A Study on the Right to Assistance for Families of Children with Disabilities

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Abstract

The achievement of disabled children's rights to education, recovery from diseases, and their engagement in social events not only depends on the supply of public resources, but also on the family's ability to attend to them. In an security pattern which focuses on individual cure is inclined to neglect the extra expense, time invested and the cost of their employment burdened on the care-givers. By using the methods of normative analysis and functional comparison, this paper defines the family assistance right as a bundle of rights which focuses on the rights and interests of children with disabilities, whereby the children and their caregivers may request financial support, care services, and procedural safeguards according to related laws. This paper also analyzes the related regulations of China from three dimensions—— the accessibility to such services, the accessibility of services, and the continuity of support. And it comes to the conclusion that the major shortcomings of current security of their rights lie in the fragmentation of support measures, inadequate identification of care costs, insufficient link between cash payments and service provision, and no enough arrangements for the transition from their childhood to adulthood. When it comes to the ways of improvement, they should be based on an assessment of family needs, focus on clarifying the state's obligations, coordinate cash subsidies with care services, ensure the right to participate in relative events for children and their caregivers, and make proper plans to bridge the protection gap between their childhood and adulthood as well.

Keywords

Children with disabilities; right to family assistance; family care; social rights; State guarantee obligations.

1. Introduction

Preserving the rights of children with disabilities usually covers the right of receiving education, medical recovery and fundamental living. However, availability of public services does not lead to continuous access for children. Recovery training requires transport, company and home-based practice, and school education requires additional communication, cooperation from home and everyday support. The time and resources required for these activities are often at the families' own cost. When the caregivers have to reduce occupation time and suffer from physical and mental pressure because of constant caring, or when they lack professional guidance, the preservation policies established in appearance might be unable to turn into the rights that children can acquire in practice.

This dilemma reveals the connection between preservation of individual rights and the caring capability of families. While children are rights holders, their families act as a crucial area for their growth and access to public services. If measures of preservation only focus on the number of recovery trainings or the amount of allowance that children have received, the cost on families for accessing these services, including transport, accommodation, absence from

work and caring, might be ignored. In the meantime, regarding families as natural and infinite caring resources with no need for support will result in a continuous dependence of social welfare policies on family labour, and will bound the risks of caring within private domain.

Existing research has made valuable contributions in special education, rehabilitation assistance, child welfare, and family support, but these discussions require further integration. Firstly, the children's specific rights and the caregivers' support needs are always studied separately, which is hard to explain how the decline of family capacity influences children's rights and interests. Secondly, there are too many descriptions of subsidies and service programs, which has a lack of analyses about qualification recognition and needs assessment. Thirdly, there is also a lack of consistent discussion about childhood support and adult safeguard that tends to equate the age changes with the end of care needs.

This article therefore addresses two questions. Firstly, how should we transform the state's obligation, which supports the disabled children's family to identifiable rights contents? Secondly, how does relevant systems ensure that the children can gain support consistently when the family care conditions change? The study adopts normative analysis and functional comparison method, and develops an argument around payment adequacy, services accessibility and support continuity.

2. The Normative Construction of the Right to Family Assistance and the Analytical Framework

2.1. From Individual Impairment to Care Relationships

To understand the care needs of children with disabilities, we need to pay attention to both individual functional conditions and social environment. Medical assessment can identify demands of rehabilitation assistive equipment and health services, but it's difficult to explain the restrictions on children in education and social participation. In appropriate facilities, Incomprehensive information long services distance and the lack of professional staff may also cause barriers. Therefore, the purpose of the right to family assistance is not only to compensate the differences of individual functions, but also to reduce the impact of environmental barriers on children and their caregivers.

Vulnerability theory provides relational explanations for state guarantees. Children with disabilities mainly depend on outer care during their growth, and their caregivers also face risks due to employment conditions, disease, aging and insufficient resources. The situations of children and caregivers mutually interacts. The caregivers whose health is impaired may pause recovery arrangements and insufficient public support is likely to place an extra burden on families. Consequently, the state is responsible for guaranteeing the sustainable operation of caregiving relationships, rather than implementing remedies only when families fall into severe difficulties. [1]

Substantive equality further requires systems to identify additional conditions for different families to achieve equal rights. The same educational or rehabilitation service may entail markedly different access costs for families facing different types of disability, living in different locations, or possessing different caregiving capacities. The legitimacy of differentiated support lies in making up for identifiable barriers to participation instead of universally deeming children with disabilities and their families as lacking abilities or living in poverty. Needs assessment should focus on individual differences and avoid replacing concrete judgments with group labels.

2.2. Normative Foundations and the Boundaries of Rights Holding

The right to family assistance has dual normative foundation in both domestic laws and International human rights law. Law on the Protection of Persons with Disabilities prescribe

that rehabilitation services should rely on children's families, and ask government to provide assistance for the disabled and their families who struggle to live a life. This indicates that family shoulders the duty of giving care, which make it the subject of public support.

The prescription of substance assistance, the guarantee of life and education of disabled people in the Constitution provide tough constitutional basis for the right to family assistance. However, the fact that the state should take on the obligation of actively offering guarantee does not mean that the children with disabilities all lose the ability to labor, and that any family has the right to apply for the subsidy for a specified amount. The requirements of offering special care to children, supplying assistance to families and equal family life in the International Convention need to be transferred to clarified payment conditions, responsibilities and procedures via domestic specific regulations.

The right to family assistance in this paper refers to a bundle of rights, centered on children's rights and interests, which includes the rights and interests of children with disabilities, whereby the children and their caregivers may request financial support, care services, and procedural safeguards according to related laws. This conception is used to integrate the scattered support measures, but this does not mean that current regulation has make this right a complete and independently enforceable right that may be directly cited. Depending on the extent of realization, the right to family assistance can be categorized into legally established rights and interests that have already been clarified, matters requiring support through administrative assessment, and legitimate claims that remain institutional recognition.

The holders of rights need to be recognized at different levels. Children with disabilities have the rights and benefits of receiving education, medical rehabilitation and social security and so on, and such rights are applied or exercised by their guardians completely or with their help. Care-givers can gain training or other support based on their care burden. Family can serve as a unit for assessing economic circumstances and comprehensive needs, but this does not mean that family has the independent capacity as a subject of law. Institutional arrangements should identify applicants, beneficiaries, and recipients of payments so that the family's collective interests do not obscure the child's actual interests.

2.3. Components of the Right and Dimensions of Evaluation

The right to family assistance should include financial support first, used to cover the extra life expense of life， care and service related to disabilities. Basic living assistance, nursing subsidies, and rehabilitation assistance function differently. They are not interchangeable, and it is not proper to rely on a single type of subsidy to cover all family expenses. To assess the sufficiency of delivery, it is necessary to consider the intensity of care, uncompensated necessary expenses, other support programs, and the fact that whether a family can sustainably meet the basic needs of the children.

What's more, the right to family assistance need to involve service support, which includes rehabilitation guidance, care-giver training, psychological support, day care, and services used to provide rest time for the care-givers. Cash subsidies can enhance purchasing power, but they do not automatically transfer to professional services. In areas where services are insufficient, increasing the amounts of subsidy may still fail to solve the problem that families have no accessibility to such assistance. Therefore, service accessibility should consider the distance, cost, operating hours, staff competence, and the degree of service suitability, rather than merely the number of service providers.

Programmatic guarantees make above support feasible. The children with disabilities and the care-givers should gain information which is easy to understand, participate in the making of assessment of requirement and the plan to support, and obtain explanations and a review when their application is rejected, services are interrupted, or a dispute arises during the assessment. Children's right to express themselves need to be supported according to their ages, ability to

comprehend and the way of communication, and this right cannot be excluded due to existing barriers. Therefore, the assessment frame of regulations should include the sufficiency of delivery, accessibility of services and the continuity of texts.

3. Institutional Barriers of Family Assistance Arrangements in China

3.1. Fragmented Provision and Comprehensive Needs

China has established arrangements that include benefits for persons with disabilities, rehabilitation assistance for children with disabilities, social assistance, and educational support. Organized around different target groups and administrative functions, these arrangements facilitate specialized implementation. They may, however, divide a family's comprehensive needs across multiple application procedures. Families must determine which eligibility conditions their children meet while also preparing documentation, contacting departments, and coordinating services.

The regulations may be difficult to be realized due to a lack of code for practice. The key lies in whether the qualifications, responsibilities, and procedures in different regulations are properly connected, whether the outcome of an application is clear, and whether there is a responsible entity when services are interrupted. If there is absence of a unified mechanism for identifying and referring needs, families may need to take on the cost of cross-sector coordination, during which those families with limited resources or weaker capacity to access information will probably find themselves at a disadvantage.

Therefore, the integration of regulations should be based on the real situations of families. When children with disabilities need support in education, medical rehabilitation and care services, each sector can maintain their professional division of the labor, but they need to reduce the burden of families by co-assessing, giving referral feedback and continuously following up. The aim of integration is to make the professional services able to respond to children's need, rather than consolidating all tasks into a single department.

3.2. Insufficient Recognition of Additional Costs and Inadequate Benefit Arrangements

Disability-related expenditures include both direct costs such as rehabilitation training and assistive devices, as well as some indirect costs including transportation and accommodation, care-giving, and loss of employment opportunities. The subsidy focused on the expense of the medical programs may cover the institutional services, but it does not cover the necessary conditions for families to use such services, especially under the condition that rehabilitation resources are concentrated in urban areas, the cost of accessing services outside their local areas may become a significant barrier.

Assessments of insufficient subsidies require support from reliable evidence. Generally, the income of families with disabled members cannot directly represent the income of families with children with disabilities; individual cases involving high rehabilitation costs likewise cannot prove that all families are generally operating at a deficit. Similarly, incorrectly converting annual consumption expenditures into monthly figures, or directly using the proportion of subsidies relative to general consumption to assess the level of protection, both weaken the argument. Institutional evaluations should be based on specific needs and on costs that remain uncovered; direct comparisons should be avoided between data covering different functions or different statistical criteria.

The standards of subsidy are different in different areas, which does not certainly disobey the principle of equality. Governments can make reasonable adjustments according to the differences between the life expenses, financial conditions and the provision of services. The more notable questions are that whether low-income areas have the capacity to provide basic

safeguards, whether the allocation of central and local funds can meet the needs of disadvantaged areas, and whether equal care needs receive comparable support. The aim of policies is to ensure the equality of basic safeguards and opportunities, rather than the equality of the amount of subsidies.

3.3. Requirements for Family Participation and Insufficient Support

Family's participation helps connect the institutional rehabilitation and daily life, but this requires that the needs match families' ability. If parents are frequently asked to participate in the process of rehabilitation and there are not flexible service time, alternative care, and necessary expense support, the public services are likely to transfer their costs of practice to the families. As a result, care-givers face the conflict of their job and care-giving, and the reduction in their income will limit their children's ability to use services in turn.

This dilemma cannot be simply credited to the lack of parents' duty, and it cannot be assumed that such services can be replaced by children's grandparents endlessly. There may be limit in grandparents' knowledge of health, employment and care-giving. Market-based care-giving may be limited by the expense and quality of services. Choices differ in families. Regulations should recognize the real care conditions, rather than assessing the level of family cooperation on the basis of the time of attendance or unified care model.

The care support has meanings in gender. If the responsibility of giving care is mainly taken on by women, simply encouraging the parents to increase capital invested in care may harden such unequal division of labor. The support policies should create conditions for both the father and mother in a family, and reduce the risk of any member's quitting from employment for a long time by providing community services, care service where the care-giver can have a rest temporarily and professional instructions.

3.4. Gaps in Responding to Age Transitions and Changes in Caregiving Capacity

When the children with disabilities enter adulthood, the regulations of service eligibility, application procedures, and guardianship may change, but the need of care is not gone. If systems are implemented separately according to age, without transitional assessments and advance planning, they may result in disruptions in social support. Adult persons with disabilities cannot be treated as children, yet their care needs and transitional mechanisms are indispensable.

Guardianship arrangements should distinguish the applicable conditions. The advance guardianship arrangement prescribed in Article 33 of the Civil Code refers to an adult with full capacity for civil conduct who makes a prior arrangement for guardianship for themselves. The fact that parents enter into a testamentary guardianship agreement is not equal to appoint a guardian for their disabled children in the future. Article 29 prescribes that parents serving as guardians may appoint a guardian through a will. Any such arrangement should still be assessed separately based on the children's age, ability to conduct related behaviors, and specific legal circumstances.

Disability itself does not mean that an entity lack for the civil capability. For those who can make independent decisions by themselves, social support should respect their choices and provide necessary assistance. For those requiring guardianship under the law, the future planning should address the problems of guardians, daily services, property management and supervision at the same time, avoiding the problem of designating a single guardian as the substitute for comprehensive care arrangement.

4. Comparative Examination of Arrangements in Other Countries

The evolution of family policies for persons with disabilities internationally has involved three shifts in their underlying values: from individualism to familialization, from familialization to

defamilialization, and from defamilialization to refamilialization. Legislative approaches in different countries are now gradually converging, with attention extending from individuals with disabilities to the overall functioning of families with children with disabilities. [2]

First, caregivers' needs should be recognized within institutional arrangements. British support arrangements for families of children with disabilities identify caregivers as actors beyond the private sphere of the family and accord them an independent legal status as rights holders. Assessments of parent carers offer an approach to examining caregiving capacity, personal preferences, and the conditions necessary for sustained care. They connect caregivers' needs with children's needs while identifying each separately, rather than assuming that meeting children's needs necessarily resolves caregivers' difficulties. [3]

Second, financial support can address both expenditure and employment changes arising from care. France's education allowance for children with disabilities and its supplementary benefits take account of disability-related expenditure, the need to employ care workers, and parents' reduction or cessation of paid work to provide care. These arrangements connect benefit levels to specific costs and caregiving circumstances instead of relying solely on disability categories to determine fixed payments. [4]

Third, cash assistance should be combined with public services. Swedish family policies and respite services in the United States illustrate the respective contributions of public support and diverse service resources. Public support can reduce families' dependence on market services, while professional organizations can supplement different forms of care. Both suggest that institutional development should address families' purchasing power and the actual supply of services, rather than treating the payment of benefits as the completion of public responsibilities. [5]

Fourth, financial planning must be coordinated with welfare eligibility rules. In America, certain assets-identification exceptions have been established for eligible special-needs trusts and joint trusts. However, whether a trust is counted as a resource and whether payments affect benefits still depend on the specific rules. Payments directly to beneficiaries differ from payments made on behalf of beneficiaries in nature and may lead to different consequences. China should first establish a clear system for accountability and referral, assess the effectiveness of the support measures through piloting policies, and then extend to the implementation of complex care payment and asset-management.

5. The Ways to Strengthen the Protection of the Right to Family Assistance

5.1. Clarifying Support Responsibilities and Comprehensive Assessment Procedures

The legal protection of the right to family assistance should clarify the beneficiaries, support content, administrative responsibilities, and procedures for implementation. The family assistance can be added to related laws, and regulations economic assistance, service provision, and relief arrangements can be specified via supporting rules. Whether a dedicated chapter should be established depends on the needs of institutional integration, which should not be regarded as a sufficient condition for solving the problem.

Comprehensive assessments should pay attention to the situations of children’s functions, needs of education as well as rehabilitation, the financial conditions of family, the intensity of care and the alternative care resources. Disability ratings can provide a reference, but it is insufficient to fully represent care needs. The assessment results should be transferred into a support plan, clarifying the services provided, who is responsible for revision, and allow the families to apply for a reassessment when circumstances change.

In term of administrative implementation, local governments may designate a lead coordinating department and establish a unified service channel, while clarifying the division of responsibilities among relevant agencies, including civil affairs authorities, education authorities, health authorities, medical insurance service institutions and federations of persons with disabilities. Information shared should be strictly limited to something necessary, avoiding collecting children's health data and family privacy information beyond reasonable limits. The value of a unified service counter lies in reducing duplicate applications and ensure that various needs are effectively met through referral and feedback mechanisms.

5.2. Coordinating Financial Compensation and Care Services

Economic support should be structured through a combination of basic safeguards and tiered needs-based subsidies. At the national level, clear basic programmers and calculation principles may be formulated; local authorities may then set specific standards based on living costs and assessed needs, and establish a regular review mechanism. In addition to price fluctuations, adjustments should also take into account changes in the prices of essential services and care costs, so as to prevent nominal increases in funding from reducing the real value of support.

Funding arrangements should be aligned with the allocation of responsibilities. Central government support should appropriately take into account service costs in areas facing difficulties, the eligible beneficiaries, and local fiscal capacity; local governments, in turn, should enhance transparency regarding the use of funds and service performance. The focus of evaluation should include whether children with disabilities continue to receive the support they need, rather than merely examining the scale of funding expenditures. For newly established insurance programs, their relationship with existing medical insurance, assistance programs, and long-term care systems should be assessed first, so as to avoid imposing additional burdens and redundant infrastructure development.

Service provision should progressively expand support at home, day care, short-term residential care, and respite care. Respite care allows caregivers a temporary break while safeguarding the quality and safety of children's care. Its implementation requires qualified personnel, individualized care records, risk management, and quality oversight. In remote areas and for families with limited care resources, home visits, transport assistance, and referrals to professional services can improve access to existing resources. [6]

5.3. Safeguarding the Participation of Children with Disabilities and Their Caregivers

Children with disabilities and their caregivers should participate in developing support plans and evaluating services. Families should have a substantive voice in educational decision-making, and their participation rights require legal recognition and protection. Institutions should use approaches suited to children's understanding and expression to identify their preferences and discomfort and adopt a child-centered approach when views differ. Family participation should receive professional support and must not become a reason for institutions to relinquish their educational and rehabilitation responsibilities. [7]

The support of time for cares can be progressively advanced through flexible service arrangements, alternative care options, and work schedule negotiations. When exploring specialized care leave, it is necessary to clearly define the applicable conditions, duration, methods of certification, and cost sharing, while balancing care needs with employment protection to prevent employers from excluding relevant workers due to anticipated costs.

The safeguards of the procedure should include processing information, assessment basis, result explanation, review channels, and service complaints. For matters with specific statutory entitlement conditions, relevant remedies should be provided in accordance with the law. For support claims that have not yet been concretized, the content of the requests must be clarified

through improvements of the system. The abstract concept of the right to family assistance can't replace concrete legal bases.

5.4. Establishing Transition Arrangements for Adulthood and Supplementary Financial Support

The transition planning should start before children with disabilities reach adulthood, which is expected to include assessment their needs of the education, rehabilitation, employment and care. Such planning should clarify the handover of services and offer necessary care arrangements, and make sure that services and supports will not be disrupted suddenly due to the change in age. When there is a reduction in family's ability to provide care, related entities need to offer alternative resources, rather than stepping in until their parents' passing away.

Special needs trusts can provide long-term asset management and payment arrangements for families with sufficient property, but their scope of application should be approached cautiously. Trusts primarily address financial arrangements; they do not automatically provide care services and cannot replace public protection. Changes in trustees and operational risks should be addressed with reference to the independence of trust property and mechanisms for continued management, rather than being equated directly with the loss of assets. [8]

To improve the trust system for people with special needs, it is essential to clearly define the registration of trust assets, reasonable fees, payment records, and oversight arrangements. What's more, it is necessary to explore the integration of small-amount collective management with professional services. When determining eligibility for social assistance, a distinction must be drawn between trust principal, actual income, disposable funds, and necessary care costs. This prevents supplementary arrangements from undermining basic safeguards and stops trusts from being used as a vehicle to circumvent asset verification.

6. Conclusion

The core of the right to family assistance is to make the care conditions on which the achievement of children's right depends included in public responsibility and the state's obligation. Serving as the unit of assessment and support, families cannot take the place of the primary role of children. The care-givers take on the family responsibilities, which does not mean that the state can rely on their labor without limit. Understanding the right to family assistance by regarding it as a bundle of rights helps connect the children's interests, needs of care-givers and the public support, at the same time avoid the problem of equaling the theoretical proposition and the right prescribed by current laws.

The improvement of the regulations of the right to family assistance need to focus on the sufficiency of services, the accessibility of services, and the continuity of support, clarifying children's needs via comprehensive assessment, share costs through cooperation in economic and service resources, guarantee the practice of regulations by ensuring holders of rights' participation and legal remedies, and respond to long-term risks by making adult transition planning. This paper mainly give analyses using the methods of normative analysis and functional comparison. Further research should use surveys and institutional pilots to examine extra care costs, barriers in using related services, and risks associated with the transition to adulthood, thus providing a more reasonable basis for the standards of support and the allocation of responsibilities.

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