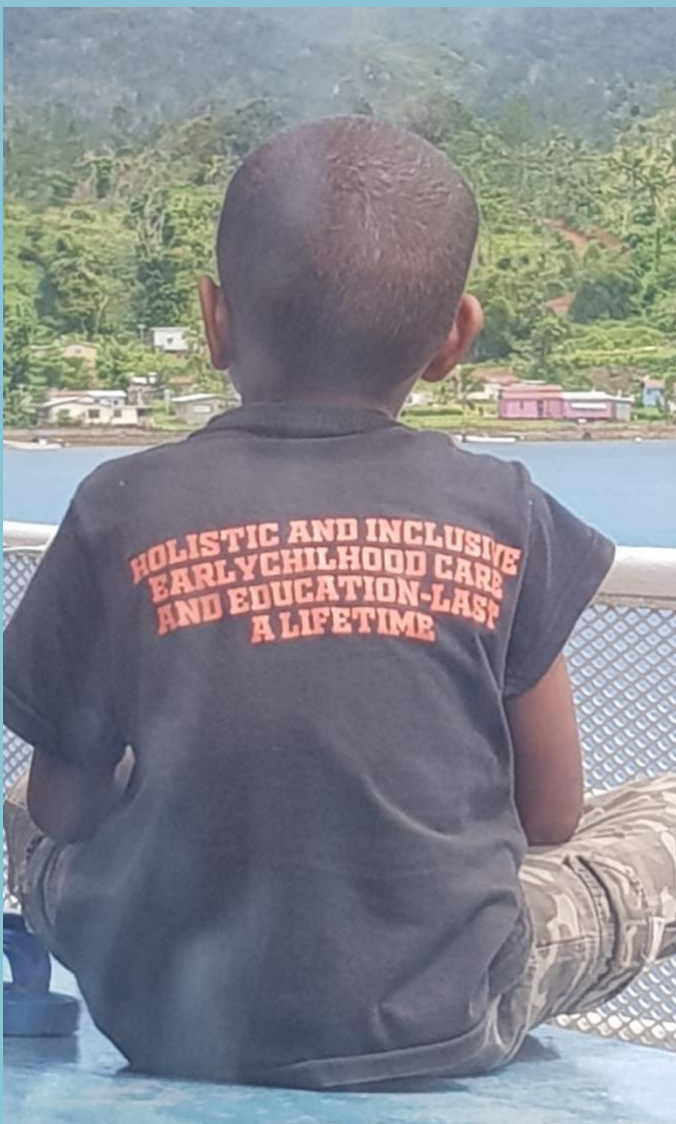




Nossal Institute for Global Health  
Melbourne School of Population and Global Health

## Early identification and intervention for children with disability in Fiji – current practices and opportunities

March 2023



Contact:  
Fleur Smith  
[smith.f@unimelb.edu.au](mailto:smith.f@unimelb.edu.au)

# Table of Contents

Abbreviations .....	4
Key Terms.....	4
<b>Introduction .....</b>	<b>5</b>
<b>Background .....</b>	<b>5</b>
<b>Study aims.....</b>	<b>9</b>
<b>Methods.....</b>	<b>9</b>
Participants .....	10
Data Analysis.....	11
Ethics .....	12
<b>Findings.....</b>	<b>13</b>
Composite journey maps .....	14
Stage 1: Identification of needs .....	16
Stage 2: Accessing intervention and supports.....	22
2.1 Availability and utilisation of intervention and support services .....	22
2.2 Barriers to intervention and support services for children with disability .....	24
2.3 Facilitators of access to intervention and support services for children with disability.....	29
Stage 3: Outcomes – impact of intervention and unmet needs.....	32
Overarching theme: Cross-sector collaboration.....	37
<b>Summary &amp; Recommendations.....</b>	<b>40</b>
Limitations.....	44
References .....	44

## Research team

Fleur Smith, Nossal Institute for Global Health, The University of Melbourne

Sureni Perera, Frank Hilton Organization, Fiji

Dr Manjula Marella, Nossal Institute for Global Health, The University of Melbourne

## Acknowledgements

This study was funded by the Department of Foreign Affairs and Trade under the “Partnership for Provision of Disability Technical Advice and Services” implemented by the CBM-Nossal Institute Partnership for Disability Inclusive Development.

We thank all the members of the advisory group for their valuable time and contributions to the design and outputs of this study. The advisory members were: Mereoni Daveta, Salote Biukoto, Jovesa Korovulavula, Robyne Leven, Joti Mala, Joy Millan, Dr Kate Milner, Dr Kelera Naulumatua, Dr Ilisapeci Tuibeqa, and Dr Sue Woolfenden.

Thank you to Manon Duay and Kirsty Teague for their work on reviewing and synthesising the background literature.

Special thanks to all the participants for generously sharing their experiences and perspectives.

Front cover photo credit: S. Perera

## Abbreviations

AT	Assistive Technology
CRA	Community Rehabilitation Assistants
CWM Hospital	Colonial War Memorial Hospital
DSW	Department of Social Welfare
ECD	Early Childhood Development
ECI	Early Childhood Intervention
FEMIS	Fiji Education Management Information System
FHO	Frank Hilton Organization
FSB	Fiji Society for the Blind
HIC	High income country
LMIC	Low- and Middle-Income Country
MCH	Maternal and Child Health
MHMS	Ministry of Health and Medical Services
MOE	Ministry of Education
MWCPA	Ministry of Women, Children and Poverty Alleviation
NICU	Neonatal Intensive Care Unit
OPD	Organizations of Persons with Disabilities
SIA	Spinal Injury Association
UNCRC	United Nations Convention of the Rights of the Child
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities

## Key Terms

<b>Early Childhood</b>	The period from conception to eight years of age. A period of rapid brain development and considered to be the most critical stage of human development.
<b>Early Childhood Development</b>	Refers to a child's physical, cognitive, social and emotional development during the early childhood period.
<b>Early Childhood Intervention</b>	Services or programs to support young children with, or at risk of, developmental delays or disabilities and their families. May include specific interventions to enhance children's development, strengthen family competencies and capacity, and promote inclusion and participation. Sometimes also referred to as 'early intervention'.
<b>Early Childhood Education</b>	Refers to formal education and care settings for children prior to reaching school age. Often also called preschools, kindergarten, nursery.

## Introduction

The earlier children with, or at risk of, developmental disability are identified and receive timely, coordinated support and intervention, the better their outcomes and those of their family (2, 3). However, systems for early identification, support and intervention for children with disability in many low- and middle-income countries (LMICs), including in Pacific Island countries, remain weak, and there is little available evidence on effective practices for co-ordinated care across sectors.

This study sought to understand current pathways and practices in early identification and intervention for children with disability in Fiji, and identify gaps and opportunities to strengthen cross-sectoral collaboration and provide timely, coordinated care and support for young children with, or at risk of, disability and their families.

## Background

Early childhood intervention refers to a range of services and supports for children with developmental disability including supports to optimise children's development, strengthen capacity of families in supporting their child, and promote inclusion and participation of children with disability and their families in community(4).

Under-five mortality rates have reduced in LMICs due to advances in maternal and child health care. However far less attention has been paid to children who survive with developmental delays and disability. Recent evidence suggests that the risk of disability in children under five years of age is 10 times higher than the risk of mortality (5). In 2016, the Global Burden of Disease study estimated that 52.9 million or 8.4% of children under five have developmental disabilities, with 95% of these living in LMICs (6).

Children with disability are at risk of exclusion and poor health and developmental outcomes compared to children without disability. They are more likely to experience poor health and nutrition, lack appropriate stimulation, not attend school or early education, feel discriminated against, be subject to abuse, and report feeling unhappy (7). Additionally, several studies indicate that families of children with disability are at greater risk of social inequities such as poverty, family violence, stigma and discrimination, and caregivers are at risk of poorer mental and physical health (8, 9, 10, 11, 12, 13, 14, 15, 16, 17).

Identifying children with, or at risk of, disability early and connecting them and their family with appropriate support is vital for improving outcomes and removing inequities.

### **Early childhood development as a growing global concern**

In recent years, there has been growing recognition that young children need the opportunity to 'thrive' not just survive, with momentum among researchers, policy makers and development actors to support programming for early childhood development (ECD). While not specifically addressing the needs of children with disability, the World Health Organization's (WHO) Nurturing Care Framework (NCF) articulates that care in the first years of life is especially important for children with developmental disability and lays a foundation for their lifelong health, wellbeing and productivity (1). The NCF (Figure 1) outlines a multi-sectoral systems level approach that brings together health, early education, nutrition, child protection and responsive caregiving with the aim of ensuring all children can reach their potential.

Figure 1: Components of Nurturing Care (1)



At a regional level, the need for cross-sectoral approaches to ECD was also highlighted at the Pacific Early Childhood Development Forum in Fiji in October 2019 with a commitment to develop a Pacific multi-sectoral model for ECD, with actions included to support children with disability (18).

To enable children with disability to realise their potential alongside their peers, current evidence suggests an inclusive ECD approach includes early identification of developmental disability, inclusive universal services and specific early childhood intervention (ECI) (4, 19, 20). Yet the reality in many LMIC settings is either a lack of specialised services and barriers to accessing care that is available (19, 21). The result is a missed opportunity for early and timely support and intervention in the crucial early years. Country level implementation of ECD strategies and frameworks such as the NCF and the Pasifika Call to Action on ECD must therefore comprise disability-inclusive mainstream and specific approaches for young children with disability.

#### Early identification and intervention in LMICs

Early identification of children with developmental disabilities aims to identify children with delays to their development where support and services may be beneficial and equips decision makers to establish and strengthen systems. The lack of awareness, resourcing, systems and contextually appropriate tools for early identification of disability, particularly in LMICs has been identified as a barrier to ECI program access and growth (19).

The key mechanisms for early identification typically include routine developmental screening and monitoring, generally by trained health or education personnel, followed by referral for further assessment and service provision when indicated (22, 23). Formal structures for developmental monitoring are established in most high-income settings where validated protocols and tools are used to screen and record developmental milestones, identify concerns and refer to relevant assessment and services. Another crucial mechanism for early identification of children with disability is recognition by caregivers and their capacity to seek support from service providers (24). Evidence from high income countries (HIC) indicate both facilitators and barriers to caregiver identification and help seeking such as socio-economic status, family history of developmental disabilities, birth order and ethnicity (24). Yet there is little to be found in the literature on this in LMICs.

Evidence on best practice for specialist ECI programs indicate the use of skilled personnel, delivering family-centred and culturally responsive care, and utilising daily routines and play-based approaches (19).

While much evidence exists on ECI in HIC settings, translating this evidence for use in low-resource settings presents challenges. There are differences in aetiology or social determinants, the availability of workforce (eg allied health specialties) and other resources, and awareness and acceptance of ECI services between settings. (25). Despite a lack of evidence on what is feasible and effective for ECI from LMICs, learnings can be drawn from innovative community and family based intervention models that address caregiver support and competence, and community-level barriers (e.g. stigma) that are increasingly used to deliver ECI in LMICs (1, 22, 26, 27, 28, 29).

## **Fiji and children with disability**

Fiji is a middle-income Pacific Island nation with a population of 884,887(30) and is a regional leader in the Pacific with established health, education and social sectors.

Fiji is an archipelago consisting of 332 islands, although 70% of the population live on the main island of Viti Levu concentrated around the capital city, Suva. For the 44% of the population who live in rural and remote island areas travel to and from the larger urban centres where the majority of services are available is challenging, impacting access to specialist health care and other supports. The use of traditional medicine and other cultural practices are common.

In the 2017 census, 13.7% of the population reported at least one area of functioning difficulty(30). Preliminary results from the 2021 Multiple Indicator Cluster Survey (MICS) indicate that 8.8% of children aged 2-17 years in Fiji were reported to have functioning difficulty in at least one domain, and just 82.9% of children 36-59 months were considered to be 'developmentally on track' (SDG 4.2.1)(31).

Services for children with disability have existed in Fiji for several decades but have primarily been for school aged children. The Frank Hilton Organization (formerly The Fiji Crippled Children's Society – Suva Branch) is a non-profit organisation established in the 1960s to provide care and education for children with disability. FHO now receive some government funding and have more recently established an Early Intervention Centre that provides individual and group based services for young children with disability and their families(32).

Other recent developments for children with disability in Fiji in the health and education sectors include policies on special and inclusive education, systems for identification children with disabilities in schools (33, 34, 35, 36, 37, 38), and the establishment of developmental paediatric training for doctors (39).

In 2019, a caregiver support program for young children with cerebral palsy was piloted and evaluated to test its feasibility and acceptability in Fiji (40). Its conception was based on growing evidence from other LMIC settings trialling programs that promote responsive caregiving with trained, but non-specialist, workers and utilising peer-to-peer support (20, 26, 28, 41, 42, 43, 44). Pre-published results indicate acceptability among caregivers and implementing partners and variable feasibility within current constraints (40).

Other disability-related studies have specifically explored barriers and enablers for people with communication difficulties in Fiji (45, 46, 47, 48). Findings highlight the need for culturally relevant and sensitive services for those with communication disability to overcome the impact of negative community attitudes, however also indicate positive help seeking and support for family members with communication disability within available networks.

Peer reviewed literature from the wider Pacific on children with disability has little available on services or early identification for young children with disability, but focuses on access to education, prevalence studies and the work of Jenkin and colleagues in Vanuatu and Papua New Guinea on the voices of children with disabilities, their lived experience and priorities (49).

## **Imperative for action**

As recognised by the NCF supporting children's development requires the collaboration and co-ordination of multiple sectors, critical for children with disability who often require a range of supports that span sectors. Services for children with disability in LMICs are often limited or not integrated into existing systems (20, 21, 22), with inadequate governance, guidance or coordination to enable effective early access to intervention and support (50).

Addressing these challenges is necessary not only for reasons of ethics and equity, but also for achieving global, regional and national commitments to development action that is disability-inclusive. Fiji adopted a national Rights of Persons with Disabilities Act in 2018, and has ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD)(51) and Convention on the Rights of the Child (CRC)(52), both of which include specific articles outlining the rights of children with disabilities to the same opportunities as all children. The WHO Western Pacific Regional Framework for Rehabilitation highlighted the need for action by member states to strengthen and expand early identification and the provision of services for children with

developmental delays and disability (53). The specific inclusion of early childhood development in the 2030 Agenda in SDG 4.2 (*access for all children to quality early childhood development, care and pre-primary education*)(54) acknowledges the importance of these crucial early years, and recognises there are subsequent advantages for society when all children achieve optimal development. Further, as one of Fiji's development partners, and a key supporter of the education and health sectors, objectives of the Australian Government Department of Foreign Affairs and Trade's (DFAT) 'Development for All strategy 2015-2020'(55) support action on early identification and intervention of childhood disability by improving equity for children with disabilities and creating opportunities for their participation in education and work.

With a clear global imperative to ensure early identification and intervention for children with developmental disability, and a dearth of evidence from LMICs, and even less from Pacific Island countries, a scoping visit to Fiji was conducted in March 2019 by the lead researcher to meet with several ECI stakeholders. Findings from this visit indicated: a) low level of awareness of developmental disabilities at community, service provider and government levels; b) poorly defined and understood pathways of care for children with developmental delays and disabilities. There was clear appetite from both government and service provider stakeholders to better understand and strengthen these pathways and achieve better outcomes for children with disability and their families.



## Study aims

The aims of this study were –

- To explore gaps and opportunities for strengthening systems for early identification and timely intervention for children with, or at risk of, developmental delays and disability in Fiji.
- Propose recommendations for strengthening systems across sectors in Fiji to enable children with, or at risk of, developmental delays and disability and their families to access timely, co-ordinated intervention and supports.
- Contribute to building an evidence base on care pathways for children with disability in LMICs.

To achieve these aims, the study sought to answer the following questions -

- a. What are the current practices in Fiji for developmental monitoring of babies/young children, early identification of impairment/disability and referrals to early childhood intervention services and support?
- b. What is the experience of caregivers\* and children with disability in their journey to accessing services and supports at different developmental stages?
- c. How could existing health, education and social support systems and services be strengthened to improve outcomes for these children and their families and meet obligations under the relevant UN conventions?

*\*Throughout this report the term ‘caregivers’ is used to refer to both biological parents and others undertaking the primary caregiving role.*

## Methods

A qualitative study was undertaken to explore both supply side and demand side factors influencing identification of developmental disability and the access and uptake of services for young children with disability. The study was conducted in 3 areas of Fiji - Suva, Serua and Kadavu - to capture the perspectives from those in urban, rural and remote island communities.

An advisory group was established at the commencement of the study and included representatives from Ministry of Health and Medical Services (MHMS), Colonial War Memorial (CWM) hospital, Ministry of Education (MOE), Ministry of Women Children & Poverty Alleviation (MCWCPA) Disability unit, Pacific Disability Forum (PDF), DFAT, the Fiji Program Support Facility and UNICEF. The advisory group provided advice and oversight of contextual issues relevant to the study design, participant recruitment, validation of findings and review of study deliverables.

In-depth interviews were conducted from February to June 2021 with caregivers of 12 children with disability and 17 key stakeholders (including one group interview) from the government and service provider levels representing health, education, social welfare and disability sectors.

Due to the travel restrictions associated with the COVID-19 pandemic, data collection was conducted jointly by the Melbourne based researcher (FS) from the University of Melbourne and a local Fiji-based researcher (SP) from the Frank Hilton Organization. The Melbourne-based researcher conducted interviews with key stakeholders remotely using Zoom. The Fiji-based researcher conducted face to face interviews with caregivers in all three areas and with some stakeholders in Serua and Kadavu where there was insufficient internet connection for remote interviews. The Fiji-based researcher received training prior to data collection and was supported by the Melbourne team throughout the study.

## Participants

Four caregiver participants were purposively recruited from each of the study sites through existing networks of the local researcher. Caregivers of children with a range of conditions/impairments and of varying ages were chosen to capture experiences of the journey of accessing care at different developmental stages, and included those at various stages of accessing intervention and supports. Of the 12 caregiver interviews, 9 were with a female caregiver and 3 were with both male and female primary caregivers, with 15 participants in total. The characteristics of caregiver participants are further outlined in Table 1 below, and child characteristics in Table 2.

Table 1. Caregiver interview participants

<b>Location</b>	Suva	4
	Serua	4
	Kadavu	4
<b>Interview participants</b>	Female caregiver only	9
	Both male and female caregivers	3
<b>Ethnicity</b>	I-Taukei	9
	Indo-Fijian	3

Table 2. Child characteristics

Child number	Child's age (years)	Child's gender	Child's condition
1	5	male	Blind, cleft lip and palate
2	4	female	Suspected autism
3	2	female	Down Syndrome
4	6	male	Cerebral palsy
5	13	male	Cerebral palsy
6	2	female	Cerebral palsy
7	5	male	Global developmental delay, seizures
8	5	male	Global developmental delay
9	4	male	Cerebral palsy
10	4	male	Cerebral palsy
11	2	male	Down syndrome, club foot
12	4	female	Delayed speech development, seizures

Caregivers were interviewed using a semi-structured interview guide and were asked about their experience of identification or assessment of disability, referral pathways and access to services and supports, impact of supports (or lack thereof) on the child and caregiver, their perceptions of disability and intervention, and factors impacting care/support seeking behaviours in relation to disability. Language translation was provided to enable caregivers across ethnic groups to participate.

Stakeholders were identified by the advisory group and invited to participate by via email or phone by the research team. Some additional participants were identified by snowball sampling by the local team in the course of the fieldwork. Of the 17 stakeholder interviews, 16 were individual interviews and 1 was a group interview of 3 participants. Of the total of 19 interview participants, 4 were male and 15 were female. The characteristics of key stakeholder interviews in terms of study sites and sectors are further outlined in Table 3.

**Table 3. Stakeholder interviews**

Sector	Number Interviews	Suva	Serua	Kadavu	Service provider level	Government level
<b>Health</b>	7	3	2	2	6	1
<b>Education</b>	3	3	-	-	2	1
<b>Disability</b>	3	3	-	-	2	1
<b>Social welfare</b>	4	2	1	1	3	1
<b>TOTAL</b>	<b>17</b>	<b>11</b>	<b>3</b>	<b>3</b>	<b>13</b>	<b>4</b>

Key stakeholders were interviewed using a semi-structured interview guide and were asked about their knowledge, perceptions and experiences of current practices in early identification and intervention for children with developmental disability, including factors impacting on referral, access, uptake and co-ordination of care for children with, or at risk, of disability.

All interviews were audio recorded and transcribed, with translation into English where interviews are conducted in local language.

### Data Analysis

Transcriptions of interview recordings were entered into the coding software Nvivo for analysis by the Melbourne-based researchers. Data was analysed inductively and deductively. The objectives of the research provided initial structure for thematic analysis, with emerging themes and subthemes added and data coded accordingly.

In addition, journey mapping was used to analyse the caregiver interviews. Journey mapping is adapted from the market research sector and is a process of examining individual’s stories to understand their unique and complex experiences of accessing services and systems (56). The caregiver journey maps were then analysed to identify common experiences and synthesised into 3 composite journey maps that reflected the broad experience of participants.

Findings were presented at a workshop with the advisory group for discussion and feedback, where input was also obtained for formulating recommendations for the local context.

## **Ethics**

Ethics approval was obtained from the University of Melbourne Human Research Ethics Committee and the Fiji National Research Ethics Review Committee at the Ministry of Health and Medical Services prior to the commencement of data collection. All interview participants were provided with a plain language statement about the study and given the opportunity to ask further information and seek clarifications before providing informed consent to participate.

## Findings

In this report, we present an overview of the journey that families of children with developmental disability in Fiji take to access intervention and support services.

After mapping and analysing the journeys of the 12 families, the journeys were synthesised into three composite journeys that highlight some of the more common experiences.

These three journeys are as follows and are summarised on the next pages -

- > Journey of child with complications/risk factors identified at birth
- > Journey of a child without any known risk factors/complications at birth
- > Journey of a child from a remote island

Analysis of the 12 journeys demonstrated three key stages that families experience. Thematic findings are reported according to the three stages.

Stage 1: Identification of needs

Stage 2: Accessing intervention and supports

Stage 3: Outcomes – impact of intervention and unmet needs

In each stage we report the key themes arising from the experiences of families, the perceptions of stakeholders of the journey, and factors influencing the journey including barriers and facilitators to timely and appropriate intervention and supports.

At the end of each stage, we have summarised the key system touchpoints\* that families of children with disability encounter or interact with during that stage of the journey; what is working well to enable identification and developmental disability and access to intervention; and what could be improved to further enable timely access to intervention and supports.

An additional theme of ‘cross-sector collaboration’ that spans all stages of the child and family journey is discussed at the end of this section

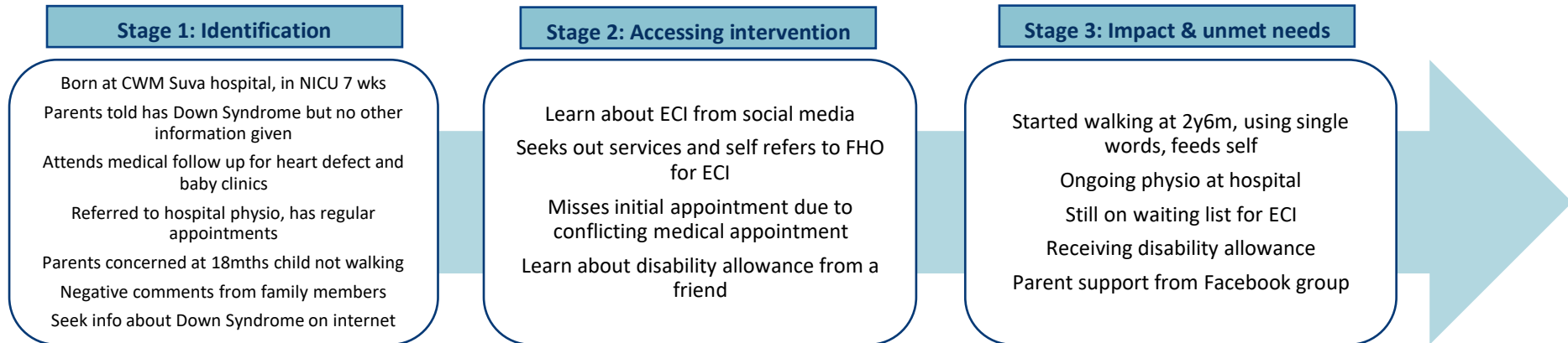
We understand that families move through the system in varied ways and that they will not necessarily have experienced all points outlined in this project or in the way that we have outlined them; phases are not necessarily linear and may be overlapping but have presented them separately for simplicity.

*\* Touchpoints are organisations, services or supports that a parent/child/family engages with, providing a potential opportunity for them to be supported towards their goal, in this case access to intervention for children with developmental disability.*

## Composite journey maps

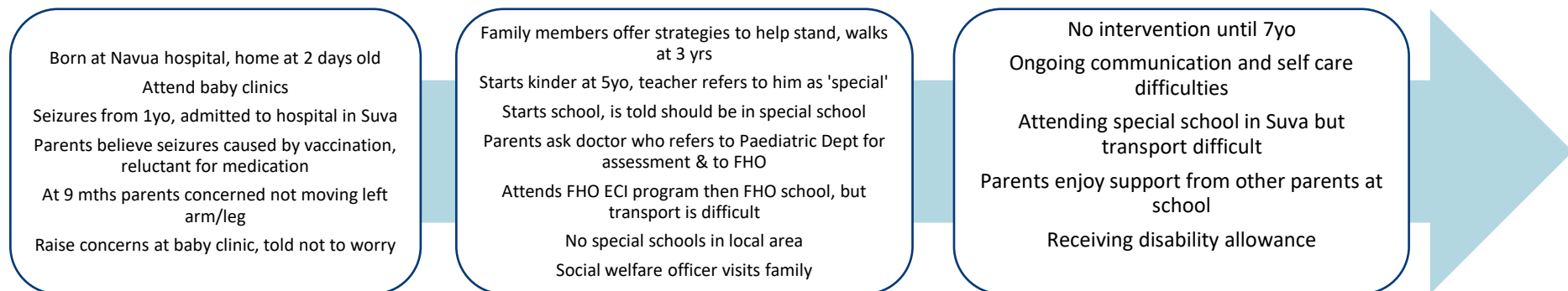
### Journey of child with complications/risk factors identified at birth

*Lani\*\* is a 3-year-old girl who lives with her parents and baby brother in Suva. Lani has Down Syndrome. She has started walking about 6 months ago and she is saying single words and using gesture to communicate. She can feed herself and is starting to learn toilet training. She loves playing with her little brother.*



### Journey of a child without any known risk factors/complications at birth

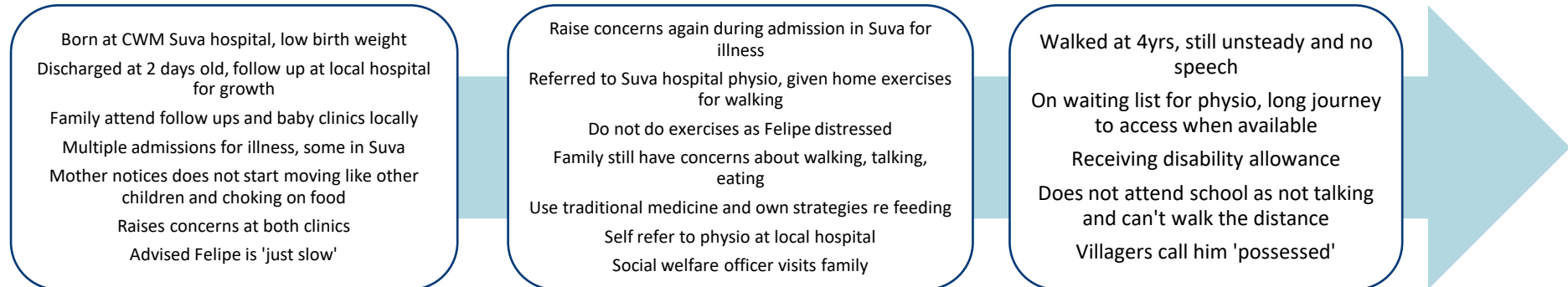
*Josefa is a 12-year-old boy living in Serua. He is the eldest of 5 siblings. He has cerebral palsy and epilepsy. He has weakness in his left arm and leg and his speech is difficult to understand. He is not yet fully continent and needs help with getting dressed. He likes to play with the soccer ball.*



*\*\* names used are not names of study participants*

## Journey of a child from a remote island

*Felipe is a 6-year-old boy who lives in a remote village on Kadavu with his mother and maternal grandparents. He has a history of motor and speech delays, feeding difficulties and some challenging behaviours. He loves listening to music.*



## Stage 1: Identification of needs

In this stage, most interactions between families of children with or at risk of disability and the service and support systems, are with the health sector. This includes birth and neonatal services, as well as medical follow up for early complications, and families accessing routine health care including maternal and child health services. Findings suggest that the focus of interactions at this stage is on medical and health needs and there is little in the way of information, identification, referral or monitoring of known or potential developmental concerns.

### Health system interactions for birth and neonatal care

All of the families in this study, started their journey with their child's birth in a hospital. For the majority, even those from the remote island of Kadavu, this was at the Colonial War Memorial (CWM) Hospital in Suva. Others were born at health facilities nearer to where they live (e.g. Ba Mission, Navua Hospital), however were transferred to larger facilities (e.g. CWM, Lautoka) if there were complications or risk factors (e.g. maternal hypertension, low birth weight) or an evident congenital condition (e.g. club foot, Down Syndrome, cleft lip and palate). In the case of complications, caregivers reported a longer stay in hospital, up to several weeks, with some babies admitted to the Neonatal Intensive Care Unit (NICU) during this time. Those babies born without any complications of the pregnancy or birth, or signs of a congenital condition or other risk factors were discharged home a few days after birth without any follow up, other than MCH baby clinics.

Children with complications frequently had hospital-based follow up once they were discharged home. Follow-ups included specialist outpatient clinic appointments, surgical follow up (e.g. for congenital cardiac conditions, cleft palate repair), and regular growth monitoring for children with low birth weight. Most follow up services occurred at CWM Hospital in Suva, with some families reporting ongoing regular appointments. Follow up health services provide continuity of care and a potential opportunity for identification of developmental delays and disability, and referral to intervention and support. However, while most caregivers expressed an intention to attend medical follow up services for their child, the distance to services and cost of transport was reported as a barrier for families, especially those from rural and remote areas.

*Staying in Kadavu, we go to Suva [for follow up]. Two weeks check in Suva then we came back to Kadavu. Go back to Suva come back to Kadavu, no help [in Kadavu]. Every two weeks, until last year. (Caregiver, Kadavu)*

These challenges were also highlighted by stakeholders who added further about lost opportunities for follow up.

*Sometimes even cases who are booked don't come... so even you know, like we always call our patients a day prior to the clinic. And so they say that they're coming, but because of some bad weather conditions or transportation problems, financial issues, they don't turn up. (Stakeholder, Health)*

A lack of understanding of the reason for follow up appointments was an additional barrier to attendance, with one caregiver describing that they attended their local health centre rather than travelling to Suva, not realising that the follow up in Suva was for a specialist clinic (club foot) that could not be provided at the local health centre.

In addition to attending follow up appointments for existing medical and health care issues, caregivers reported accessing routine health care services for more general health needs such as when their child was ill (e.g. chest infection, seizure). They variously described attending their local health facility or private doctors, with transfers and referrals between health facilities occurring when more complex care was needed.



Similarly, all caregivers reported taking their child to the 'baby clinic' for their routine maternal and child health checks. Both caregivers and stakeholders reported 'baby clinic' visits are a widely accepted and adhered to practice in the care of a young child. Stakeholders described that these clinics were the likely first point of contact to monitor and detect developmental delays or disability among children.

*When the children are born, they are going to health centres for their baby clinic. So they are the first people who can identify the impairment or disability in children. (Stakeholder, Education)*

### Lack of information and early identification

Caregivers of children with known complications or conditions reported a lack of information or communication from health care staff in the period after birth, or the months following, about their child's condition or any potential implications for their child's development. Some of these caregivers reported being told of a diagnosis at birth or later, but of not receiving any other information about what this meant for their child's development, additional supports that their child may need, or advice for managing their child's needs at home.

*Parent: They just told me Down Syndrome without even discussing the meaning of this word.*

*Interviewer: were you given any advice about how to care for your child?*

*Parent: I wouldn't say they gave me advice because the doctor only said they need to take the bloods..... I asked one day, what are the bloods for and she said that's because she [baby] has Down Syndrome. That's it. Just that. (Caregiver, Serua)*

Others reported that they were not told of their child's condition at all.

*She [mother] did not know the son was cleft and blind. We went together to see the son, the son was in the NICU Room. We went together and the doctor did not explain to her that the son's condition was like that. When she looked at the son, she was shocked. She cannot carry him. She wanted to run (Caregiver, Kadavu)*

Although health care workers were the first point of contact for many families of children with developmental disability, there was little evidence of them identifying or initiating conversations about possible developmental delays or disability, or of recommending any follow up or referral for these.

While attendance at baby clinics was high, caregivers reported that their child's development was not discussed and did not seem aware that this was a part of these clinic checks. Although the health card completed by nurses at the baby clinics includes developmental milestones, caregivers reported delayed milestones were often not noted on the card or discussed with them. The child in the quote below walked at 4 years of age, although his baby clinic card indicated he was walking at 18 months.

*His ligaments are weak, his hands and legs. He was four years old then he can stand up. (Caregiver, Kadavu)*

Health sector stakeholders acknowledged that the focus on health needs during routine health care interactions was a barrier to identification of developmental disability and referrals for early intervention.

*We normally address care on a child as general, as a child health without the focus on whether they have disability or not. They get sick, they come and see us, and it's just when they're sick then we intervene. But there are other special areas of their needs that are being ignored at the moment which we think we need to improve on. (Stakeholder, Health)*

This lack of any specific communication and information around developmental needs is a key barrier to accessing services. It may in part be attributed to a lack of knowledge and awareness by health workers of child development and disability and early intervention, as highlighted by some stakeholders -

*If there are subtle signs of developmental delay, you know, like it's not quite obvious the nurses would not recognise it, or some of them would, it's quite sad to say that they could just push it under the rug and not inform us. Most of the cases that we get referred to from the south facilities are those with obvious signs of a disability here. And by the time when we go through the history and the developmental process, we realize that they have been delayed way earlier but it wasn't picked up (Stakeholder, Health)*

In addition to health worker knowledge, one stakeholder felt that effective systems for early identification of children needing support for their development and potential disability are largely absent in Fiji, leading to late identification and missed opportunities for early intervention. Although, it was also reported that capacity building is underway to improve early identification of developmental delays in health facilities. According to one stakeholder, training is being conducted for health workers on a developmental screening tool, the Ages and Stages Questionnaire (ASQ), with the tool being implemented for routine screening of all children presenting for health care, including in all CWM outpatient clinics.

*So what we've realized so far in developmental paediatrics in Fiji, is we are catching cases quite late. They come to us when they're in the school year, they're already attending school. ....so we're starting trying to screen every kid presenting to outpatient. So every kid that comes into our doorstep, we are trying to perform an ASQ [Ages and Stages Questionnaire] and we have done awareness classes for all the nurses in outpatient department and in the wards. So a new case that gets admitted or seen an ASQ is done irrespective of....we're hoping that if we can early detect them, then we can do something early like an early intervention (Stakeholder, Health)*

While this may aid to improve identification, it was also reported that lack of knowledge of where to refer to is a barrier for many health workers, and that awareness raising of these options may enable health workers to act when concerns were identified.

*I think another barrier is, you know, the knowledge or awareness of knowing what are the available help or assistance, that the health workers would refer the child with a disability. And I think given the spectrum of disability, I think it'll really help a lot if health care workers are provided with, if a child has the disability, where the child or the parent could be referred for further early intervention. (Stakeholder, Health)*

While there are many health touchpoints for the identification of developmental delay and disability, for some children identification occurs upon entry into early education or primary education. Teachers then become the point of contact for discussing developmental concerns and making referrals for assessment and follow up. The MOE's Fiji Education Management Information System (FEMIS) was reported as a tool to enable identification of students with disability in schools. Despite this system it was raised that many teachers do not have adequate awareness on disability, so may be delayed in identifying a child in their class as having a disability and implementing supports, especially for those with more 'hidden' impairments.

*But the challenging part would be the time frame for the child to receive those supports. Because when they come in the [ECE] center, it takes the teacher, like for physical disabilities it is visible for us to see, like for this child he has braces on his leg, so we already know that that child is on braces and he needs support to walk. But the ones who cannot be identified like moderate hearing impairment and all that, then takes the teacher quite long to assess that and get to identify the needs of the child and then almost half a year goes away. So, by then the child is already about to move to the next step that is year one. (Stakeholder, Education)*

For some it appears that initial identification occurs through outreach visits to villages by the disability unit from the Department of Social Welfare (DSW) at the Ministry for Women, Children and Poverty Alleviation (MWCPA). It was reported that fieldworkers from this unit go house to house in villages and identify those, of any age, who meet criteria for the disability allowance, using the Functional Independence Measure.

### Emerging developmental concerns and initial help seeking

Regardless of whether their child has a known diagnosis or not, caregivers reported voicing their concerns through existing touchpoints within the health sector when they recognised their child was showing developmental delays or functional difficulties. Various factors related to help seeking behaviours, systems for developmental monitoring, health worker knowledge and awareness, and cultural factors were identified influencing early identification of developmental delays or disability and referrals.

All caregivers reported an awareness early on that their child's development was different to that of other children, particularly if it was not their first child. Many reported noticing that their child was not moving (e.g. rolling over, crawling, standing) or talking at the same age as other children. Some reported having concerns as early as 4 months. However, most said they believed their child might just be 'slow' or 'late' and did not immediately seek help. Several caregivers reported raising concerns during routine health care but were ignored or dismissed by health workers, and were advised 'to wait and see' or that their child was 'just slower than other children'. As a result, many did not pursue further assessment or intervention until many months or years later, if at all.

*They just told me that it will take him a long time to do something. When I came [to the clinic], at 1 year he was still only rolling around. Then they told me, it's normal, Down Syndrome, they are weak. After that I didn't take him anywhere, we just stayed together and I've been taking care of him. (Caregiver, Serua)*

*Then they said you should wait until 8 years, when his brain will develop then he will start to walk, like that. (Caregiver, Suva)*

Some caregivers reported that they could have sought help sooner rather than 'wait and see' if they had more information about their child's condition earlier.

*Maybe if we were familiar with the symptoms at the very earlier age maybe we could have, she could have gone [to intervention] early. From hospitals, we could have prepared to come early to Frank Hilton then maybe we could have, you know tackle her situation a bit more, because I kept thinking she's going to grow out of it you know. But at that time we just left it at that and we didn't ask for, it's not that we didn't want to but we just didn't know where to go to. (Caregiver, Suva)*

However, despite concerns being dismissed, several caregivers described proactively seeking information and support for their child's development. This, again, was mostly from health services, indicating this as the key touchpoint for families within the service system at this stage. Continued voicing of concerns and help seeking appeared in some cases to finally prompt referral for further investigation or intervention.

*After 8 months when I see he was not moving, nothing, then I just go myself to the hospital and they say he will walk. They didn't tell me anything that he got any problem. They said he will walk after 1 year like that. But after one year he was still like that. Then I went again and I told them, then they shift me to CWM. I was having the [developmental] clinic there, from that time until now (Caregiver, Suva)*

Caregivers also started to look more broadly for support, beyond their existing health system interactions. Community rehabilitation assistants (CRAs) described that it was not uncommon for caregivers to approach them when they are out in the community with concerns about their child.

*Some will come to us. They will say ‘my child is not rolling over’, or I have 2, 3, 4 other children, they have all done this but this one is a bit late. (Stakeholder, Health)*

Some caregivers reported using the internet to find support and information about their child’s condition when they did not receive adequate information from their health care provider.

*When we came home after that, I took the phone, I started to Google the thing up to check what was Down Syndrome....[my child] has the same features maybe, with the neck like this and the eyes maybe and the clubbed hands and feet, that’s all I know about it. But ever since then I’ve joined this group, the Australian Group, Down Syndrome Mummies and Families with Down Syndrome Babies. And we, me and my husband, we get to learn from what they say. (Caregiver, Suva)*

While stakeholders acknowledged the challenges with delayed identification and support from the health care system, they also highlighted challenges with delayed presentation of children with development delays or disability. Various barriers were reported by the stakeholders including negative prior health care experiences and cultural factors. One stakeholder described that cultural norms would dictate that in most cases caregivers would not question a person of authority if their concerns were dismissed by health workers,. Stigma and negative beliefs surrounding disability was also considered a factor in preventing early identification and help seeking, although this mostly raised by stakeholders and not caregivers.

*One of the main cause [of parents not seeking help] is stigma. And the fear of knowing, you know, stigma in the sense. If they feel that their child is developmentally slow, they will usually keep that child at home, and not seek attention, because that would bring out the fault within the kid and in the family. And fear of knowing, because if they do accept that something is wrong, then there is something is wrong. (Stakeholder, Health)*

### Summary of Stage 1:

<p><b>Key touchpoints</b></p>	<ul style="list-style-type: none"> <li>○ Hospitals for medical follow up of known complications</li> <li>○ Routine health care for illnesses or emerging issues</li> <li>○ Maternal and child health services - ‘baby clinics’</li> <li>○ Informal networks of information – e.g. family, internet</li> <li>○ Community outreach by department of social welfare disability unit</li> </ul>
<p><b>What is working well</b>  (Entry points for strengthening)</p>	<ul style="list-style-type: none"> <li>○ Caregivers seek health care services for their children when sick</li> <li>○ Caregivers attend routine baby clinics</li> <li>○ Systems are in place for medical follow up of children with known complications</li> <li>○ CWM Dept of Paediatrics is building undertaking capacity building of health workers in developmental screening</li> <li>○ Caregivers are noticing differences in their child’s development and functional abilities</li> <li>○ Caregivers are actively seeking information and support</li> <li>○ Identification by social welfare during community outreach</li> <li>○ Identification by MoE FEMIS for children who attend ECE/school</li> </ul>

<p><b>What is not working well</b></p> <p>(Barriers to be addressed)</p>	<ul style="list-style-type: none"><li>○ Caregivers lack information from health workers about their child's condition and reasons for follow up</li><li>○ Lack of communication or information to caregivers about child development, when to be concerned, and where to seek help leads to delayed help seeking</li><li>○ Lack of local services in rural areas for medical follow and cost of transport to urban centres up prevents some families attending appointments and becoming 'lost' in the system</li><li>○ Lack of effective referral pathways for intervention even when known developmental disability from birth (e.g. Down Syndrome)</li><li>○ Developmental delays are not being identified by baby clinics</li><li>○ Caregivers' developmental concerns are being dismissed or advised to 'wait and see' leading to delayed referral</li><li>○ Health care and ECE workers lack knowledge of developmental delay and disability and available referral options</li><li>○ Stigma and negative community attitudes to disability prevent caregivers seeking help</li></ul>
--	---

## Stage 2: Accessing intervention and supports

### 2.1 Availability and utilisation of intervention and support services

As described in stage 1, many of the caregivers in this study become aware early in their child's life that their child was experiencing developmental delays or functional difficulties and began to seek help. Although their concerns were often dismissed, caregivers continued to be persistent in learning about and accessing services and supports for their child, either through referral by service providers or self-referral.

Caregivers and stakeholders described the services and supports available for children with disability in Fiji as screening and assessment; early intervention and therapy; assistive technology; education facilities; financial and social welfare supports; organizations of persons with disabilities (OPDs); and informal supports.

#### Screening and assessment services

Participants reported limited services were available for formal assessment diagnosis of developmental delays and disability. Services for audiology screening and vision assessments were offered through non-governmental agencies/organisations such as the FHO, Project Heaven and Fiji Society for the Blind. The Developmental Paediatric service at CWM hospital have a weekly Developmental Assessment Clinic. It is reported that this clinic is used for assessing and diagnosing cases and providing medical reports which are used to refer or provide information to other non-health organisations, such as mainstream schools, special education and early intervention.

#### Early intervention and therapy services

Early intervention and therapy services most discussed by participants were those provided by the Frank Hilton Organization (FHO) and hospital-based physiotherapy services. Other services include those provided by the Fiji Society for the Blind, special schools, and Community Rehabilitation Assistants (CRAs). These services variously provided interventions to support motor skills, communication, behaviour support, provision of assistive technology (e.g walker), parent education, strategies for home practice, and access to parent groups.

Referral was either via self-referral after learning about the service from family or friends, or by referral from other service providers, such as the paediatric department at CWM or private doctors. There was little in the way of referrals from Suva based providers to locally based providers, where they existed (e.g. physiotherapy), for rural and remote families.

Services were predominantly located in Suva, although some provided outreach services. Several caregivers reported either not knowing about services or that they had been referred and were waiting for an appointment. Kadavu caregivers reported little interaction with intervention services, while stakeholders on Kadavu reported referring families of children with disability to and NGO or faith-based organisations for generic counselling support that due to the lack of any specific intervention services.

In addition to FHO, some other special schools throughout Fiji were reported to also have their own early intervention centres. However, it was discussed by some stakeholders that many of these did not have the programs or resources to accommodate the needs of young children with more significant support needs.

Physiotherapy was the most widely discussed and accessed therapy type by caregivers, likely reflecting a lack of other allied health specialties in Fiji rather than a lack of demand. Physiotherapy is available at FHO and within public hospitals and health centres, mostly in the urban centres. However, it was reported that the physiotherapy workforce is also minimal and, in many cases, responsible for all age groups and conditions, not specific to paediatrics.

## Access to assistive technology

The main providers of assistive technology were identified as the Spinal Injury Association (SIA) and FHO. There were also reports of AT being provided by faith-based organisations and corporate organisations such as Vodaphone. The disability unit at DSW were also reported to assess and support access to AT by liaising with AT service providers. Several stakeholders acknowledged that there is a very limited supply of AT suitable for the needs of children, and even less so in rural and remote areas. One stakeholder noted, however, that the need for AT is sometimes the factor that prompts a parent to first seek assistance for their child.

Many of the caregivers expressed a need for assistive technology (AT) for their child, with just one reporting receiving any (a walker). Among both caregivers and stakeholders, most discussion of AT related to mobility devices. There was little mention of other types of AT often needed by children with developmental disability, such as those for seating, positioning, communication or self-care.

## Education

Schools, in particular special schools, were identified by stakeholders as a key support for children with disability once they reached school age, but there was little discussion of children with disability attending early education. Many participants were aware of the Special and Inclusive Education Policy promoting inclusive education for children with disabilities in their local community, however most participants, both stakeholders and caregivers, associated education for children with disability as being in special schools.

Nevertheless, few of the children from the study had attended either early education or school, with several caregivers reporting they did not think their child could attend due to their impairments. One parent had a child attending mainstream primary school but needed to attend to support their child. Another parent reported their child had started attending their local mainstream school but now attends a special school as recommended by the teacher at the mainstream school.

*We are looking for somewhere since at this age they [should be] in class one, last year they were in Kindy. We were thinking about where he will go to school so he can learn. He only knows few words which we could not make it out. He is really slow maybe we will take him to school when he is eight years old..... I thought of him as his age group are going to school, but he couldn't go to school because he is not able to take him to the toilet and he is too weak if somebody pushes him.  
(Caregiver, Kadavu)*

Stakeholders were aware of a hesitation by some caregivers to send their child with disability to mainstream education, and also noted a lack of resourcing to support inclusion.

*If I look into the facilities, the facilities is for the normal children. All the facilities provided in the [early education] centres, almost all the centres I have gone through, the facilities are for the normal children.... We are not having any kind of assistive devices for them, and the other facilities like washroom all these are for the normal children, (Stakeholder, Education)*

They also noted a lack of inclusive and special education options in some areas, especially remote island areas like Kadavu resulting in many children with disability not attending school.

## Financial/social welfare supports

Financial support is reported to be available for families of children with disability through the Department of Social Welfare (DSW) at the Ministry of Women, Children and Poverty Alleviation in the form of a disability allowance. Disability officers go out in the community to identify and assess those that are eligible, including to rural and remote areas. Some also heard about the allowance via word of mouth from friends or others in the community, indicating that there is a level of awareness of this support in the



community. Almost all caregivers identified that they were receiving, or had applied for, the disability allowance.

Some caregivers also reported receiving financial assistance from family and accessing support from charitable organisations for essential supplies. Financial assistance was reported by caregivers as necessary to meet basic needs, such as food, as well as disability related needs including diapers for children with incontinence, and transport costs to attend appointments or special education.

### Organizations of Persons with Disabilities

While caregivers did not mention any interactions with or support from OPDs, some stakeholders were aware of OPDs and their role in providing advocacy and support for people with disability, including children. The OPDs discussed were usually focused around a specific population, for example the Spinal Injury Association (SIA), Association of the Deaf, Counter Stroke, and Fiji Society for the Blind. While it was reported that some of these provide supports for children (e.g. SI assisting with AT), there are no OPDs specifically for children with disability and their families to provide specific support and advocacy for their needs.

### Informal supports

Several caregivers discussed the informal supports and strategies they used to support their child and family. For some participants, their extended family was a key source of support. Family assisted by providing care for their child, encouragement and support to caregivers, and suggesting strategies to promote the child's functional abilities. Extended family members who also have a child with a disability or experience with people with disability through their work were highlighted as a particular source of support for caregivers. However, family was not always a source of support, with some reporting stigma and negative attitudes from family and deliberately distanced themselves from their family as a result.

Several caregivers spoke of their religious beliefs and practices as a source of support and encouragement in caring for their child with a disability.

*We pray too, we pray a lot about it to help us because sometimes it could be very tiring mentally, physically. (Caregiver, Suva)*

Other informal sources of support included Facebook groups and other caregivers with children attending the same services.

*I share with them if they have something ideas they share with me. Because we sit under one roof so the parents from [the centre] they are very nice so we get more ideas. When I go back to my home I'm just alone. But in school we get more ideas. As parents we discuss about our kids, about our children's future. (Caregiver, Serua)*

## 2.2 Barriers to intervention and support services for children with disability

While in this stage of the journey families were starting to be aware of and utilise intervention and support services, a number of barriers to access were identified both at the family and community level, and at the service and system level.

### Family and community level barriers

#### Family contextual factors

Families' financial status and competing demands present barriers to accessing services for children with disability.



Family financial constraints were identified by both caregivers and stakeholders as a key barrier. Financing the cost of transport and other related expenses for families from rural and remote areas is a particular challenge.

*So if our children identified in Lautoka say needs to come down, they have to come all the way to Suva. If our children in the islands need services, they have to wait till someone can pay for them coming.....this is one of the areas that we're struggling with. (Stakeholder, Social Welfare)*

Caregivers reported having to prioritise money for basic needs such as food and diapers, over costs of transport to attend appointments or any other disability-related costs, including assistive devices. One caregiver noted that costs of diapers and food to enable her child to travel to appointments were too great a barrier, so ceased attending intervention.

*It [travelling to Suva for early intervention] was very much difficult because only my husband is working now, I was working before but I can't work because of [child's name]. So fare is the main problem and secondly he is in diaper, I have to buy his diaper and other expenses to travel to town.....we have to buy something to eat. (Caregiver, Serua)*

Relatedly, caregivers reported needing to prioritise earning an income to support their family, and this meant failing to attend appointments for their child. One caregiver noted that she would like to attend appointments with her child but that her workplace did not allow her to take the time off.

Children with disability often have multiple needs that are addressed through different services. This presents further challenges with juggling multiple appointments. One caregiver reported that missing their initial early intervention appointment because of a conflicting medical appointment, which resulted in going back on the waiting list for services. Caregivers also discussed having to balance the needs of their other children and that this made it difficult to attend regular appointments.

#### **Lack of information and awareness about developmental disability**

A lack of awareness among caregivers and the community more broadly about developmental disability was identified.

As noted in stage 1, many caregivers reported receiving little information about their child's condition or impairments, leading them to believe these were 'normal' or that they would 'grow out of it', and in turn not understanding the need or benefits of intervention or support. For example, one parent reported that, although eligible, they were not accessing the disability allowance because they believe their child will grow out of their disability.

One parent stated that the interview for this study was the first time someone had spoken to them about their child's disability. Several stakeholders held the opinion that many caregivers have low awareness of disability, impacting on help seeking and accessing services for their child. Some felt that there were caregivers who viewed their child with a disability as a burden and that this was a contributor to not providing them with intervention or stimulation.

*There needs to be a lot of awareness, and advocacy, to change the mindset of parents, mindset of the community, to accept a child with disability so that they can be in early detection, and then intervention helps for the betterment of a child with disability. (Stakeholder, Social Welfare)*

There was also a sense among some stakeholders that caregivers in urban areas are more educated about disability than those in rural areas, although there was acknowledgement that those in rural areas may not have as much access to information, for example due to lack of internet access.

### Lack of knowledge of available services

Caregivers were asked if they had heard of 'early intervention' and what they understood early intervention to mean. Some responded that they had not heard of early intervention, while others reported that they had not heard of it until their own child was referred.

Many associated the idea of early intervention with physiotherapy and improving mobility, not realising that it could help to support other areas of their child's development and function. Some thought that early intervention could not start until a child was 4 or 5 years old believing that "before then the child is just slow" and needed to be given time to catch up, or that intervention was a 'waste of time' until their child started to show some progress.

*We should try to make them respond [talk] first at home so that it does not waste all of our time you know (Caregiver, Serua)*

Stakeholders felt that many do not understand the benefits of intervention and will keep their child at home, rather than seek out services.

One caregiver described that they thought early intervention was to prepare their child for school. This was supported by the views of several stakeholders who also described the key purpose of early intervention as being to reduce a child's disability so that they would be able to attend mainstream school.

When asked if they knew of organisations that could help their child, several caregivers said that they did not know of any and that they had not been offered any help. This was supported by the views of stakeholders who felt lack of knowledge about services was a key reason for delays in accessing services

*I've noticed sometimes parents don't know what services are there. Unless they know what it is, then they will ask for it. In Fiji, not everybody knows, if there's something wrong with your child, that you can go to the doctor, and then you go to the early childhood intervention center (Stakeholder, Disability)*

There was a suggestion by some stakeholders that many in the community believe that schools are the earliest support available and do not consider accessing services prior to school age.

*So only when it's the time to go to school, it's like I'm going to put my child into special school. Some people have a perception that because this is the first time that they access the service, then this is early intervention (Stakeholder, Disability)*

### System and Service level barriers

#### Centralised services

Both caregivers and stakeholders reported most services and specialists, and even special schools, are centralised in the larger urban centres with little available in rural and remote areas.

*I went for our school visit up in [a rural area] and there were five students that we came across two students who very extensive needs and they were just like, lying there at home. No therapy, no nothing, no intervention, nothing has been done for the child. (Stakeholder, Education)*

Distance to services and transportation is a major access factor for families, especially for those living outside the urban areas where transport was reported to be inconsistent or absent. Some participants reported living in remote locations that require boat access or are only accessible on foot. Even in areas nearer to Suva some reported needing to catch multiple buses and leave home very early to get to

appointments. Changing tides and weather all add complexity for both families trying to get to appointments, or outreach programs trying to reach families.

Catching public transport in itself was challenging for some families. One parent commented that she declined a referral for physiotherapy for her child because travelling on public transport was too difficult for them.

*I said no I can't because my baby most of the time she is shaking [having seizures] and when I take her in the bus everybody just watching her and I feel bad. (Caregiver, Serua)*

Some rural and remote families were reported to try to find relatives for their child to live with in Suva so that they can attend early intervention services. While some services are providing outreach services these do not currently cover all parts of Fiji.

*Because our outreach only goes to the west, to the north and Ovalau. But we're hoping that as we get more referrals, we're able to get more funding to reach out to more places. (Stakeholder, Disability)*

There were reports of a plan by the government to build intervention centres for people with disability in the divisions to increase access to services. However, it was also reported that this funding is only for infrastructure not for service delivery. It is anticipated that this would be provided by existing service providers like FHO, albeit with the recognition that services already face workforce pressures.

#### **Lack of service availability & capacity**

Both caregivers and stakeholders discussed a lack of service availability, with both describing that even once a child's needs were understood there is a lack of referral options, even in the urban areas. Both groups discussed that there were often extensive waiting times for existing services and supports.

*I told them many times [that my child needs help]. They just take the [phone] number but until now, they didn't do anything. (Caregiver, Suva)*

Some caregivers even reported contemplating whether they should go overseas to access the supports that their child needs due to the lack of availability in Fiji.

#### **Lack of funding**

Stakeholders identified that current funding is insufficient to adequately resource services for children with disability, with further funding needed for human resources, training, and specialised equipment (e.g. Braille machines, AT). While some existing funding comes from the Fiji Government, stakeholders indicated there is still a need to supplement this with funding from external donors and fundraising activities.

There was a sense among some stakeholders that disability, and children with disability in particular, are not seen as a priority for funding resources. A stakeholder reported that they feel any funding received is the 'leftover scraps' after funding has been allocated to other areas.

Some service providers described needing to be 'resourceful' to address funding gaps by making equipment or paying for consumables and other items for families out of their own pocket.

One stakeholder noted that the reach of their services fluctuates depending on the funding available in a given period – when they receive enough funding they can provide comprehensive services throughout Fiji, and at other times they need to scale back.

*Funding is a big challenge for us. We need to have enough funding to access all those areas, because outer islands if we want to visit, for example, we are wanting to go there to see children, so with funding like in the last three years from 2013, to 2016, the government of Australia, DFAT, they funded us. So in those three years, we we're able to do most of our screening in all the areas because the funds were there. That is what I am saying, we do have problem, we try to get funding and if we have we do it. (Stakeholder, Disability)*

### **Workforce and training**

In addition to lack of funding for human resources, as noted above, there is a lack of a trained workforce in Fiji to provide intervention and support services for children with disability, a barrier raised by both stakeholders and caregivers.

Stakeholders reported insufficient numbers of paediatricians and paediatric registrars specialising in developmental paediatrics, and a lack of allied health professionals including physiotherapists, occupational therapists, speech pathologists, psychologists and counsellors. Fiji has a small physiotherapy workforce and local training for physiotherapists, other allied health professions are provided by therapists from overseas, often on an ad hoc volunteer basis. These visiting therapists provide training and support for local staff, who in many cases do not have any formal training.

*We do not have enough physios. I don't know, if we have enough speech therapist. I don't think we have any occupational therapist. So all these other therapy support services are not available (Stakeholder, Education)*

Lack of workforce impacts on services capacity, and limits referral options for those who and identify children with disability. One stakeholder commented that this leads to a feeling or 'hopelessness' for both the health workers and the families that cannot access appropriate services once the need has been identified.

*Every time we diagnose a case, like for a kid who has language disability, we don't have a speech therapist, or we don't have all these occupational therapists, behavioural therapists, like, you know, like, to have the services to refer these kids to, you know. Like we diagnose, diagnosing them is not a problem, it's who to refer them to. That's a problem. (Stakeholder, Health)*

The limited training opportunities available in Fiji was discussed as contributing to poor worker satisfaction and staff turnover among the existing intervention and support workforce, and a barrier to building the workforce.

Examples of previous training programs were discussed, but these were funded by overseas donors and delivered by overseas experts. One of the examples reported was the training by Save the Children UK that became the Community Rehabilitation Assistant (CRA) program. However, the program appears unsustainable with only a few CRAs left, training discontinued and limited funding available from the relevant ministries. One CRA participant noted that while the work is very satisfying, it is hard work and they receive low pay and recognition. These reasons were quoted as a challenge to attract new recruits or retain the current staff, coupled with a sense that the program was a low priority for the government.

While some providers seek training overseas, a lack of government funding for positions for allied health and others working to support children with disability means that many do not return to Fiji or pursue unrelated work.. While there is an absence of locally based professionally trained therapists or other sustainable models of workforce development, the availability and quality of intervention will continue to depend on support from overseas. As one stakeholder noted,

*We can only provide speech pathology when visiting specialists are available - if your child is coming in with some speech delay, we won't be able to have them assessed, because we don't have a full time speech pathologists doing assessments at the moment. (Stakeholder, Disability)*

## **2.3 Facilitators of access to intervention and support services for children with disability**

Participants discussed facilitating factors that enable greater access to services. At the community level, this included an increasing awareness of disability, while more accessible service models, building relationships and a supportive policy environment were facilitating factors at the service and systems level.

### **Community level factors**

#### **Increasing disability awareness in the community**

Stakeholders reported an increasing awareness in the community of the needs and rights of people with disability, particularly since Fiji ratified the UN Convention on the Rights of People with Disability (UNCRPD). The Disability Act, policies on inclusive education and ongoing advocacy by OPDs appear to have highlighted the right of children with disability to attend school and in doing so raised community awareness of disability more generally. As a result, some stakeholders believed that caregivers are more receptive to discussions about their child with disability and greater understanding of their rights. There is also increasing awareness of the services available and the benefits of intervention, with one stakeholder noting –

*The awareness is there now, people now are coming out, like the parents they used to hesitate to come to us and say, 'My child is blind'. But with lots of awareness and counselling, they have now come to us for support (Stakeholder, Disability)*

According to stakeholders, much of this awareness is due to word of mouth over time, and the increased sharing of information via social media platforms, such as Facebook, by both caregivers and service providers. Some stakeholders reported conducting specific awareness raising activities in the community, including talks with caregivers and other service providers.

### **System and Service level factors**

#### **Accessible service models**

Models of service delivery that take services closer to the communities, or with set timeframes for intervention may facilitate access and uptake of services according to stakeholders.

Outreach-based services in particular appear to enable access to supports. This was evidenced by the high number of participants accessing social welfare payments, most of whom reported that social welfare officers had visited them at home.

Other examples of outreach-based programs reported by stakeholders, are FHO's mobile device service, the CRA program, and some physiotherapy services. One CRA commented that while often families initially choose to travel to Suva for intervention, many prefer a local or home-based service such as that by CRAs in the longer term. While they felt this preference was particularly due to transport costs, they noted that this model enabled caregivers to engage more easily in their child's intervention and see their child's potential.

*She thought, 'my son he can't do anything'. And then, you know, during my visit, I always go and then the boy started to turn, started to play, started to making sound, babbles and the mother, you know, she completely changed. (Stakeholder, Health)*

Some service provider stakeholders reported recently adapting their service delivery model to make it easier for families to access services. For example, the paediatric department at CWM Suva providing

outreach clinics to health facilities in the divisions so that families do not have to travel to Suva. FHO reported they deliver some services to incorporate structured programs that run for a set number of weeks which has made it easier for families to plan for and attend.

*Now that we have these structured programs that we know that are going to last six to eight weeks we're finding that a lot of parents are actually wanting to bring their kids into stay with family in Suva, so that they can access these services. (Stakeholder, Disability)*

However, while stakeholders spoke of these service models as facilitating access, apart from social welfare, none of these were raised by parent participants.

### **Building relationships**

Building and maintaining relationships at various levels was found to be a factor in facilitating greater availability and access to services for children with disability. Intervention service providers spoke about how building relationships with other service providers was helping to facilitate more awareness of their services and subsequently more appropriate and timely referrals. They noted that by taking time to meet with mainstream services (e.g. health and education) that these sectors were starting to talk more about disability and reaching out for advice about how to support children with disability.

One stakeholder talked about the importance of maintaining good relationships with government ministries and balancing this with the need for ongoing advocacy for further improvements.

*You want to maintain relationships because you want resourcing, you want services and we have to be like, political enough in terms of our own advocacy to say, 'No, you're doing great, but I think you can improve on this one' (Stakeholder, Disability)*

Similarly, a government level stakeholder also discussed the benefits of good relationships between ministries and service providers for advice and sharing of information about the needs of the community and service providers, as this can be used to inform policy and decision making.

Developing relationships between service providers and the community was also identified as a key facilitator. Several stakeholders discussed the importance of going into communities and engaging with village heads who could play a key role in facilitating the identification of children with disability and their engagement in support services. Some also spoke of the benefits of repeat visits to communities to build rapport and trust, with examples given of caregivers keeping their child hidden initially but on subsequent visits engage with a service provider and seek support for their child.

### **Increasing political will to support disability**

Many stakeholders reported a sense of a growing awareness by government about disability and the needs of people with disability. The passing of the Disability Act 2018 was cited as being evidence of this. One stakeholder expressed that Fiji had made significant steps forward to address the needs of people with disability –

*There's the disability allowance, there's funding to the OPDs, there's resourcing to ministries targeting persons with disabilities, some of the things are starting to change (Stakeholder, Disability)*

Others spoke of policies already in place or in progress that specifically relate to children, including children with disability, that are having a positive impact. The Special and Inclusive Education policy and implementation plan, which includes early childhood education, was identified by one stakeholder as being key to increasing the number of children with disability accessing early education. Additionally, it was noted

that policy is backed by government funding of some services for children with disability including special schools, Project Heaven, and partial funding for FHO.

In line with global developments, an increasing focus on early childhood development in Fiji was identified. Stakeholders noted that a review of the national child health policy was underway, with the belief that it would be more inclusive of children with disability and in turn may contribute to greater service provision.

*Just one and a half months ago, they were trying to relook at policies and strengthen policies, and regarding children with disabilities, and so forth....But you know, for every step we take, we are thankful for this. It was really not happening before. (Stakeholder, Health)*

### Summary of Stage 2:

<p><b>Key touchpoints</b></p>	<ul style="list-style-type: none"> <li>○ Health services</li> <li>○ Frank Hilton Organization</li> <li>○ Special schools</li> <li>○ Mainstream schools and early childhood education centres</li> <li>○ Department of Social welfare disability unit</li> <li>○ Informal supports – family members, online parent groups</li> </ul>
<p><b>What is working well</b></p> <p>(Entry points for strengthening)</p>	<ul style="list-style-type: none"> <li>○ Emerging networks and referral pathways between and within organisations providing support for children with disability</li> <li>○ Some caregivers are proactively seeking help and self-referring to services</li> <li>○ Caregivers accessing Informal networks of support and information and using family-led solutions to meet their child’s needs</li> <li>○ Community awareness of some supports, e.g. FHO and social welfare payments</li> <li>○ Outreach service models improve access for those in rural and remote areas</li> <li>○ Increasing community awareness of inclusive education and disability generally</li> <li>○ Disability and child development starting to be addressed at a policy level</li> </ul>
<p><b>What is not working well</b></p> <p>(Barriers to be addressed)</p>	<ul style="list-style-type: none"> <li>○ Caregivers are unable to attend appointments due to work and financial constraints</li> <li>○ Lack of parent awareness of disability, the benefits of intervention or available services</li> <li>○ Lack of consistent, effective referral pathways and care coordination between services and sectors, including to local services for rural families</li> <li>○ Limited availability of assessment, intervention and support services</li> <li>○ Lack of resourcing and capacity of existing services</li> <li>○ Most services located in urban centres</li> <li>○ Cost and access to transport prevents families accessing services</li> <li>○ Limited availability of a trained workforce to provide intervention and support</li> <li>○ Lack of supply and funding for child specific AT</li> <li>○ Caregivers reluctant to send children to school/limited support for inclusion</li> <li>○ Absence of a OPD/advocacy group focused on the needs of children with disability and their families</li> </ul>



### Stage 3: Outcomes – impact of intervention and unmet needs

At the time of interviews, caregivers identified they were receiving varying levels of ongoing support for their child and family from hospital-based physiotherapists, the Frank Hilton Organization, special schools, the disability allowance, Facebook parent groups, traditional medicine and massage, and informal support from family or other caregivers of children with disability. However, several reported that they were still waiting for or completely lacking needed supports.

Caregivers described the impact that access, or lack thereof, to intervention and supports has had on their child and family, and the unmet support needs at this point in their journey.

#### Benefits of access to intervention and supports

Positive impacts resulting from access to intervention and supports for children with disability and their families included increased caregiver knowledge and empowerment, access to AT, peer support and access to education.

Caregivers described that through attending intervention services they had learned about their child's condition and how they could support their child's development, inclusion and participation in family and community life. They learnt strategies or activities to use at home to promote their child's development, such as for walking or feeding themselves, and to manage their self-care in a way that is safe for child and caregiver. These services also helped caregivers develop an awareness of what their child can do and what they have the potential to do

*They're able to tell us some of the techniques that we need to do at home to help [my child]. Now he can sit on a chair together with the [other] students, and one of his biggest achievement now that that he is able to get down from the bed and go up again and get down. (Caregiver, Suva)*

Intervention was reported to empower caregivers and give them confidence to support and advocate for their child, take them out in the community, and involve them in some of the usual activities of childhood like going to school and playing with peers.

Caregivers also benefitted from information about the potential role of AT for their child and enabled some families to access AT, for example walkers, wheelchairs or hearing aids. Access to AT in turn has the potential to facilitate greater access to the community, education and social activities.

*And then we started coming to Frank Hilton then we got the wheelchair. It came one week before my cousin's birthday in Albert Park. ...I said this is a blessing with a wheelchair, we could take [child] to Albert Park. (Caregiver, Serua)*

A further benefit of intervention services, discussed by both caregivers and stakeholders, was the opportunity to meet other caregivers of children with disability. This peer support was highly valued by caregivers for sharing experiences, information and ideas, and for the emotional support it provides.

*We are parents, we three parents are like we are one. So any information like I have regarding my child or personally I share with them, if they have some ideas they share with me. Because we sit under one roof so the parents from [the program] they are very nice so we get more ideas. (Caregiver, Serua)*



## Unmet needs and impact of lack of access to intervention and supports

Unmet needs and negative impacts relating to developmental skills and functioning, access to the community, access to education, ongoing stigma and exclusion, and caregiver support were all discussed as negative outcomes of a lack of timely access to intervention and supports for children with disability.

### Impact on function

Several caregivers spoke about an unmet need for timely intervention to support the development of their child's skills and independence, including for communication, mobility, self-care (e.g. toileting), social skills and behaviour. One caregiver reported feeling that delayed access to intervention had impacted her child's opportunity to develop motor skills and mobility.

*Maybe if he was small [when] he accessed to these things [intervention] maybe he can work, he will be more mature, improvement in his hands and legs and body will be, but now it is late.  
(Caregiver, Serua)*

Others expressed a need for communication related intervention and strategies. Caregivers reported feeling frustrated that they did not know how to communicate with their child and were unable to understand their child's wants and needs, including when their child is sick or in pain.

*Sometimes she wants something and I don't really know what is it. She'll be pointing and doing all this and indicating this and I'll just say, "what is it you want? You tell Mama. Tell Mama, come on, you can do it." And she'll just start pointing. That's the biggest challenge, the communication.  
(Caregiver, Suva)*

Caregivers expressed concerns about how to manage as their child gets older and how to keep them safe without advice, support and strategies for communication and managing behaviours.

*She loves to climb and then I had to keep her somewhere that is sealed and safe with her knowing that she won't climb over. She will be growing you know she can't be small all the time. (Caregiver, Suva)*

Alongside concerns about lack of skill progression from lack of intervention, were concerns about the risk of increasing functional impairment. One stakeholder discussed the potential risks to children who are Deaf or hard of hearing if they do not have access to hearing aids, sign language education and other tools for communication, and the lifelong impacts this has on opportunities for learning, inclusion and participation.

### Lack of access to AT

The impact of a lack of access to appropriate AT that meets the changing needs of children was raised by several caregivers and stakeholders. Unmet needs for AT were considered to impact a child's mobility and the management of their self-care, with caregivers describing having to lift, carry and physically support their child around the home and when out in the community.

*I just tell them many times that I need one wheelchair.....I just want him to get something like, to make him go here and there. Like even when he wants to go to town or something like that. I have to carry him and because I have 3 children, so I have to look after [all of] them (Caregiver, Suva)*

A lack of expertise to prescribe appropriate AT, as well as a lack of availability of appropriate seating and postural support were described, with reports of ad hoc AT such as old car seats and outgrown prams being used. A lack of access to continence products needed for older children unable to fit into baby's diapers was also reported. These unmet needs have implications not only for a child's physical development, hygiene and dignity, but for their ability to access and participate in activities outside the home, such as attending education, playing with peers, or even attending appointments for intervention or health care.

*Those are some of the things when we go out [in the community] we see them [children with disabilities] lying there. You know growing big every day, I guess it's hard for the grandparents or whoever is looking after them, the supporters to take them around. So wheelchairs, the diapers also. Those are some of the things they need. Because most of them, they are kept home, they not access to the outside environment. (Stakeholder, Social Welfare)*

### **Impact on access to education**

The lack of access to intervention to develop skills and functional abilities, provide AT, and support caregivers has a flow-on impact on access to education, including early education, for children with disability. Caregivers reported a reluctance to send their children to school due to their poor communication skills, not being toilet trained, or mobility issues, alongside a lack of awareness of their right to attend school and the requirement of education settings to be inclusive.

*We were thinking about where he will go to school so he can learn. We observed him, he only knows few words which we could not make it out. He is really slow.....he couldn't go to school because he is not able to take himself to the toilet and he is too weak if somebody pushes him. (Caregiver, Kadavu)*

There were reports from stakeholders that they believed children with disability who are at school but have not had any intervention are more likely to drop out of school, or be limited in their education options and less likely to have the opportunity to attend mainstream school.

*If you get services at a young age, they go to mainstream school when they turn six, or they turn seven, they go to mainstream school. But because the intervention services does not exist we think that, okay, they're super slow learner, so just go to special school, and that's it. (Stakeholder, Disability)*

### **Impact on family - lack of support for carers**

Participants spoke about the impact a lack of access to intervention and support has on caregivers and families as a whole. This included unmet needs around access to support for caring for their child, emotional and psychological support, and financial support.

One parent expressed that they felt completely unsupported, as if nobody was helping them. Another reported feeling isolated because there was no one else who could care for her child because of his impairments –

*No one can look after him especially because he doesn't talks clear so no one can understand what he is saying (Caregiver, Suva)*

In some cases, it was reported that siblings would miss school to care for their sibling with a disability so that their caregivers could continue to work, due a lack of other care options or resourcing for disability-inclusion in early education centres.

Recognising the pressure on caregivers and lack of support, one stakeholder said –

*The onus is just on the parents who is going to look after the child, whatever the parents might do with them, or whatever little knowledge they have (Stakeholder, Education)*

The need for greater access to psychological support for caregivers was raised by another stakeholder and seen as vital to caregivers being able to care for their child and provide for all their needs.

Although most families in the study were receiving the disability allowance, several caregivers reported struggling financially to meet even the basic needs of their family and needing to prioritise these over the costs associated with their child’s disability-specific needs. Insufficient financial support for families of children with disability resulted in caregivers having to choose between earning an income or taking their child to intervention services. This was supported by stakeholders who also expressed that current government financial assistance is inadequate to meet the needs of families with a child with disability.

**Stigma, exclusion and lack of stimulation**

The exclusion of children with disability from many of the usual opportunities and experiences of children was highlighted as an impact.

Caregivers discussed that because of a lack of intervention and support, that their child misses out on opportunities for peer interactions, play and recreational activities. One caregiver talked about wanting her child to be able to communicate so that she could play with a group of children. Another spoke about the experiences she hoped her child would have -

*I prayed and wished for this child to run one day, to go outdoors, to go to places he has never been to and to swim in the sea. (Caregiver, Serua)*

However, caregivers and stakeholders also spoke about children being kept at home due to both a fear of stigma and discrimination, and a lack of empowerment and support for families – factors that negatively reinforce one another.

Caregivers reported that they would avoid taking their child to family functions and community events due to negative comments and attitudes. This experience was echoed by one stakeholder who had observed such stigma faced by a child whose family had not had any access to supports –

*This child is always locked in the house, so this child wails inside and remains inside....but when he wanders off, people call names at him, you know. They despise him. (Stakeholder, Social Welfare)*

Stakeholders also spoke of the lack of opportunity and stimulation for some children with disability without access to support who are ‘lying idle in their homes, no stimulation, not attending schools’, with one commenting on the potential long-term impact of this on a child’s opportunities and outcomes -

*These are the [children] who are highly likely to be stigmatized, marginalized in the community, and they will be left unattended through most of their entire life. (Stakeholder, Education)*

**Summary of Stage 3:**

<b>Key touchpoints</b>	<ul style="list-style-type: none"> <li>○ Social welfare disability allowance</li> <li>○ Special schools</li> <li>○ Frank Hilton Organization</li> <li>○ Hospital based physiotherapists</li> <li>○ Informal supports – family, other caregivers of children with disability</li> </ul>
<b>What is working well</b>  (Entry points for strengthening)	<ul style="list-style-type: none"> <li>○ Families that access intervention are empowered to support and advocate for their child</li> <li>○ Access to intervention provides strategies, advice and access to AT that promote skill development, function and independence</li> <li>○ Caregivers highly value peer support from other caregivers of children with disability</li> <li>○ Access to early intervention leads to better opportunities for education and community participation</li> </ul>

<b>What is not working well</b> (Barriers to be addressed)	<ul style="list-style-type: none"><li>○ Many children and families still waiting for supports</li><li>○ Children and families are lacking intervention to address motor skills, communication, behaviour, sensory impairments, and self-care</li><li>○ Children are using inappropriate AT or do not have access to AT that they need</li><li>○ Lack of intervention impacts on opportunities for participation in education, family and community activities, and with peers</li><li>○ Schools and ECE centres are not adequately resourced for inclusion of children with disability</li><li>○ Caregivers feel unsupported and isolated</li><li>○ Lack of carer supports can lead to caregivers losing income or siblings missing school</li><li>○ Families of children with disability experience financial pressures to meet basic needs and disability-specific needs</li></ul>
---	--

## Overarching theme: Cross-sector collaboration

In line with the multi sector approach articulated in the Nurturing Care Framework, addressing the needs of young children with disability requires the input of multiple sectors. Ensuring timely access to appropriate support and intervention requires sectors to work together to provide co-ordinated, collaborative care across all stages of a child and family's journey.

Stakeholders were asked their views on collaboration between sectors in Fiji involved in the support of children with disability and their families, with both positive experiences and opportunities for further strengthening identified.

### Examples of sectors working well together

Evidence of cross-sector collaboration was reported. However, much of it is informal and through the initiatives of motivated individuals. Some examples of collaboration are between health services and DSW to facilitate families to access the disability allowance, and between DSW and FHO to refer children identified in the community. FSB also reported collaborating with both the health and education sectors to undertake vision screenings in school and ECE settings.

On Kadavu health sector stakeholders reported that there is collaboration occurring between health and social welfare, but raised concerns about the lack of support options locally beyond referring to disability allowance and counselling services.

Other emerging collaborations were discussed which included the formation of district level disability committees by the NCPD, DSW liaising with NGOs for AT and FHO supporting schools who have children attending FHO programs.

However, stakeholders raised concerns over not having formal processes for referrals and collaborations as they may result in inconsistencies and children being '*lost in the system*'.

### Opportunities for strengthening

Although appetite appears to exist for greater collaboration and coordination between sectors, sharing of data and information, communication and referral mechanisms, and agreements on the division of responsibilities in the care of children with disability were all identified as areas needing improvement and critical to progressing effective early intervention.

### Agreements on shared responsibility

Several stakeholders identified a lack of clarity or agreement at a government level of who is responsible for what with regards to early intervention, and children with disability more generally. Early intervention was described by some as appearing to 'fall through the cracks' with 'a lot of checking boxes but no one actually taking responsibility'.

While several identified that the MOE is seen as the key ministry for children, if children with disability are not attending ECE or school, their reach is limited, despite a mandate to support out of school children into schools. Nevertheless, it was noted that MOE does not have sole responsibility for children with disability, and that there are aspects of policy and programming more appropriately addressed through other sectors, but that this sharing of responsibility was not happening.

*If it's like funding for children, then Ministry of Education, go okay that's our funding because it's children. But they don't talk to health to say, okay, you do the health aspect and we do the education aspects,..... so if it's better coordination, then the resources can be better put to use.  
(Stakeholder, Disability)*

On the other hand, according to participants disability is mostly associated with the MWCPA, however children and disability are the responsibility of different departments within this Ministry and according to one participant, do not work together.

The responsibility for community health workers, an integral touch point for families in the community for early identification and initial help seeking, was a factor further complicating collaboration raised by one stakeholder. Community health workers were reported as being employed under the Ministry of Fijian Affairs not MOH, therefore consideration needs to be given to how they are included in any attempts for systemic change that seeks to improve coordination.

Finally, it was also raised that while bilateral development programs, such as Australia's bilateral Fiji Program Support Facility are working to support the development of various sectors including health and education, that a lack of collaboration between sectoral programs within the Facility mirrors what is happening between Ministries in Fiji and reinforces these gaps.

*So our system, early intervention is falling through all these pockets. So if we have already established roles, it only makes sense that when like, DFAT provides funding, that they will only have like a health department and one that supports education. But then that's just, that's just creating, that's widening the gap. (Stakeholder, Disability)*

#### **Communication and coordination between sectors**

Co-ordination between various government ministries and their respective sectors was identified as a challenge.

While the education and social welfare ministries both have units focused on disability, it was discussed that this is lacking within the Ministry of Health and Medical Services (MHMS). It was felt that if all relevant ministries had disability units these could be responsible for coordination across ministries on matters relating to children with disability.

The current lack of communication and coordination between the health and education sectors to support children with disability, in particular, was highlighted as a difficulty by several stakeholders.

While it was acknowledged that health and education need to complement each other to support children with disability that this is not routinely occurring. It appears that effective mechanisms for referral in both directions between health and education are not in place, with both sides stating that they relied on caregivers to self-refer and provide the information about their child and the reason for referral without any documentation from the 'referring' sector.

#### **Shared data systems**

The need for systems that facilitate better sharing of data between ministries to enable care and management of children with disability from birth through to school age was raised by several stakeholders from all sectors. It was reported that currently the various ministries with responsibilities for children, and specifically children with disability, do not have any arrangements in place for sharing data and information that could enable better coordination of care and supports.

*That is one of the gaps at the moment, because everyone is working in silo. We (education) have our own data system, Ministry of Health has their own data system, ministry of social welfare has their own data system. But when we try to assist, all assists on the same thing, looking at children with disabilities, or people with disabilities. (Stakeholder, Education)*

The exception to this appeared to be between DSW and FHO who have initiated some data sharing arrangements.

*So the sharing of databases we reached a compromise, where we said, okay, because this is a need, then we agree, I will show you the database, you can use the information in the database, if it's for the betterment of the children, and that's fine with me. That's the relationship we have at the moment. (Stakeholder, Social Welfare)*

Outside the education sector there was a lack of awareness of MOE's FEMIS which includes information about students with disability. It was felt that if this information could be shared outside the education system, for example with health services, then it would enable better communication across sectors and better service provision.

*The referral is word by mouth to parents. They told the parent, your child is slow, you need to go to hospital. So when a parent comes into outpatient department they tell us, our teacher said that my child is slow in class, and we need to come here for assessment. I feel that gap can be lessened if the FEMIS report is done prior to coming to us and we get a FEMIS report as well. You know, there is no relationship with the Ministry of Education, like the schools and us. (Stakeholder, Health)*

#### Summary of cross-sector collaboration:

<p><b>What is working well</b>  (Entry points for strengthening)</p>	<ul style="list-style-type: none"> <li>○ Emerging collaborations occurring between organisations</li> <li>○ Disability units already in place within some key ministries</li> <li>○ Individuals who are championing early identification and coordination of care</li> <li>○ MOE's FEMIS disability module provides an example of an information system for disability that could be utilised in designing systems for referral and data sharing</li> </ul>
<p><b>What is not working well</b>  (Barriers to be addressed)</p>	<ul style="list-style-type: none"> <li>○ Lack of agreements and guidelines on what each sector/Ministry is responsible for when it comes to children with disability and how they can work together</li> <li>○ Ministries working in silos without sharing information that could enable coordinated care</li> <li>○ Lack of formal referral mechanisms between sectors and organisations</li> </ul>

## Summary & Recommendations

This qualitative study explored the journey of 12 families of children with developmental disability in Fiji to accessing intervention and support. Three key stages of the journey emerged, 1) identification of needs; 2) experiences of accessing intervention and support services; and 3) outcomes of intervention and unmet needs. Stakeholders from government and service provider levels of the health, disability, education, and social welfare sectors provided their perceptions of current practices and factors influencing early identification of disability and access to intervention.

Themes that emerged from both caregiver and stakeholder interviews were mapped to the three journey stages and explored in terms of barriers and facilitators. A further overarching theme of 'cross sector collaboration' emerged which identified systemic factors impacting across all stages of the journey.

Key findings from the three stages and overarching theme are summarised below. Recommendations are provided for each based on the study findings and include suggestions made by study participants. The recommendations outline potential actions to remove barriers and create an enabling environment, as described in the Nurturing Care Framework (figure 2), for the identification, care and support of children with disability. Recommendations are presented for the consideration of actors across sectors, some may be more relevant for one sector or Ministry, others will require collaboration across sectors. It may be useful for the proposed recommendations to be discussed at a multi-sectoral forum to determine feasibility, priority and responsibility for implementation.



Figure 2: Enabling environments for nurturing care (1)

### Stage 1: Identification of needs

Children with developmental delays and disability are not being identified as early as they could be. There are significant interactions between families and the health sector in the first years of a child's life for both medical follow up care and routine care, including MCH 'baby clinics'. These provide opportunity for developmental monitoring, early identification of disability, and referral; however, this opportunity is frequently missed.

Health care interactions currently focus on the health and medical needs but do not routinely consider developmental needs or provide information to caregivers about possible developmental concerns or available services, even when there is a known developmental disability or significant risk factors for disability.



Caregivers frequently notice differences in their child's development, such as developmental delays or functional impairments, early in their child's life and either do not seek help, or seek help and have their concerns dismissed, leading to delays in further assessment and intervention.

Many of these missed opportunities for identification and referral appear to be due to a lack of knowledge and awareness of developmental disability and the importance of early intervention among health care workers, caregivers, and the community more broadly.

While children with disability may be identified by DSW outreach visits, or once attending ECE or school, and these existing systems are potential entry points to build linkages and referrals, they are unlikely to identify children in their first few years of life or where disability or developmental concerns are less obvious.

However, there are positive developments with CWM Paediatric Department leading activities to build capacity of health workers in screening for developmental delays and disability in health facilities.

### Recommendations

- > Increase knowledge of health workers, particularly at primary care level, of developmental delay and disability and options for referral
- > Improve communication of information and support given by health workers to new parents about their child's condition, potential developmental implications, and sources of support available
- > Health workers processes to include offering referral of children with known developmental conditions/risk factors to early intervention and support services
- > Mechanisms for financial support for families of children born with complications to attend follow up health and medical appointments to enable continuity of care
- > Strengthen processes for developmental monitoring at routine baby clinics
- > Training on early identification of disability and referral for those who could be the first point of contact for families, including health workers at primary care level (e.g. village nurses/community health workers), teachers and early childhood educators, and welfare officers
- > Community awareness raising activities of developmental disability, the benefits of timely early intervention, and the services available

### Stage 2: Accessing intervention and supports

Once needs are identified, there is a lack of services to provide ECI and other supports for young children with disability and their families, especially outside urban areas. Where services do exist, families do not know about them or there are extensive waiting lists. Distance and cost of transport to available services is a significant barrier for families, especially those in rural and remote areas, hence outreach service models are one means of improving access.

Special schools are seen by many as the main support available for children with disability, albeit not in the crucial early years, an despite efforts to promote inclusive mainstream education. However, many parents believe that their child cannot attend school due to their impairments, or do not send them due to a lack of resourcing to support inclusion or lack of special education options in their area.

Among stakeholders, there is a perceived lack of priority by government to resource ECI and other supports for children with disability, with services relying on donor funding and fundraising to supplement government funding.

Lack of an adequately trained workforce to provide needed interventions, and a lack of funded positions and career development opportunities for those seeking to work in ECI or disability related services also contribute to the limited growth and capacity of services to respond to the needs of children with disability.

Despite the barriers, caregivers are seen proactively seeking support for their child, utilising informal supports, and developing their own strategies to address support needs. Awareness of disability generally in the

community is reportedly increasing, supported by recent policy and legislation, and fostered through building relationships at community level.

### Recommendations

- > Mechanisms for financial support for caregivers to take time off work to attend appointments for intervention
- > Transport allowances or subsidies for travel to and from services for families of children with disability
- > Services to provide onward referral to local services for follow up for rural and remote families where possible (e.g. hospital based physiotherapy services)
- > Funding is needed for new and existing services to increase capacity and coverage of intervention services, particularly outside the main urban areas.
- > Increased consideration of outreach models of service delivery. Learnings from the CRA program may be useful.
- > Strengthen existing national policies and action plans relating to ECD and disability to explicitly include *children with disability*, backed with appropriate resourcing
- > Develop locally contextualised, sustainable mechanisms to build the capacity of the early intervention/disability support workforce including through training, mentoring, and opportunities for career progression

### Stage 3: Outcomes – impact of intervention and unmet needs

Many children and families have significant unmet support needs. This impacts on child and family wellbeing with potential lifelong consequences. Parents report feeling unsupported and isolated. Without appropriate support and intervention children with disability miss out on opportunities to optimise independence and function, and are excluded from many of the usual experiences of childhood such as playing with peers, attending school and engaging in community activities.

A lack of access to paediatric AT results in the use of inappropriate substitutes or none at all. This has wide-ranging implications for dignity, safety, hygiene, physical wellbeing, and communication for children and caregivers, as well as for inclusion and participation in daily life.

Families of children with disability face ongoing financial pressures. Many are having to choose between meeting everyday household needs and the costs associated with disability-specific supports. Being unable to afford transport to attend appointments leads to children becoming 'lost in the system', with some effectively 'hidden' without any support or intervention. While most families in the study were accessing the disability allowance, they report the current allowance is insufficient to provide for their child's needs. Many caregivers also need to choose between working to support their family or caring for their child and attending appointments for intervention. In some cases, siblings are missing school to care for children with disability. Caregiving pressures are compounded by a lack of properly resourced disability-inclusive ECE and schools.

Conversely, children who received intervention report improved function, independence and participation in family and community life. Caregivers who access services feel empowered to care for, support and advocate for their child, and highly value the peer support from meeting other parents of children with disability while attending services.

### Recommendations

- > Develop and resource models of care to provide interim advice and support for families on service waiting lists
- > Establish a OPD/advocacy group specifically for children with disability and their families to represent and give voice to the lived experience of families of children with disability
- > Consider a review of the disability allowance to reduce financial pressure on families of children with disability

- > Promote community awareness of the right to education and early education for children with disability
- > Support caregivers by Increase resourcing for disability-inclusive ECE/childcare
- > Additional resourcing to support inclusion and participation of children with disability in mainstream schools
- > Establish mechanisms for the funding, procurement, and supply of paediatric assistive technology, including options for local fabrication of simple devices and equipment for mobility, seating, communication and self-care
- > Establish an AT pool for paediatric equipment that children have outgrown to be re-issued to other children
- > Funding for continence products, especially for older children, to attend ECE and school

### Cross-sector collaboration

While there are some examples of collaboration between sectors, a lack of communication and co-ordination between sectors is impacting the timely identification, referral, and holistic support of children with disability and their families. There is opportunity to strengthen this through better understanding of shared responsibilities, improved mechanisms for communication, and formalised systems for referral and sharing of information.

Each sector currently has its own tools and mechanisms for identifying disability, largely to determine eligibility for their supports, but lack formal mechanisms for sharing information between sectors that could facilitate co-ordinated care. However, there are emerging networks and referral pathways between and within organisations, often driven by motivated individuals, which could be built upon and formalised.

Fiji has a growing focus and commitment to both ECD and disability, including in policy and legislation. These legislative frameworks can be further strengthened to ensure they are inclusive of young children with disability and support action for systemic change.

### Recommendations

- > All key ministries to have a disability focal point who collaborate with each other to coordinate access to services and supports for children with disability
- > Establish formal agreements and guidelines between health, education, social welfare and disability service providers as to responsibilities with regards to children with disability, including identification of disability
- > Establish effective referral mechanisms between service providers across sectors
- > Look at options for sharing information and data between sectors that could enable co-ordinated care while ensuring privacy and confidentiality
- > Consider developing a common identification tool and referral form so that consistent language is used between sectors
- > Identification and referral mechanisms need to be supported by training for relevant workers in each of the sectors
- > Develop a directory of services available for children with disability to be provided to health and ECE workers and the community

## Limitations

The data collection for this study occurred in 2021. It is acknowledged that work on progressing services for children with disability has occurred since this time. Similarly, events such as the outcome of the election in December 2022 and any associated changes to the responsibilities of line ministries may mean some findings are no longer accurate.

It is recognized that this study included a small sample of caregivers from only 3 areas of Fiji, hence the findings provide just a small insight into the needs and experiences of families of children with disability and are not representative of the experiences of all families of children with disability in Fiji. Findings may also not be generalizable to other contexts where systems and cultural influences on supports and outcomes for children with disability may differ.

## References

1. World Health Organization, UNICEF, World Bank Group. *Nurturing Care for early childhood development: a framework for helping children survive and thrive to transform health and human potential.* . Geneva: World Health Organization; 2018.
2. Guralnick M. Effectiveness of early intervention for vulnerable children: a developmental perspective. *American journal on mental retardation.* 1998;102(4):319-45.
3. Scherzer AL, Chhagan M, Kauchali S, Susser E. Global perspective on early diagnosis and intervention for children with developmental delays and disabilities. *Dev Med Child Neurol.* 2012;54(12):1079-84.
4. World Health Organization, UNICEF. *Early Childhood Development and Disability: A discussion paper.* Geneva: WHO; 2012.
5. Global Research on Developmental Disabilities Collaborators. Accelerating progress on early childhood development for children under 5 years with disabilities by 2030. *Lancet Global Health.* 2022;10.
6. Global Research on Developmental Disabilities Collaborators. *Developmental disabilities among children younger than 5 years in 195 countries and territories, 1990-2016: a systematic analysis for the Global Burden of Disease Study 2016.* *Lancet Global Health.* 2018;6(10).
7. UNICEF. *Seen, Counted, Included: Using data to shed light on the wellbeing of children with disabilities.* New York: UNICEF; 2021.
8. Scherer N, Verhey I, Kuper H. Depression and anxiety in parents of children with intellectual and developmental disabilities: A systematic review and meta-analysis. *PLoS ONE.* 2019;14(7).
9. Hoyle JN, Laditka JN, Laditka SB. Mental health risks of parents of children with developmental disabilities: A nationally representative study in the United States. *Disability and Health Journal.* 2021;14(2).
10. Jones L, Bellis MA, Wood S, Hughes K, McCoy E, Eckley L, et al. Prevalence and risk of violence against children with disabilities: A systematic review and meta-analysis of observational studies. *The Lancet.* 2012;380(9845):899-907.
11. Emerson E, Llewellyn G. The exposure of children with and without disabilities to violent parental discipline: Cross-sectional surveys in 17 middle- and low-income countries. *Child Abuse and Neglect.* 2021;111.
12. Bizzego A, Lim M, Schiavon G, Esposito G. Children with developmental disabilities in low-and middle-income countries: More neglected and physically punished. *International Journal of Environmental Research and Public Health.* 2020;17(19):1-16.
13. Masulani-Mwale C, Mathanga D, Silungwe D, Kauye F, Gladstone M. Parenting children with intellectual disabilities in Malawi: the impact that reaches beyond coping? *Child: Care, Health and Development.* 2016;42(6):871-80.
14. Miodrag N, Burke M, Tanner-Smith E, Hodapp RM. Adverse health in parents of children with disabilities and chronic health conditions: A meta-analysis using the Parenting Stress Index's Health Sub-domain. *Journal of Intellectual Disability Research.* 2015;59(3):257-71.
15. Nakamanya S, Siu GE, Lassman R, Seeley J, Tann CJ. Maternal experiences of caring for an infant with neurological impairment after neonatal encephalopathy in Uganda: A qualitative study. *Disability and Rehabilitation.* 2015;37(16):1470-6.
16. Ramanandi VH, Parmar TR, Panchal JK, Prabhakar MM. Impact of parenting a child with cerebral palsy on the quality of life of parents: A systematic review of literature. *Disability, CBR and Inclusive Development.* 2019;30(1):57-93.
17. Vadivelan K, Sekar P, Sruthi SS, Gopichandran V. Burden of caregivers of children with cerebral palsy: An intersectional analysis of gender, poverty, stigma, and public policy. *BMC Public Health.* 2020;20(1).
18. UNICEF. *2019 Pacific Early Childhood Development Forum: Implementing Pasifika Call to Action on ECD.* Nadi, Fiji: UNICEF; 2020.

19. Vargas-Barón E, Small J, Wertlieb D, Hix-Small H, Gómez Botero R, Diehl K, et al. Global survey of inclusive Early Childhood Development and Early Childhood Intervention programs. Washington DC: RISE Institute; 2019.
20. Milner KM, Bernal Salazar R, Bhopal S, Brentani A, Britto PR, Dua T, et al. Contextual design choices and partnerships for scaling early child development programmes. *Archives of Disease in Childhood*. 2019;104:S22-S33.
21. Cieza A, Kamenov K, Sanchez MG, Chatterji S, Balasegaram M, Lincetto O, et al. Burden of disability in children and adolescents must be integrated into the global health agenda. *The BMJ*. 2021;372.
22. Yousafzai AK, Lynch P, Gladstone M. Moving beyond prevalence studies: Screening and interventions for children with disabilities in low-income and middle-income countries. *Archives of Disease in Childhood*. 2014;99(9):840-8.
23. World Health Organisation. Monitoring children's development in the primary care services: moving from a focus on child deficits to family-centred participatory support. Report of a virtual technical meeting, 9-10 June 2020. Geneva: World Health Organisation; 2020.
24. Sapiets SJ, Totsika V, Hastings RP. Factors influencing access to early intervention for families of children with developmental disabilities: A narrative review. *Journal of Applied Research in Intellectual Disabilities*. 2021;34(3):695-711.
25. Hadders-Algra M. Early diagnosis and early intervention in cerebral palsy. *Frontiers in Neurology*. 2014;5(SEP).
26. Zuurmond M, O'Banion D, Gladstone M, Carsamar S, Kerac M, Baltussen M, et al. Evaluating the impact of a community-based parent training programme for children with cerebral palsy in Ghana. *PLoS ONE*. 2018;13(9).
27. UNICEF East Asia and the Pacific Regional Office. Promising practices on disability inclusion in East Asia and the Pacific. Bangkok, Thailand: UNICEF 2020.
28. Salomone E, Pacione L, Shire S, Brown FL, Reichow B, Servili C. Development of the WHO Caregiver Skills Training Program for Developmental Disorders or Delays. *Frontiers in Psychiatry*. 2019;10.
29. Masulani-Mwale C, Kauye F, Gladstone M, Mathanga D. Development of a psycho-social intervention for reducing psychological distress among parents of children with intellectual disabilities in Malawi. *PLoS ONE*. 2019;14(2).
30. Fiji Bureau of Statistics. 2017 Population and Housing Census. Suva, Fiji; 2018.
31. Fiji Bureau of Statistics. Fiji Multiple Indicator Cluster Survey 2021, Fact Sheet. Suva, Fiji: Fiji Bureau of Statistics; 2021.
32. Organization FH. Frank Hilton Organization 2023 [Available from: <https://www.frankhilton.org.fj/>].
33. Sharma U, Michael S. Parental perspective about inclusive education in the Pacific. *International Perspectives on Inclusive Education* 2017. p. 71-86.
34. Sprunt B, McPake B, Marella M. The UNICEF/Washington group child functioning module—accuracy, inter-rater reliability and cut-off level for disability disaggregation of Fiji's education management information system. *International Journal of Environmental Research and Public Health*. 2019;16(5).
35. Sprunt B, Hoq M, Sharma U, Marella M. Validating the UNICEF/Washington Group Child Functioning Module for Fijian schools to identify seeing, hearing and walking difficulties. *Disability and Rehabilitation*. 2019;41(2):201-11.
36. Sprunt B, Marella M. Measurement accuracy: Enabling human rights for Fijian students with speech difficulties. *International Journal of Speech-Language Pathology*. 2018;20(1):89-97.
37. Tones M, Pillay H, Carrington S, Chandra S, Duke J, Joseph RM. Supporting Disability Education through a Combination of Special Schools and Disability-Inclusive Schools in the Pacific Islands. *International Journal of Disability, Development and Education*. 2017;64(5):497-513.
38. Sharma U, Forlin C, Marella M, Jitoko F. Using indicators as a catalyst for inclusive education in the Pacific Islands. *International Journal of Inclusive Education*. 2017;21(7):730-46.
39. Woolfenden S, Milner K, Tora K, Naulumatua K, Mataika R, Smith F, et al. Strengthening health systems to support children with neurodevelopmental disabilities in Fiji—A commentary. *International Journal of Environmental Research and Public Health*. 2020;17(3).
40. Koyamaibole L, Teague K, Naulumatua K, Morgan A, Tuibeqa I, Woolfenden S, et al. Toso Vata (moving together): adaptation and feasibility of a caregiver support early intervention for children with cerebral palsy in Fiji. *The 3rd International Developmental Pediatrics Association Congress; 9-12 Dec 2019; Manila, Philippines* 2019.
41. Kohli-Lynch M, Tann CJ, Ellis ME. Early intervention for children at high risk of developmental disability in low- and middle-income countries: A narrative review. *International Journal of Environmental Research and Public Health*. 2019;16(22).
42. Smythe T, Zuurmond M, Tann CJ, Gladstone M, Kuper H. Early intervention for children with developmental disabilities in low and middle-income countries - the case for action. *International health*. 2021;13(3):222-31.
43. Tekola B, Girma F, Kinfu M, Abdurahman R, Tesfaye M, Yenus Z, et al. Adapting and pre-testing the World Health Organization's Caregiver Skills Training programme for autism and other developmental disorders in a very low-resource setting: Findings from Ethiopia. *Autism*. 2020;24(1):51-63.

44. Tann CJ, Kohli-Lynch M, Nalugya R, Sadoo S, Martin K, Lassman R, et al. Surviving and Thriving: Early Intervention for Neonatal Survivors with Developmental Disability in Uganda. *Infants and Young Children*. 2021;34(1):17-32.
45. Hopf SC. Services for people with communication disability in Fiji: clinical insights. *Journal of Clinical Practice in Speech-Language Pathology* 2014;16(2):81-6.
46. Hopf SC, McLeod S. Services for people with communication disability in Fiji: Barriers and drivers of change. *Rural and Remote Health*. 2015;15(3).
47. Hopf SC, McLeod S, McDonagh SH, Rakanace EN. Communication disability in Fiji: Community cultural beliefs and attitudes. *Disability, CBR and Inclusive Development*. 2017;28(1):112-41.
48. Hopf SC, McLeod S, McDonagh SH, Wang CEN, Rakanace EN. Communication disability in Fiji: Community self-help and help-seeking support. *International Journal of Speech-Language Pathology*. 2017;20(5):554-68.
49. Jenkin E, Wilson E, Clarke M, Campain R, Murfitt K. Listening to the voices of children: understanding the human rights priorities of children with disability in Vanuatu and Papua New Guinea. *Disability and Society*. 2017;32(3):358-80.
50. Almasri N, Smythe T, Hadders-Algra M, Olusanya BO. Prioritising rehabilitation in early childhood for inclusive education: a call to action. *Disability and Rehabilitation*. 2022.
51. United Nations. Convention on the Rights of Persons with Disabilities [Available from: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>].
52. United Nations. Convention on the Rights of the Child 1989 [Available from: <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child>].
53. World Health Organization. Western Pacific Regional Framework on Rehabilitation. Manila: World Health Organization Regional Office for the Western Pacific; 2019.
54. United Nations. Sustainable Development Goals - Goal 4 Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all [Available from: <https://sdgs.un.org/goals/goal4>].
55. Australian Government Department of Foreign Affairs and Trade. Development for All 2015-2020 - Strategy for strengthening disability-inclusive development in Australia's aid program. Canberra: Department of Foreign Affairs and Trade; 2015.
56. Underwood K, Smith A, Martin J. Institutional mapping as a tool for resource consultation. *Journal of Early Childhood Research*. 2019;12(2):129-39.



Contact:

Fleur Smith

[smith.f@unimelb.edu.au](mailto:smith.f@unimelb.edu.au)