

Research in Brief



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A Classification of Care Burden on Families with Disabled Members and Social Support for Family Caregiving¹⁾

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The caregiving burden perceived by families with disabled members encompasses psychological, social, and economic challenges. This study classifies, by employing Q-methodology, the subjective perceptions of caregiving burden among families of children with disabilities into different types and elucidates the trends associated with each type. The care burden on families with disabled children is categorized in this study into three types: 'proactive response', 'concerned-for-the-future-of-disabled-children', and 'voicing-for-support'. After examining classifiable commonalities in respondents' subjective perceptions about caregiving burden, we offer several suggestions. First, a formal support system should be established that provides health check-ups and health support to family caregivers of disabled individuals. Second, there is a need for universal support and crisis-response assistance for families with disabled members. Third, long-term measures should be pursued to enhance the user's trust in the quality of social care. Fourth, a trustworthy system of practical support should be built to assist in the self-reliance of children with disabilities living with their families.

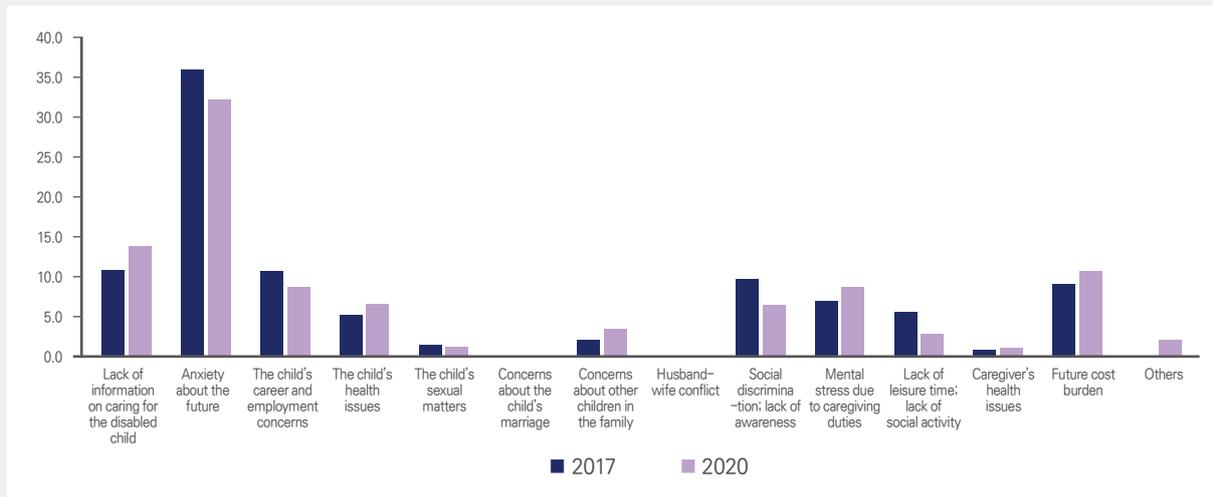
1) This is a reworking of part of *A Study on the Policy for the Families Caring for People with Disabilities* (2021)

Introduction

The burden of caregiving that families with disabled individuals perceive consists of not only the psychological stress that the caregiver in the family experiences but also the socioeconomic burden involved and the burden arising from the caregiving duties adding to other family responsibilities.

The National Survey of People with Disabilities found that the largest percentage of surveyed families cited “an undefined feeling of anxiety about the future” as the first of the difficulties they face caring for their disabled children. This concern ranked above other challenges such as ‘lack of information needed for caregiving’, ‘child’s future employment’, and ‘burden of future costs,’ thus highlighting how significant the psychological anxiety is that families with disabled members feel (see Figure 1).

[Figure 1] Difficulties that families with disabled children experience



Note: Caregivers of children with disabilities aged 20 or younger.

Sources: 2017 National Survey of People with Disabilities. KIHASA. <https://data.kihasa.re.kr/kihasa/kor/databank/DatabankList.html>

The Q-methodology as employed in this study is found instrumental in that it allows for identifying the subjective perceptions that families of disabled members have of caregiving burden and classifying them around dominant commonalities, thereby ascertaining predefined perspective categories and even broadening the spectrum of perspectives on the topic.

Survey of subjective perceptions of caregiving burden among families with disabled members

This study employed Q-methodology to classify and analyze the subjective perceptions that families of individuals with disabilities have about caregiving burden. Q-methodology is a research approach that takes as a sample a set of statements generated from interviews with participants and a literature review. These statements (Q-sample), constructed around the research topic at hand, are presented to participants (P-sample), who are then to rank-order them according to their level of agreement or disagreement. This is followed by the sorting of participants into groups through a factor analysis of the scores assigned to the statements. A Q-sample, a batch of statements reflecting the state of affairs of a given topic, should be constructed so that they contain as wide a variety of viewpoints as possible about the topic. The significance lies less in how large the sample is than in ensuring that the statements encompass a diverse range of thematic aspects related to the topic.

[Figure 2] A survey of subjective perceptions of caregiving burden among families with disabled members



The Q-statements were constructed through focus-group interviews with primary family caregivers of children with disabilities and a literature review of research articles employing qualitative approaches to the caregiving burden on families with disabled members. In the process, we identified a set of thematic categories of subjective perspectives concerning the caregiving burden on families with disabled members and refined the statements. We finalized a total of 31 statements through consultations with external experts.

[Table 1] Thematic categories of subjective perceptions of caregiving burden among families with disabled members

Thematic categories	
• As a parent, I feel sorry for my other children	• Care burden concentrated on mothers (health burden, the difficulty of sharing caregiving duties, etc.)
• Coming to terms with disability in the family	• Isolated and severed from social connection since becoming a parent of a disabled child
• Sources of support: self-help group, family, etc.	• Psychological difficulties (psychiatric treatment)
• Public perception	• Social care support needed in raising children with disabilities
• In despair about the disability of the child	• The direction of social care support (future)
• Discontent about public support	• Mother's career pause (There's no me); there's no life of my own apart from the child.
• Cost burden due to caregiving	• Anxiety about the future
• The reality of having to go on getting the disabled child treated	• Others

Source: Yi, Min-Gyeong et al. A Study on the Policy for the Families Caring for People with Disabilities. 2021. KIHASA

The P-sample consists of 25 primary family caregivers of children with disabilities, with whom we conducted in-person interviews.

[Table 2] P-sample composition (parent's age; type of the child's disability)

(Unit: individual)

		Parent's age				
		30~39	40-49	50-59	80+ (Grandparent)	Total
Child's disability type	Physical disability; brain legion	2	2	2	-	6
	Hearing disability	-	-	1	-	1
	Intellectual disability	1	6	2	1	10
	Autism spectrum disorder	1	5	1	1	8
Total		4	13	6	2	25

Source: Yi, Min-Gyeong et al. A Study on the Policy for the Families Caring for People with Disabilities. 2021. KIHASA

[Table 3] P-sample composition (parent's age; age of the disabled child)

(Unit: individual)

		Parent's age				
		30~39	40-49	50-59	80+ (Grandparent)	Total
Child's age	Preschool age	2	1	-	-	3
	School age	2	11	-	1	14
	Over high-school age	0	1	6	1	8
Total		4	13	6	2	25

Our factor analysis of the rank-ordered statements, each assigned a score according to respondents' level of agreement or disagreement, categorized the family caregivers into three distinct types.

[Table 4] Statements with high agreement/disagreement levels, by type

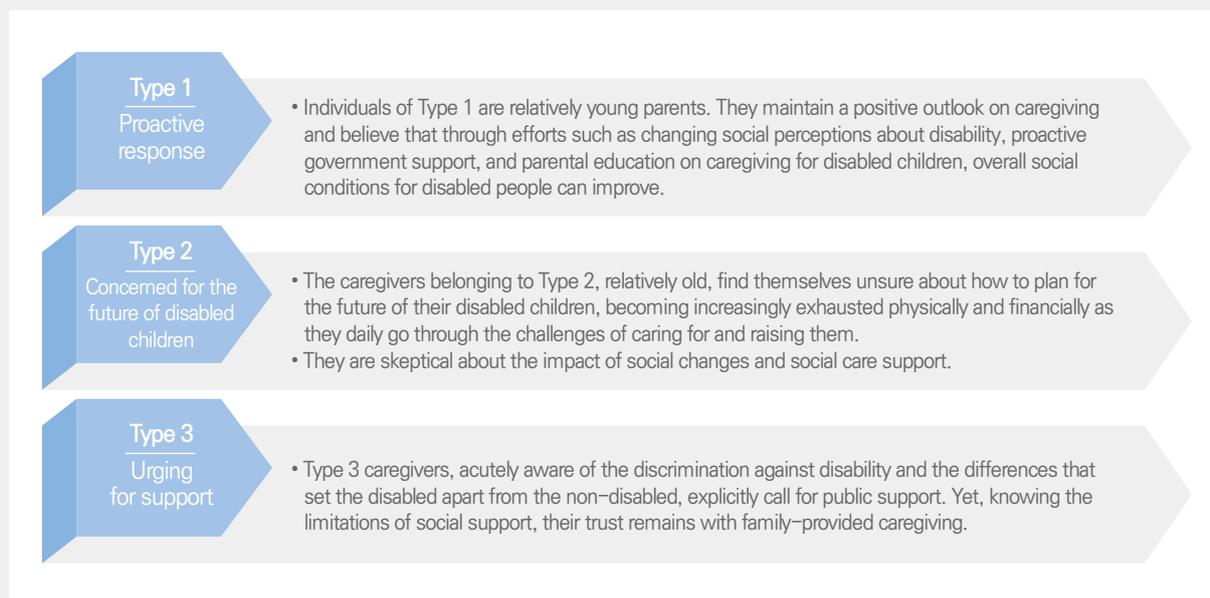
	P-sample	Statements with high agreement/high disagreement
Type 1	<ul style="list-style-type: none"> • P-sample: 8 participants • Average parental age: 42.3 years • Disabled children <ul style="list-style-type: none"> – Average age: 12.3 years – Disability types: physical disability; developmental disability – Daily living activities support: support needed in most or all areas of daily living activity (6 out of 8 participants) 	<Statements with high agreement levels>
		<ul style="list-style-type: none"> • Although disabled people are slow and different, it is important that society at large perceives them with an understanding mind as fellow social members. (Z=1.854) • Proactive policy measures are needed, such as introducing a system where the state takes responsibility for child care. (Z=1.51) • There is a need for education for parents-to-be. Z=1.393) • There is a need for support for the care of disabled children, regardless of the family's ability to afford care costs. (Z=1.391)
		<Statements with high disagreement levels>
		<ul style="list-style-type: none"> • I'm so committed to the treatment and care of my disabled child that I can't afford to look after my psychological and mental wellbeing. (Z=-1.268) • Conflicts continue with family members who do not understand the disability, eventually leading to family breakdown. (Z=-1.339) • The hardest part of caring for a child with a disability is getting my family's cooperation and understanding, and in the end, I have to do it all alone. (Z=-1.47) • I find it hard to open up that I have a disabled family member. (Z=-1.532) • My aspirations and goals fade over time, and I give up on them. (Z=-1.557)

	P-sample	Statements with high agreement/high disagreement
Type 2	<ul style="list-style-type: none"> • P-sample: 8 participants • Average parental age: 52.3 years • Disabled children <ul style="list-style-type: none"> – Average age: 15.6 years – Disability types: physical disability; developmental disability; hearing disability – Daily living activities support: support needed in most or all areas of daily living activity (4 out of 8 participants) 	<p style="text-align: center;"><Statements with high agreement levels></p> <ul style="list-style-type: none"> • The disabled child is my own all right, but sometimes I don't know what to do with the child's behavior. (Z=1.91) • My physical energies drain away over time caring for my disabled child, and I become at a loss for what to do. (Z=1.694) • I doubt that my disabled child will ever become self-sufficient as an adult. (Z=1.365) • It's frustrating that I can't do anything about my disabled child having to live on their own after their parents are gone. (Z=1.239)
		<p style="text-align: center;"><Statements with high disagreement levels></p> <ul style="list-style-type: none"> • The hardest part of caring for a child with a disability is getting my family's cooperation and understanding, and in the end, I have to do it all alone. (Z=-1.072) • It's unreasonable to expect families to locate the necessary information and access disability support services on their own. (Z=-1.259) • I believe that when my disabled child has grown up, our society will have become a better place for disabled people. (Z=-1.542) • Conflicts continue with family members who do not understand the disability, eventually leading to family breakdown. (Z=-1.919) • I find it hard to open up that I have a disabled family member. (Z=-2.2)
Type 3	<ul style="list-style-type: none"> • P-sample: 7 participants • Average parental age: 49.1 years • Disabled children <ul style="list-style-type: none"> – Average age: 16.0 years – Disability types: brain lesion; developmental disability – Daily living activities support: support needed in most or all areas of daily living activity (4 out of 7 participants) 	<p style="text-align: center;"><Statements with high agreement levels></p> <ul style="list-style-type: none"> • Proactive policy measures are needed, such as introducing a system where the state takes responsibility for child care. (Z=2.028) • The parents of disabled children live a life that is different altogether, emotionally and socially, from the lives of parents of non-disabled children. (Z=1.403) • Even if, after we, the parents, are gone, my disabled child receives care from another family member or through public assistance, it won't be comparable to the care I provide. (Z=1.208) • Families with disabled members get socially discriminated against and judged for their disabilities. (Z=1.094)
		<p style="text-align: center;"><Statements with high disagreement levels></p> <ul style="list-style-type: none"> • I have no life of my own apart from caring for my disabled child. (Z=-1.025) • The hardest part of caring for a child with a disability is getting my family's cooperation and understanding, and in the end, I have to do it all alone. (Z=-1.161) • Conflicts continue with family members who do not understand the disability, eventually leading to family breakdown. (Z=-1.522) • I believe that when my disabled child has grown up, our society will have become a better place for disabled people. (Z=-1.741) • Raising a disabled child and raising a non-disabled child are not that different. (Z=-2.253)

Note: A z-value greater than 1 is considered a high agreement level; a value less than -1 is considered a high disagreement level.

The three types that emerged from the classification of caregiving burden are 'proactive-response type' (8 individuals), 'concerned-for-the-future-of-disabled-children type' (8 individuals), and 'urging-for-support type' (7 individuals). Figure 3 illustrates the patterns of perceptions about caregiving burden for the identified types.

[Figure 3] Characteristics of caregiving burden as perceived by family caregivers of disabled members, by type



Sources: Yi, Min-Gyeong et al. A Study on the Policy for the Families Caring for People with Disabilities. 2021. KIHASA

Concluding remarks

Families with disabled members, after many years of caregiving and providing education and rehabilitation specific to the disability, experience physical and mental exhaustion and are often left at a loss for what to do about the future of their disabled children (Type 2). Often finding themselves limited in their ability at the individual or family level to pull through the difficulties they experience in caring for their children with disabilities, they call for the state to step in (Types 1 and 3), but the confidence they have in support from the government can be low (Type 3). Only if accompanied by improvements in the quality of services can expanded disability support gain confidence from disabled individuals and their families and help them reduce their anxiety about the future.

Based on these findings, we make several policy suggestions. First, a formal support system should be established that provides on a regular basis health check-ups and health support to family caregivers of disabled individuals, given that, taking on the role of primary caregiver over an extended period of time, they experience physical, as well as mental, exhaustion.

Second, both universal support and crisis response are necessary. Respite care and other services intended for family caregivers should have universal coverage. This would involve easing the eligibility restrictions currently placed on the child's age and disability type. Efforts should be made to develop and widely implement a short-term case management model for providing comprehensive crisis response

support, by such means as counseling, education, and connecting to required services, for households having to come to terms with a new disability in the family or going through a long-term absence of the primary caregiver due to physical illness or mental exhaustion.

Third, long-term plans must be implemented to enhance public trust in the quality of social care, which requires fostering a service provision environment conducive to increasing the competencies of care workers. This undertaking would involve improving education to turn out qualified care workers, raising pay enough for care workers to stay competent, and establishing a monitoring system. Other means of support, such as an allowance for private caregivers, should also be considered as alternatives in the event that, for example, services are not readily available due to the severity of the disease.

Fourth, a trustworthy system of practical support should be built to assist in the self-reliance of children with disabilities living with their families. In order to help families with disabled members ease the undefined feeling of anxiety, it is necessary for the government to come up with a trustworthy plan of action to provide support for the self-reliance of their disabled children, including strategies for supporting disabled children in transition to adulthood and in their independent living in the community.