

SUPPORT FOR DOWN SYNDROME FAMILIES: NEEDS, EXPECTATIONS, AND FEATURE IDEAS

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Abstract

Families are the primary caregivers of children with Down syndrome (DS) and often face complex challenges involving medical, emotional, social, and economic aspects. These challenges require support systems that go beyond clinical care and address psychosocial and practical family needs. This study aimed to identify the needs, expectations, and innovative feature ideas desired by families of children with DS as a foundation for developing comprehensive and sustainable family support systems. This study employed a descriptive mixed-method design, integrating quantitative and qualitative approaches. A total of 156 parents or primary caregivers of children with DS in Indonesia participated through an online survey. Quantitative data were analyzed descriptively, while qualitative data were analyzed thematically to explore family experiences and expectations regarding support features. The findings revealed that the main family needs included educational support (42.95%), parental guidance (28.21%), and emotional and social support (17.31%). Families also suggested various digital-based support features, such as interactive educational modules, online consultations with health professionals, therapy activity scheduling tools, parent community forums, and motivational content. These features were perceived as helpful in improving knowledge, caregiving skills, and emotional well-being. In conclusion, support for families of children with DS should adopt a comprehensive, family-centered, and participatory care model. The utilization of digital technology is considered an effective medium for empowerment, communication, and access to support. This approach is expected to strengthen family resilience, enhance the quality of life of children with DS, and promote inclusive and sustainable family support systems.

Keywords: Down syndrome, family support, family needs, digital platform, family-centered care.

Abstrak

Keluarga merupakan pengasuh utama anak dengan Down syndrome (DS) dan sering menghadapi tantangan kompleks yang meliputi aspek medis, emosional, sosial, dan ekonomi. Kondisi ini menuntut adanya dukungan yang tidak hanya bersifat klinis, tetapi juga memperhatikan kebutuhan psikososial dan praktis keluarga. Penelitian ini bertujuan untuk mengidentifikasi kebutuhan, harapan, serta ide fitur inovatif yang diinginkan oleh keluarga anak dengan DS sebagai dasar pengembangan sistem dukungan keluarga yang komprehensif dan berkelanjutan.

Penelitian ini menggunakan desain deskriptif dengan metode campuran (mixed method) yang mengintegrasikan pendekatan kuantitatif dan kualitatif. Sebanyak 156 orang tua atau pengasuh utama anak dengan DS di Indonesia berpartisipasi melalui survei daring. Data kuantitatif dianalisis secara deskriptif, sedangkan data kualitatif dianalisis menggunakan analisis tematik. Hasil penelitian menunjukkan bahwa kebutuhan utama keluarga meliputi dukungan edukatif (42,95%), bimbingan orang tua (28,21%), serta dukungan emosional dan sosial (17,31%). Keluarga juga mengusulkan fitur dukungan berbasis digital seperti modul edukasi interaktif, konsultasi daring dengan tenaga profesional, penjadwal aktivitas terapi, forum komunitas orang tua, dan konten motivasi. Fitur-fitur ini dinilai dapat meningkatkan pengetahuan, keterampilan pengasuhan, dan kesejahteraan emosional keluarga. Kesimpulannya, dukungan bagi keluarga anak dengan DS perlu diarahkan pada model pelayanan yang komprehensif, partisipatif, dan berpusat pada keluarga, dengan pemanfaatan teknologi digital sebagai sarana pemberdayaan dan komunikasi yang efektif.

Kata kunci: Down syndrome; dukungan keluarga; kebutuhan keluarga; platform digital; perawatan berpusat pada keluarga.

INTRODUCTION

Down syndrome (DS) is the most common chromosomal condition associated with intellectual disability, occurring in approximately one in every 700 live births worldwide, and it presents a lifelong impact on the affected individuals and their families (1,2). Children with DS exhibit a broad range of developmental delays and health complications, including hypotonia, congenital heart disease, thyroid dysfunction, and speech and language impairments, all of which require sustained medical and psychosocial attention. Beyond the individual clinical manifestations, families of children with DS often experience complex challenges that extend across emotional, social, and economic dimensions (3–5). Parents frequently face emotional distress upon diagnosis, financial strain due to ongoing medical and educational needs, and social isolation as a result of stigma or limited societal understanding of intellectual disabilities.

These challenges underline the importance of a comprehensive support system that addresses not only the medical and developmental aspects of care but also the broader psychosocial and community based needs of families (6–8). Effective family support has been consistently shown to play a critical role in enhancing both child and family quality of life, supporting better developmental outcomes, and improving family resilience. However, despite increasing awareness of the significance of family involvement, the existing support mechanisms both formal (healthcare, education, and social services) and informal (peer and community networks) often fail to meet the diverse and evolving needs of these families (3,9).

In many contexts, support programs are fragmented, lack cultural sensitivity, or are not sufficiently tailored to the individual needs and expectations of families of children with DS. Consequently, families may feel marginalized or excluded from the decision making processes related to their child's care, leading to dissatisfaction and decreased engagement with service providers. Therefore, there is a pressing need to explore in depth the specific types

of support that families require, their expectations from health and community systems, and their ideas for innovative features that could enhance existing support platforms. Understanding these dimensions holistically will provide a foundation for developing more inclusive, family centered interventions and sustainable community support frameworks for families of children with DS (3,7,9).

The rationale for this research arises from the recognition that families are the primary caregivers and advocates for children with DS, and their experiences, needs, and expectations are central to improving care outcomes (9–11). While numerous studies have examined the medical and developmental aspects of DS, fewer have focused on the lived experiences of families who navigate complex systems of care with limited support and resources. Families often report feeling inadequately supported by healthcare providers, educators, and community services, resulting in unmet needs that affect their emotional well being and their capacity to provide optimal care (5,9).

Effective support for DS families requires a family centered care model that emphasizes mutual respect, information sharing, collaboration, and empowerment (3,12). Such a model promotes partnerships between professionals and families, ensuring that interventions are responsive to the individual circumstances, values, and priorities of each family. However, existing studies suggest a gap between the conceptual framework of family centered care and its practical implementation (3,6,9). Service delivery models are often designed from professional perspectives, without sufficient incorporation of families' real experiences, expectations, or innovative suggestions. Moreover, the absence of user driven feature design in current support systems whether digital or community based further limits their accessibility, usability, and overall impact.

Therefore, this research seeks to bridge this critical gap by systematically identifying what families of children with DS truly need and expect, and by exploring

their ideas for practical and innovative features that could enhance their support experience. By doing so, the study aims to generate empirical evidence that can inform the design of future interventions, technologies, and policies, ensuring that these initiatives are family informed, culturally relevant, and sustainable in the long term (6,9,10)

This research is designed with the overarching goal of strengthening support systems for families of children with DS through an in depth understanding of their needs, expectations, and feature ideas. The specific objectives include: Identify the specific needs of families: To explore and document the specific needs of families of children with DS, including medical, developmental, social, and emotional support needs. Understand family expectations: To understand the expectations of these families regarding the support they receive from healthcare providers, educators, and community services .

Through these objectives, the research aims to contribute actionable insights that inform the design and improvement of comprehensive, responsive, and sustainable support systems for families of children with DS. The ultimate goal is to enhance the overall quality of life and well being of both the children and their caregivers by aligning services and interventions with their lived realities, expectations, and aspirations.

RESEARCH METHOD

This study employs a descriptive mixed method design that integrates quantitative and qualitative approaches to comprehensively explore the support needs, expectations, and feature ideas of families of children with DS. The quantitative component aims to identify patterns and frequencies of family needs and expectations through structured questionnaires, while the qualitative component provides in depth insights into participants' experiences, perceptions, and suggestions for feature development. This combination allows for both statistical generalization and contextual understanding of family challenges and aspirations. The study design emphasizes

a family centered research approach, ensuring that participants' voices directly inform the conceptualization of future support features and systems.

The research was conducted in Indonesia, involving families of children with DS who are members of various parent associations, community support groups, and online forums. Data collection was carried out over a two month period, from June to July 2025. The online method was chosen to increase accessibility for participants from different regions, ensuring a wider representation of demographic and socioeconomic backgrounds. The data collection utilized digital forms distributed with collaboration DS organizations to ensure inclusivity and convenience for respondents.

The population of this study includes all parents or primary caregivers of children with DS in Indonesia. The sample was selected using a purposive sampling technique, targeting participants who meet the following inclusion criteria: (1) parents or guardians of a child diagnosed with DS, (2) actively involved in the child's care and development, and (3) willing to participate voluntarily.

A total of 156 respondents participated in the study. This sample size was considered adequate for descriptive analysis and thematic exploration, allowing the researchers to identify both dominant trends and unique perspectives. The inclusion of diverse participants from various educational, occupational, and regional backgrounds enhanced the representativeness and richness of the data.

The primary instrument used in this study was a structured questionnaire developed by the researchers, consisting of both closed ended and open ended questions. The questionnaire comprised three main sections: 1) Demographic information: age, gender, education level, occupation, and region of residence of the parents, as well as the age and condition of the child with DS, 2) Support needs and expectations: open ended questions measuring the perceived importance and availability of various forms of support, including medical, developmental, emotional, social, and informational

domains. 3) Feature ideas and suggestions: open ended questions allowing participants to express their opinions, preferences, and innovative ideas regarding potential support features or digital applications.

The instrument was validated by expert judgement. Data were collected through an online survey using a secure and user friendly platform (Google Forms). Respondents provided informed consent before participating, ensuring adherence to ethical standards. Quantitative data were analyzed using descriptive statistical techniques, including frequency and percentages. Cross tabulation was used to explore variations based on demographic characteristics such as parental education or child age. Qualitative data were analyzed through thematic content analysis, following a systematic process of coding, categorizing, and interpreting textual data to identify recurrent themes related to family needs, expectations, and feature suggestions. The analysis involved several steps: (1) familiarization with data, (2) open coding to identify key phrases and ideas, (3) grouping similar codes into subthemes, and (4) synthesizing the subthemes into major themes.

To ensure the trustworthiness of qualitative findings, triangulation was conducted by comparing themes with quantitative patterns and consulting with experts in DS family support. The integration of both data types provided a comprehensive understanding of the phenomenon, strengthening the validity and applicability of the research results.

This research adheres to ethical principles including informed consent, confidentiality, voluntary participation, and data protection. Participants were informed about the purpose of the study, their right to withdraw at any time, and the confidentiality of their responses. No identifying personal information was collected, and the data were used solely for academic purposes. Ethical clearance was obtained from the institutional review board prior to data collection with number 67/II.I.AU/KET.ETIK/VI/2025.

RESULT

A total of 156 respondents participated in this study, representing parents or primary caregivers of children with DS from various regions in Indonesia. The majority of respondents were mothers actively involved in daily caregiving and in seeking information related to their children's development. Their participation reflects a strong motivation to enhance knowledge, share experiences, and contribute ideas for developing a digital support platform tailored to families of children with DS.

Respondent Characteristics

Characteristics	f	%
Child's Age		
0-2 years old	65	41,67
3-5 years old	26	16,67
6-12 years old	29	18,59
13-17 years old	23	14,74
>18 years old	13	8,33
Child's Gender		
Male	81	51,90
Female	75	48,10
Highest Level of Education		
Elementary School/Equivalent	8	5,13
Junior High School/Equivalent	10	6,41
Senior High School/Equivalent	49	31,41
Diploma	24	15,38
Bachelor's Degree	47	30,13
Postgraduate Degree	18	11,54
Occupation		
Housewife	94	60,26
Civil Servant	14	8,97
Entrepreneur	11	7,05
Private Employee	24	15,38
Other	13	8,33
Respondent Age		
21 - 30 Years Old	47	30,13
31 - 40 Years Old	90	57,69
41 - 50 Years Old	18	11,54
Over 50 Years Old	1	0,64

Source: Primary Data 2025

The majority of the respondents were mothers aged 31–40 years (57.69%), indicating that most caregivers of children with DS are in their active parenting years. Most of the children with DS were aged 0–2 years (41.67%), suggesting that many respondents have younger children in early developmental stages. Regarding gender, male children (51.9%) were slightly more represented than female children (48.1%). In terms of education, most respondents had completed Senior High School (31.41%) or Bachelor's degree (30.13%), reflecting a generally well educated

population. Occupation wise, the largest group was housewives (60.26%), followed by private employees (15.38%), suggesting that many mothers may dedicate their time primarily to caregiving responsibilities. Overall, these demographic data provide a comprehensive overview of the respondents' backgrounds, which help contextualize their responses in subsequent analyses regarding needs, expectations, and preferred features for family support systems.

Family Expectations Toward a Digital Support Platform

Analysis of responses revealed that most families expressed positive expectations regarding the creation of a digital platform designed specifically for parents of children with DS. The matic analysis identified several key expectation categories, including:

Expectation Category	Description	f	(%)
Educational Support	Expect access to reliable knowledge about DS, therapy, nutrition, and child development.	67	42,95
Parental Guidance	Need for guidance and tools to assist daily care and home based stimulation for children.	44	28,21
Emotional & Social Support	Desire for community and peer interaction to share experiences and reduce isolation.	27	17,31
Professional Consultation	Expect direct access to experts such as doctors, therapists, or psychologists for consultation.	13	8,33
Ease of Use & Accessibility	Want a simple, practical, and user friendly application.	5	3,21
Total		156	100

Source: Primary Data 2025

Analysis of responses revealed that most families expressed positive expectations regarding the creation of a digital platform designed specifically for parents of children with DS. Thematic analysis identified several key expectation categories, including:

1. Many respondents hoped that the platform could serve as a reliable source of knowledge about DS, child development, therapy, nutrition, and educational approaches (educational support 43%). Common statements included *"expanding insight and knowledge"* and *"helping parents understand their children's condition."* This reflects a strong demand for accessible, evidence based information presented in simple and understandable formats.
2. Respondents emphasized the need for tools and information that could guide them in managing daily care and stimulation for their children at home (parental guidance and empowerment (28%). Examples include *"assisting parents in caring for their children and providing guidance on activities at home."*
3. Several parents highlighted the importance of community and peer connection, expressing a desire for a platform that facilitates interaction, sharing experiences, and mutual encouragement among parents (Emotional and social support 17%).
4. Some participants suggested that the platform should include access to experts, such as therapists, psychologists, or doctors, to allow direct consultation or Q&A sessions (professional consultation 8%).
5. A small proportion of respondents mentioned that the application should be simple, practical, and easy to use, especially for parents who may not be technologically adept (accessibility and ease of use (4%).

These findings indicate that families view a digital platform not only as an information hub, but also as a comprehensive support ecosystem that can empower, connect, and guide them in their parenting journey.

Suggestions for Application Features or Content

The second part of the survey asked participants to propose specific features or content ideas for the envisioned application. Responses were rich and diverse, producing several dominant themes:

Feature Category	Description	f	(%)
Educational Modules	Content on DS, therapy, education strategies, and parenting skills in multimedia formats.	55	35,26
Consultation & Expert Access	Virtual consultation with doctors, therapists, or educators (chat or video).	34	21,79
Activity & Therapy Scheduler	Tools for scheduling therapy sessions and tracking developmental activities.	28	17,95
Parent Community Forum	Discussion forums for parents to share experiences, advice, and emotional support.	23	14,74
Motivational & Success Stories	Inspirational stories to motivate parents and promote positive parenting attitudes.	9	5,77
Reminders & Notifications	Automatic alerts for therapy sessions, doctor visits, or learning activities.	7	4,49
Total		156	100

Source: Primary Data 2025

The second part of the survey asked participants to propose specific features or content ideas for the envisioned application. Responses were rich and diverse, producing several dominant themes:

3.1 The most frequently educational modules (35,26%) suggested content

involved materials on DS, including development milestones, therapy techniques, early stimulation, education strategies, and emotional management for parents. Respondents requested structured modules presented in multimedia formats (articles, videos, and infographics).

3.2 Many participants proposed that the application include virtual consultation features where parents can interact directly with healthcare or educational professionals (Consultation and Expert Access 21,79%). Suggested formats included chat based consultation, video calls, or scheduled Q&A sessions.

3.3 Respondents recommended features for daily routines, therapy schedules, and activity tracking (activity and therapy scheduler 17,95 %), to help parents organize their child's developmental program and monitor progress.

3.4 Another popular idea was to include a peer sharing forum or parent support group where users can share experiences, exchange advice, and motivate one another (parent community forum 14,74%).

3.5 A number of parents wished for stories of success and motivation, showcasing other families' experiences in raising children with DS to inspire hope and positivity (motivational and inspirational content 5,77%).

3.6 Several respondents suggested adding automatic reminders for therapy sessions, doctor visits, or learning schedules to help parents stay consistent in their child's care routine (reminders and notifications 4,49).

Parents demonstrated a strong desire for an integrated, user friendly, and informative platform that combines educational materials, professional access, and emotional support into a single digital ecosystem.

Integration of Needs, Expectations, and Feature Ideas

The combined findings from both parts of the questionnaire illustrate a coherent and interrelated framework of family needs: 1) Families require accurate and practical knowledge as a foundation for confident caregiving, 2) They expect responsive and empathetic professional support, accessible without barriers of

distance or cost, 3) They value peer interaction as a means of reducing emotional stress and building solidarity, 4) They appreciate the idea of digital innovation that simplifies daily management and empowers them in the long term.

This alignment indicates that an effective support platform for DS families should integrate education, communication, and motivation in a seamless and inclusive manner. The results highlight the critical importance of understanding family perspectives in developing digital health and support systems for children with DS. The convergence between educational, emotional, and practical needs reflects that families seek holistic and participatory solutions rather than isolated interventions. Therefore, this research provides an essential evidence base for designing future digital platforms that are user driven, empowering, and sustainable, aligning with the real life experiences and aspirations of DS families.

DISCUSSION

Family Expectations Toward a Digital Support Platform

The study's findings provide a comprehensive understanding of the needs, expectations, and feature ideas of families raising children with DS. Based on responses from 156 parents and caregivers, the results reveal that the most dominant expectation from families is the availability of educational support (42,95%), followed by parental guidance (28,21%), and emotional and social support (17,95%). These results align with the first research objective.

Educational support is the most significant expectation among families raising children with DS. This aligns with findings from other studies that highlight the importance of educational resources and inclusive education for children with DS. For instance, parents often express concerns about the adequacy of educational provisions and the need for specialized support to address their children's unique learning needs (13). Additionally, the role of early intervention programs and inclusive education is

emphasized as crucial for the development and integration of children with DS (5).

Parental guidance is the second most important expectation. This includes the need for information and resources to help parents navigate the challenges of raising a child with DS. Studies indicate that parents often feel inadequately informed by healthcare providers and benefit significantly from support groups and educational workshops that provide practical advice and emotional support. Moreover, guidance on managing daily life and fostering the child's development is essential for parents to feel competent and supported (14,15).

Emotional and social support is also a critical need for families. The availability of social support networks, including family, friends, and support groups, has been shown to significantly impact the well being and satisfaction of parents raising children with DS (16–18). Social support helps mitigate stress and enhances the overall family functioning by providing emotional comfort and practical assistance (19,20). Additionally, the stigma and societal attitudes towards DS can affect families, making social support even more vital for their emotional resilience and social inclusion (4,21).

The results also show that a portion of respondents (8,33%) expect direct consultation access to professionals such as doctors, psychologists, and therapists. This indicates a strong demand for integrated care within a digital platform, combining educational resources with professional guidance. According to literature on telehealth and digital care models, providing virtual access to experts can increase service accessibility, particularly for families in remote areas. Similarly, the need for ease of use (3,21%) reflects the importance of user centered design principles, ensuring that the platform remains inclusive for parents with varying technological literacy levels.

The study's findings underscore the critical needs of families raising children with DS, particularly in terms of educational support, parental guidance, and emotional and social support. Addressing these needs through comprehensive support systems and resources can significantly

enhance the quality of life for both the children and their families.

Suggestions for Application Features or Content

The families of children with DS have multifaceted support needs encompassing educational, professional, organizational, emotional, and motivational dimensions. These needs are interconnected and reflect both the daily caregiving challenges and the broader social and psychological aspects of raising a child with DS. The insights gained from 156 respondents illustrate the priorities and expectations that families hold toward the development of effective support systems, particularly in digital or community based formats.

The most prominent area of need identified was educational support, emphasizing the families' strong desire for accessible, comprehensive, and reliable information about DS. Parents frequently express uncertainty about the best ways to stimulate their children's development and navigate complex medical and therapeutic information (3,12). Educational modules that include multimedia learning resources covering cognitive stimulation, communication enhancement, physical therapy, and inclusive education can empower families with practical knowledge and skills. This aligns with previous research showing that informed parents are more confident and effective in supporting their child's development. Therefore, structured educational modules represent not only a learning tool but also a source of empowerment that fosters autonomy in caregiving.

The second most frequently prioritized feature was consultation with experts, which reflects the importance of direct, personalized interaction between families and healthcare or educational professionals. Access to therapists, genetic counselors, and pediatricians enables parents to receive tailored advice that addresses their child's specific needs and developmental stage (3,12,22). The demand for professional consultation also highlights the families' perception that traditional healthcare services often lack continuity and accessibility. Teleconsultation or hybrid models could

therefore bridge this gap, providing timely and consistent professional guidance. This finding aligns with earlier studies emphasizing that family centered care and collaborative decision making are essential for improving outcomes in children with DS.

The third key feature, activity schedulers, underscores the families' need for practical tools to organize daily life. Children with DS often benefit from structured routines that promote predictability and emotional stability (3,4,23). Scheduling tools that integrate therapy plans, medical appointments, and recreational activities can improve family time management while supporting consistent developmental stimulation. Moreover, such tools can reduce caregiver stress by streamlining daily tasks. Similar findings have been reported in studies where digital scheduling applications improved adherence to therapy programs and reduced parental burnout.

Community forums represent another essential component of family support. Parents of children with DS frequently seek connection with others who share similar experiences, as peer interaction fosters empathy, emotional understanding, and mutual learning (5,9,24). The establishment of both online and in person communities enables families to exchange information, share coping strategies, and feel less isolated. Prior studies have shown that peer to peer networks significantly enhance emotional resilience and provide informal yet valuable sources of advice. Thus, incorporating community features into support systems not only fulfills emotional needs but also creates a sense of belonging and shared purpose among families.

Meanwhile, motivational content, reminders and notifications address the psychosocial and practical aspects of caregiving. Motivational stories and success narratives serve as psychological reinforcement, helping families maintain optimism and perseverance in their caregiving journey (5,25). Exposure to positive experiences and real life success stories of individuals with DS can reshape perceptions of disability and foster hope for their children's future. On the other hand, reminders and notifications although less

frequently mentioned play a crucial role in helping parents manage complex daily schedules, medication routines, and therapy adherence (22,23). These features are particularly valuable for families balancing multiple responsibilities and can prevent missed opportunities for developmental interventions.

When viewed collectively, these findings clearly align with the research objectives, which sought to identify the specific needs, expectations, and preferred features among families of children with DS. The study demonstrates that effective family support systems must integrate educational, consultative, organizational, and emotional functions in a single accessible platform. This comprehensive model of support reflects the principles of family centered care, where families are not merely recipients of care but active participants in designing and implementing strategies that benefit their children (3,24).

Furthermore, these results reinforce the theoretical framework of holistic and participatory care, emphasizing the interplay between knowledge, emotional well being, and social inclusion. By combining structured learning, professional guidance, community interaction, and motivational support, such systems can contribute to improved family resilience and child development outcomes. These findings are consistent with global trends in health innovation, where digital technologies are leveraged to promote accessibility, personalization, and empowerment in caregiving contexts (5,12,23).

In conclusion, the study highlights that families of children with DS require multidimensional and integrated support mechanisms. Addressing these needs through a unified, user friendly, and evidence based support system can enhance parental confidence, reduce caregiving stress, and ultimately improve the quality of life for both parents and children. The insights generated from this research thus provide a solid empirical foundation for developing practical, technology driven solutions that truly respond to the lived experiences of families with DS.

CONCLUSION

This study highlights that families of children with Down syndrome have multidimensional needs encompassing educational, emotional, social, and professional aspects. The majority of parents expect accessible and reliable information, practical guidance for daily caregiving, and opportunities for interaction with professionals and peer communities. These findings underline the importance of developing integrated support systems that combine education, consultation, and community interaction to enhance both parental competence and emotional resilience.

Furthermore, the results reveal strong interest in digital solutions that facilitate access to information, expert consultation, and peer support within a single, user friendly platform. Such an approach reflects the growing relevance of family centered and participatory care models, ensuring that support interventions align with the lived realities and expectations of families.

In conclusion, strengthening support for families of children with Down syndrome requires collaborative, culturally sensitive, and technology based initiatives. Future efforts should focus on designing evidence based digital platforms that promote empowerment, inclusion, and sustainability to improve the overall quality of life of both children and their caregivers.

RECOMENDATIONS

Based on the findings of this study, several recommendations are proposed to strengthen support systems for families of children with DS. First, health and educational institutions should collaborate in developing integrated digital platforms that provide evidence based information, access to professional consultation, and spaces for peer interaction. Such platforms can serve as centralized resources that enhance parents' knowledge, confidence, and caregiving skills while fostering emotional well being through community engagement.

Second, healthcare providers and policymakers should adopt a family centered approach in designing interventions and services. This includes

active involvement of parents in decision making, continuous education programs, and culturally sensitive support tailored to local needs. By emphasizing partnership and mutual respect between families and professionals, services can become more responsive and sustainable.

Third, it is recommended that further research explore the long term impact of digital support systems on family resilience and child development outcomes. Future studies should also assess usability, accessibility, and scalability across different demographic and socioeconomic groups to ensure inclusivity and equity.

Lastly, public health advocacy and awareness campaigns should be strengthened to reduce stigma, promote social inclusion, and encourage the broader community to support families of children with Down syndrome. Collective efforts from the government, non governmental organizations, and society at large are essential to build an environment that empowers families and enhances the overall quality of life for children with DS.

DAFTAR PUSTAKA

1. Noroozi F, Farrar Z, Gharibi T, Gashmard R. Family Self-Support in Managing Down Syndrome Children: A Qualitative Study. *Scientific World Journal* [Internet]. 2024;2024. Available from: <https://www.scopus.com/inward/record.uri?eid=2-s2.0-85195014679&doi=10.1155%2f2024%2f9992595&partnerID=40&md5=a5aed3608cb59a079dd740b3944fb709>
2. Ting CH, Rahman MM, Chen YY, Safii R, Puteh SEW, Saimon R, et al. Employment of people with Down syndrome: A scoping review. *Narra J* [Internet]. 2024;4(3). Available from: <https://www.scopus.com/inward/record.uri?eid=2-s2.0-85213315697&doi=10.52225%2fnaarra.v4i3.1431&partnerID=40&md5=40d163108098710a812ffcbd98c18c5d>
3. Melvin K, Meyer C, Ryan B. "We don't know what we don't know": Providing information about communication to families of children with Down syndrome. *Child Care Health Dev* [Internet]. 2019;45(3):423–32. Available from: <https://www.scopus.com/inward/record.uri?eid=2-s2.0-85064546414&doi=10.1111%2fcch.12658&partnerID=40&md5=b8cb528c1ad954d3f87c4dc7747db27f>
4. Nesterchuk NY, Sydoruk IO. INVOLVING PARENTS IN THE SOCIAL ADAPTATION OF CHILDREN WITH DOWN SYNDROME. *Rehabilitation and Recreation* [Internet]. 2022;2022(12):67–72. Available from: <https://www.scopus.com/inward/record.uri?eid=2-s2.0-85188594452&doi=10.32782%2f2522-1795.2022.12.9&partnerID=40&md5=147581f0beb9ea61fe9db0ab6f76f761>
5. Wahab AA, Monoto EMM. Engaging and empowering parents of children with Down Syndrome-the role of parents support group. *International Medical Journal Malaysia* [Internet]. 2016;17(Specialissue1):131–3. Available from: <https://www.scopus.com/inward/record.uri?eid=2-s2.0-85065552901&partnerID=40&md5=e834ca8ed056b129eb9d5b0b2db71b4b>
6. Marshall J, Tanner JP, Kozyr YA, Kirby RS. Services and supports for young children with Down syndrome: Parent and provider perspectives. *Child Care Health Dev* [Internet]. 2015;41(3):365–73. Available from: <https://www.scopus.com/inward/record.uri?eid=2-s2.0-84927010784&doi=10.1111%2fcch.12162&partnerID=40&md5=4bf2e6147946838ff065ed9b683558fc>
7. Saul RA, Meredith SH. Beyond the genetic diagnosis: Providing parents what they want to know. *Pediatr Rev* [Internet]. 2016;37(7):269–78. Available from: <https://www.scopus.com/inward/record.uri?eid=2-s2.0-85064546414&doi=10.1111%2fcch.12658&partnerID=40&md5=b8cb528c1ad954d3f87c4dc7747db27f>

- ord.uri?eid=2-s2.0-84976869162&doi=10.1542%2fpir.2015-0092&partnerID=40&md5=5ffae2a9d601e31015694e95ff39b72d
8. Masdah S, Meilantika AD, Jiu CK, Ariyanti S. Mapping The Needs Of Digital Information Services For Children With Special Needs. *International Journal of Health Science*. 2025 Jun;3(2):386–412.
9. Hart KM, Neil N. Down syndrome caregivers' support needs: a mixed-method participatory approach. *Journal of Intellectual Disability Research [Internet]*. 2021;65(1):60 – 76. Available from: <https://www.scopus.com/inward/record.uri?eid=2-s2.0-85096678884&doi=10.1111%2fjir.12791&partnerID=40&md5=7749834108513c609890e5abfd60a958>
10. Noroozi F, Farrar Z, Gharibi T, Gashmard R. Family Self-Support in Managing Down Syndrome Children: A Qualitative Study. *Scientific World Journal [Internet]*. 2024;2024. Available from: <https://www.scopus.com/inward/record.uri?eid=2-s2.0-85195014679&doi=10.1155%2f2024%2f9992595&partnerID=40&md5=a5aed3608cb59a079dd740b3944fb709>
11. Wahab AA, Monoto EMM. Engaging and empowering parents of children with Down Syndrome-the role of parents support group. *International Medical Journal Malaysia [Internet]*. 2016;17(Specialissue1):131–3. Available from: <https://www.scopus.com/inward/record.uri?eid=2-s2.0-85065552901&partnerID=40&md5=e834ca8ed056b129eb9d5b0b2db71b4b>
12. Early D, Thompson M, Simpkins S, Luedtke-Hoffmann K, Poskey G. The Journey: Parental Expectations and Perceptions of Therapy Services for Children with Down Syndrome. *Pediatric Physical Therapy [Internet]*. 2022;34(3):318–26. Available from: <https://www.scopus.com/inward/record.uri?eid=2-s2.0-85134084008&doi=10.1097%2fPEP.0000000000000905&partnerID=40&md5=efd5aa20e7fa5cdbf65f57cdd531a71>
13. Van Herwegen J, Ashworth M, Palikara O. Parental views on special educational needs provision: Cross-syndrome comparisons in Williams Syndrome, Down Syndrome, and Autism Spectrum Disorders. *Res Dev Disabil [Internet]*. 2018;80:102–11. Available from: <https://www.scopus.com/inward/record.uri?eid=2-s2.0-85056482161&doi=10.1016%2fj.ridd.2018.06.014&partnerID=40&md5=2bbfd1170796bfed8dce81efb35ad181>
14. Steffensen EH, Rosvig LH, Santoro S, Pedersen LH, Vogel I, Lou S. Parenting a child with Down syndrome: A qualitative study of everyday practices in Danish families. *J Genet Couns [Internet]*. 2022;31(3):758 – 770. Available from: <https://www.scopus.com/inward/record.uri?eid=2-s2.0-85121513898&doi=10.1002%2fjgc4.1542&partnerID=40&md5=d323b839547e4374d6cd8ec3a61ac248>
15. Desimpelaere EN, De Clercq LE, Soenens B, Prinzie P, De Pauw SSW. Parenting a child with Down syndrome: A qualitative study on parents' experiences and behaviors from a self-determination theory perspective. *J Pediatr Nurs [Internet]*. 2024;74:e14–27. Available from: <https://www.scopus.com/inward/record.uri?eid=2-s2.0-85175480908&doi=10.1016%2fj.pedn.2023.10.021&partnerID=40&md5=9161f997c79795ff48e31a8f2c1422d0>
16. Fatima I, Suhail K. Protective factors for subjective well-being in mothers of children with down syndrome. *Pakistan Journal of Psychological Research [Internet]*. 2019;34(4):655–69. Available from: <https://www.scopus.com/inward/record.uri?eid=2-s2.0-85134084008&doi=10.1097%2fPEP.0000000000000905&partnerID=40&md5=efd5aa20e7fa5cdbf65f57cdd531a71>

- ord.uri?eid=2-s2.0-85079432377&doi=10.33824%2fPJPR.2019.34.4.36&partnerID=40&md5=de69d3509768b6c9b8f62d0ff77c9f9b
17. Onyedibe MCC, Philip LIU, Mefoh C, Onuiri C. Parents of children with down syndrome: Do resilience and social support matter to their experience of carer stress? *Journal of Psychology in Africa* [Internet]. 2018;28(2):94–9. Available from: <https://www.scopus.com/inward/record.uri?eid=2-s2.0-85063890422&doi=10.1080%2f14330237.2018.1455308&partnerID=40&md5=9e9c45f4a05986bf4258c0a426b9b401>
18. Guzmán EMR, López RM, Pedro-Viejo AB. Analysis of family adaptation to children with Down syndrome during childhood using the Double ABCX model; [Análisis de la adaptación de las familias con hijos o hijas con síndrome de Down durante la infancia desde el modelo Doble ABCX]. *Alternativas* [Internet]. 2022;29(2):309 – 334. Available from: <https://www.scopus.com/inward/record.uri?eid=2-s2.0-85134592297&doi=10.14198%2fALTERN.21156&partnerID=40&md5=fde192727ddc512fa9c18a9cc1392d97>
19. Hsiao CY. Family demands, social support and family functioning in Taiwanese families rearing children with Down syndrome. *Journal of Intellectual Disability Research* [Internet]. 2014;58(6):549–59. Available from: <https://www.scopus.com/inward/record.uri?eid=2-s2.0-84899969378&doi=10.1111%2fjir.12052&partnerID=40&md5=86ad7807b26c7618696955c7f56411cf>
20. Putra BM, Badayai ARA, Soedjiwo NAF, Suroyo S, Guidi E, Zakaria SM. Demographic factors as mediators between sociopsychological variables and psychological well-being in parents of children with Down syndrome. *Psikohumaniora* [Internet]. 2025;10(1):139–58. Available from: <https://www.scopus.com/inward/record.uri?eid=2-s2.0-105016761938&doi=10.21580%2fjpp.v10i1.25583&partnerID=40&md5=d09c4fbc8919f729c3c2c349add220ed>
21. Huiracocha L, Almeida C, Huiracocha K, Arteaga J, Arteaga A, Blume S. Parenting children with Down syndrome: Societal influences. *Journal of Child Health Care* [Internet]. 2017;21(4):488–97. Available from: <https://www.scopus.com/inward/record.uri?eid=2-s2.0-85034744463&doi=10.1177%2f1367493517727131&partnerID=40&md5=35aac0a55eb633bb4cdb27edd35a326b>
22. Cosgrove B, Knafl K, Van Riper M. A Mixed Methods Analysis of Care Coordination Needs and Desirable Features of an M-Health Application to Support Caregivers of Children With Down Syndrome. *Journal of Pediatric Health Care* [Internet]. 2023;37(1):30–9. Available from: <https://www.scopus.com/inward/record.uri?eid=2-s2.0-85144589705&doi=10.1016%2fj.pedhc.2022.08.002&partnerID=40&md5=053e1f2398b34eb042ebb76eb66ca34f>
23. Habib-Hasan Z, Sheikh MS, Hoodbhoy Z, Azam I, O’Neil M. Early intervention physical therapy using “parent Empowerment Program” for children with down syndrome in Pakistan: A feasibility study. *J Pediatr Rehabil Med* [Internet]. 2020;13(3):233–40. Available from: <https://www.scopus.com/inward/record.uri?eid=2-s2.0-85097004264&doi=10.3233%2fPRM-190605&partnerID=40&md5=3ad178c00964c672c98c2e199cab8c39>
24. Marshall J, Ramakrishnan R, Slotnick AL, Tanner JP, Salemi JL, Kirby RS. Family-Centered Perinatal Services for Children With Down Syndrome and Their Families in Florida. *JOGNN - Journal of Obstetric, Gynecologic, and*

- Neonatal Nursing [Internet]. 2019;48(1):78–89. Available from: <https://www.scopus.com/inward/record.uri?eid=2-s2.0-85059342949&doi=10.1016%2fj.jogn.2018.10.006&partnerID=40&md5=b27163b1048df010afc55e65a9d5e643>
25. Li EPY, Liu YM, Lok NCY, Lee VWK. Successful experience of people with Down syndrome. *Journal of Intellectual Disabilities* [Internet]. 2006;10(2):143–54. Available from: <https://www.scopus.com/inward/record.uri?eid=2-s2.0-33646201310&doi=10.1177%2f1744629506064010&partnerID=40&md5=9c826949b35e536814381a29e0f53edc>