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# Mapping The Needs Of Digital Information Services For Children With Special Needs

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## Abstract

Parents of children with Down syndrome face ongoing challenges in accessing relevant and trustworthy health information. With the increasing use of digital platforms, understanding parents' needs and preferences is crucial for developing effective and inclusive digital health services. This study aims to map the digital health information needs of parents of children with Down syndrome, identify preferred information sources and digital platforms, and explore expectations regarding features of digital health applications. Methods use A descriptive quantitative study was conducted using a structured questionnaire distributed to parents of children with Down syndrome in Indonesia. Data were analyzed to assess patterns of digital information usage, platform preferences, and specific content and feature expectations. The results findings indicate that 83.6% of parents frequently seek digital health information, with WhatsApp groups (81.8%) and community networks like POTADS (80.0%) being the most accessed sources. Parents expressed a strong preference for digital tools that are free, user-friendly, and available in the local language. The most desired features in a health application include home-based therapy guidance (94.5%), educational videos (87.3%), parent forums (72.7%), and online consultation with healthcare professionals (67.3%). There is a high demand among parents for digital health platforms that offer accessible, relevant, and interactive content tailored to the needs of children with Down syndrome. Designing effective digital services requires collaboration across sectors and the integration of digital health literacy initiatives into existing family support systems to ensure equitable access and improved care outcomes.

**Keywords:** Down Syndrome, Digital Health, Digital Literacy, Parental Needs, Health Information Access

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## 1. Introduction

Children with Down syndrome represent a unique population that requires tailored support and resources to address their specific developmental, educational, and health-related needs. Down syndrome, a genetic condition caused by the presence of an extra chromosome 21, is associated with a range of physical and intellectual disabilities. These challenges necessitate a comprehensive approach to information services that can empower families and caregivers to provide effective support for their children.

Effective communication is a cornerstone of development for children with Down syndrome. Many of these children experience speech and language delays, which can hinder their ability to express needs, engage socially, and participate in educational settings. Research indicates that families of children with Down syndrome often feel overwhelmed by the amount of information available and struggle to find resources that are both relevant and accessible. They express a strong desire for more targeted information from healthcare professionals, educators, and support organizations. This need for information is particularly acute during the early years following diagnosis, when parents are navigating a complex landscape of therapies, educational options, and health care services.

A study highlighted that parents prefer a collaborative approach, where they can engage in two-way communication with professionals (Melvin et al., 2019). This partnership is essential for sharing insights about their child's unique needs and for receiving tailored advice that can enhance their child's communication skills. However, there are significant gaps in the provision of specific information, which can hinder the effectiveness of family-centered care. The lack of accessible resources can lead to feelings of isolation and frustration among families, underscoring the need for improved digital information services that cater specifically to their needs (Bingöler Pekcici et al., 2021).

Digital technologies have emerged as powerful tools in supporting children with Down syndrome and their families. The proliferation of mobile applications, online platforms, and digital games offers new avenues for enhancing communication, learning, and social interaction. A systematic review of technology supports for children with Down syndrome reveals a diverse array of tools designed to target various individual capabilities, from cognitive development to social skills enhancement. However, the effectiveness of these technologies is often difficult to ascertain due to small sample sizes and the emerging nature of this research area (Shahid et al., 2022). For instance, digital games have been developed to stimulate cognitive abilities in children with Down syndrome, focusing on areas such as imitation, perception, and fine motor skills. These games not only provide entertainment but also serve as valuable educational resources that can be tailored to the child's developmental level. Furthermore, the integration of assistive technologies, such as speech-generating devices and communication apps, can significantly enhance the ability

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of children with Down syndrome to express themselves and engage with their peers (Karagianni and Drigas, 2022).

The integration of health management information systems (HMIS) is critical in managing the health needs of individuals with Down syndrome. These systems can help create detailed databases that include essential patient information, thereby improving the efficiency and quality of health services. By centralizing health records, HMIS can facilitate better coordination among healthcare providers, ensuring that children receive comprehensive and continuous care (Shaqiri and Sofiu, 2024a). Moreover, digital health literacy is essential for families to navigate and utilize these digital services effectively. Parents must be equipped with the skills to access and interpret health information, understand their child's medical needs, and engage with healthcare professionals. Training programs that focus on enhancing digital health literacy can empower families to take an active role in managing their child's health and well-being (Wrona et al., 2025).

Parents of children with Down syndrome often seek information about their child's health condition, available healthcare services, and other resources. The initial period following the diagnosis is particularly challenging, with parents needing substantial information and psychological support (Slaná et al., 2020). Many parents report feelings of anxiety and uncertainty as they grapple with the implications of the diagnosis. Online communities and support groups can play a significant role in providing emotional support and practical advice, helping parents connect with others who share similar experiences. Research indicates that online platforms can reduce feelings of isolation among parents and provide a space for sharing resources, strategies, and success stories (Boursier et al., 2022a). These communities can serve as valuable sources of information, offering insights into effective therapies, educational programs, and advocacy efforts. Additionally, the availability of webinars, online workshops, and virtual conferences can further enhance parental knowledge and skills, enabling them to advocate effectively for their child's needs.

Educational services for children with Down syndrome must be inclusive and adaptive to their needs. The use of online resources and professional development tools can help educators make reasonable adjustments to support these children effectively. Training programs that focus on inclusive teaching strategies can equip educators with the knowledge and skills necessary to create supportive learning environments (Morley et al., 2017; Walsh et al., 2018). Furthermore, virtual learning environments can address connectivity issues and provide tailored educational content for children with disabilities. The COVID-19 pandemic has accelerated the adoption of online learning, highlighting the potential for digital platforms to deliver personalized education. However, it is essential to ensure that these platforms are designed with accessibility in mind, allowing children with Down syndrome to engage fully with the curriculum (Calle-Urgilez et al., 2018).

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The mapping of digital information services for children with Down syndrome reveals a multifaceted landscape where communication, health management, and educational support are intertwined. Addressing the specific needs of these children through digital technologies and comprehensive information provision can significantly enhance their development and quality of life. Ongoing research and development in this area are essential to create effective and inclusive digital solutions. By fostering collaboration among families, educators, healthcare providers, and technology developers, we can create a supportive ecosystem that empowers children with Down syndrome to thrive.

## 2. Research Method

This study used quantitative research study design. The participant will consist of families with children diagnosed with Down syndrome, recruited from online support groups. A target sample size of 55 families will be aimed for to ensure statistical power for the quantitative analysis. Inclusion criteria will include families with children aged 0 to 3 years with a confirmed diagnosis of Down syndrome. Exclusion criteria will include families who are not fluent in the primary language of the study or those who have children with multiple disabilities that may confound the results. Ethical approval for the study will be obtained from the relevant institutional review board. Informed consent will be secured from all participating families, ensuring that they understand the purpose of the study, their right to withdraw at any time, and the confidentiality of their responses. Data will be anonymized and stored securely to protect participants' privacy. Additionally, the study will adhere to ethical guidelines for research involving vulnerable populations, ensuring that the well-being of children and families is prioritized throughout the research process.

Data were collected using a questionnaire distributed via Google Forms, which included semi-structured questions. This format allowed participants to provide both quantitative responses (e.g., multiple choice and Likert scale items) This approach enabled wider reach and convenience for participants while maintaining anonymity. Informed consent was obtained at the beginning of the form, and participation was entirely voluntary. The data collected through the Google Form questionnaire were analyzed using a quantitative approach**.** Quantitative data from closed-ended questions were analyzed using descriptive statistics, such as frequencies and percentages, to summarize participants' characteristics and responses.

## 3. Results And Discussions

### a. Result

1. Characteristics of Informants

a) Age at Giving Birth

This research was conducted on informants at intervals between the ages of 21 - 46 years ((less than equal to 35 years as many as 30 people and more

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than 35 years as many as 25 people). This study highlights the significant influence of maternal age on digital literacy and information-seeking behaviors related to the care of children with special needs (Altinay et al., 2024; Altindağ Kumaş and Sardohan Yildirim, 2024). Younger mothers (≤35 years), comprising 30 participants, generally demonstrated greater comfort and proficiency with digital technologies. They are more accustomed to using the internet and digital tools for both educational and entertainment purposes for their children, reflecting a higher level of digital literacy and confidence in navigating various online platforms. In contrast, older mothers (>35 years), with 25 participants, exhibited varying levels of digital proficiency. While some may face challenges due to limited exposure or lower confidence in using technology, many still actively seek online information, particularly concerning their children's health and development. However, this group often requires additional support and guidance to make the most of digital information services.

In terms of digital parenting, there are noticeable differences in awareness and self-efficacy across age groups. Younger mothers tend to have higher digital parenting awareness, which is crucial for managing their children's online activities and ensuring their safety in digital spaces. Although older mothers remain engaged in digital parenting, they may benefit from targeted interventions designed to enhance their skills and confidence in this area. Additionally, both age groups actively seek information online, but their approaches and preferences differ. Younger mothers are more likely to use social media and online forums, whereas older mothers often prefer more traditional online sources or direct consultations with healthcare professionals (Baumann et al., 2020).

Therefore, age-specific support strategies are essential. For younger mothers, advanced digital literacy programs should be developed to build on their existing skills and promote more sophisticated use of technology to support their children's learning and well-being. For older mothers, basic to intermediate digital literacy training is necessary to boost their confidence and ability to use digital tools effectively (Altinay et al., 2024; Gözetici and Dönmez, 2024). These efforts should be complemented by personalized support and resources tailored to their specific needs and preferences. In conclusion, considering maternal age in the design of digital information services for children with special needs is crucial. Tailored programs can significantly enhance the accessibility and effectiveness of these services, ensuring that all

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mothers regardless of age are empowered to support their children's development and well-being through digital means.

b) Education

The results showed that the highest proportion of parents held a Senior High School or equivalent education (34.5%), followed by those with a Bachelor's degree (32.7%). Meanwhile, 18.2% of parents had a Diploma, 7.3% had completed postgraduate studies, 5.5% had a Junior High School or equivalent level of education, and only 1.8% had completed elementary school or equivalent. These findings indicate a diverse educational background among the parents, with the majority having at least a high school education or higher.

The varying educational attainment levels underscore the need for differentiated strategies to support parents. Tailored educational programs such as workshops and simple, visually guided materials should be designed to enhance understanding of digital tools and special needs resources, particularly for those with lower levels of education. Parents with higher educational backgrounds are often more capable of self-advocacy; therefore, focused empowerment initiatives should aim to build these capabilities in parents with less formal education through mentoring, community support, and ongoing training.

Community-based initiatives also play a vital role in bridging gaps. These programs should provide inclusive, accessible support that is easy to understand regardless of literacy level. Tools like audio-visual materials, peer support groups, and multilingual resources can improve access and comprehension for all educational levels. The educational attainment of parents plays a critical role in shaping their capacity to support children with special needs. Recognizing this diversity allows stakeholders to design inclusive, equitable interventions that accommodate different literacy and comprehension levels. By implementing targeted strategies, educational institutions, healthcare providers, and community organizations can empower all parents regardless of their background to become effective advocates and supporters in their children's developmental journeys.

c) Work

The majority of parents in the study were housewives, accounting for 61.8% of the respondents. This was followed by private-sector employees at 20.0%, and civil servants (PNS) at 9.1%. Meanwhile, 5.5% were categorized under "Other" occupations, and 3.6% identified as entrepreneurs. These results indicate that most families are supported by non-formal or domestic work, with a smaller proportion engaged in formal employment or self-employment.

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The occupational distribution of parents in the study reveals a strong reliance on non-formal and domestic roles, particularly among housewives, which necessitates the development of inclusive support systems. A significant number of parents identified as housewives, emphasizing the need for programs that recognize and empower non-formal workers. These individuals often lack access to formal employment benefits and structured support, making it essential to provide them with accessible information and resources tailored to their daily realities. Initiatives such as community-based education sessions, peer support groups, and flexible digital resources can greatly enhance their capacity to care for and advocate on behalf of their children with special needs.

For parents employed in the private sector, balancing work responsibilities with caregiving can be a substantial challenge. Therefore, promoting work-life balance through employer-supported initiatives such as flexible working hours, remote work options, and family-friendly policies can enable greater parental involvement in their children's education and developmental needs. Encouraging a more supportive work culture not only benefits families but also contributes to broader social well-being.

In addition, a small percentage of parents in the study are entrepreneurs. These individuals often juggle the demands of running a business while caring for their children. Support programs offering business development training, financial literacy, and time management tools can empower them to grow their enterprises while maintaining active roles in their children's lives. Networking platforms that connect entrepreneurial parents facing similar challenges can also foster knowledge exchange and mutual support.

Understanding the diverse occupational backgrounds of parents is critical in shaping effective support strategies. Whether parents are housewives, employees, or entrepreneurs, tailored interventions that respect their unique circumstances can greatly enhance their ability to support children with special needs. Stakeholders including policymakers, educators, and community organizations must consider these occupational dynamics when designing inclusive programs. By doing so, they can ensure that all parents are empowered to contribute meaningfully to their children's growth and development.

d) Birth Order

The distribution of children's birth order in this study shows that the majority were second-born (32.7%) and third-born (27.3%). First-born children made up 20.0% of the sample, followed by fourth-born (12.7%) and fifth-born (5.5%). A small proportion (1.8%) of children were seventh in birth order. This

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indicates that most children in the sample come from families with multiple children and tend to be born in the middle order rather than as the eldest.

The distribution of birth order in this study where second-born (32.7%) and third-born (27.3%) children form the majority, followed by first-born (20.0%), fourth-born (12.7%), fifth-born (5.5%), and a small fraction of seventh-born children (1.8%) highlights a significant concentration of children in the middle order. This pattern provides valuable insight into how family dynamics and parental attention may influence the identification and support of children with special needs, particularly in relation to their access to and use of digital information services.

Middle-born children often grow up in environments where parents are already managing multiple responsibilities, including the needs of older and younger siblings. As a result, these children may receive less focused attention unless their needs are explicitly recognized. In families with more than one child, parents may rely more heavily on digital tools to manage information, seek guidance, or access educational and health resources. This reliance on digital information becomes even more crucial when navigating the complexities of special needs care for children who are not the first child and thus may not receive the same level of undivided attention. First-born children, although fewer in this study (20.0%), typically receive more intensive monitoring and direct parental involvement, particularly in early developmental stages.

2. Health problems that occur

| Health Problems | n | % |
|---|---|---|
| a. Heart and Blood Vessels | 37 | 67,3 |
| b. Endocrine/Hormone (Thyroid/Gonadal) Problems | 14 | 25,5 |
| c. Blood Disorders | 0 | 0 |
| d. Gastrointestinal Tract | 9 | 16,4 |
| e. Infections and Defense System Disorders | 8 | 14,5 |
| f. Neurology | 3 | 5,5 |
| g. Ear, Nose and Throat Disorders | 11 | 20 |
| h. Eyesight | 2 | 3,3 |

The data shows that the most common health issues experienced by the children were related to the heart and blood vessels, reported by 67.3% of participants. This was followed by endocrine or hormonal problems such as thyroid or gonadal disorders (25.5%) and ear, nose, and throat (ENT) disorders (20.0%). Other reported issues included gastrointestinal tract disorders (16.4%), infections and immune system disorders (14.5%), and neurological conditions (5.5%).

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Eyesight problems were reported in 3.3% of cases, while blood disorders were not reported at all (0%). These results highlight the prevalence of cardiovascular and endocrine-related health issues among the children, underscoring the need for ongoing monitoring and multidisciplinary healthcare support.

3. Physical characteristics that appear in children

| Physical characteristics | n | % |
|---|---|---|
| a. relatively smaller head compared to normal people (microchephaly) with a flat area at the nape. | 19 | 34,5 |
| b. The fontanel is larger and closes more slowly (average age 2 years). | 17 | 30,9 |
| c. Slanted eye shape with the center corner forming folds (epicanthal folds). | 42 | 76,4 |
| d. Small mouth shape with a large tongue (macroglossia) so that it appears protruding out. | 19 | 34,5 |
| e. Ear canals can be smaller so that they easily get blocked and can cause hearing loss if not treated. | 10 | 18,2 |
| f. Straight/horizontal transverse palm lines (simian crease) | 22 | 40,0 |
| g. Decreased muscle tone (hypotonia) | 21 | 38,2 |
| h. Depressed nasal bridge, lobe of the nose and | 31 | 56,4 |
| i. Smaller airway so Down syndrome children are prone to nasal congestion. | 13 | 23,6 |
| j. Short body. Most people with Down's Syndrome do not reach the average adult height. | 13 | 23,6 |
| k. Small chin (micrognatia) | 10 | 18,2 |
| l. Small dentition (microdontia), appearing later in an improper order. | 10 | 18,2 |
| m. White spots on the iris (Brushfield spots) | 4 | 7,3 |
| n. Flat nose bridge (snub) | 32 | 58,2 |
| o. small ear size with lower position | 21 | 38,2 |
| p. small mouth and always open | 14 | 25,5 |
| q. large tongue size | 18 | 32,7 |
| r. Neck appears shorter | 31 | 56,4 |
| s. Neck has thicker skin folds than normal children | 20 | 36,4 |
| t. the distance between fingers is wide | 10 | 18,2 |
| u. Ring finger is bent inward | 5 | 9,1 |

The findings indicate a range of physical characteristics commonly found in children with Down syndrome. The most prevalent features include slanted eyes with epicanthal folds (76.4%), flat nose bridge (58.2%), short neck appearance (56.4%), and a depressed nasal bridge (56.4%). Other frequently observed traits are simian crease on the palms (40.0%), hypotonia or reduced muscle tone (38.2%),

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small ears in lower position (38.2%), and thick neck skin folds (36.4%). Additional characteristics included macroglossia (large tongue) (32.7%), macrocephaly or small head with flat nape (34.5%), delayed fontanel closure (30.9%), and open small mouth posture (25.5%). Less commonly observed features were Brushfield spots on the iris (7.3%), bent ring finger (9.1%), and wide finger spacing (18.2%). These physical features are consistent with clinical descriptions of Down syndrome and can aid early recognition and diagnosis. Understanding these characteristics is crucial for planning appropriate care, education, and intervention strategies.

4. Down Syndrome Information

| Information | n | % |
|---|---|---|
| **Frequency** | | |
| a. Every day | 24 | 43,6 |
| b. Several times a week | 22 | 40,0 |
| c. Once a week | 4 | 7,3 |
| d. Rarely | 5 | 9,1 |
| e. Never | 0 | 0 |
| **The main sources of digital information used today** | | |
| a. WhatsApp Group | 45 | 81,8 |
| b. Facebook | 17 | 30,9 |
| c. Instagram | 34 | 61,8 |
| d. TikTok | 24 | 43,6 |
| e. YouTube | 31 | 56,4 |
| f. Health website | 18 | 32,7 |
| g. Mobile applications (Halodoc, Alodokter, etc.) | 5 | 9,1 |
| h. Direct consultation with medical personnel | 23 | 41,8 |
| i. Communities such as POTADS | 44 | 80 |
| j. Others | 4 | 7,3 |

The majority of parents reported accessing digital health information daily (43.6%) or several times a week (40.0%), while a smaller percentage accessed it once a week (7.3%) or rarely (9.1%). No respondents indicated that they never accessed digital information. In terms of digital information sources, the most commonly used platforms were WhatsApp Groups (81.8%), Down syndrome-related communities such as POTADS (80.0%), and Instagram (61.8%). Other frequently accessed sources included YouTube (56.4%), TikTok (43.6%), and direct consultations with medical personnel (41.8%). Lesser-used sources were Facebook (30.9%), health websites (32.7%), and mobile health applications such as Halodoc or Alodokter (9.1%). A small number of respondents (7.3%) reported using other unspecified platforms.These findings highlight the strong reliance on social media and peer communities as primary sources of digital health information

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for families with children with Down syndrome. It underscores the importance of integrating accurate, accessible information into these commonly used platforms.

5. Preference for Digital Platforms

| Characteristics | n | % |
|---|---|---|
| **Willing to use specialized digital apps for parents of DS children** | | |
| a. Yes | 52 | 94,5 |
| b. No | 0 | 0 |
| c. Undecided | 3 | 5,5 |
| **Most preferred digital platform** | | |
| a. Mobile Application | 8 | 14,5 |
| b. Website | 2 | 3,6 |
| c. WhatsApp Group | 41 | 74,5 |
| d. Instagram/Facebook | 2 | 3,6 |
| e. YouTube | 2 | 3,6 |
| f. Others | 0 | 0 |
| **Reasons for choosing a platform** | | |
| a. Easily accessible | 39 | 70,9 |
| b. Save quota | 15 | 27,3 |
| c. The content is relevant | 12 | 21,8 |
| d. There is a community | 30 | 54,5 |
| e. Can have direct interaction (chat/consultation) | 34 | 64,8 |
| f. Others: | 1 | 1,8 |
| **Expected features in the app** | | |
| a. Educational video about Down Syndrome | 48 | 87,3 |
| b. Therapy guidelines that can be done at home | 52 | 94,5 |
| c. Therapy calendar and schedule reminder | 29 | 52,7 |
| d. Online consultation with doctor/psychologist | 37 | 67,3 |
| e. Discussion forum among parents | 40 | 72,7 |
| f. Map of health services and inclusive schools | 32 | 58,2 |
| g. Daily child development records | 34 | 61,8 |
| h. Voice assistant / quick question and answer feature | 21 | 38,2 |
| i. Others: | 2 | 3,8 |

The results of the study show that most parents expressed a willingness to use a specialized digital application designed to support families with children who have Down Syndrome. When asked about their preferred platform, the majority (74.5%) favored WhatsApp Groups, indicating a preference for accessible and familiar communication tools. Only a small number selected other platforms such as mobile applications (14.5%), websites, Instagram/Facebook, or YouTube (each 3.6%).

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Parents cited several reasons for choosing a particular platform. The most common reason was ease of access (70.9%), followed by the ability to engage in direct interaction such as chat or consultation (64.8%), and the presence of a supportive community (54.5%). Saving internet data quota (27.3%) and relevance of content (21.8%) were also important considerations. In terms of features expected in a digital application, parents showed a strong interest in practical and informative tools. The most requested feature was home-based therapy guidelines (94.5%), followed by educational videos about Down Syndrome (87.3%) and discussion forums for parent-to-parent interaction (72.7%). Other desirable features included online consultations with healthcare professionals (67.3%), child development tracking (61.8%), a map of health services and inclusive schools (58.2%), therapy calendars or reminders (52.7%), and voice assistant or quick Q&A tools (38.2%). These findings underscore the need for a comprehensive, interactive, and user-friendly digital platform tailored specifically to the needs of families with children who have Down Syndrome, integrating education, therapy, community support, and accessible communication features.

6. Parents' Perception of the Existence of Applications

| **Characteristics** | **n** | **%** |
|---|---|---|
| **Willingness to use applications available for free and in Indonesian language** | | |
| Yes, definitely | 50 | 90,9 |
| Maybe | 5 | 9,1 |
| Not sure | 0 | 0 |
| No | 0 | 0 |
| **Application Requirement Level** | | |
| Not important at all | 2 | 3,6 |
| Not important | 0 | 0 |
| moderately important | 3 | 5,5 |
| Important | 9 | 16,4 |
| Very important | 41 | 74,5 |
| **Total** | **55** | **100** |

The study results indicate a strong interest and readiness among parents to adopt digital applications designed to support families of children with Down Syndrome. A significant majority (90.9%) of respondents stated they would definitely use a digital application if it were available free of charge and in the Indonesian language. An additional 9.1% responded “maybe,” while none expressed uncertainty or refusal to use such an application. When asked about the perceived importance of having such an application, the majority (74.5%) rated it

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as very important, and 16.4% considered it important. A smaller portion (5.5%) viewed it as moderately important, and only 3.6% regarded it as not important at all. These findings highlight a clear demand for locally accessible, cost-free digital solutions that can assist parents in managing care and support for children with Down Syndrome.

**b. Discussion**

1) Health Information Access

The findings of this study revealed that a significant majority of parents of children with Down syndrome actively seek health-related digital information, with 43.6% accessing it daily and 40.0% several times a week. This underscores the critical need for timely, accurate, and easily accessible information tailored to their children's developmental and medical needs. These findings align with previous research that emphasizes the challenges parents face in the initial post-diagnosis period, where informational and psychological support are paramount (Chawla et al., 2023). However, digital health literacy remains a barrier for some, particularly for those with lower educational backgrounds. Although most participants in this study had at least a senior high school education, a minority had only primary or secondary school education. This gap highlights the need for inclusive digital solutions and targeted literacy interventions to empower all families regardless of educational level.

Recent studies conducted between 2019 and 2024 have provided valuable insights into the sociodemographic profiles and healthcare needs of children with special health care needs (CSHCN). One large-scale evaluation revealed that the average age at which children were admitted to health boards for special needs assessments was 7.41 years, with boys representing a higher proportion (58.3%) than girls (41.7%) (Canpolat et al., 2024). The most common reason for referral was to obtain eligibility for disability-related benefits, with cognitive development delays being the most frequently diagnosed concern. These findings highlight the importance of early screening and support systems that can recognize and respond to developmental concerns, particularly in young boys.

In terms of access to health services, telemedicine has emerged as a promising alternative to traditional in-person care. Studies have shown that telemedicine visits for CSHCN are not only safe and effective with high appointment completion rates and low rates of adverse events but are also perceived by families as more convenient and family-centered (Hooshmand and Foronda, 2018). Importantly, one comparative study found that while telemedicine did not significantly reduce family costs compared to in person visits, it offered greater

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flexibility and satisfaction, making it a viable long-term care option for families facing logistical barriers.

Despite these advancements, many families continue to face challenges in accessing high-quality information and care. Disparities in digital or eHealth literacy affected by factors such as parental education, age, and primary language remain a significant obstacle, limiting the ability of some parents to make informed health decisions for their children. Moreover, socioeconomic determinants such as employment status and household income were found to influence access to critical services, including oral healthcare, especially during the COVID-19 pandemic when routine care was disrupted (Arabulan et al., 2025; Masdah et al., 2025).

Transitioning from pediatric to adult care presents additional difficulties for young people with special needs. Studies indicate that approximately 65% of adolescents who aged out of public programs experienced at least one adverse transition event, including gaps in insurance coverage or delayed access to care. However, those who received Supplemental Security Income (SSI) or participated in special education programs during childhood reported better continuity of care, suggesting that structured support during adolescence plays a key role in facilitating smoother transitions into adult health systems.

Family-centered care (FCC) continues to be a cornerstone in improving health outcomes and reducing disparities. Providers who demonstrate cultural sensitivity, actively listen to families, and involve parents as partners in decision-making are more likely to meet the comprehensive needs of CSHCN. Recent evidence shows that these FCC principles can significantly reduce racial and ethnic disparities in unmet therapy needs, further reinforcing the importance of relationship-based, individualized care. In conclusion, current research underscores the necessity of personalized and equitable healthcare systems for CSHCN. The effective integration of telemedicine, attention to information access and digital literacy, structured transition planning, and a sustained commitment to family-centered care are all critical in supporting these children and their families across the continuum of care.

2) Platform Preferences

Social and community-based platforms were identified as the most commonly used digital information sources. WhatsApp Groups (81.8%) and Down syndrome communities like POTADS (80.0%) were preferred over professional or commercial health platforms. Parents expressed a preference for informal, interactive, and community-driven platforms. These preferences support findings by (Bird et al., 2019), who noted that familiar, socially engaging platforms enhance users' comfort and trust. The study also found that parents favored platforms that

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allow for direct communication and quick responses, such as chat or video consultations. This supports the model of "collaborative care" in digital health, where ongoing dialogue between families and professionals leads to more tailored and responsive services (Bird et al., 2019).

Social media has become an essential tool for many parents seeking health information for their children. A substantial proportion of parents globally such as 82.2% of Australian parents report using social media for health-related purposes (Frey et al., 2022). Similarly, in the United States, a large number of parents and expectant mothers frequently engage with platforms like YouTube, Facebook, and Instagram to obtain health information on a daily basis (Waring et al., 2023). The widespread adoption of these platforms is driven by several motivating factors. Parents are attracted to the continuous availability of information, the opportunity to share experiences and opinions, and the emotional support offered by peer communities. Many use social media not only to prepare for medical consultations but also to validate or supplement the information provided by healthcare professionals, seek second opinions, or find support after a diagnosis.

The benefits of social media in this context are multifaceted. It offers a space where parents, particularly those raising children with chronic conditions or disabilities such as Down syndrome or cancer, can find both informational and emotional support. Peer interaction helps reduce feelings of isolation and increases caregivers' sense of competence in managing their child's condition. Social media also presents a powerful opportunity for public health professionals to disseminate evidence-based content and promote health literacy at scale. By leveraging popular platforms, health authorities can reach diverse populations and encourage healthy behaviors through engaging, accessible messaging (Frey et al., 2022; Nagelhout et al., 2018).

However, several challenges accompany the use of social media for health information. Chief among them is the issue of information credibility. Many parents struggle to distinguish between reliable and misleading content online, leading to increased risk of misinformation, particularly in urgent or high-stress situations. This issue is more pronounced among low-income populations, where limited time and digital literacy can exacerbate vulnerability to false or harmful information. Consequently, experts have called for stronger monitoring, regulation, and quality control of health content shared on social platforms. Without adequate oversight, parents may unknowingly adopt practices or beliefs that are not supported by medical evidence (Pretorius et al., 2019).

The impact of social media on family well-being also varies depending on usage patterns. For instance, research has shown that fathers who use social media

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primarily for maintaining social connections and entertainment report better family health outcomes. In contrast, similar patterns were not observed in mothers, suggesting that the context and purpose of social media use may influence its effect on family dynamics and stress levels (Olpin et al., 2023).

To mitigate risks and maximize benefits, improving parental health literacy is essential. Providing parents with accessible, evidence-based health information in various engaging formats such as infographics, short videos, and Q&A sessions can help combat misinformation (Frey et al., 2023; Pretorius et al., 2019). Public health campaigns should also prioritize education on how to critically evaluate the credibility of online sources and guide parents toward reputable platforms. Ultimately, while social media presents undeniable advantages for modern parenting, Its effective use relies heavily on informed, digitally literate users and active collaboration between public health professionals, healthcare providers, and platform developers.

3) Expected Features in a Digital Application

Respondents demonstrated strong interest in a comprehensive mobile application that integrates educational, therapeutic, and interactive components. The most desired features included: home-based therapy guidelines (94.5%), educational videos (87.3%), parent discussion forums (72.7%), Online consultations with professionals (67.3%) and developmental milestone tracking (61.8%). These expectations reinforce the findings from multiple recent studies showing that families benefit most from applications that combine information, monitoring, and psychosocial support into one user-friendly interface. Moreover, such tools can improve early intervention outcomes, caregiver empowerment, and care coordination for children with special needs (Arthurs et al., 2022).

Recent studies have consistently demonstrated that families of children with special needs derive substantial benefits from mobile applications that integrate health information, care monitoring, and psychosocial support into a single, user-friendly interface. These digital tools are proving to be essential not only in enhancing early intervention outcomes but also in empowering caregivers and improving overall care coordination. As technology becomes more embedded in daily life, mobile health applications are emerging as a practical and scalable solution to many challenges faced by families navigating complex care systems (Wagner et al., 2023).

In terms of early intervention and accessibility, mobile health apps have shown potential to improve clinical outcomes by promoting adherence to care plans, increasing accessibility to services, and facilitating timely interventions. Despite their promise, the integration of mobile apps into routine care is still limited,

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especially among underserved families. Applications like *Family on Track* and *LinkI* have been specifically developed to assist parents in navigating early intervention (EI) services and to improve communication among caregivers, therapists, and educators. These platforms offer intuitive interfaces that simplify the process of scheduling therapy, accessing educational content, and tracking progress elements crucial to effective early childhood intervention (Jeon et al., 2024; Wagner et al., 2023).

Another critical advantage of mobile apps lies in their ability to empower caregivers. By equipping parents with the tools and knowledge needed to manage their child's condition more effectively, these apps enhance the caregiver's role as an advocate and partner in care. For example, mobile applications developed for children with attention-deficit/hyperactivity disorder (ADHD) and intellectual disabilities have shown measurable improvements in attention span and cognitive function, as reported by both parents and clinicians (Ha et al., 2022). Caregiver empowerment also encompasses cost reduction, as these tools can minimize the need for frequent in-person visits and provide immediate access to support resources. Moreover, by improving the caregiver's confidence and competence, mobile apps promote more proactive involvement in decision-making and service planning. (Ammari and Schoenebeck, 2015; Bornman et al., 2020; Szlamka et al., 2023).

Mobile health apps also play a pivotal role in care coordination an essential component for managing children with multiple service needs. Effective coordination often requires real-time communication between primary care providers, specialists, educators, and support networks (Kaslovsky and Sadof, 2010; McAllister et al., 2007; Ming et al., 2023). Mobile platforms can serve as a bridge, facilitating seamless integration of electronic health records (EHRs), secure messaging, and shared goal tracking. Apps such as *IEP-Connect* have been specifically designed to support students with special educational needs by coordinating therapy goals and educational plans. These tools have demonstrated high usability, satisfaction, and practical value among families and professionals alike (Siyam and Abdallah, 2022).

Equally important is the psychosocial support offered by these applications. Caring for a child with special needs is emotionally demanding, and caregivers often experience stress, anxiety, and isolation. Mobile interventions can provide coping strategies, virtual peer support, and even mental health screening tools. During the COVID-19 pandemic, for example, app-based interventions were found to improve parenting self-efficacy and reduce symptoms of depression and anxiety

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among caregivers. Such support systems are particularly vital during periods of uncertainty or limited access to in-person services (Chua and Shorey, 2022).

In conclusion, mobile health applications that integrate educational content, care coordination features, and emotional support offer a comprehensive and effective approach to supporting families of children with special needs. These tools not only facilitate early and personalized intervention but also empower caregivers and improve collaboration among care providers. As mobile health technology continues to evolve, ensuring equitable access and user-centered design will be critical to maximizing their impact on child development and family well-being.

4) Implications for Digital Service Development

This study offers clear implications for the design of digital health services for families of children with Down syndrome. First, digital applications must be: Free of charge, Delivered in the local language (Indonesian) and Intuitive and easy to navigate. Second, cross-sector collaboration among developers, healthcare professionals, educators, and parent advocacy groups is essential. Such partnerships will help ensure that platforms are not only technically sound but also socially and culturally appropriate (Albano Reis, 2024). Third, health policymakers and service providers should integrate digital health literacy programs into existing family support services to ensure equitable access and maximize the benefits of digital tools for all users (Cardoso et al., 2024).

Designing digital health services for families of children with Down syndrome requires careful attention to accessibility, language, and user interface design to ensure broad usability and effectiveness. First, these services must be free of charge to eliminate financial barriers, particularly for families in low and middle-income countries (LMICs), where the cost of healthcare and digital tools can be prohibitive (Hui et al., 2022). Offering services at no cost is essential for promoting equitable access and ensuring that all families, regardless of socioeconomic status, can benefit from digital health innovations. Second, the delivery of services in the local language, such as Indonesian, is vital to overcome language barriers and ensure that users can fully understand and engage with the content. Local language support not only enhances comprehension but also improves user satisfaction and encourages continued use (Zhou et al., 2024). Third, digital platforms must be intuitive and easy to navigate, particularly for users who may not be familiar with technology or medical terminology. This includes the use of simplified interfaces, clear visual cues, and responsive touch features that improve accessibility for first-time or low-literacy users. Incorporating user-centered design principles and focusing on a seamless user experience throughout the product lifecycle is key to maximizing adoption and long-term engagement (Dorn, 2012; Tscharn et al., 2016).

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By addressing these three core elements cost, language, and usability developers and stakeholders can create digital health services that are inclusive, practical, and truly supportive of families caring for children with Down syndrome.

Cross-sector collaboration among developers, healthcare professionals, educators, and parent advocacy groups is critical to the successful development and implementation of digital health platforms, particularly those aimed at supporting families of children with special needs. These partnerships bring together diverse expertise and resources, enabling the co-creation of solutions that are both technically robust and socially responsive (Jørgensen et al., 2025). When effectively managed, such collaboration can enhance service delivery, improve patient outcomes, and foster system-level innovation (Austin et al., 2021; Liu et al., 2019). For instance, in the field of mental health, cross-sector partnerships have led to more coordinated and efficient care, although they are not without challenges, including bureaucratic delays and communication gaps. Similarly, partnerships between academic institutions and the technology industry have demonstrated strong potential for driving digital health innovation by combining rigorous research frameworks with practical healthcare applications. Projects like AIR Louisville, which brought together government, non-profits, and tech companies, illustrate how these collaborations can achieve measurable clinical outcomes while informing public health policy (Barrett et al., 2018).

Despite these benefits, several barriers can impede effective collaboration. Miscommunication, misaligned goals, and differences in organizational culture or timelines often lead to friction and reduced efficiency (Ford et al., 2021; Liu et al., 2019). Regulatory and logistical challenges such as unclear policies, limited time commitments, and high turnover among partners can further complicate coordination (Gakh et al., 2024; Wu, 2025). Moreover, interpersonal dynamics and cultural differences may hinder trust-building, particularly when communication lacks authenticity or fails to consider local context (Liu et al., 2019). These issues are especially pronounced in involving stakeholders from high-income and low- to middle-income settings, where disparities in resources and communication styles must be sensitively managed.

To overcome these challenges and unlock the full potential of cross-sector collaboration, several strategies should be prioritized. Policy reforms and stronger organizational support are necessary to create enabling environments for partnership (Jørgensen et al., 2025). Establishing shared goals, transparent communication, and integrated digital platforms can facilitate smoother coordination (Napp and Conklin, 2022). Long term engagement and trust-building among partners are also crucial, with community involvement playing a central role

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in ensuring that solutions are contextually relevant and socially accepted. Finally, investing in education and training for local stakeholders helps build capacity and ensures that digital health innovations are designed with and for the communities they aim to serve (Kouri and Gröhn-Rissanen, 2009). In summary, cross-sector collaboration, when supported by thoughtful planning and inclusive practices, can catalyze innovative, scalable, and equitable digital health solutions.

Integrating digital health literacy programs into existing family support services for parents of children with Down syndrome is essential to improving both care outcomes and parental empowerment. Current evidence indicates that a significant proportion of parents in this group exhibit low health literacy; one study reported that 63.1% had inadequate levels, while only 18.5% demonstrated adequate health literacy (Akça et al., 2024). This underscores the urgent need for targeted, accessible, and inclusive literacy interventions. Digital health interventions have shown promise in enhancing parental knowledge and health-related behaviors, although there remains a gap in research specifically focusing on families of children with Down syndrome (Mörelius et al., 2021). Telehealth and online learning tools have further demonstrated their effectiveness during the COVID-19 pandemic. For example, programs such as ABRACADABRA improved literacy outcomes for children with Down syndrome (Murphy et al., 2023), while telehealth-based developmental monitoring was found to be both applicable and satisfactory among caregivers (Ozalp Akin et al., 2022).

To address this gap, comprehensive digital health literacy programs should be developed, incorporating modules that educate parents about Down syndrome, health condition management, and the effective use of digital platforms and tools. Programs such as i-PiCSS, which combine telepractice and online learning, offer useful models for this approach (Akemoğlu et al., 2022). Encouraging participation in online communities can also provide dual benefits of emotional support and shared learning, reducing feelings of isolation often experienced by parents (Boursier et al., 2022b). Moreover, existing digital tools such as GUÍA which has been shown to improve parents' understanding and confidence in interpreting genetic test results can be adapted to include Down syndrome-specific information, thereby offering personalized and relevant support (Suckiel et al., 2023).

Accessibility and inclusivity must remain central to these initiatives. Content should be tailored to different literacy levels, presented in user-friendly formats, and available in multiple languages to accommodate the diverse backgrounds of families (Mörelius et al., 2021). Collaborating with healthcare providers is also key to successful integration, as providers play a vital role in recommending digital tools, reinforcing usage, and guiding parents through

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complex health information (Shaqiri and Sofiu, 2024b). In conclusion, embedding digital health literacy programs within family support services holds great potential to empower parents, reduce health disparities, and ensure better developmental and health outcomes for children with Down syndrome. By leveraging technology, community, and clinical collaboration, these programs can form a comprehensive support system for families navigating lifelong care needs.

## 4. Conclusion

This study provides a comprehensive overview of the digital information needs of families raising children with Down syndrome, revealing key insights into health information access, platform preferences, application features, and systemic implications for service design. The findings underscore that while parents are actively engaged in seeking digital health information particularly through informal, community-based platforms such as WhatsApp and POTADS there remains a critical need for accessible, high-quality, and contextually relevant content. The study also shows that parents are overwhelmingly willing to use digital applications that are free, in their local language, and easy to navigate. Furthermore, they express strong interest in features such as home-based therapy guidelines, educational content, communication tools with healthcare professionals, and peer discussion forums.

To effectively meet these needs, the development of digital health platforms must prioritize inclusivity, usability, and affordability. Cross-sector collaboration among developers, educators, healthcare providers, and parent advocacy groups is vital to ensure that these platforms are not only technically sound but also socially and culturally appropriate. Additionally, integrating digital health literacy training into family support services is essential for reducing disparities and ensuring that all families regardless of socioeconomic or educational background can access and benefit from these digital tools. Ultimately, empowering parents through inclusive digital services has the potential to improve early intervention outcomes, strengthen care coordination, and enhance the overall well-being of children with Down syndrome and their families.

## 5. Compliance with ethical standards

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### Disclosure of conflict of interest

This research collaboration is a positive thing for all researchers so that conflicts, problems and others are absolutely no problem for all writers.

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**Statement of informed consent**

Every action we take as authors is a mutual agreement or consent.

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