

# POLICY BRIEF

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

### Background

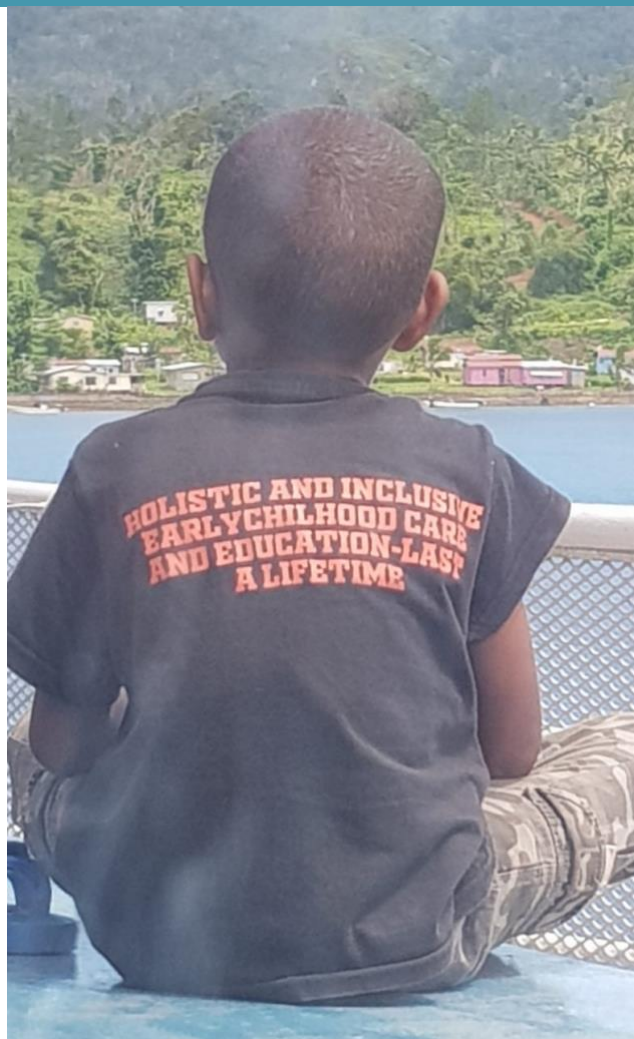
The earlier children with, or at risk of, developmental disability are identified and receive timely, coordinated support and intervention, the better their outcomes and those of their family (1, 2). However, systems for early identification, support, and intervention for children with disability in many low- and middle-income countries (LMICs), like Fiji, remain weak, and there is little evidence available on effective practices for co-ordinated care across sectors.

Under-five mortality rates have improved 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, with recent evidence suggesting risk of disability in children under five years of age is 10 times higher than their risk of mortality (4).

Children with disability are more likely to experience poor health and nutrition, lack appropriate stimulation, not attend education settings, be discriminated against, be subject to abuse, and report feeling unhappy than children without disability (5). Their families are at greater risk of social inequities including poverty, family violence, stigma, and poor caregiver physical and mental health.

### Aim

This study sought to understand existing identification and intervention pathways in Fiji for children with disability, and opportunities for strengthening systems across sectors to provide timely, co-ordinated care and support.



**Fijian children with disability face many barriers to timely intervention and support.**



## Methods

This qualitative study explored the journey of families of children with developmental disability in Fiji to accessing intervention and support. 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.

In-depth interviews were conducted with caregivers of 12 children with disability, and 17 key stakeholders from government and service provider levels of the health, disability, education, and social welfare sectors. Participants provided their experiences and perceptions of current practices and factors influencing early identification of disability and access to intervention.

## Journey mapping

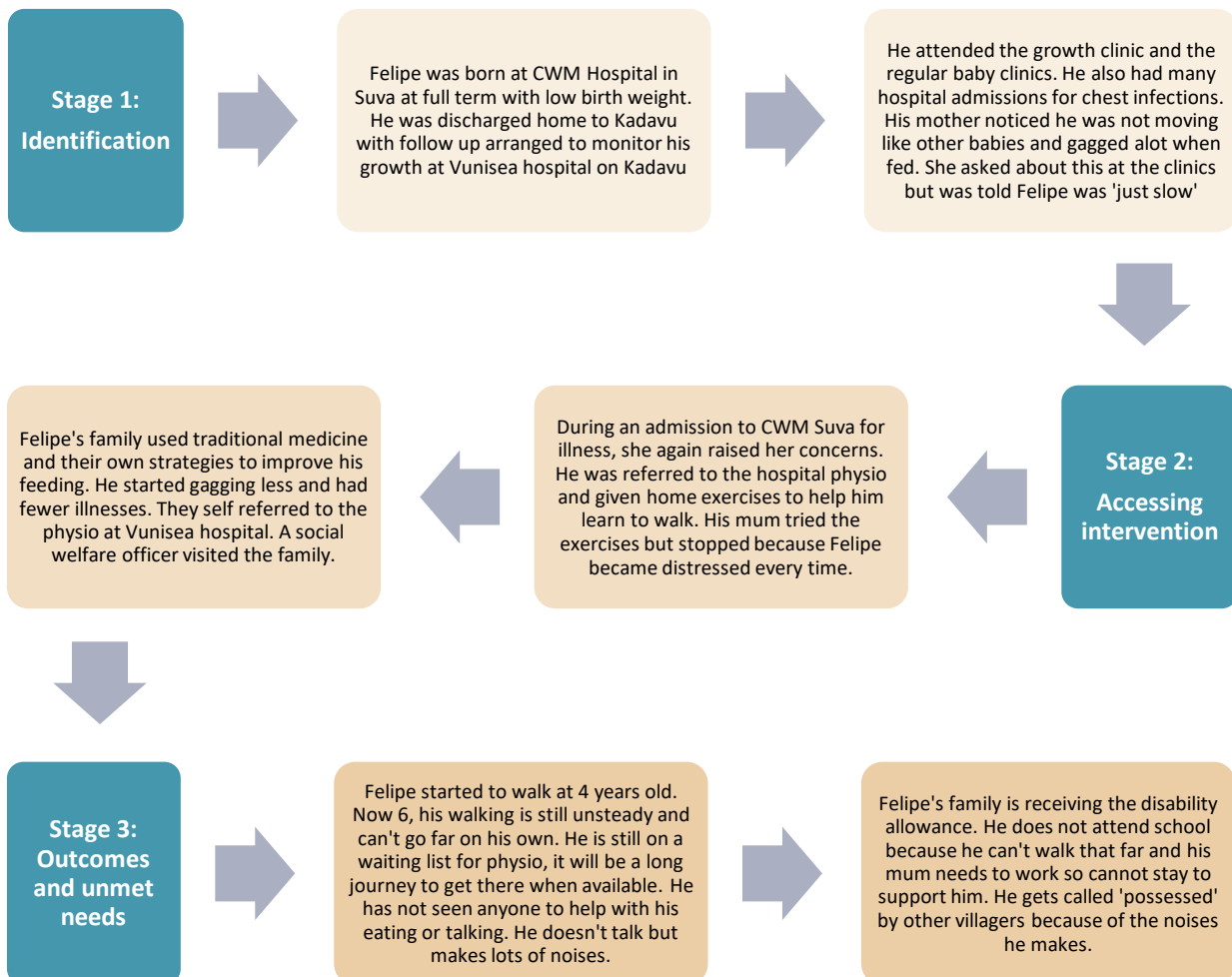
Journey mapping was used to analyse the caregiver interviews. Journey mapping is a process of examining individual's stories to understand their unique and complex experiences of accessing services and systems (3). Three key stages of the journey emerged, **1) identification of needs; 2) experiences of accessing intervention and support services; and 3) outcomes of intervention and unmet needs.**

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

- ⇒ Journey of children with complications/risk factors identified at birth
- ⇒ Journey of children without any known risk factors/complications at birth
- ⇒ Journey of children from a remote island (shown below)

### *Felipe's story – 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.*



## Key Findings & Recommendations

Themes from both caregiver and stakeholder interviews were triangulated to the three journey stages and explored in terms of barriers and facilitators. A further overarching theme of 'cross sector collaboration' was also explored which identified systemic factors impacting across all stages of the journey. Key findings and recommendations for each stage are summarised below. 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.

### 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 with the health sector in the first years of a child's life for both medical follow up care and routine care, including at 'baby clinics'<sup>1</sup>. These provide opportunity for developmental monitoring, early identification of disability, and referral; however, this opportunity is frequently missed.

Health care interactions focus on health and medical needs but do not routinely consider developmental needs or provide information to families about this, even when there are significant risk factors or a known developmental disability.

Caregivers frequently notice differences in their child's development compared to other children early in their child's life and either do not seek help or seek help and have their concerns dismissed. This leads to delays in further assessment and intervention.

Many of these missed opportunities 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. Many children with disability become 'lost' in the system as a result. CWM<sup>2</sup> Paediatric Department is leading activities to build capacity of health workers in identifying disability in children presenting to health services.

Children with disability may be identified by social-welfare outreach visits, or by teachers once attending education settings, but they are unlikely to identify children in their first few years of life or where disability or developmental concerns are less obvious.

### Recommendations

- > Training on early identification of disability and referral for those who may 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
- > Increase support for CWM Department of Paediatrics to build capacity of health workers at all levels in screening for developmental delays and disability, and making appropriate referrals
- > Strengthen processes for developmental monitoring at routine baby clinics
- > Improve information given by health workers to new parents about their child's condition, potential developmental implications, and sources of support available
- > Consider of mechanisms for financial support for families of children born with complications to attend follow up health and medical appointments to enable continuity of care and not being 'lost' to follow up
- > Raise community awareness 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 intervention and support services 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 services is a significant barrier for families, especially those in rural and remote areas. Many must choose between working and attending intervention services with their child. Emerging outreach service models are one means of improving access.

Many see special schools as the main support available for children with disability and do not consider need for supports during the crucial early years. However, many caregivers also believe their child cannot attend school because of their disability, or report not sending them due to a lack of resourcing to support inclusion or a lack of local special education options.

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<sup>1</sup> Maternal, neonatal and child health clinics

<sup>2</sup> Colonial War Memorial Hospital Suva

Stakeholders perceive a lack of priority by government to resource ECI<sup>3</sup> and other supports for children with disability, with existing services relying on overseas donor funding and fundraising to supplement government funding.

Insufficient numbers of trained workforce, a lack of funded positions, and poor career development opportunities for those working in ECI and other disability-related services all contribute to the limited growth and capacity of services to respond to the needs of young children with disability.

However, despite barriers, caregivers proactively seek support for their child, often utilising informal supports and developing their own strategies to address support needs. Awareness of disability generally in the community is improving, supported by recent policy and legislation, and fostered through relationships built between service providers and the community.

### Recommendations

- > Consider of 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
- > Onward referral to local services for follow-up for rural and remote families where available (e.g., hospital based physiotherapy services)
- > Increase funding for new and existing services to improve capacity and coverage outside the main urban areas
- > Consider outreach models of service delivery. Learnings from the CRA<sup>4</sup> 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 with disability and their families have significant unmet support needs. Without appropriate support and intervention children with disability miss out on opportunities to optimise independence and function, and are excluded from many aspects of daily life, such as playing with peers, attending school and engaging in community activities; and caregivers feel unsupported and isolated.

The lack of paediatric assistive technology (AT) in Fiji leads to use of inappropriate substitutes or none at all. This can have wide-ranging implications for dignity, safety, hygiene, physical wellbeing, and communication for children and caregivers, and impacts access, inclusion, and participation across all domains of life.

Families of children with disability face ongoing financial pressures. Many are choosing between meeting everyday household needs and disability-specific costs. Most families receive the disability allowance, but report it is insufficient to provide for their child's support needs. In some cases, siblings are missing school to care for children with disability so that parents can work. Caregiving pressures are compounded by a lack of properly resourced disability inclusive ECEC centres<sup>5</sup> and schools.

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

### Recommendations

- > Develop and resource models of care to provide interim advice and support for families on service waiting lists
- > Establish an OPD<sup>6</sup>/advocacy group specifically for children with disability and their families, providing representation and voice to the lived experience of families of children with disability

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<sup>3</sup> Early Childhood Intervention

<sup>4</sup> Community Rehabilitation Assistants

<sup>5</sup> Early childhood education and care centres (may also be known as day care, childcare, preschool)

<sup>6</sup> Organisation of Persons with Disabilities

- > 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, alongside adequate resourcing for inclusion in mainstream education settings
- > Increase resourcing for disability inclusive ECE/childcare to enable caregivers to work and opportunities for appropriate stimulation and early learning for young children with disability
- > Establish mechanisms for the funding, procurement, and supply of paediatric assistive technology for mobility, seating, communication and self-care (including continence products), including options for local fabrication and maintenance of simple devices
- > Establish a pool for paediatric equipment that children have outgrown to be re-issued to other children

## Cross-sector collaboration

A lack of clear communication and co-ordination mechanisms between sectors impacts the timely identification, referral, and holistic support of young children with disability and their families.

Each sector currently has its own tools and mechanisms for identifying disability, largely to determine eligibility for the supports they provide. Information is not routinely shared between sectors in a way that enables co-ordinated care. There are examples of collaboration through emerging networks and referral pathways between and within organisations, but these are often driven by motivated individuals. However, these could be built upon and formalised. Stakeholders discussed a need for better understanding of shared responsibilities, improved mechanisms for communication, and formalised systems for referral and sharing of information.

At a policy level, Fiji has a growing focus and commitment to both ECD and disability. These policies and strategic frameworks can be further strengthened by explicitly being 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, using consistent language across sectors
- > Ensure introduction of any identification and referral mechanisms is supported by training for relevant workers in each of the sectors
- > Develop a directory of services available for children with disability that is available for all sectors and the community

## Conclusion

Opportunities are being missed to identify and refer children with developmental disability early. Once identified, lack of services & workforce, ad hoc referral systems, and family financial constraints lead to unmet support needs, impacting child and family wellbeing. Addressing these issues needs a cross sector approach.

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Photo credit: S. Perera

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