

Giving Voice to the Unheard "Medically Cleared, but No Place to Go"— Helping Parents Love and Bond with Their Children with Special Needs

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Research Article

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Abstract

Advances in pediatric medicine have improved the survival of children with disabilities. However, prenatal diagnosis and disability disclosure can cause profound parental distress amid the NIPT testing business and persistent eugenic attitudes. Parents may struggle with guilt and rejection. This study examines practical approaches to parental psychological crises, parent–infant bonding, and every child's right to be loved. A free support model integrates 24-hour counseling, Welcome Home (overnight shelter), grief care, bonding support, parenting skills guidance, and multidisciplinary collaboration. It later expanded to home-based care provided by volunteer foster parents with nursing or other relevant qualifications. This study sheds light on the silent suffering of unwelcome children with nowhere to go. Healthcare professionals must not overlook these unloved children left staring at the ceiling. It is our sincere hope that these practice-based insights will contribute to an inclusive society where all parents and children can live together with smiles.

1. Introduction

Advances in perinatal and pediatric medicine and maternal and child health services have substantially improved the survival of children with disabilities and medical conditions. However, cases in which parents experience profound despair and psychological distress following prenatal diagnosis or the disclosure of a disability at birth are not uncommon. In their book, *Report on the "Selection of Life": Who Excludes the Vulnerable?*, Chiba and Kamihigashi (2020) examine specific contemporary issues, including the "testing business" surrounding non-invasive prenatal testing (NIPT), opposition movements against the construction of facilities for people with disabilities, and cases of social hospitalization and treatment refusal of children with disabilities by their biological parents. The publisher's description presents the book as an examination of the continuing marginalization and exclusion of vulnerable people in contemporary Japanese society.

The 2016 attack at Tsukui Yamayuri-en, a residential facility for people with disabilities in Sagami-hara, was an extreme manifestation of eugenic ideology directed against people with disabilities. A former facility employee killed 19 residents and injured 26 other people, including staff members (Ministry of Health, Labour and Welfare, 2016; Nishikado, 2019). The attack exposed the profound social impact of discriminatory beliefs that deny the value of the lives of people with severe disabilities. The history of the disability rights organization Aoi Shiba no Kai also illustrates the conflict between social eugenic thinking and the rights of people with disabilities. In response to public sympathy for a parent who had killed a child with a disability in the 1970s, members of the organization challenged calls for a reduced sentence and questioned the social assumptions that made the killing appear understandable or excusable (Yokozuka, 2007). These historical events demonstrate how social attitudes toward disability and the isolation of families can become entangled in tragic circumstances.

Recent news reports have also preserved the words and experiences of parents involved in fatal or attempted murder-suicide incidents involving children with disabilities. In one case, a 44-year-old mother

was arrested on suspicion of killing her seven-year-old daughter, who required mechanical ventilation, by removing her ventilator. The mother reportedly stated, “I thought I would kill my daughter and then die myself” (Mainichi Shimbun, 2025). In another case, a father entered a dam lake with his 10-year-old daughter, who had developed a disability following acute encephalopathy in early childhood, in an attempted murder-suicide that resulted in the daughter’s death. During the court proceedings, it was reported that he had deepened his assumptions without consulting people around him (Mainichi Shimbun, 2026a). A further report described a mother who took her daughter with an intellectual disability to a riverside at night, placed a sash around the child’s neck, and told her, “Mother will follow you later,” before injuring herself. The report described the mother’s mounting anxiety about what would happen to her daughter after her own death (Mainichi Shimbun, 2026b). These reports underscore the need to consider parental distress in relation to isolation, anxiety about the child’s future, and the perceived absence of viable care arrangements.

Some report that they have reached their limits even before they have begun providing care at home.

According to a 2023 survey on children in residential care conducted by Japan’s Children and Families Agency (2024), approximately 27% of infants residing in infant care institutions were reported to have a disability, chronic illness, or medical care needs. This finding suggests that the psychological conflict and caregiving difficulties experienced by parents following prenatal or postnatal diagnosis, disclosure of a disability, or the emergence of medical care needs may be associated with placement in alternative care or prolonged social hospitalization.

In raising a child with a disability, parents may experience intense psychological agitation during the process of coming to terms with the child's condition, including shock, denial, rejection, anger, and conflict. Furthermore, Japanese society continues to exhibit forms of social prejudice rooted in the implicit privileging of being nondisabled and productive, alongside a strong normative expectation that individuals should not cause difficulties for others. Driven by these social values, parents face an intense conflict between their own feelings of rejection—namely, “I cannot accept this child”—and social norms. This conflict manifests as an internalized form of eugenic thinking, leaving parents in a state of extreme psychological distress (Nishikado, 2019).

Such psychological conflict and isolation may become apparent in medical settings as refusal to consent to surgery, refusal to take a child home or assume caregiving responsibilities, or anger directed toward healthcare professionals. Some children remain hospitalized despite being medically fit for discharge because the home environment is not ready, parents have not reached a point at which they feel able to assume care, or appropriate community-based services and placements are unavailable. These cases illustrate the distinction between medical readiness for discharge and the social and psychological conditions necessary for a safe and sustainable transition to an appropriate care environment.

A nationwide survey of hospitals with pediatric beds in Japan identified prolonged hospitalization among children requiring medical care, including cases in which discharge was complicated by family

circumstances and issues relating to social care rather than medical needs alone (Japan Pediatric Society, 2022). A report on perinatal healthcare provision and discharge support has also addressed the need to reduce prolonged social hospitalization (Ministry of Health, Labour and Welfare, 2021). The persistence of social hospitalization in perinatal and pediatric settings therefore represents a structural challenge that cannot be resolved solely through medical treatment.

Furthermore, parental rejection, anger, and despair during the process of coming to terms with a child's disability may be directed toward the institutions and professionals closest to the family. In perinatal and pediatric settings, healthcare professionals must address not only the child's medical care but also intense parental psychological resistance and difficult interactions. Under conditions of limited bed capacity and staffing, professionals may themselves experience considerable difficulty and a sense of inadequacy in responding to these complex situations.

According to a survey by Japan's Children and Families Agency (2023b, p. 5), 9.7% of postpartum women screened by municipalities scored 9 or higher on the Edinburgh Postnatal Depression Scale (EPDS) within one month postpartum. However, only 7.2% of municipalities reported regularly conducting liaison meetings with local agencies, including psychiatric healthcare institutions. Furthermore, in a fiscal year 2022 survey on postpartum care services, 43.6% of municipalities identified "responding to cases involving mental illness" as a challenge in service implementation.

In neonatal intensive care units (NICUs) and pediatric wards, psychosocial support has been discussed as an integral component of care for infants and their parents. Hynan and Hall (2015) proposed psychosocial program standards for parents in NICUs, emphasizing the need to incorporate parental psychosocial needs into neonatal care. A scoping review of parental peer-to-peer support programs in NICUs identified the importance of involving NICU staff early in program development and evaluating the effects of peer support on parents and infants (Pascual et al., 2024). These approaches highlight the importance of addressing parental mental health and parent–infant relationships alongside the provision of medical treatment.

However, healthcare institutions cannot be expected to address parental rejection and anger while also independently coordinating discharge arrangements, community services, and access to alternative care. Addressing these challenges requires collaboration across medical, psychological, governmental, and welfare services.

The present study aims to identify practical ways of addressing the difficulties encountered by perinatal and neonatal healthcare settings in responding to parental distress and the prolonged social hospitalization of children. Drawing on problems arising in support settings, it examines parental psychological crises, social attitudes toward children with disabilities, and practices that support parent–child relationships. In particular, it considers how support can acknowledge and respond to intense parental conflict and rejection while promoting attachment formation and bonding between parents and children, preventing avoidable social hospitalization, and ensuring the child's best interests, including connection to alternative care arrangements when necessary.

2. Methods

2.1. Participants and Program Overview

The program provides free perinatal mental health support to parents facing psychological distress from pregnancy through the postpartum period, including those whose infants are hospitalized in neonatal intensive care units (NICUs) or pediatric wards. Its objectives are to prevent psychological crises and avoid unnecessary mother–infant separation while promoting parent–infant bonding.

Core services include counseling, temporary accommodation with childcare support, mother–infant relationship therapy, and parenting education. With participants’ consent, the organization coordinates care with healthcare providers, social workers, public health nurses, municipal authorities, child welfare agencies, legal institutions, and adoption services.

1. 2.2. Data Sources and Study Design

2. 2.2. Study Design and Data Sources

This retrospective descriptive study used document-based analysis of materials published by a Japanese disability family support organization between April 1, 2022, and March 31, 2023. Materials relevant to the study objectives were reviewed to examine the organization's support practices and the experiences of families described in the documents. Quantitative information was summarized descriptively where available, and qualitative content analysis was used to identify recurring themes. The study did not aim to estimate causal effects or establish the effectiveness of individual interventions.

2.3. Ethical Considerations

The study protocol was approved by the peer support organization’s ethics committee. The organization’s name and identifying details were withheld to protect the privacy of children and families. Detailed bibliographic information for the 13 source documents is retained confidentially under organizational supervision and is not publicly disclosed to reduce the risk of identification.

2.4. Analytical Approach and Domains of Analysis

Quantitative and qualitative content analyses were conducted on Organization A’s public reports, statistical materials, and first-person narratives. The analysis covered five domains: parental distress and bonding; family support; interagency collaboration; parenting education and support tools; and service limitations and adaptations. Quantitative data were summarized descriptively, while qualitative analysis identified recurring themes related to parental experiences, support needs, and barriers to care.

3. Results

3.1. Overview of Service Utilization and Initial Psychological Challenges

During the fiscal year from April 1, 2022, to March 31, 2023, the organization recorded 230 cumulative consultations, 14 instances of overnight or temporary care, 54 instances of psychological therapy, 32 participants in parenting education, and 49 participants in parent–child salon activities. Online views of parenting education materials were excluded because the materials were publicly accessible.

Across the materials reviewed, diagnosis and medical management had been initiated at medical institutions, and many families were already involved with child guidance centers or public agencies.

In some cases, parents—particularly mothers—exhibited depressive states accompanied by intense rejection, despair about the future, severe fear, and feelings of self-blame immediately following the diagnosis of their child's disability.

3.2. Practical Outcomes of Core Support Programs

1) Parent–Infant Bonding

By integrating lived-experience peer empathy with professional psychotherapy (counseling, family therapy), support workers listened to and validated parents' internal guilt—specifically the painful conflict of wanting to love their child but feeling unable to.

2) Welcome Home as a Safety Net

Tense and rigid facial expressions observed during initial consultations gradually softened, with parents and children visibly regaining smiles. Furthermore, the space served as a voluntary sanctuary not only for parents and children with disabilities, but also for young carers (siblings) seeking a safe personal environment.

The service also offered siblings, including those at risk of becoming young carers, a place where they could feel at ease and take a break from the pressures of family life.

3) Transition to Public Services Through Multidisciplinary and Regional Collaboration

Through continuous coordination with medical institutions (such as Medical Social Workers), child guidance centers, disability support agencies, and municipal officials, the program fulfilled a neutral mediation function.

4) Provided Support Tools:

1. Handwritten letter for parents
2. Pamphlet on perinatal depression

3. Practical guide for supporting mothers at home
4. Picture book for siblings of children with disabilities
5. Growth tracking booklet for children with Down syndrome (specialized maternal and child health handbook)

3.3. Limitations and Challenges Identified in Practice

1. Limitations of Overnight Care for Children with Complex Medical Needs:

Due to the difficulty of maintaining 24-hour on-site nursing coverage, the program could not fully accommodate emergency respite needs for children requiring advanced medical management (e.g., mechanical ventilation).

2. Geographical Accessibility:

Because the support center was located in a suburban area covering a broad region, travel costs and transportation burdens presented ongoing challenges for distant families.

3. Restrictions on In-Person Gatherings During Infectious Disease Outbreaks:

During periods of widespread infectious disease, center-based, face-to-face gatherings and salon events were significantly restricted.

3.4. Service Adaptation: Implementation of the Volunteer Foster Parent Model

To overcome these limitations (medical care constraints, travel distance, and infection risks), the program expanded into a decentralized support scheme by recruiting and registering Volunteer Foster Parents (private short-term caregivers), including nurses and professionals from other fields.

Under the Child Welfare Act, these caregivers assumed short-term residential care in their own homes as "persons currently taking care of the child." This model simultaneously achieved legal compliance, addressed complex medical needs, reduced family travel burdens, aligned with family-based care guidelines, and minimized infection risks through decentralized care.

3.5. First-Person Parental Narratives

This section presents first-person accounts from parents of children with disabilities, illustrating the lived realities and psychological experiences of these families.

Narrative 1: Rejoicing in a Child's Existence

"There is a truly shining light inside my daughter. Even if she doesn't fit onto standard growth charts, within a space of 'tolerance'—where she is neither compared to others nor forced into a rigid box—she is growing into a person who takes pride in her irreplaceable uniqueness. We have learned that every single person can discover their own worth within this tolerance, and we now strive to be tolerant toward everyone. I am deeply thankful from the bottom of my heart for this life with my daughter, who has Down syndrome."

Narrative 2: A Child's Rich Emotional World

"This child is so full of energy every single day, expressing pure joy or anger. I find myself captivated by her overflowing emotions. Right now, her presence is not darkness—she is light. When our family comes home, she jumps up and down with excitement, calling out our names. Her smile brings smiles to the whole family. It is said that around 40,000 children in Japan cannot live with their parents due to various circumstances, but children living in facilities for children with disabilities are not even included in that number. Regardless of whether a child has a disability or not, my deepest wish is for all children to grow up wrapped in the love of a family."

Narrative 3: Navigating External Expectations and Utilizing Support Resources

"I felt he was an angel granted to us by God. However, raising a child with a disability brought constant pressure to try harder, frequent hospital visits, and rehabilitation appointments. These demands left little time for housework, work, or his siblings, causing emotional distress for our entire family."

Things improved when we began prioritizing what was best for our family rather than meeting others' expectations. Support from my husband's parents and transportation provided by the developmental center eased our burden. Now, our family lives more peacefully, and our son remains our joy and a deeply precious member of our family."

Narrative 4: Systemic Limitations Facing Families in Crisis

"A father facing severe caregiving difficulties described his experience seeking help from a child guidance center. Despite expressing his wife's profound physical and mental exhaustion and pleading for urgent assistance, no concrete support was provided. Even after being transferred to another caseworker, no progress was made. Ultimately, he stated: 'To be completely honest, I don't really expect anything from the child guidance center anymore.'"

4. Discussion

4.1. From Despair to Seeing the Child as Cute: Changes in Parental Feelings

Parents may experience profound psychological conflict between wanting to love their child with a disability and being unable to feel the affection they believe they should: “I want to love my child, but I cannot.” This ambivalence and associated guilt may be intensified by societal expectations of parental love, eugenic ideologies, and norms against burdening others.

Professionals should look beyond parents’ words and behaviors and strive to understand the conflicts and concerns underlying them, rather than interpreting rejection as an absence of attachment or judging decisions about caregiving and medical treatment. Expressions of rejection, including wishes to relinquish care or erase the child’s existence, may reflect concerns about the burden on siblings or a desire to protect the family. Similarly, reluctance to consent to painful medical treatment may reflect distress over the child’s suffering or concern for other family members, rather than a lack of understanding or attachment. Well-intentioned expressions of affection toward the child and expectations that parents should share such feelings may further intensify their guilt. Practitioners should therefore acknowledge parents’ distress without judgment, rather than urging them to feel affection or conform to social expectations.

Parental rejection is not necessarily permanent. Some parents who initially chose to relinquish care subsequently reconsidered their decisions and resumed caregiving within a supportive, nonjudgmental environment. Acknowledging parents’ ambivalence and striving to understand their underlying conflicts may provide a foundation for psychological change.

4.2. A Welcoming, Home-Like Place to Turn to

For parents experiencing intense rejection and fear about the future during the early stages of coming to terms with their child’s disability, this program’s 24-hour emergency accommodation service offered more than simply a place to stay. Knowing that there was a welcoming, home-like place where they could turn when things became too difficult to manage may itself have provided hope and emotional reassurance.

4.3. NICU and Hospital-Based Family Support

All cases involved disclosure of a child’s condition or treatment at a medical institution. Challenges included prolonged hospitalization for social reasons when parents refused to take their children home despite medical readiness for discharge, as well as difficulties in responding to parents’ intense rejection and anger. Medical institutions alone have limited capacity to address both parental psychological distress and the practical arrangements needed to establish a suitable caregiving environment in the community.

Through sustained support and collaboration across a wide-area network, there were cases in which prolonged social hospitalization was resolved and families were connected with appropriate community-based services.

4.4. A Volunteer, Nurse-Qualified Foster Parent Model

This model is based entirely on unpaid volunteer caregiving by foster parents with nursing qualifications who welcome children into their own homes.

Three main limitations were identified: (1) limited capacity to accommodate children requiring medical care on an emergency basis because nurses could not be continuously present 24 hours a day; (2) travel burdens for families living far from the service; and (3) restrictions on centralized, in-person support during infectious disease outbreaks.

In response, the program adopted a distributed caregiving approach using the homes of *Volunteer Foster Parents* (temporary caregivers), including registered foster parents with nursing qualifications. This approach was intended to address children's medical care needs, reduce travel burdens, distribute infection-related risks, and provide care in a family setting. This model is consistent with Japan's policy of prioritizing family-based care for children requiring alternative care, while recognizing the importance of providing care in family-like environments when residential care is necessary (Ministry of Health, Labour and Welfare, 2011, 2012).

4.5. Family Joy and Hope

Supporting families requires more than offering advice or telling parents what they should do. It is essential to listen without judgment, avoid blaming parents or overwhelming them with well-intentioned but prescriptive advice, and recognize the joy, love, and hope that children bring to their families.

Family narratives revealed not only caregiving difficulties and distress but also family strengths and resources. These included recognizing a child's individual development beyond what standard developmental indicators may capture, experiencing joy in the child's existence, receiving support from relatives, and using developmental support services and transportation assistance. Effective support requires practitioners to recognize these positive aspects and the values that matter to each family, identify parental psychological crises early, and coordinate practical support resources.

The father's account also highlighted the structural challenges facing public child welfare services in Japan. Child guidance center staff carry heavy workloads, particularly in responding to child abuse, which can limit the time available to listen carefully to parents' distress. This should not be seen simply as a failure of individual professionals, but as a challenge that calls for broader community involvement.

4.6. Medically Cleared, but No Place to Go: Challenges in NICUs and Inpatient Pediatric Wards

A nationwide survey conducted by the Japan Pediatric Society targeting 2,458 hospitals with pediatric beds highlighted the challenges faced by children requiring medical care whose prolonged hospitalization cannot be explained by medical factors alone (Hoshino et al., 2026). In particular, when children requiring medical care who do not have severe motor and intellectual disabilities require alternative care arrangements, they may be unable to access general residential child welfare facilities or specialized facilities for children with severe motor and intellectual disabilities. Consequently, they may

be compelled to remain hospitalized, compromising their opportunities to receive developmental support and education (Hoshino et al., 2026).

This situation places substantial burdens on medical institutions, including bed shortages, the need to respond to parents and caregivers, and complex discharge planning. Above all, however, it deprives children themselves of opportunities to grow up in a warm family environment where they are loved. From the perspective of children's right to live happy lives, intervention in parents' psychological crises and the provision of a safe living environment for children after discharge cannot be addressed separately. These issues need to be addressed in an integrated manner as interconnected clinical challenges in perinatal and pediatric care.

4.7. Giving Children the Chance to Be Loved

Our primary approach has been to provide sustained support for attachment formation and family reunification. However, when it is ultimately impossible for parents to provide care, we have considered and presented a range of alternative social care arrangements, including foster care and special adoption, to safeguard the best interests of the child.

4.8. Medically Ready for Discharge, but with Nowhere to Go: The Plight of Children Remaining in Hospital

"The child had been left in the hospital for more than six months after birth. We could not even contact the biological parents, and their consent for surgery could not be obtained. When I first met the child, they were already over one year old but were still wearing newborn-sized clothes, so I hurried out to buy new clothes" (Matsushima, 2026).

The child was lying in the farthest corner of the hospital's growing care unit (GCU), in a state that made them appear almost like an object rather than a person. Although the child had celebrated their first birthday during hospitalization, they were still wearing newborn clothing, with their hands and feet protruding from garments that had become painfully tight. It felt as though the child's dignity and personhood were not being respected.

The nurses at the hospital had cared for the child with genuine dedication, yet no one came to visit (Koshizen, 2026).

When healthcare professionals and related institutions confront the prolonged hospitalization of children for social reasons in perinatal and pediatric care settings, should they not be guided by an ethical perspective that extends beyond disease management and discharge planning?

Specifically, it is essential to adopt the perspective of the child's best interests and consider what kind of environment is truly necessary for that child to live a happy life. This requires a sincere and respectful approach toward those working to secure the child's discharge and establish an appropriate home environment. Addressing and supporting parents' profound suffering and grief can have a lasting impact on a child's life.

Society and the healthcare system must not overlook children who are forced to spend their days in hospital corners, staring at the ceiling without experiencing love or meaningful human connection. The "silent voices" of these children must not go unheard.

Support for children with disabilities or medical care needs and their families must be structured as an integrated set of interconnected challenges encompassing: (1) mental health support beginning in the perinatal period; (2) nonjudgmental psychological support in coming to terms with a child's disability; (3) interventions to promote parent–child attachment; (4) multidisciplinary collaboration among medical institutions, developmental support services, and welfare agencies; and (5) the provision of a safe and appropriate caregiving environment after hospital discharge.

In the author's view, establishing broad support networks that listen to parents' anguished cries for help while continuing to present diverse care arrangements and options represents a meaningful and practical step toward preventing prolonged hospitalization for social reasons and realizing an inclusive society that safeguards the dignity of children and families, regardless of disability.

4.9. Limitations

This article does not constitute a study designed to evaluate the effectiveness of the interventions described.

Furthermore, because parents' psychological states and changes in parent–child relationships were not assessed using standardized measures, the effects of psychological support cannot be objectively determined. Feedback from service users and observations by support providers are valuable sources of information; however, they alone cannot establish causal relationships between psychological support and improvements in psychological well-being, the continuation of parental caregiving, or reductions in the duration of hospitalization for social reasons.

5. Conclusion

The author sincerely hopes that the practical insights presented in this study will contribute to the realization of an inclusive society in which all parents and children can live together with smiles, regardless of whether a child has a disability.

Declarations

Conflict of interest statement

The author has no conflict of interest to declare.

FUNDING

The author received no financial support for this research, authorship, or publication.

COMPETING INTERESTS

The author declares no competing interests.

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

This retrospective descriptive study analyzed previously published materials and anonymized secondary data from a Japanese disability family support organization. No interviews or new data collection involving families were conducted, and no confidential identifiable consultation records were accessed. The organization's identity and potentially identifying details were withheld to protect family privacy.

The study was conducted in accordance with the *Ethical Guidelines for Medical and Biological Research Involving Human Subjects*. The study and manuscript were approved by the organization's ethics committee, and written authorization to use the materials was obtained from its representative. The committee waived individual informed consent because the study used previously published information and anonymized secondary data. No individual families were recruited or contacted.

DATA AVAILABILITY STATEMENT

The data supporting this study are not publicly available due to privacy and ethical considerations.

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