Preconditions to Inclusion Issues Paper:

Support Services

What are support services in the Pacific?

Support services enable persons with disabilities to fully participate in everyday life and preserve their dignity, autonomy and independence. In the Pacific, these services are needed to support persons with disabilities to live independently in the community, perform daily activities, engage in all aspects of life on an equal basis with others, exercise legal capacity, and access general services, such as education, justice, and health.

Specific support services required to meet these needs in the Pacific context can include human supports (e.g. carers, personal assistants), communication support (e.g. sign language interpreters, Braille, readers, guide interpreters for persons with deafblindness), support in decision-making, mobility support (e.g. guides), independent living, support systems (e.g. circles of support, buddy systems, self-advocacy supports, peer-led supports), as well as respite care services, peer-to-peer and other supports for carers.

Support services are responsive to the needs of the person requiring support (and their family unit as appropriate) and vary according to the diversity of their disability.

Role of support services as a precondition in the Pacific

Support services are an essential precondition to inclusion because, without them, persons with disabilities will be excluded from participating in community and daily life, accessing programs and services, living independently in accordance with their choices, and contributing to their communities. Depending on the needs of persons with disabilities, support services may be required even where environments are fully accessible and assistive technologies (AT) are available. Support services can also 'bridge the gap' where AT and accessibility needs are not sufficiently met in the individual's context. The overall aim of support services is to facilitate inclusion in the community, programs and everyday life on an equal basis with others.

As with social protection, the role of support services aligns with Pacific culture and tradition's strong concepts of togetherness and ensuring care, respect and inclusion of all family members. Further cultural values regarding caring for individuals with disabilities within the family unit are also relevant to support services, as is the existence at times amongst family members, and others providing support, of prejudicial attitudes towards disabilities (particularly psychosocial and intellectual disability) or even just lack of awareness of how to give the best rights-based support for their family members. It is therefore critical that support services policies and programs: (a) build upon existing cultural

systems and values to build upon existing strengths, be culturally appropriate, and do no harm; and (b) include awareness-raising and training for communities and families, especially those providing and receiving care, regarding the inherent rights, dignity and value of persons with disabilities, and how to give rights-based care.

There is a very high risk that, without the support services they require, persons with disabilities will have significantly reduced agency and autonomy over their lives and may even be institutionalised. This is particularly so for people with psychosocial or intellectual disabilities or those with high support needs. Developing strong and appropriate community-based support services is therefore a key aspect of de-institutionalisation.

Support services under the CRPD

Persons with disabilities have a right to support services under the UN Convention on the Rights of Persons with Disabilities (CRPD). Article 4 specifically calls on governments to provide support services to persons with disabilities, whilst Article 19 specifically reinforces access to community support services that will encourage the inclusion and engagement of persons with disabilities in their communities.

Current status of support services in the Pacific

Support services are a hugely under-resourced precondition throughout the Pacific. Whilst almost no formal research or analysis has been done in this sector, anecdotal evidence suggests that the majority of support services in the Pacific are provided informally, such as through family members. Female family members often undertake this responsibility, contributing significantly to the unpaid work of these women and girl caregivers in the Pacific and reducing their own ability to engage in education, livelihood, and other opportunities.

Anecdotal evidence also suggests that where formal support service providers do exist in the Pacific, they are mainly non-governmental services or Organisations of Persons with Disabilities (OPDs). These provide examples of the type of formal support services that need to be systemically developed, funded, and embedded on national scales to fulfil the preconditions and rights under the CRPD.

Key issues for support services in the Pacific

- An initial barrier to persons with disabilities accessing support services in the Pacific is the lack of awareness by them, their families and representative groups about the nature of support services and their right to be provided with these.

- Another significant barrier is the lack of quality, CRPD-compliant and community-based support services across the Pacific. Sign-language interpreters, trained personal assistants and support in decision-making are particularly needed. Planning and provision of services need to be accompanied by workforce planning and development and should also take a life-cycle approach – that is, considering the various support needs of children, youth, adults, and older persons with disabilities.

- An important issue to consider in planning for support services is the culturally important role of the family in the Pacific, as well as expectations and wishes that may exist from the person with disabilities and their family members for support to be provided within the family unit. Support services and systems need to be developed to respond to this context and provide complementary support where appropriate, including support to the whole family where support continues to be provided informally by family members. Examples here include social protection carer payments, respite and peer support for carers, and innovative programs and campaigns to ensure support and opportunities for women and girls in families with members with disabilities.

- Another aspect of this linkage between social protection and support services is recognising the indirect cost of disability that is placed on a family unit when a person with disabilities is unable to work and the impact of this. Anecdotally, this often leads to a particular family member of the individual with disabilities – who had been acting as the individual's preferred and trusted carer – needing to leave the family home to seek more profitable employment opportunities elsewhere (such as in a bigger city or even overseas) so that they can send larger pay checks home to cover the family expenses. This then leaves the person with disabilities without their carer. Appropriate social protection payments such as disability benefits and carer allowances would address this situation.

- Being in a position to receive support services often places persons with disabilities in highly vulnerable positions. It is important to establish safeguarding systems and policies to protect persons with disabilities in this regard, including raising their awareness about their rights and about linkages with the OPDs who can support them, particularly if they need to access support services outside the family unit.

- A critical aspect of developing support systems in the Pacific is building individual and formal support services and strengthening informal support systems throughout the community. This includes more direct peer-to-peer support systems and broader community building (such as sports, religion, drama, youth and community clubs) to strengthen support networks available to persons with disabilities and their families. These should build upon local context, cultures and strengths.

- There are critical gaps in the workforce regarding support services, particularly for personal assistants, sign language interpreters, and support in decision-making. Again, workforce development needs to consider local culture and context, and it is particularly important not to exacerbate a 'brain drain' issue that means local needs would still not be met.

- More broadly, there is significant policy and framework gaps regarding support services across the region. To date there is no overarching legal, policy direction, significant budgetary allocation, on regional or national levels. Strong leadership is required to drive this critical issue forward.

Further resources:

Centre for Inclusive Policy. (2023). *The Disability Support Gap: Community support systems for persons with disabilities in low- and middle-income countries*.

International Disability Alliance (IDA), Office of the High Commissioner for Human Rights (OHCHR), UNICEF, International Disability and Development Consortium (IDDC), & CBM Global. (n.d.). *Towards sustainable support systems for community inclusion of persons with disabilities*.

Office of the High Commissioner for Human Rights (OHCHR). (2022). *Guidelines on deinstitutionalization, including in emergencies.*

Office of the High Commissioner for Human Rights (OHCHR). (2023). *Support systems to ensure community inclusion of persons with disabilities*.

Pacific Disability Forum (PDF). (2019). *Deaf people in the Pacific Island Countries*.

Special Rapporteur on the Rights of Persons with disabilities. (2023). *Transformation of services for persons with disabilities*. A/HRC/52/32.