

Research in Brief



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Support for Families of Persons with Disabilities: An International Comparison and Its Implications for Policy

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Introduction

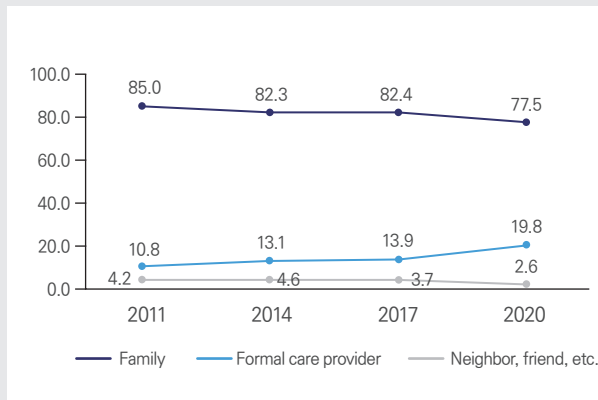
Support for families of persons with disabilities is an area where family policy overlaps with disability policy. To put it another way, it combines ‘support for family caregiving’ and ‘support for persons with disabilities and their families’. This study defines family policy as “public support for family caregiving”, and examines what support programs are in place in several selected countries to support family caregiving in families of persons with disabilities.

For Korea, it is with the legislation of the Act on Welfare Support for Children with Disabilities (2012) and the Act on Guarantee of Rights and Support for Persons with Developmental Disabilities (2015), that “support for families of persons with disabilities” gained legal recognition. Since then services have been provided in an increasing variety for a growing population of eligible beneficiaries. However, support for families of persons with disabilities in Korea is considered as neither something to which those eligible can claim a right nor something the state is mandated to provide. Moreover, the eligibility for such support is constrained considerably by such conditions as the age of the disabled person, the type of disability he has, and the family’s income level.

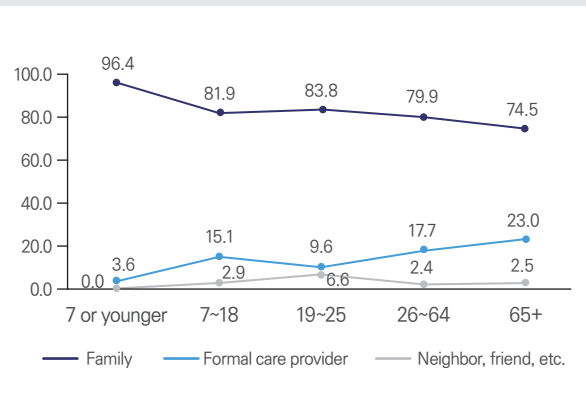
Although it is characteristic of disability that it comes about throughout the life course, this brief focuses on families of children with disabilities, a population that bears relatively little relevance to the “independent living paradigm” and the “principle of self-determination.” Children with

disabilities are also a population whose families bear heavy care responsibilities and a burden of high-level care costs. In Korea, an estimated 96 percent of children aged six and under with disabilities, and 82 percent of all children with disabilities, have a family member as the main caregiver.

[Figure 1] Main caregivers for people with disabilities needing assistance in daily living, 2011~2020 (in %)



[Figure 2] Main caregivers for people with disabilities needing assistance in daily living, by the disabled person's age, 2020 (in %)



Source: National Survey of Disabled Persons, for each year

This study examines the cases of the UK, Germany, Sweden, and Korea, countries regarded to have in place advanced family policies, in terms of the following ‘support for family caregiving’ components.

- (1) Financial support for caregiving: cash support, tax break, pension credit, etc. for family and other informal caregivers
- (2) Support for work-caregiving reconciliation: measures such as employment protection for family caregivers who are on leave for family care, flexible work schemes and wage compensation for family caregivers who need to reduce their working hours to care for someone in the family.
- (3) Support for persons with disabilities: social services—home-visit and facility-based services—that provide care and independence support for persons with disabilities.
- (4) Support for families of persons with disabilities: personalized services—education, counseling, and respite services—for families of persons with disabilities.

Support for families with persons with disabilities in the UK, Germany, Sweden, and Korea

The UK's Children Act (1989) mandates local authorities to provide various services for children with disabilities and their families. These services include those related to registration, provision of information regarding available services, and care needs assessment on the family caregiver as well as on the child with a disability. Family caregivers are entitled to request care needs assessment if they care for someone in the family at least 35 hours a week, pursuant to the Carers (Recognition and Services) Act 1995 and the Carers (Equal Opportunities) Act 2004.

In Germany, support for persons with disabilities is delivered through an “integrated system” where needs arising from disability are looked on as part of human diversity. “Integrated” here means support services for persons with disabilities are incorporated into the same social security system that also serves non-disabled persons. The German family policy entitles, in the same system, families of children with disabilities and families of non-disabled children alike to support services. Diversity here implies diversity in provisions and regulations concerning needs and situations that may arise as a consequence specifically of disability.

Sweden represents the epitome of the child-friendly, family-friendly welfare model that the Nordic countries have as a defining characteristic. It is where social support for women's labor force participation has been at its most proactive in Europe. The Swedish family policy is universal social assistance in nature. To what extent public care services are provided for how long and to whom depends on the outcome of individual needs assessment administered as stipulated in the Social Services Act. Also, the “Act Concerning Support and Service for Persons with Certain Functional Impairments”, implemented in 1994 with the aim of bringing changes to the living conditions of persons with severe disabilities, has been instrumental to guaranteeing an adequate standard of living for persons with disabilities and their families.

In Korea, the concept of “healthy family” began gaining wide application in the 2000s. In the process, Korea's universal family policies and defamilization policies accentuated the government's role in support for family caregiving. The Framework Act on Healthy Families and the Equal Employment Opportunity and Work-Family Balance Assistance Act mark as two important milestones along this course. The Framework Act on Healthy Families, the first legal mechanism in Korea to regard the family as a realm needing state intervention, has served as a legal basis for broadening the government's effort to develop and implement services aimed at helping individuals develop, maintain, and improve their family life. The Equal Employment Opportunity and Work-Family Balance Assistance Act is the legal framework in which various policy measures have been created to help people better reconcile work and family life, including childcare leave, a reduced work schedule (during the child care period), and family caregiving leave.

[Economic support for family caregiving]

Varying though family support policies are in many respects across countries, there are components that are commonly found in them, including child allowance paid in social compensation for child care (mostly universal in nature), tax break, and a pension entitlement that covers the period during which one has left work because of family caregiving responsibilities. It is usually the case that economic support for family caregiving for a disabled child continues for a certain period time even after the child passes the age at which a non-disabled child is considered no longer eligible for support.

In the UK, benefits are paid in compensation for the extra costs arising from a disability of certain severity, regardless of family income level. The UK also offers tax deductions on income and assets for family caregiving. Family carer's allowance is payable to those who put in 35 hours or more a week caring for a family member with a disability, in compensation for the forgone hours of work or education.

Under the integrated family policy in Germany, a parent of a child with a disability can receive parental allowance concurrently with child allowance. Parents can choose between child allowance or childcare tax deduction. For a parent of a child with a disability, the amount of parental allowance is 10-percent higher, and child allowance is payable even after the child turns 18.

In Sweden, parents of children with disabilities can claim, on top of the usual caregiving allowance, another allowance to cover extra costs arising from disability.

Korea's child allowance has no additional component specific to disability. In the case of home childcare allowance, the amount is higher for a child with a disability than for a non-disabled child, while the duration over which it is payable is a total of 86 months for both. Allowance for children with disabilities is paid to low-income families, pursuant to the Act on Persons with Disabilities. Also, there is a personal deduction in Korea that offers a favorable tax treatment to families with disabled members.

[Table 1] Economic support for caregiving in the UK, Germany, Sweden and Korea

	UK	Germany	Sweden	Korea
General childcare component	<ul style="list-style-type: none"> Child allowance/ carer's allowance Tax deduction: child tax credit, etc. 	<ul style="list-style-type: none"> Parental allowance <ul style="list-style-type: none"> Parents can claim payment for the first 14 months of the child's life. Parents cannot work more than 30 hours per week while in receipt of parental allowance Child allowance or childcare tax deduction <ul style="list-style-type: none"> Until the child reaches 18. 	<ul style="list-style-type: none"> Child allowance for children aged 16 or younger (eligibility can be extended up to 20 years of age) Pension rights are guaranteed for parents in the first 4 years of child care, with pension contributions paid out of public funds such as child allowance. 	<ul style="list-style-type: none"> Child allowance <ul style="list-style-type: none"> -Paid until before the child turns 8 Home childcare allowance <ul style="list-style-type: none"> -For a child with no disability: KRW200,000 a month for the first 11 months; KRW150,000 a month for the 12th~23rd months; KRW100,000 a month for the 24th~86th months -For a child with a disability: KRW200,000 for the first 35 months; KRW100,000 a month for the 36th~86th months
Disability-specific component	<ul style="list-style-type: none"> Disability living allowance <ul style="list-style-type: none"> -Compensation for extra costs arising from disability -Non-means-tested Tax deduction/exemption on income and assets (extra space needed for a person with disability) Carer's allowance <ul style="list-style-type: none"> -Eligibility requirements for both the carer (disability severity) and the cared for (minimum weekly caregiving hours) -Pension credit for caregivers 	<ul style="list-style-type: none"> Parental allowance is increased by 10 percent for parents of disabled children younger than 14 years of age with a disability grade of GdB20 or higher. Support is provided with no age limit, if the child cannot support on her own due to a disability that occurred before the age of 25. 	<ul style="list-style-type: none"> Allowance for a carer of a disabled child <ul style="list-style-type: none"> -Income-tested. Compensation for additional costs due to the child's disability <ul style="list-style-type: none"> -Not income-tested. 	<ul style="list-style-type: none"> Disabled child's allowance <ul style="list-style-type: none"> -Low-income families of a child younger than 18 years of age with a disability Personal tax deduction

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Ministry of Health and Welfare. Guidebook on Child Care Programs 2021.

Ministry of Health and Welfare. Guidebook on Disability Pension, Disability Allowance, and Disabled Children's Allowance 2021

[Support for the time spent on family caregiving]

Support for the time spent on family caregiving is public assistance that comes mainly in two types. A family caregiver as an employee can claim for a period of time necessary to spend on family caregiving (and employment protection for this period) and the financial compensation for the time taken off work for that purpose. In the UK, an employee with a child 18 years of age or younger with a disability has the right to request the employer for flexible work hours.

Employees in Germany can request short-term leave or reduced work hours to care for a child with a disability or someone in the family in need of care. Parents of a child with a disability can claim, irrespective of the child's age, child care allowance and disability allowance from the German public pension system.

Under the Swedish law, parents of a child with a disability are entitled for child care leave and reduced work hours even until the child turns 21.

In comparison, in Korea, family caregiving leave, or absence granted from work for family care, as stipulated in the Equal Employment Opportunity and Work-Family Balance Assistance Act, does not come with any element related to caregiving for a child with a disability.

[Table 2] Support for time needed for family caregiving in the UK, Germany, Sweden, and Korea

	UK	Germany	Sweden	Korea
Relevant legal basis	<ul style="list-style-type: none"> • Employment Act 2002 	<ul style="list-style-type: none"> • Gesetz über die Pflegezeit 	<ul style="list-style-type: none"> • Parental Insurance Act 	<ul style="list-style-type: none"> • Equal Employment Opportunity and Work-Family Balance Assistance Act
Support for time needed for family caregiving	<ul style="list-style-type: none"> • Employees with parenting responsibilities for a child under 6 or a child aged 18 or younger with a disability are entitled to apply for flexible working hours/place. 	<ul style="list-style-type: none"> • Short-term absence from work -Employees have the right to take up to 10 working days off if the situation is such that a family member is need of acute care, with caregiving allowance paid for the period. -Unpaid family care leave (up to six months) is available for workers at a firm with 15 employees or more. -Workers at a firm with 25 or more employees, when in need to provide family care, are entitled to have a 15-hour work week for up to 24 months. 	<ul style="list-style-type: none"> • A working parent can have family caregiving leave of up to 120 days per year for a child with a condition. -For a child 11 years of age or younger -For a child with a disability, the age limit extends to 21. • Parents of a disabled child may take leave of 10 days per year. • Right to reduced work hours - Working parents with a child aged 8 or younger have a right to reduce their work hours by 25 percent, with a correspond change in wage. - Parents of a child with a disability are entitled to have reduced work hours until the child becomes 21. 	<ul style="list-style-type: none"> • Family care leave -Employees with a family member who needs care can take family care leave of up to 90 days per year. • Family care days off • -Employees with a family member who needs care may take a total of 10 days off per year (20 days in certain cases and 25 days for a single parent). • -Reduced work hours for family care • -Employees can request a reduced work hours (15 to 30 hours a week) for family care purposes, health care of their own, for preparation for retirement, or for education.

- Sources: 1) UK: Hall. (2002). Employment Act 2002 outlined.
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<https://www.bmas.de/DE/Arbeit/Arbeitsrecht/Teilzeit-flexible-Arbeitszeit/pflege-und-beruf-vereinbaren.html>
- 3) Sweden: Duvander. (2017). Miittinen, Engwell and Teittinen. (2013). Parent-carers of disabled children in Finland and Sweden: Socially excluded by labour of love? pp. 107–124.
- 4) Korea: Ministry of Employment and Labor (2019). Guidebook on Reduced Working Hours for Family Care, Individual Health, Reparation for Retirement, and Further Education; Ministry of Employment and Labor (2021). Project Work Handbook on Maternal Protection and Work-Family Balance

[Support services for persons with disabilities]

The system of support for persons with disabilities usually involves an initial needs assessment and a subsequent support planning. Such a needs assessment considers both the needs of a child with a disability and the needs of the child’s family. Support then is delivered by the responsible local authorities by means of both public and private resources, to those assessed as eligible.

In the UK, children with disabilities have the right to get a needs assessment carried out by local social service authorities. The assessment is conducted from a holistic perspective, encompassing both the needs of both the child and the family. If the initial needs assessment finds a child with a disability eligible for support, decision will be made as to the specifics and means (via a personal budget, for example) of the support to be provided. In the UK system, children who are assessed as needing additional support in education can be provided with support through, after a further assessment, the Education, Health and Care Plan (EHC).

It is the characteristic of the German system that if anyone with a disability wishes to get support services, the individual or her family should first apply for the needed support. Upon such application, a case management office is assigned to conduct a needs assessment and identify the needs of the individual. The next step involves developing, based on the result of the assessment, an individualized “participation plan” for the disabled person. The benefit level is determined after a process of consultation and negotiation in planning dialogues held with the participation of the prospective beneficiary and the assigned provider agency.

The Swedish law stipulates that the responsibility lies with the state for providing care for persons with disabilities and older persons. Local social service authorities are responsible for carrying out comprehensive needs assessments on both a disabled person and her family and for providing services identified as needed for them, pursuant to the Social Services Act and the Act Concerning Support and Service for Persons with Certain Functional Impairments.

In Korea, support services are provided for persons with disabilities based on the result of a comprehensive needs assessment survey carried out of registered people with disabilities. Different categories of service needs get identified in the process, and information is provided to the disabled individuals on existing services that would fit their needs. Registered disabled persons are provided with support services to the extent corresponding to their eligibility levels.

[Table 3] Assessment of service needs among persons (children) with disabilities in the UK, Germany, Sweden, and Korea

	UK	Germany	Sweden	Korea
Needs assessment systems	<ul style="list-style-type: none"> Parents of disabled children have the right to request a needs assessment carried out by local social service authorities. Children with special education needs are subject to a further needs assessment connected to the EHC Plan. 	<ul style="list-style-type: none"> The Federal Participation Law (2016) has shaped a systematic support process with comprehensive needs assessments undertaken on child with disabilities and their families. 	<ul style="list-style-type: none"> Local authorities are responsible for implementing social services, including support for persons with disabilities. -Children with disabilities and their families are provided with support based on comprehensive needs assessments, pursuant to the Social Services Act and the Act Concerning Support and Service for Persons with Certain Impairments. 	<ul style="list-style-type: none"> Needs assessments are carried out on persons with disabilities upon their registration. -Information is given on available services. -Upon registration, one can apply for disability-related deductions and disabled person's license plate. For newly registered persons with disabilities, the needs assessment survey can be used as a point of access to mobility support services. -Also, one can choose services one needs from those listed on the social benefits application form.

- Sources: 1) UK: HM Government. (2018). Working Together to Safeguard Children guidance. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/942454/Working_together_to_safeguard_children_inter_agency_guidance.pdf
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- 4) Korea: Ministry of Health and Welfare (2021). Guidebook on Welfare Programs for Persons with Disabilities (I) (2021).

[Services for families of persons with disabilities]

Support for families of persons with disabilities comes largely in two types: support for persons with disabilities intended for reducing the burden families have in caregiving and support that is for family caregivers.

In the UK, the 2014 Care Act gives all carers a right to ask local authorities for an assessment of their needs and receive support according to the results of the needs assessment. The UK system offers personal budget and direct payment schemes, with the focus placed on keeping the users directly involved.

In Germany, family policy gives families of children with disabilities a right to apply for support services, while needs and circumstances that are unique to disability are eligible for support from a separate system of services intended for persons with disabilities. The component of “care benefits” includes services intended to allow family carers to have time to take a rest (day/night care services

provided in semi-residential facilities and other services provided during the time when the family is away).

Sweden’s Social Services Act and the Act Concerning Support and Service for Persons with Certain Functional Impairments together have set up services that are responsive to the needs of family caregivers for support. In the Social Services Act in particular, the focus is placed on support for family caregivers, with such services as “in-home relief” and “short-term stay away outside the home” stipulated.

Korea has a diverse range of support programs for families of persons with disabilities—care services to supplement family caregiving, support for family caregivers so that they have time for themselves, consultation and education programs for family caregivers. However, the eligibility for these programs depends considerably on such conditions as the age of the disabled person, the type of disability he has, and the family’s income level.

[Table 4] Support services intended for families of persons with disabilities

	UK	Germany	Sweden	Korea
Support services	<Support for children with disabilities with the needs of their families taken into account> <ul style="list-style-type: none"> • Provision of increased leisure opportunities for children with disabilities • Community-based day center placement • Economic support for home adaptations <Support for family caregivers> <ul style="list-style-type: none"> • Short-term respite services • Information services 	<Support for children with disabilities with the needs of their families taken into account> <ul style="list-style-type: none"> • Day/night care at a semi-residential facility • Temporary care while in the absence of the family caregiver (up to 6 weeks) • Short-term care (access to assisted-living facilities) • Relief care (care allowance) • Economic support for the purchase of in-home care equipment <Support for family caregivers> <ul style="list-style-type: none"> • Housework support • Medical rehabilitation for parents of children with disabilities • Companion services • Economic support for family attendants 	<Support for children with disabilities with the needs of their families taken into account> <ul style="list-style-type: none"> • Companion services • Short-term stay away from home • 24-hour in-home assistance (short-term live-in assistance) <Support for family caregivers> <ul style="list-style-type: none"> • Companion services • In-home respite service • Stay-in-touch services for emotional support and information provision • Home care services (companion service, etc.) 	<Support for children with disabilities with the needs of their families taken into account> <ul style="list-style-type: none"> • Care services in supplement of family caregiving <Support for family caregivers> <ul style="list-style-type: none"> • Consultation for parents of children with developmental disabilities • Respite support for families of children with developmental disabilities • Education programs for parents of children with developmental disabilities

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Concluding remarks

Different countries have different backgrounds against which their family policies have grown. What they all have in common is social support for families of persons with disabilities. Such support is provided in addition to, or separately from, other social services, based on the special needs of persons with disabilities and their families. In Korea, families of persons with disabilities take on a heavy load of caregiving responsibilities. However, Korea's disability policy as it stands lacks support for families as caregivers of persons with disabilities. Moreover, in Korea's family policy, support for persons with disabilities is still in its developing phase. Also, discussions ongoing in Korea as to economic support for family caregiving? such as child allowance? do not address enough of economic support that takes disability into account. Various schemes of institutional support, including family care leave, family care days and reduced work hours, have yet to attain to full implementation

There is a need for a comprehensive infrastructure of support for family caregivers of persons with disabilities. Also needed is a dual approach whereby social services for persons with disabilities are implemented on an expanded scale in combination with entitlement programs for the wellbeing of non-disabled family members. Family caregivers need increased social support, financial and in other forms, so that they can reconcile caregiving and work. Single parents with heavy caregiving responsibilities for children with disabilities who still have to earn a living need reduced or flexible work hours and flexible leave of absence.

Further discussions need to take place with a view to seeking ways to compensate parents of children with disabilities for their caregiving and the costs of education and rehabilitation.

Children with disabilities themselves would need an initial needs assessment that takes their family situations into account and an integrated system that provides a continuum of support across different developmental and life-course stages. Such a system of support means a well-coordinated structure highly responsive to the needs that families of children with disabilities have in childcare, education and welfare.

Ensuring the health and wellbeing of family caregivers would require proactive support. Among the ways of doing this is by switching current programs of support for families of persons with disabilities to a set of universal programs that run with relaxed age and disability-type criteria.