikatsu\\_chousa\\_c\\_h28.pdf](https://www.mhlw.go.jp/toukei/list/dl/seikatsu_chousa_c_h28.pdf)

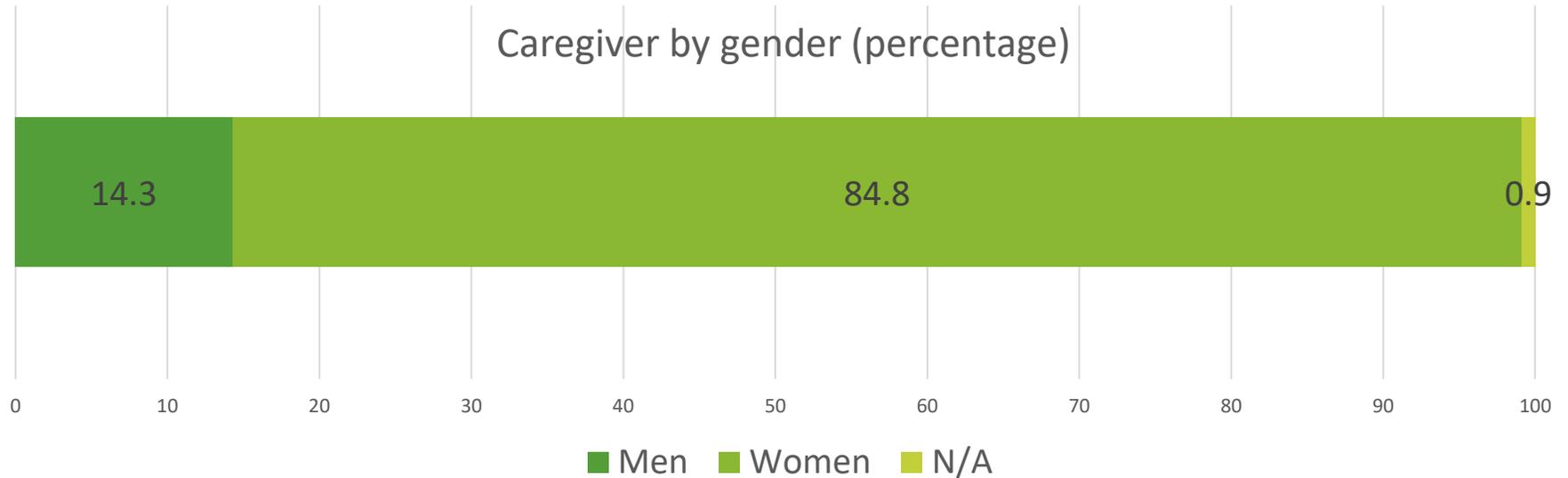
## \* Status of Livelihood Protection Receipt

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	Physical disability certificate	Disability certificate	Mental disability certificate
Persons who are not on welfare	70.4%	77.6%	63.6%
Persons who are on welfare	2.9%	3.7%	0.0%
Unknown	19.8%	25.9%	19.4%

Ministry of Health, Labour and Welfare (2018) [https://www.mhlw.go.jp/toukei/list/dl/seikatsu\\_chousa\\_c\\_h28.pdf](https://www.mhlw.go.jp/toukei/list/dl/seikatsu_chousa_c_h28.pdf)

### (3) Family and Care



	Men	Women	N/A
Total number of caregivers (N=448)	64	380	4
Percentage(%)	14.3	84.8	0.9

## \* Support that Caregivers Believe is Necessary

1. A service that allows care recipients to continue their lives while receiving care <b>after the death of their parents</b> or family	61.8%
2. A service that can be used <b>in an emergency</b> and <b>does not change the life</b> of the care recipient	46.9%
3. Information service that is useful for caregivers	39.5%

## (c.f) For Disabled Children Who Need Medical Care

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- The main caregivers of those aged 0-19 who need medical care tend to be their mothers (94%).

- Difficulties reported by mothers. (Free description)<sup>1</sup>

“There is no place to leave the child and no one to take care of them in an emergency, such as when I or the other children are ill.”

“There is no place to leave the child confidently when something happens to me. Relatives cannot be relied upon in their advanced age. I'm always worried because I don't know what to do during these times.”

<sup>1</sup>Ministry of Health, Labour and Welfare, (2020b) <https://www.mhlw.go.jp/content/12200000/000653544.pdf>

## (4) Life Changes Caused by the Coronavirus Disease 2019 Pandemic

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<b>Longer care time<sup>1</sup></b>	<b>37.0 %</b>
Increasing their own fatigue and stress due to providing long-term care	36.0%

<sup>1</sup>Average 5.7 hours / day

Carers Japan (2020)

# \* Reduction in the Use of Formal Support Services

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(Free description)<sup>1</sup>

“Not receiving services because of fear of infection.”

“We were refused the planned short stay.”

“The facility requested us to refrain from using the service and shorten the usage time.”

“Moving support has been discontinued, and the rhythm of life for the child with a disability has become unstable.”

<sup>1</sup>Carers Japan (2020)

cf. “Formal services were reduced or eliminated” (87%). “Respite services were available.” (13%)

(Inclusion International 2021: 23)

# Brief Summary

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(Living situation)

- 92.0% of people with intellectual disabilities and 67.8% of people with mental disabilities live with their parents.

(Income)

- Income is concentrated in the "60,000 yen or more and less than 90,000 yen" **bracket** (61.9% for people with intellectual disabilities, 62.0% for people with mental disabilities, 42.0% for people with physical disabilities).

(Family and care)

- Most of the care for persons with disabilities is carried out exclusively by females (**i.e.**, mothers).

(Life Changes Caused by the Coronavirus Disease 2019 Pandemic)

- The burden of care for mothers has increased: “There is no place to rely on in an emergency.”
- People with intellectual or mental disabilities are personally and financially dependent on their mothers and families.
- Realistic “after the death of parents” problem.

# 3. Support Obligations

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- \* Regulations regarding protectors

- People with intellectual disabilities

Act on Welfare of Persons with Intellectual Disabilities (Article 15 (2))

People with intellectual disabilities are required to have protectors. In many cases, family members play the role of a protector.

- People with mental disabilities

The Act on Mental Health and Welfare for the Mentally Disabled (Amendment, 2014) abolished protectors provision, but the burden on the family remains.

(Iwai 2013)

## Cf. Civil Code (Part IV Relatives)

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(Duty to Live Together, Cooperate, and Provide Mutual Assistance)

Article 752: A husband and wife shall live together and provide mutual cooperation and assistance.

(Supporter under Duty)

Article 877 (1): Lineal relative by blood and siblings have a duty to support each other.

## 4.1 Conclusion - Difficulty of Shifting to Independence Living

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- Strong norms that “family [mother] should support and care for people with disabilities” and “if family [mother] cannot support and care, they should be admitted to a facility.”
  - Persons with disabilities have Insufficient experience and local communities have an undeveloped acceptance system.
- Insufficient income security (insufficient pension, low wage)
  - Economic dependence on family
    - ← Avoiding the opportunity to received welfare benefits because of
- Dedication to mother's care (gender role division)
  - Poverty of parents [mothers] of people with disabilities as the parents age.
  - Income of people with disabilities are included in family living expenses

## 4.2 Conclusion - Increase places to depend on

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- “Independence” means increasing the number of places to depend on (Kumagai 2016)

To increase places to depend on:

- Development of laws based on the idea of the Convention on the Rights of Persons with Disabilities
- Income security policy to help both parents and children become financially independent (Tanaka 2020)
- Development of a local acceptance system

→ A system that does not assume “care by parents (mothers)”/”support”/ and changes the perceptions of society and family members

(Supplement)

- Public services that are being developed
- Providing opportunities for experience through “community life support bases, etc.,” location of emergency response system, medical care response system?

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Thank you for your time and attention.

