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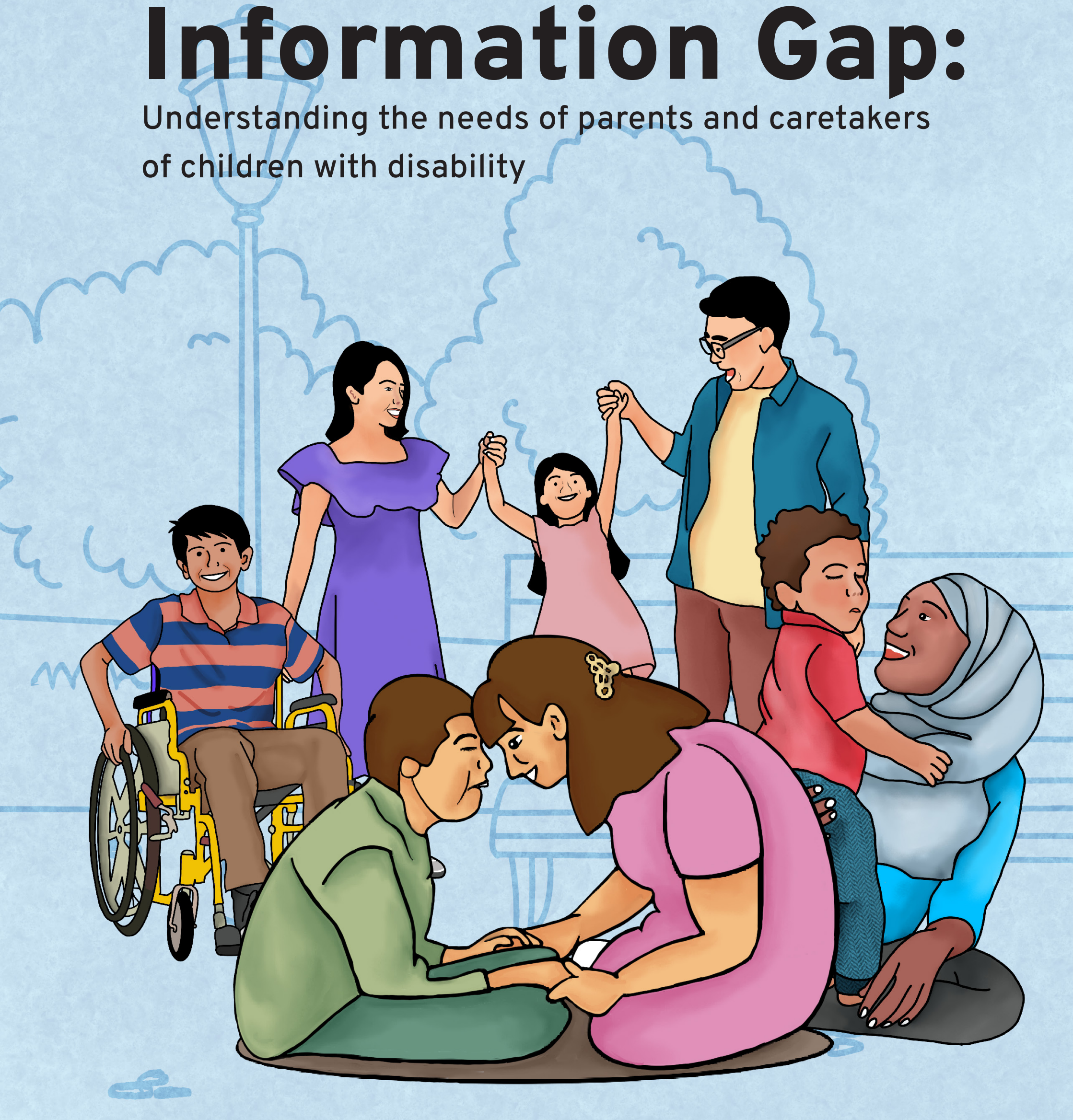
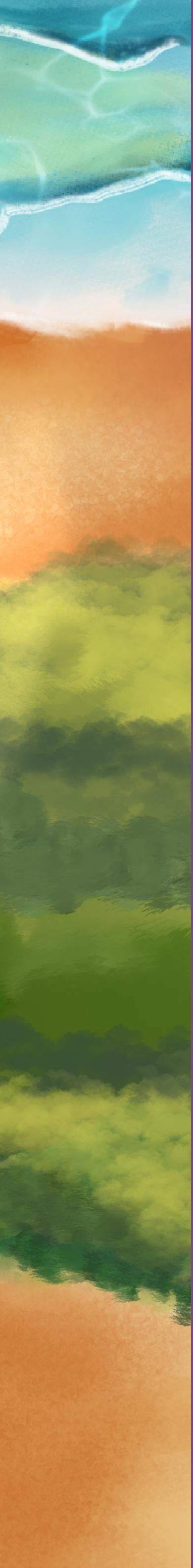
UNITED NATIONS INDONESIA

PULSE STORIES

Closing the Information Gap:

Understanding the needs of parents and caretakers of children with disability





Acknowledgments

Closing the Information Gap: Understanding the needs of parents and caretakers of children with disability is a study conducted by the UN Global Pulse Asia Pacific team as part of the Leave No One Behind (LNOB) project. The LNOB project looks at data on and data for people with disability and is a collaborative effort initiated by multiple stakeholders. It focuses on components under the mandate to 'Leave No One Behind' and responds to commitments within the UN Data Strategy to improve the collective use of data within and between UN agencies in Indonesia to deliver better results. We would like to thank all stakeholders who have contributed to this project for their continued support and collaboration, with special thanks to UN in Indonesia, Ikatan Keluarga Disabilitas Maku Gawene (IKDM) Ternate, Foundation for the Advancement of Children with Disabilities (YPAC), and Gerakan Advokasi Transformasi Disabilitas untuk Inklusi (GARAMIN) East Nusa Tenggara for their invaluable support during the user research, and UN Global Pulse Finland for the funding support.

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> “The availability of inclusive education does not only provide an opportunity for students with disability to access education, but also serves as a way to change other students’ perspectives about people with disability, and to show that they should have equal opportunities and be treated respectfully”.

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- The needs of parents and caretakers are just as crucial as those of children with disability, especially during the critical early stages of their children's development.
- Early detection and diagnosis of disability symptoms is crucial to allow parents and caretakers to provide timely treatments.
- Parents and caretakers still encounter challenges in deciding which educational options best fit their children's needs.
- Inclusive schools are often of low-standard educational quality despite playing an important role in providing access to education and in advocating for the rights of people with disability.
- Parents and caretakers rely on communities and offline information sources to support them in fulfilling their children's needs.

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Executive Summary

Closing the Information Gap: Understanding the Needs of Parents and Caretakers of Children with Disability was a study conducted by the UN Global Pulse Asia Pacific team. The research is part of the Leaving No One Behind (LNOB) project which looks at data on and data for people with disability[1] and is a collaborative effort initiated by multiple stakeholders. It focuses on components under the UN mandate to 'Leave No One Behind' and responds to commitments within the UN Data Strategy to improve the collective use of data within and between the UN in Indonesia to deliver better results.

Children with disability often face significant challenges in their daily routines and to ensure their needs are met, they require assistance from their parents and caretakers. The role of these caregivers is crucial for providing necessary support to their children, but to do so effectively, they need access to relevant information. Parents and caretakers view certain information as essential, including their children's growth and development, access to healthcare services, education, and physical therapy. However, a major obstacle that they face is the scarcity of available online and offline information. Responding to their needs, we developed a platform designed to provide relevant information that will help parents and caretakers make more informed decisions for their children.

In informing the development of the platform and to ensure that it serves the needs of parents and caretakers of children with disability, our team undertook extensive user research across Indonesia, from Ternate in North Maluku to Kupang in East Nusa Tenggara to the Greater Jakarta Area. By engaging directly with these potential platform users, we sought to deepen our understanding of their perspectives and experiences.

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[1] In this report we use the term people with disability following WHO's mandate. The use of 'disability' vs 'disabilities' is an important distinction as it denotes that disability is a universal human experience. More information: https://www.who.int/news-room/questions-and-answers/item/people-with-disability-vs-persons-with-disabilities.

From the fieldwork and sensemaking process, we drew the following insights around the needs of parents and caretakers of children with disability:

1. The needs of parents and caretakers are just as crucial as those of children with disability, especially during the critical early stages of their children's development.

As the main providers, it is equally critical that the needs of parents and caretakers are recognized and addressed to ensure that they can continue to provide the best care for their children. This is especially important during the early stages of a disability diagnosis, as parents and caretakers may have difficulties in accepting the diagnosis and coping with the next steps, which can in turn affect the care they are able to give their children.

2. The critical importance of early detection and diagnosis of disability symptoms is crucial to allow parents and caretakers to provide timely treatments that support the development and growth of their child.

Obtaining timely access to treatment and support for their children can aid greatly in their development; however, for those who live in remote locations, this may prove more difficult due to the limited resources available. Compounded obstacles such as taking time off work and monetary costs may also result in parents and caretakers being unable to gain a comprehensive understanding of their children's needs and provide proper care.

3. Despite seemingly clear education options, parents and caretakers continue to encounter challenges when deciding what path best fits their children's needs.

Parents may want their children to develop adequate social skills, however, they often find that when they are sent to standard public schools, the education system is unsuitable for them. As a result, their children are unable to reach their full potential.

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4. Inclusive schools provide important access to education and advocate for the rights of children with disability, but they struggle to provide high-quality education.
Parents enroll their children in inclusive schools to foster social interactions, but oftentimes, these schools are not fully equipped with the knowledge and infrastructure necessary to support the development of children with disability.

5. Communities and organizations of people with disability are the main reliable source of information.
As information about children with disability is not widely available online, parents and caretakers rely on communities and offline information sources to support them in fulfilling their children's needs.

In addition to the background and insights from the research, this report also covers the co-design process, an essential part of the platform's development involving various stakeholders concerned with issues of disability and inclusivity.

The platform, launched as **Akses Inklusif**, focuses on providing various types of information, including on therapy, inclusive and special schools, providers of assistive devices, and transportation options. We envision Akses Inklusif as an evolving tool that can be further developed in response to the increasing needs of parents and caretakers of children with disability, thereby bridging the information gap they experience.

About UN Global Pulse & the Asia Pacific Hub

United Nations Global Pulse is the UN Secretary-General's Innovation Lab. Originally established in 2009 to harness the power of big data and artificial intelligence (AI), UN Global Pulse operates today as a global network advancing innovation within the UN's work. We work at the intersection of innovation and the human sciences to inform, inspire, and strengthen the ability of the UN family and those it serves to anticipate, respond, and adapt to the challenges of today and tomorrow.

Our work spans a spectrum of innovations employing the five capabilities outlined by the UN Secretary-General common agenda report: data, digital, strategic foresight, behavioural sciences, and innovation. UN Global Pulse experiments and supports others in their experimentation with new capabilities and tools. Our role is not only to co-develop and scale innovation but also to encourage a culture of creativity across the United Nations.

From enhancing humanitarian crisis response, strengthening climate resilience, and improving processes in digital transformation, the UN Global Pulse Asia Pacific Hub applies innovation to accelerate the achievement of the sustainable development agenda for a better future.

The hub is designed to run portfolios of on-the-ground innovation projects that apply data, digital, foresight, and behavioural science methods to regional issues. We focus on scanning and experimenting with solutions that might be fit for regional scaling. The hub is deeply rooted in regional partnerships which facilitates access to identify challenges, map solutions and test with end-users on the ground; work in support of Resident Coordinators, and in partnership with the UN specialized agencies, funds, and programmes that lead country-level work.

Based out of Jakarta but serving the wider Asia Pacific region, the hub is a frontrunner in practicing and advocating for inclusive innovation. Drawing on a decade of successes applying system design, big data, and artificial intelligence for platform development and data analytics, Global Pulse Asia Pacific co-creates forward-thinking solutions that inform policy and decision-making and create systemic change.

The Asia Pacific hub builds on the successful partnership model that spans over 10 years between the UN and the Government of Indonesia under the Pulse Lab Jakarta portfolio. In co-developing solutions with numerous partners over the years, we have introduced futures thinking and foresight to strengthen government policy planning for MSMEs, utilised mobile network data to model internal migration to support infrastructure and service planning and policy, as well as inspired transport services to create significant safety changes for women commuters, amongst others.

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About the Leaving No One Behind Initiative

Leaving No One Behind (LNOB) is the central transformative focus of the 2030 Sustainable Development Goals (SDGs) agenda. This means that every United Nations member state is fully committed to eliminating poverty in all forms, stopping discrimination and exclusion, and reducing the inequalities and challenges that leave people behind and prevent them from reaching their full potential.

Contributing to the achievement of this mandate, UN Global Pulse Asia Pacific embarked on a journey to kick off an LNOB project. The Leave No One Behind (LNOB) project looks at data ON and data FOR people with disability and is a collaborative effort initiated by multiple stakeholders. Focusing on components under the LNOB mandate, the project serves as an opportunity to respond to commitments within the UN Data Strategy to improve the collective use of data within and between the UN in Indonesia, supported by the Resident Coordinator's Office and the Design, Monitoring, Evaluation & Learning (DMEL)

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Working Group, to deliver better results.

Details of the project's two components can be seen below:

Data ON People with Disability:

- To understand available data that have been used to inform programs for people with disability.
- To look into the existing data set, use cases, and gaps from current analysis.
- To facilitate a series of workshops with different stakeholders to identify priorities and strategies to improve the data collection and usage for a more inclusive society for people with disability.

Data FOR People with Disability:

- To showcase potential data that can be used by people with disability.
- To identify new data sources that can be directly accessible by people with disability. disabilities.

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SETTING THE CONTEXT

Opening access to information for people with disability

UN Global Pulse Asia Pacific was motivated to develop the Akses Inklusif platform due to the limited information that is available to parents and caretakers of children with disability (henceforth referred to in this report as parents and caretakers). Our platform aggregates information for parents and caretakers to better support their children

> ***Parents and caretakers of children with disability face challenges in obtaining information to meet their children’s needs***

Children with disability often face significant challenges in their daily routines and to ensure their needs are met, they require assistance from their parents and caretakers. The role of these caregivers is crucial for providing necessary support to their children but to do so effectively, they need access to relevant information. Parents and caretakers view certain information, such as their children's growth and development, access to healthcare services, education, and medical therapy, as essential; however, a major obstacle that they face is the scarcity of online and offline information for their children with disability.

Akses Inklusif – an inclusive platform providing access to information for parents and caretakers of children with disability

Responding to these needs we developed a platform designed to provide relevant information to help parents and caretakers make more informed decisions for their child. The initial concept for the platform focused on several types of information, including therapy, inclusive and special schools, assistive devices providers, and transportation options.

Throughout the development process, our team emphasized the inclusive principles as highlighted in the **UN Disability Inclusion Strategy**[2]: participation, data, and universal design, accessibility and reasonable accommodation. In order to establish a strong foundation for the platform, we knew we needed to gain a deeper understanding of the lived experiences and needs of parents and caretakers. To do this, we conducted user research in several areas across Indonesia.

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[2] United Nations, "United Nations Disability Inclusion Strategy," United Nations, accessed on November 30, 2023, https://www.un.org/en/content/disabilitystrategy/assets/documentation/UN_Disability_Inclusion_Strategy_english.pdf

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Our Research Objectives

Our user research process took us across Indonesia, from Ternate (North Maluku) to Kupang (East Nusa Tenggara) to the Greater Jakarta Area. By engaging directly with parents and caretakers, we sought to further our understanding of their perspectives and experiences, which would serve to inform how our platform is developed.

Our Methodology: Service Design

Service Design is a human-centered approach to improve the quality of interaction between services and their users by taking a thorough look at the end-to-end process and resources (i.e. people, infrastructure, and protocols) required for services to run and generate value.

In using this methodology, we aimed to better understand what is needed to develop and sustain an inclusive platform, such as data, analysis, tools, technology, capabilities, and a broader support system.

As part of the service design approach, the user research allowed us to uncover the needs of parents and caretakers in using digital technologies to find information to fulfill their children’s needs.

Using Service Design to develop Akses Inklusif

In the context of **Akses Inklusif**, we imagine that the frontstage represents parents and caretakers who access the platform to find information for their children. They see the interface of the platform and can access all the features. What parents and caretakers see on the frontend is indispensable from backstage support.

Frontstage
- Channel
- Product
- Touchpoint
- Interface

Backstage
- Technology
- Infrastructure system
- Data validation

Behind the scene
- Regulation
- Policy
- Budgeting

This is where the technology, data validation, and maintenance of the infrastructure system takes place to ensure that the platform runs smoothly. However, in order for this platform to deliver its service effectively, having an enabling policy, regulation, and budget behind-the-scenes are key factors. Without this, all backstage and frontstage activities will not function properly.

In our user research, we sought to answer three main research questions:

AREA 1: NEEDS
What are the types of information parents and caretakers require to meet the needs of their children with disability?

1. In what context do parents and caretakers need information?
2. How do they use the information?
3. What does the journey of parents and caretakers in utilizing that information look like?
4. What are the challenges experienced by parents and caretakers when searching for information for their children?

AREA 2: DESIGN
How do parents and caretakers envision the utilization of information obtained from digital platforms?

1. How familiar are parents and caretakers with digital tools to find information?
2. How do parents and caretakers perceive digital platforms to meet their needs?
3. What digital tools or platforms have parents and caretakers used?

AREA 3: SUPPORT
What support is required to ensure the sustainability of the data platform?

1. What are the available data sources required to ensure that the platform has the most updated data?
2. What kinds of technologies are required for the platform to be sustainable?
3. What technical capabilities are required to sustain and improve the platform?
4. What are potential challenges or obstacles in sustaining the platform? What are feasible anticipatory actions that could be undertaken?

Scope of respondents

DATA PLATFORM

1 Frontstage

Parents and caretakers of children with disability

Parents and caretakers who are members of or are associated with organizations of people with disability.

2 Backstage

Potential platform owners or hosts

Organizations who have the potential to host or be involved in improving and sustaining the platform.

3 Behind the scene

Key stakeholders

Important actors including data providers, non-governmental organizations, and local governments.

Guided by Service Design as our methodology, we employed a wide range of qualitative methods for data collection:

Key Informant Interviews	Interviews with domain experts or representatives of organizations of people with disability focusing on empowering and advocating for the rights of people with disability. The interviews served to guide the user research in developing instruments and preparing fieldwork activities.
Focus Group Discussions	FGDs with parents and caretakers who are part of the community or organizations for people with disability. FGDs aimed to identify the informal needs of parents and caretakers and test out initial concepts of the platform.
In-depth interviews	In-depth interviews with parents and caretakers to understand their experiences, identifying informational needs and challenges, as well as accessing information for their children. This method was also used to test out initial concepts of the platform.
Field Observations	Field observations were done for two different activities. One was during in-depth interviews and FGDs to understand the digital capabilities of parents and caretakers. The other was during visits to inclusive and special schools, public facilities, and local government offices. The latter served to observe accessibility and availability of infrastructure for people with disability.

Our team consulted domain experts and key stakeholders in disability before we began our fieldwork activities.

10 organizations of people with disabilities

16 representatives of organizations of people with disabilities interviewed

Notes:

- ● Fieldwork activities
- ● Key informant consultations

For two months, our user research team consulted various stakeholders including organizations of people with disability and representatives from organizations of people with disability, consisting of policy makers, development partners, and social enterprises that advocate for the rights and needs of people with disability. We discussed their different informational needs and gathered tips and best practices to guide our team during data collection through in-depth interviews, FGDs, and field observations, ensuring an ethical and inclusive process.

This initial scoping phase engaging with stakeholders from communities of people with disability was extensive and crucial to address the most relevant issues as identified by them. In doing so, this approach helped our team avoid any harm and unintended consequences stemming from our research.

FIELD WORK IN NUMBER

JAKARTA

5 people

5 institutions

In-depth interviews

5 parents and caretakers of children with disabilities

5 organizations of people with disabilities

KUPANG

19 people

4 institutions

In-depth interviews

2 staff of local NGOs

12 parents and caretakers

2 teachers of inclusive early childhood schools

3 teachers of inclusive schools

TERNATE

28 people

7 institutions

Focus group discussion

4 regional public hospital staff

9 parents and caretakers

10 teachers of inclusive schools

2 therapists

1 student with disability

2 staff of local NGOs

The data collection process covered a wide range of disability, from physical, developmental, behavioural, emotional and sensory impairment, to understand their varying needs.

Cerebral palsy
Learning disability
Down syndrome
Multiple disability
Rare diseases
Autism Spectrum Disorders
Intellectual disability
Vision impairment
Dyslexia
Hearing impairment
Developmental delay
Physical disability
Cerebral palsy
Blindness
Attention deficit hyperactivity disorder
Epilepsy
Deafblindness

At the start of our journey in creating Akses Inklusif, the information gathering and user research were based on three assumption:

ASSUMPTION 1

Information relating to location and availability of services for children with disability (e.g schools, therapy, hospitals, and transport stopping points) are the primary information needs of parents and caretakers.

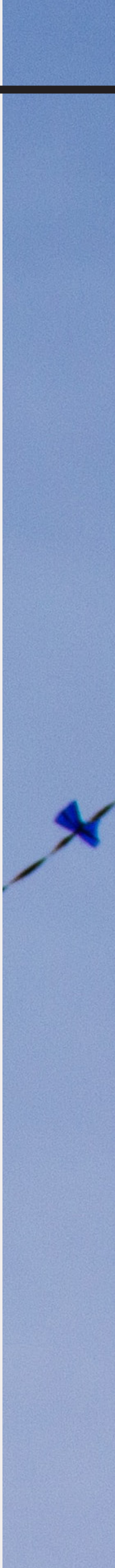
ASSUMPTION 2

Parents and caretakers are able to use digital tools to acquire information before making decisions for their children's needs.

ASSUMPTION 3

Information availability catering to the needs of children with disability is scarce.

Once data collection wrapped up, our team conducted a series of sensemaking activities to generate insights on what we learned about the informational needs of parents and caretakers.



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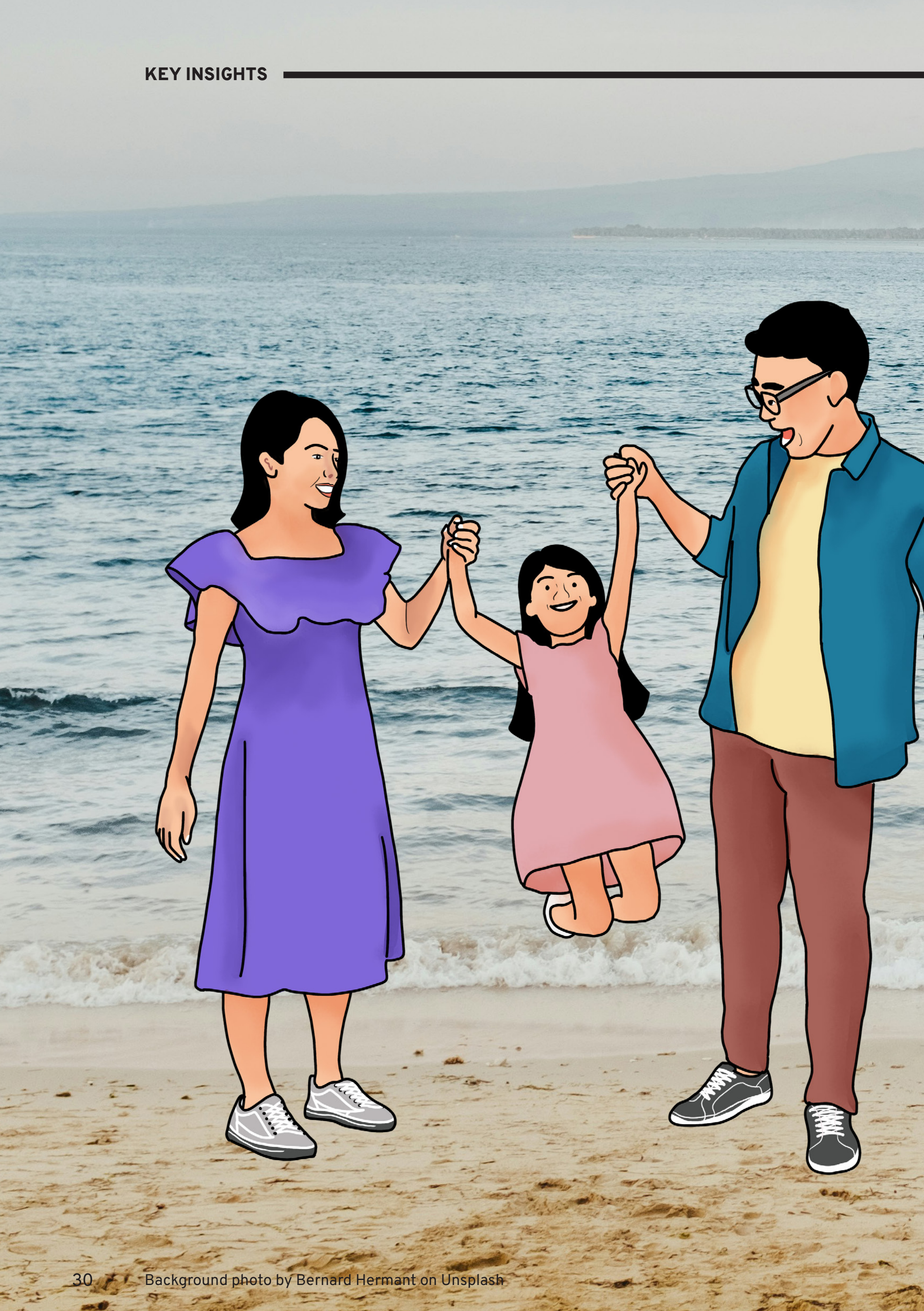
KEY INSIGHTS

Five key insights shaping the design and development of Akses Inklusif

From the comprehensive user research and fieldwork activities, we derived five key insights that have been instrumental in shaping the design and development of our inclusive platform.



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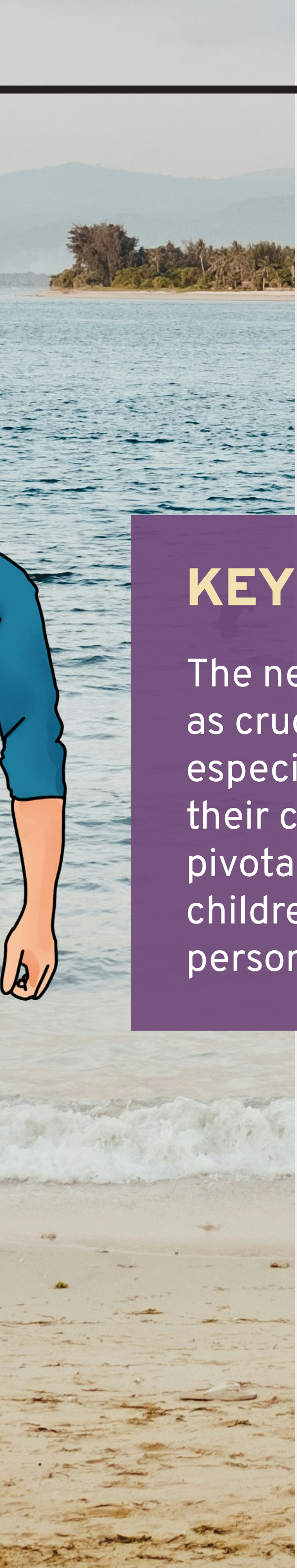

KEY INSIGHT 1

The needs of parents and caretakers are just as crucial as those of children with disability, especially during the critical early stages of their children's development. As they play a pivotal role in nurturing and supporting their children, recognizing and addressing their personal needs is essential.

During our fieldwork, several of the parents and caretakers we spoke with mentioned how they often felt their needs were overlooked. However, we learned that it is equally important for their needs to be addressed so that they can provide adequate levels of care for their children.

First and foremost, when their children are diagnosed with a disability, parents and caretakers need information on how they can care for their children. At the same time, receiving psychological support during the period following the diagnosis is also essential to help them regulate their emotions and to accept their children's condition, which can often be challenging. Yet many parents and caretakers we spoke to admitted that finding a safe space and support network was not easy.

The importance of this issue was corroborated in Ternate, when we met several physicians providing therapy services and other medical support for children with disability. They mentioned how psychological support for parents and caretakers is crucial, particularly following the initial diagnosis period, because it affects how they will take care of and nurture their children. In many cases, parents and caretakers have difficulty accepting their children's condition, which results in many children with disability not receiving the proper treatment they may need.

> ***"We do not only provide physiotherapy but also therapy or counseling services. Usually when their children are doing therapy, parents or caretakers also seek therapists to better regulate their emotions and accept their children's condition."***
> ***Health Officer, Regional Hospital of Ternate City***

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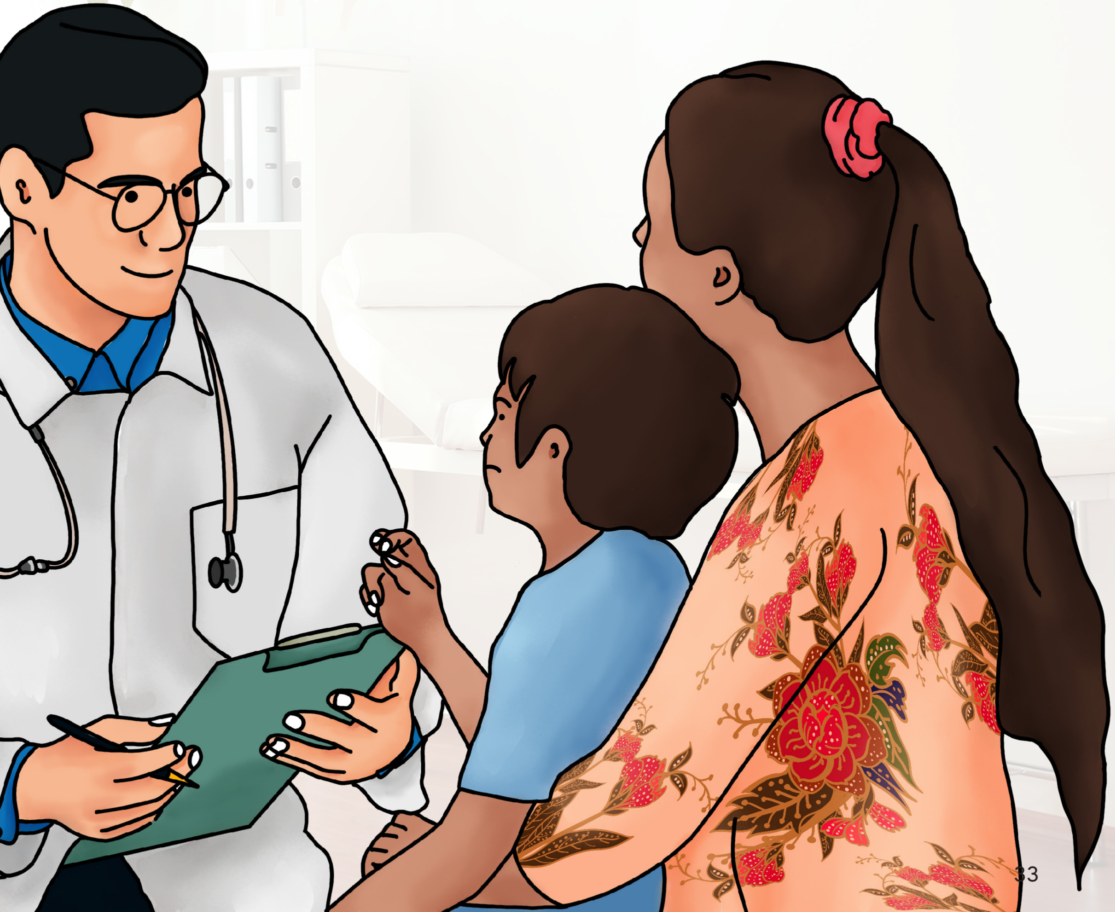
Informational needs:

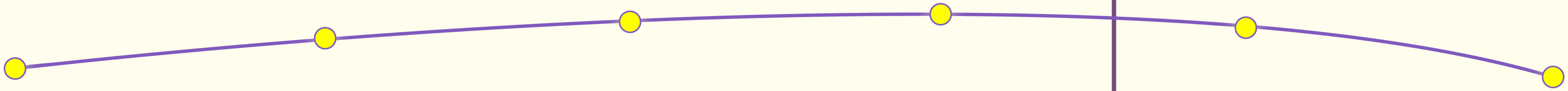
① General guide on how to take care and nurture children with disability

② Understand children’s disability

③ Learn more about hospitals and therapy centers



THE DIFFERENT NEEDS OF PARENTS AND CARETAKERS IN PHASES

PHASE	**INITIAL PHASE**				**INTERVENTION PHASE**	
	INITIAL SYMPTOMS	**WORSENED SYMPTOMS**	**GETTING PROPER MEDICAL ATTENTION AND DIAGNOSIS**	**EMOTIONAL ADJUSTMENT FOLLOWING DIAGNOSIS**	**TAKING CARE OF CHILDREN**	**PREPARING FOR THE NEXT STEP FOR THEIR CHILDREN**
MAJOR NEEDS	Information on communities for parents and caretakers.	Information on communities for parents and caretakers Information for independent early detection	Information on communities for parents and caretakers. Information for independent early detection.	Information on psychological support or support group network. Information on communities for parents and caretakers.	Information on communities for parents and caretakers Information on how to take care of children with disability.	Information on communities for parents and caretakers Information on options for informal and formal education.
ACTIVITY	 Parents and caretakers observe their children’s condition	 Parents and caretakers search for information to understand their children’s condition. At this stage, parents may be actively looking for advice and assistance from people around them.	 As their children’s condition worsens, parents and caretakers decide to bring their children to nearby healthcare providers to receive proper medical attention.	 After receiving the diagnosis and proper medical care, many parents struggle with their emotions as they find accepting their children’s condition to be challenging.	 At this stage, parents typically have accepted their children’s condition and routinely bring them to a nearby healthcare or therapy facility for treatment. Parents look for classes to adjust to their children’s needs (e.g. sign language class)	 Aside from making sure their children get proper medical attention, parents actively search for information on formal and informal education to better prepare their children to receive an education
THOUGHTS	*“My son looked healthy today when he played with other kids outside but then developed a fever when she got home. I think it’s normal when kids have a fever and I believe it will die down soon. Maybe tomorrow he can play again.”*	*“It’s been four days since my son developed a fever. The fever briefly died down but now everything seems worse. He got another fever which persists until now. He also has seizures frequently in a day. I tried traditional medications but his condition didn’t improve. I talked to my neighbors to get advice about his situation.”*	*“I tried to find information online about my child’s situation, but with the differing results, it was not clear what happened to him. My neighbor told me to go to the hospital for immediate medical attention since everything seemed to get worse.”*	*“I still could not believe that my son has a rare disorder. He looked so happy and healthy one day and everything changed overnight. I do not know how to deal with this situation. What am I supposed to do? This seems a lot to me. I want my son to recover soon.”*	*“It has been an emotional roller coaster for me as a mother. I have endured the emotional ups and downs for five years. I accept that my son has a disability. I believe this does not define his capability and future. What matters now is how to give him proper care and continuous support and treatment.”*	*“My son is now almost seven years old and now my focus is to monitor his development, making sure that his needs for therapy and education are fulfilled.”*
FEELINGS	 Indifferent	Feeling worried	Increasingly worried and anxious	Overwhelmed, confused, in denial	Accepting, feeling curious about fulfilling their children’s needs	Accepting, preparing their children to pursue formal or informal education

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KEY INSIGHT 2

The critical importance of early detection and diagnosis of disability symptoms is crucial to allow parents and caretakers to provide timely treatments that support the development and growth of their child.

Prior to their children being formally diagnosed with special needs, the major challenge we learned about was the **difficulty in getting access to information for medical attention as well as** access to other support services for early detection.

However, for parents and caretakers who reside in small cities and rural areas in particular, the problem goes beyond access to information. High quality, affordable, and appropriate healthcare and early screening services are not widely available across Indonesia, resulting in their children not getting properly diagnosed. For example, parents and caretakers of children with multiple disabilities may need to visit different specialists to get a complete understanding of their medical needs.

Compounded obstacles such as taking time off work and monetary costs may also result in parents and caretakers being unable to easily do this, preventing them from gaining a comprehensive understanding of their children's needs and providing the best care possible.

> *"It is difficult to find a doctor here who can conduct an assessment of my child's condition. Some friends even suggested going to Java where they have more doctors so it's easier to find one to help. Even if there is a good doctor here, their location is very far from home."* ***Parent, Ternate***

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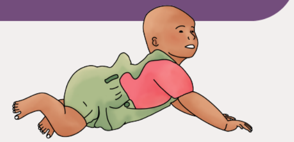
Informational needs:

1. Specialists for early identification of children with disability
2. Healthcare or screening centers
3. General information about how parents and caretakers can better understand their children's disability or medical condition

THE NEEDS OF CHILDREN WITH DISABILITY

Our study found that the needs of children with disability are centered around three main areas, including educational, health, and social adaptation needs. When children are diagnosed with a disability for the first time, their needs mostly focus on medical treatment but as they grow older, they need more information on educational and social needs.

0-5 YEARS OLD			6-12 YEARS OLD		13-18 YEARS OLD		
EDUCATION	**HEALTH**	**SOCIAL ADAPTATION**	**EDUCATION**	**HEALTH**	**SOCIAL ADAPTATION**	**EDUCATION**	**OTHERS**
Inclusive early childhood education, a kindergarten or standard public schools that have quotas for children with disability.	Various information on therapy services for different types of disability. Accredited psychologist or psychiatrists to assess early symptoms of disability. Laboratorium to run blood tests. Nearby pharmacies with complete pharmaceutical products. General guideline for independent early detection. Special pediatricians for children with disability. Information on types of foods that can potentially trigger symptoms.	Information on how children with disability adapt to their surrounding environment. Information on the types of entertainment appropriate for children with disability. Information on extracurricular activities or courses (e.g sign language class). Childcare services for children with disability.	General information about inclusive schools, their quality, availability of therapy services, and enrollment mechanism. Alternative non-formal schools. Availability of teachers' aides. Assistive learning tools.	Various information on therapy services for different types of disability. Accredited psychologist or psychiatrists to assess early symptoms of disability. Laboratorium to run blood tests. Nearby pharmacies with complete pharmaceutical products. General guideline for independent early detection. Special pediatricians for children with disability.	Adaptation strategies for children with disability in their social environment. Extracurricular activities to develop talents	Higher education institutions with special quotas for students with disability. Career or educational pathway for students with disability post-basic education.	Job vacancies Access to sign interpreters. Public facilities with clear signage. Access to public transportation and hotels.



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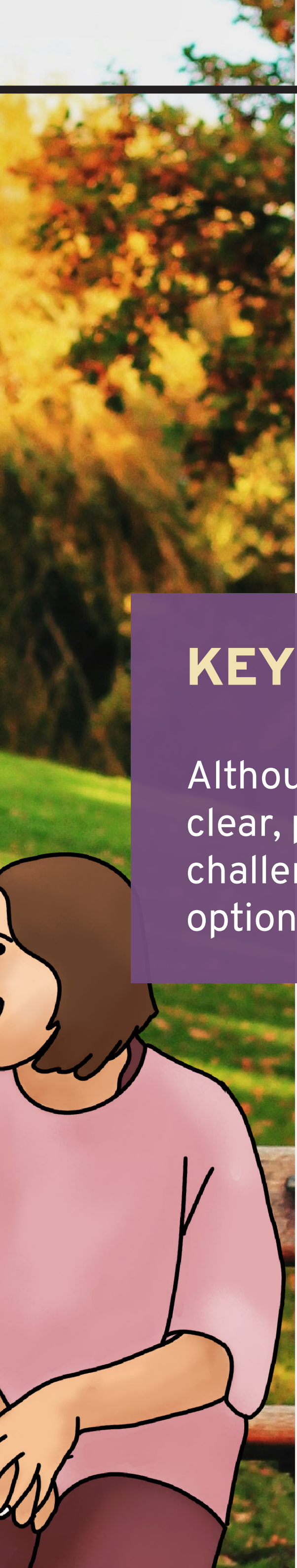

KEY INSIGHT 3

Although the educational options are seemingly clear, parents and caretakers still encounter challenges in deciding which educational options best fit their children's needs.

Choosing the right school that fits the needs of children with disability is often challenging. Parents and caretakers want their children to develop social skills, which can be done by sending them to standard public schools to interact with more peers. However, in most cases we saw, once their children began studying at a standard public school[3], parents and caretakers quickly realized that the learning methods and environment were unsuitable for them. As a result, their children are unable to reach their full potential.

Additionally, parents and caretakers belatedly recognize the importance of their children attending inclusive schools once they enter elementary school, when in reality, their children can begin attending inclusive preschools and kindergartens to better prepare them.

> ***“Parents usually search for inclusive education when their children are about to enter elementary school. They are not aware that education starts from early childhood and they can actually send their children to inclusive early education. But this option rarely comes into their minds.*** ***Therapist and inclusive education manager in Kupang.***

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[3] Standard public schools or Sekolah Umum are the standard Indonesian national education institutions for the general public that follow the teaching standards as set by the government. These institutions generally do not have classes, teachers or curricula that specifically address the needs of children with disability.

Background photo by Artur Roman on Pexels

Factors influencing parent and caretaker schooling decisions for their children:

1. School location and distance
2. Safety from bullying
3. Teaching quality
4. Tuition affordability

Informational needs

1. Suitable schools for children with disability

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KEY INSIGHT 4

Inclusive schools play an important role in providing access to education and in advocating for the rights of people with disability; however, inclusive schools are often of low-standard educational quality.

Inclusive schools are standard public schools designated by education authorities as schools that accept students with disability, whereas special schools are specifically for students with disability. In the implementation of inclusive education, all students are supposed to be accepted and treated equally with other students during the learning process. However, students with disability find it challenging to follow the learning methods and some need additional assistance during the learning process from special teaching assistants.

Our user research findings indicated that enrolling students with disability in inclusive schools helped them integrate with other students as it fosters social interactions among them. This is particularly true for students with autism, cerebral palsy, and learning disabilities. ***The availability of inclusive education does not only provide an opportunity for students with disability to access education, but also serves as a way to change other students' perspectives about people with disability, and to show that they should have equal opportunities and be treated respectfully.***

However, inclusive schools are not fully equipped to handle the needs of students with disability. In many cases, teachers in inclusive schools do not always have the experience, knowledge or bandwidth to support students with special needs. Occasionally, teachers may receive training but they are often irregular and if a teacher who has received training moves to a different school, the knowledge is not passed on to their replacement.

Additionally, certain learning disabilities require a teacher's aide to support the student and teacher, however these aides are not made available to all schools due to limited resources. These situations were especially common in areas where local governments do not yet perceive disability as a priority issue. Learning from our fieldwork, local policies play a role in determining the teaching quality and services, such as therapy, in inclusive schools.

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Informational needs

1. Availability of inclusive schools and admission rate or quota for children with disability
2. School facilities and resources (e.g teachers and facilities)
3. Reviews on the teaching quality, availability and quality of therapy services at inclusive schools

> *"I chose to enroll my children in a special school because for me, their curriculum is tailored to develop my children's potential and talent. Children with disability may not necessarily be able to integrate and develop their potential if they are sent to standard public schools." -Parent, Kupang.*

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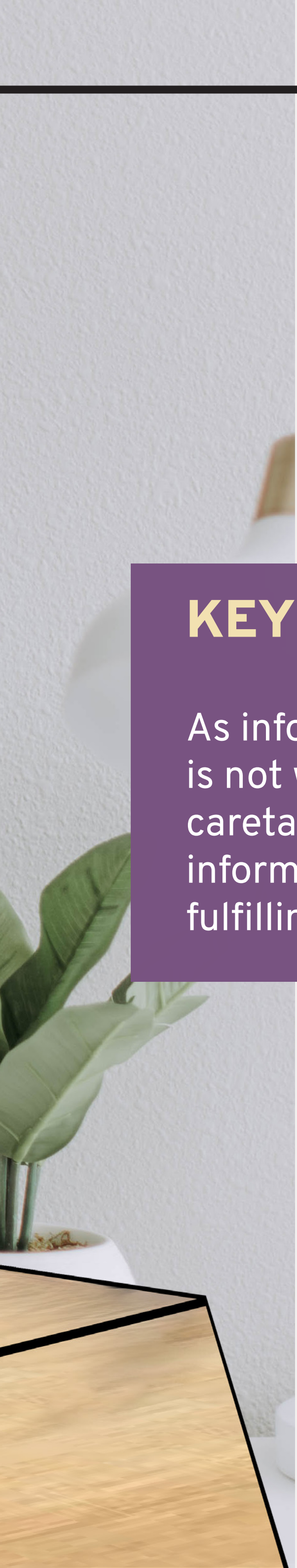

KEY INSIGHT 5

As information about children with disability is not widely available online, parents and caretakers rely on communities and offline information sources to support them in fulfilling their children's needs.

From our fieldwork activities and discussions with key stakeholders, we learned that the availability of information to fulfill the needs of children with disability is extremely limited in Indonesia. Searching for information such as therapy facilities and schools through online channels is rather arduous but the difficulty extends beyond that. Not all parents are digitally savvy and can easily operate smartphones. As a result, they are heavily reliant on receiving information from their immediate environment, such as through family, neighbors, local authorities, and community leaders (illustrated in diagram 1).

We found that there are parents and caretakers who demonstrate a high level of initiative to search for additional information online. Those who do not have access to the internet and digital tools seek information from communities of people with disability. However, there are also parents and caretakers who are more passive in obtaining information and rely on communities informing them rather than actively seeking details themselves.

> *“I obtain information about educational pathways for my child from church. They advised me to consider special schools because they have a special curriculum that suits my child’s condition. ”* ***Parent, Kupang.***

> *“I trust communities of parents for reliable information. Compared to online sources, information from communities is more complete and trustworthy. They have a database that aggregates information about inclusive and special schools. Additionally, they provide consultations and advice to choose which schools are suitable for my child.”* ***Parent, Jakarta.***

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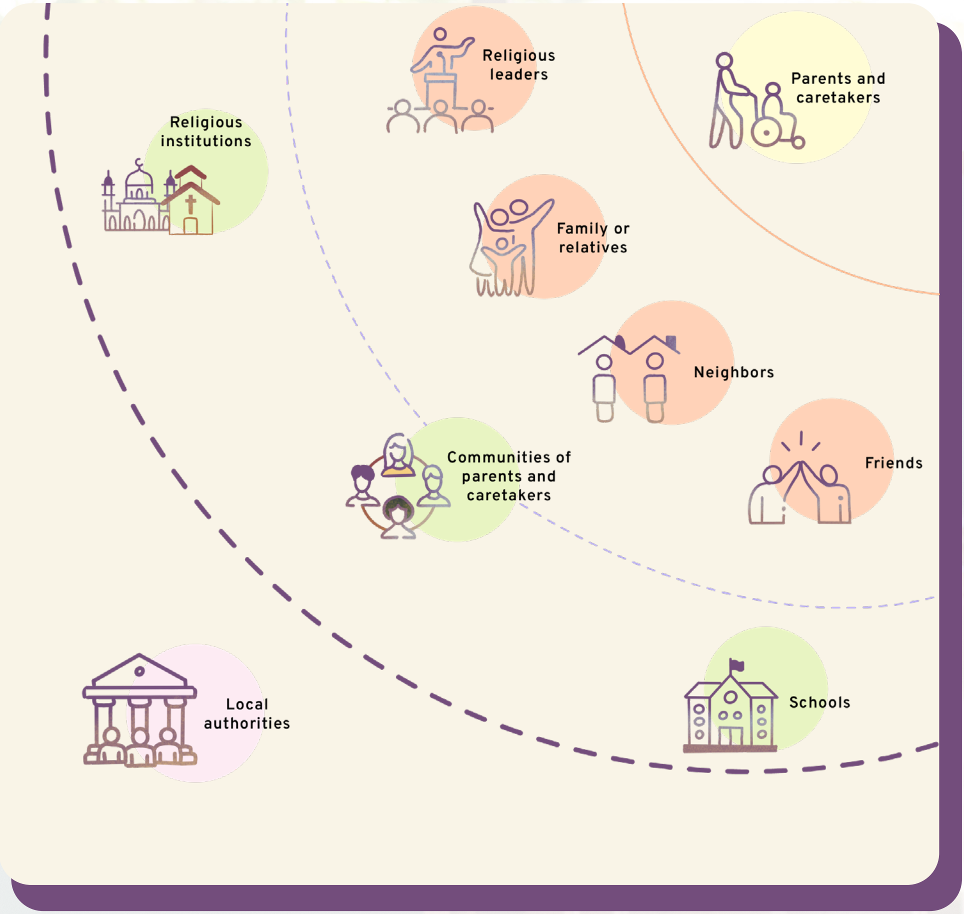


Diagram 1: Support system for parents and caretakers to obtain information

Based on user research, we identified a spectrum of varying technological capabilities among parents and caretakers

The Offline Traditionalist

Parents and caretakers in this category only own one featured phone and typically rely on local authorities to receive information.

"I never find information for my children from communities of parents. We usually just attend public forums convened by local authorities here." - Parent, Kupang

The Group Chat Reliant

In this category, parents and caretakers have had exposure with digital platforms. However, their usage is limited only to a few social media and not to search for information for their children.

"I have a WhatsApp group, social media, and marketplace accounts. But I rarely use them. I don't really understand how to find information using social media." - Parent, Ternate

The Daily Tech User

Parents and caretakers in this category have a higher frequency in searching for information for their children. They are used to using digital tools, such as social media.

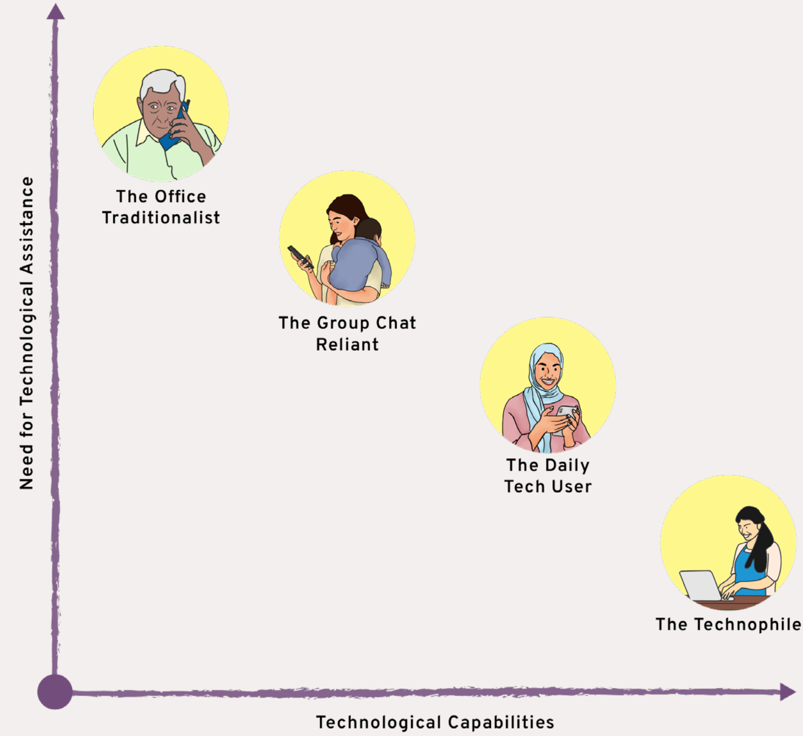
“I usually find videos on the internet. For example, the most frequent one I search for is how to train children with slow learning or learning differences.” - Parent, Kupang

The Technophile

In this archetype, parents and caretakers are not only savvy in using digital tools, but they understand how to find credible and accurate sources of information. Some of them may even find information on scientific journals or international organizations.

“I dig for as much as possible from scientific articles. Because they are the most credible and accurate source of information. I also joined an international organization in South Africa dedicated to parents because there is no such organization here in Indonesia.” - Parent, Jakarta

Digital capabilities influence to what extent parents and caretakers need assistance from technology facilitators to search for information related to the needs of their children.



Despite differences in digital capabilities, WhatsApp has become a powerful channel to find information for parents and caretakers.

Identified need
The potential role of communities in sharing information to parents and caretakers who are not digitally savvy in utilizing technology.

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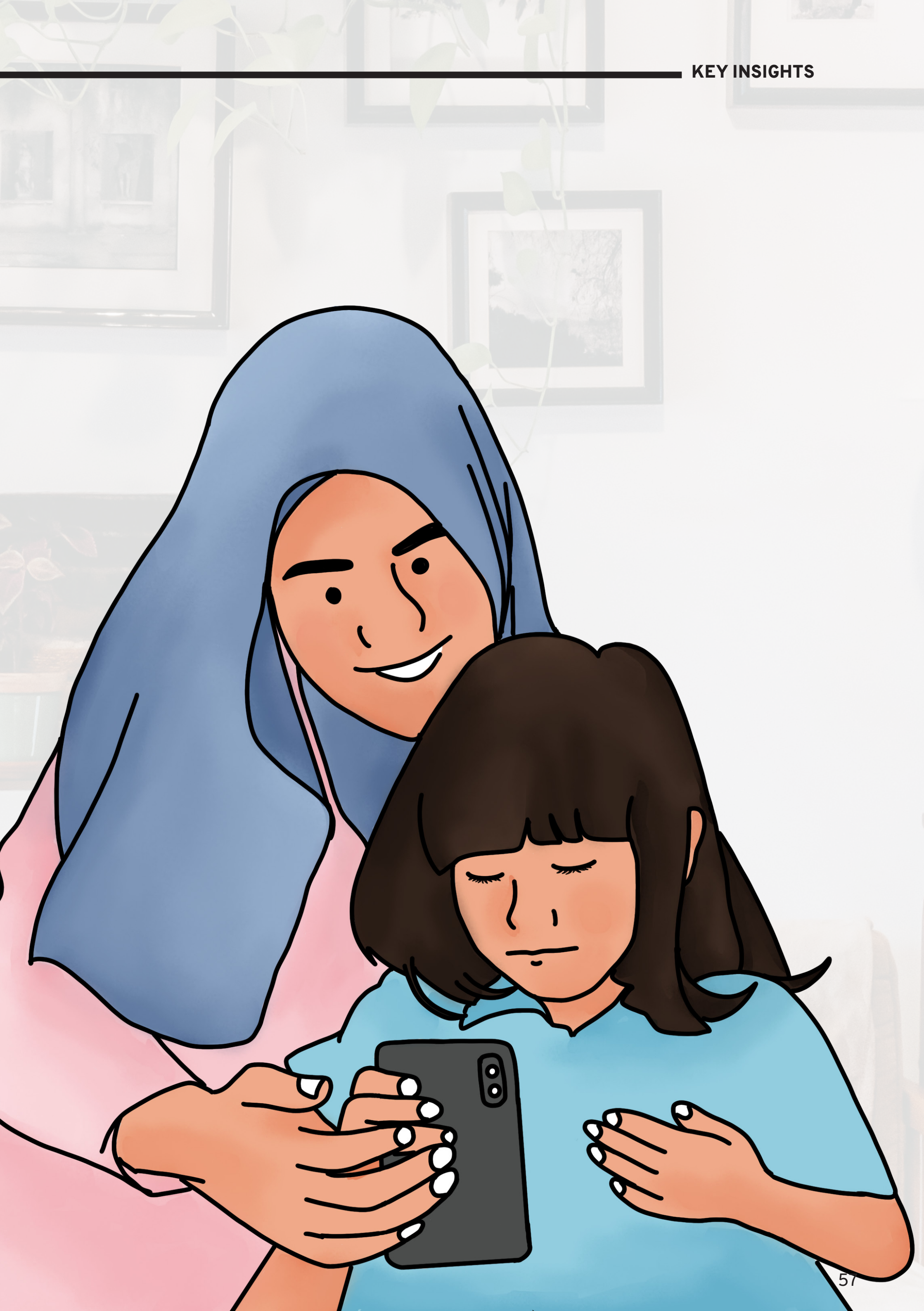

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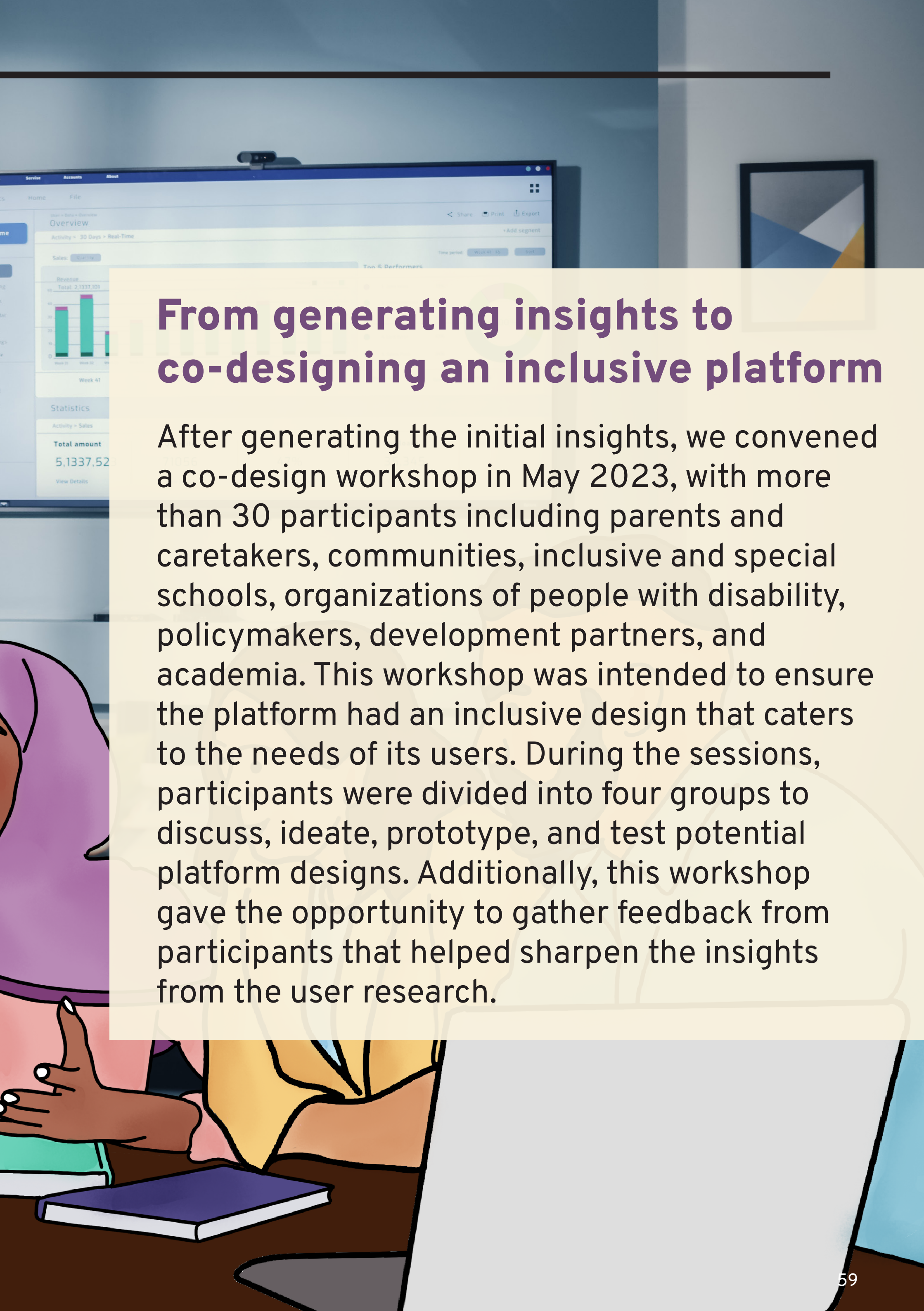


From generating insights to co-designing an inclusive platform

After generating the initial insights, we convened a co-design workshop in May 2023, with more than 30 participants including parents and caretakers, communities, inclusive and special schools, organizations of people with disability, policymakers, development partners, and academia. This workshop was intended to ensure the platform had an inclusive design that caters to the needs of its users. During the sessions, participants were divided into four groups to discuss, ideate, prototype, and test potential platform designs. Additionally, this workshop gave the opportunity to gather feedback from participants that helped sharpen the insights from the user research.

During the workshop, groups were asked to ideate based on the following prompts:

How might we design a platform that caters to the needs of parents and caretakers of children with disability?

1. What features should we add in the future development of the platform?
2. What is available data that we can feed into the platform?
3. How might we design the platform to be friendly for parents and caretakers?
4. What is the user flow for parents and caretakers when using the platform?

How can the platform we develop be beneficial for parents and caretakers who have limited digital capabilities and access to technology?

1. What are available support from communities for parents and caretakers?
2. How can parents and caretakers utilize the platform offline?

How do we envision the utilization of crowdsourcing features in the platform?

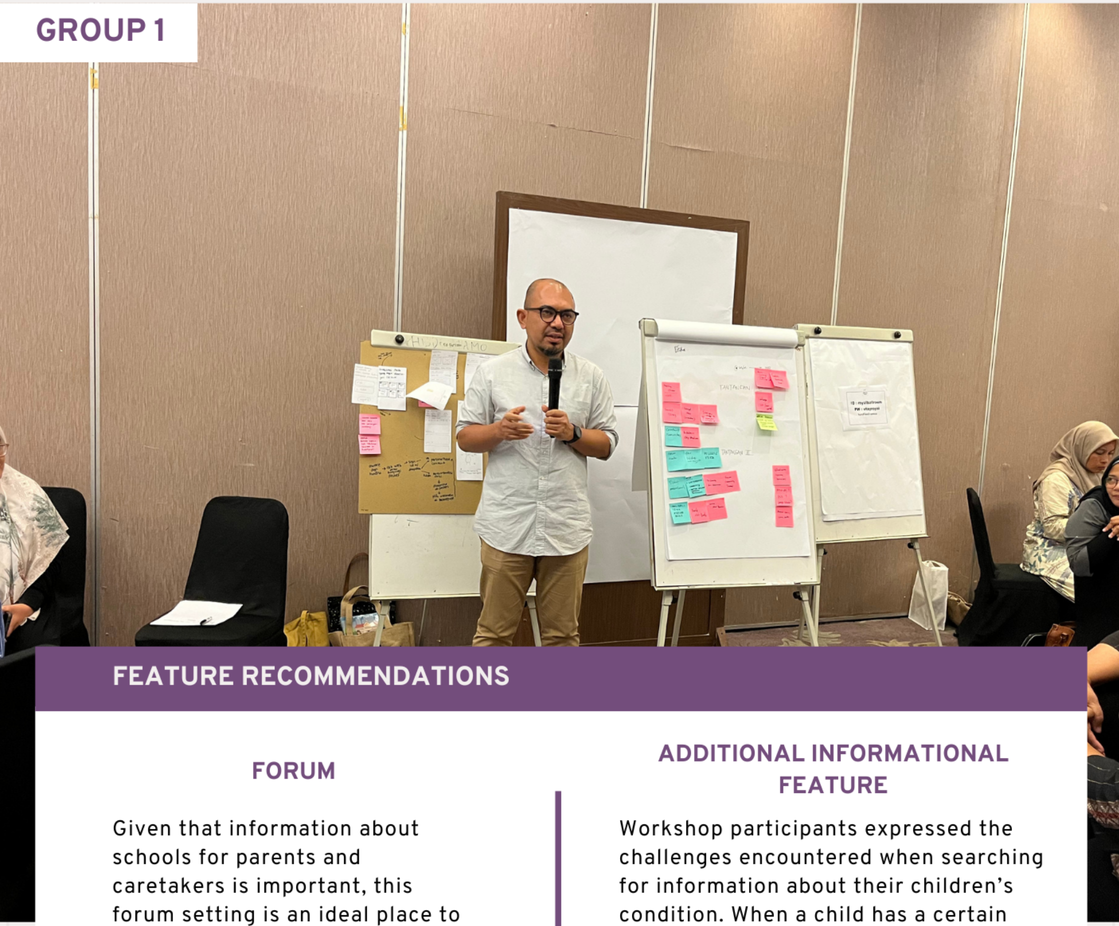
1. What roles can organizations of people with disability, communities, parents and caretakers, do to participate in the future development of the platform?
2. What kind of incentives are available and effective to attract people to get involved in the crowdsourcing efforts?
3. How might we keep the confidentiality and security of the users when they participate in crowdsourcing activities?


Early detection


Data Sekolah / Belajar
Kolab / komunitas
Early detection

Following this workshop, we had an internal session to synthesize and discuss the recommendations, which later fed into the platform's development. Once the platform is complete, UN Global Pulse Asia Pacific will seek collaborations with various stakeholders to host and propagate its use to create a wider impact.

GROUP 1



FEATURE RECOMMENDATIONS

FORUM

Given that information about schools for parents and caretakers is important, this forum setting is an ideal place to exchange experiences or share information, especially about non-formal educational pathways to develop their children's talents and hobbies.

ADDITIONAL INFORMATIONAL FEATURE

Workshop participants expressed the challenges encountered when searching for information about their children's condition. When a child has a certain type of disability, it is also often related to other medical conditions. Despite knowing this information is important, they can feel overwhelmed by the copious amounts of information they find. Therefore, this group came up with a feature design that provides information on the interrelatedness between one disability and other medical conditions.

GROUP 2

FEATURE RECOMMENDATIONS

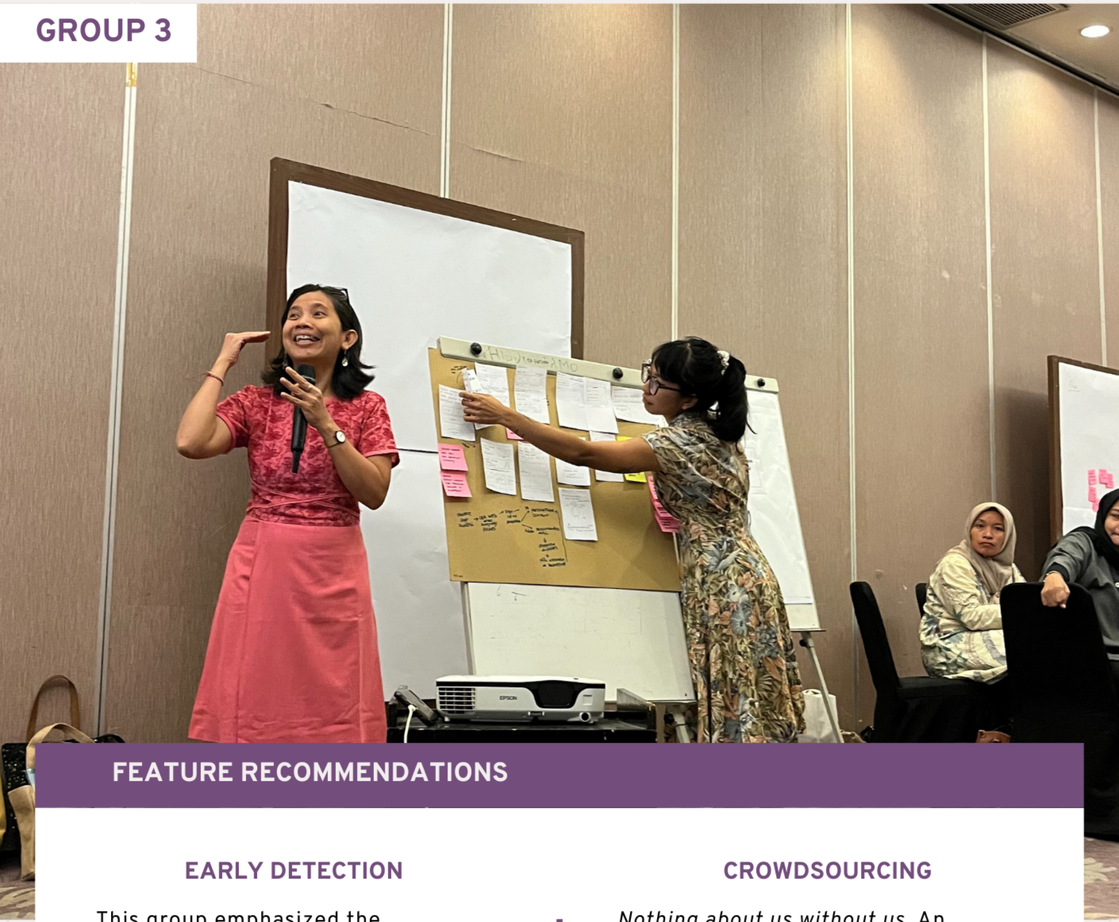
ADDITIONAL DATA AND INFORMATION

In the discussion and prototyping session, this group emphasized the importance of early detection information on the landing page. Other important information that should be incorporated into the platform, including links to new research about children with disability, regulations and rules from local governments for advocacy purposes, and a new consultation with an expert feature that parents and caretakers can do before taking their children to a medical practitioner.

CROWDSOURCING

This group provided feedback on the crowdsourcing design. Community plays an important role to ensure a functional crowdsourcing mechanism. They can act as contributors and the connectors between online and offline users. This group highlighted other types of information that can be contributed by the community through crowdsourcing, including community events, promotion from health facilities, local authorities, youth groups, among others. As not all areas in Indonesia have equal access to the internet, this group recommended the need to recruit offline volunteers to work in off-grid areas.

GROUP 3



FEATURE RECOMMENDATIONS

EARLY DETECTION

This group emphasized the importance of early detection because this phase is usually missed by parents and caretakers. In this phase, parents and caretakers may find it challenging to find information to guide them. This group came up with an idea to design several early detection infographics with general information. However, it is important to underscore that these designs are not meant to replace medical or scientific advice. In designing this feature, the group emphasized that the information should be taken from credible sources and processed and sharpened through consultations with relevant stakeholders.

CROWDSOURCING

Nothing about us without us. An inclusive platform will not be inclusive and create a wider impact if it does not provide the space to gather feedback and information from its users. Therefore, the crowdsourcing feature was the major design idea from this group. In prototyping this feature, they emphasized that the feature should be a place for parents and caretakers to share their knowledge through giving feedback or comments to the information provided on the platform.

GROUP 4

FEATURE RECOMMENDATIONS

ONBOARDING FEATURE

As not all parents and caretakers are technologically savvy, having an onboarding feature is important. An additional useful feature for users is to be presented with articles on the disability relevant to their situation on their homepage following login. This simplifies the process for them to access information without too much searching, especially if they are unfamiliar with technology.

OFFLINE CAMPAIGN AND MECHANISM

As not all parents and caretakers are active users of digital tools, having an offline mechanism is important. It is particularly important to consider how the platform is introduced to a wider community outside parents and caretakers, including community health offices (Puskesmas), schools, organizations for people with disability, and disability service units. Additionally, this group also proposed other offline mechanisms, including having a community leader as a champion of the platform and village office as a space for discussion between parents and caretakers.

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Moving Forward

Ensuring that nobody is left behind is imperative to achieve the Sustainable Development Goals (SDGs) and one of the groups this mandate addresses is people with disability. When it comes specifically to children with disability, one key issue that is often overlooked is access to information to fulfill their needs, such as inclusive and/or special schools, hospitals, and therapy facilities among others. This is particularly true for parents and caretakers who play a key role in meeting their child's needs since that information is not widely available. This is why we designed a platform that aims to respond to this need.

From the onset of our initiative, we aimed to create a platform that truly caters to the needs of our users. Therefore, gaining a holistic understanding of the users and ecosystem enablers was essential. We spent several months capturing diverse perspectives from a wide range of stakeholders to understand their needs and challenges. In our fieldwork research across Indonesia, we spoke with parents and caretakers, organizations of people with disability, policy makers, and academia. The insights gained from these discussions served to inform our team's design of the platform.

Beyond having these insights, we hope that it also sheds light on the importance of having a thorough understanding of the needs of potential users when creating a new digital solution. By developing a solution that factors in their challenges and needs, we hope that Akses Inklusif can be beneficial to parents and caretakers of children with disability, as well as to organizations of people with disability that advocate for their rights and needs. In the future, we hope this platform will continue to evolve and support the needs of not only parents and caretakers but also wider communities of people with disability, as we strive to ensure that no one is left behind.

About Akses Inklusif Platform

The “Leaving No One Behind” (LNOB) project leverages data to empower people with disability, improving their access to essential services through the Akses Inklusif platform. As a digital platform, it aggregates data from various reliable data sources, including Google Points of Interest (POI), health data from the Ministry of Health, and educational information from Dapodik, ensuring a comprehensive and trustworthy data foundation. The current version of the platform provides information on schools, therapy facilities, disability-friendly hotels, among others.

However, Akses Inklusif offers more than data access; it's an inclusive ecosystem for users to find specialized services and engage with a community. By allowing personalized profiles according to the disability most relevant to their situation and searches for educational and healthcare facilities or assistive technologies, it simplifies information retrieval. Additionally, it encourages community interaction and crowdsourced data enhancement, which is overseen by administrators.

This platform streamlines the search for information, promoting efficiency and inclusive access. Akses Inklusif represents a significant step forward in supporting the disability community with a more informed, connected, and inclusive approach.

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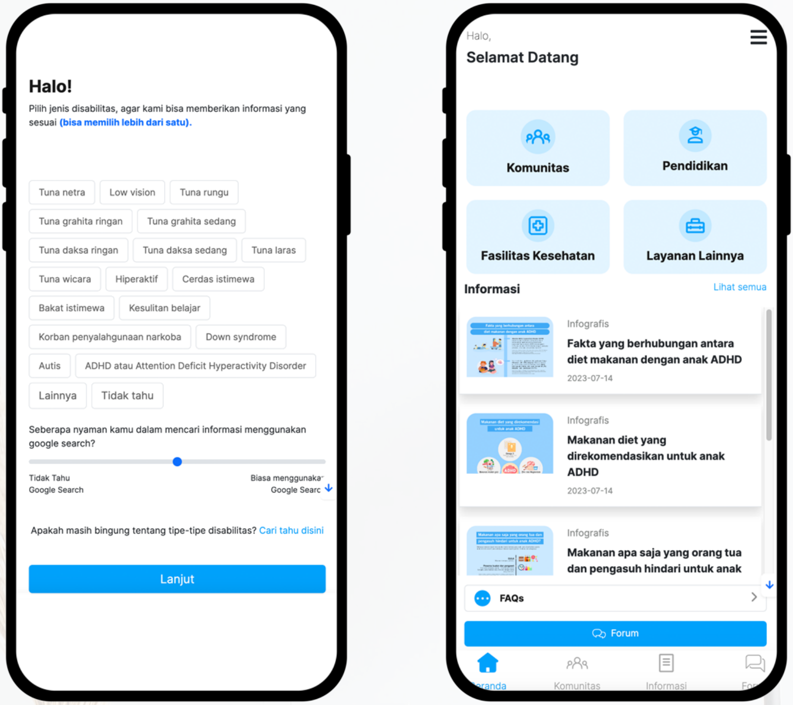

Halo!

Pilih jenis disabilitas, agar kami bisa memberikan informasi yang sesuai **(bisa memilih lebih dari satu).**

Seberapa nyaman kamu dalam mencari informasi menggunakan google search?

Apakah masih bingung tentang tipe-tipe disabilitas? Cari tahu disini

Halo,

Selamat Datang

Informasi

Infografis

Fakta yang berhubungan antara diet makanan dengan anak ADHD

2023-07-14

Infografis

Makanan diet yang direkomendasikan untuk anak ADHD

2023-07-14

Infografis

Makanan apa saja yang orang tua dan pengasuh hindari untuk anak

Picture 1. Homepage of Akses Inklusif

Try the app!

SCAN HERE >

Read our blogs series

Leaving no one behind: Making use of data innovation to respond to the needs of parents and caretakers of children with disabilities in Indonesia

SCAN HERE >

Notes from the Field: A reflection on doing a study involving people with disability

SCAN HERE >

Akses Inklusif: A Digital Platform for Essential Services and Information for Parents of Children with Disability in Indonesia

SCAN HERE >

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