# ☆ Evolution of a remote paediatric disability program

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## Background and context

Indigenous Australians experience disproportionately high rates of disability compared to the non-Indigenous population (1). The high incidence of disability has been highlighted in a number of areas, including intellectual disability (2), hearing impairment (3), Cerebral Palsy (4) and Foetal Alcohol Spectrum Disorder (5). High rates of disability in childhood continue to fuel health inequities between Indigenous and non-Indigenous Australians.

Despite the significantly higher rate of disability, Indigenous adults and children are less likely to access services (1). A number of factors contribute to low service use, including social marginalisation, cultural attitudes towards disability, low levels of literacy and culturally inappropriate services (6, 7). A substantially higher proportion of Indigenous Australians live in remote or very remote areas, which is another significant challenge associated with accessing services and participation in community life (8).

Living in a remote community presents a unique set of challenges for people with a disability and their caregivers. For many people in remote communities, English is not the main language spoken and disability is not a concept that is easily understood or translatable into traditional Indigenous languages (9). Many Indigenous people with a disability do not identify as having a disability, which can be a barrier to accessing available supports and advocating for their needs (10). It has been suggested that access to 'culturally and linguistically appropriate information' is one of the most significant barriers faced by people with a disability in remote areas (8).

Remoteness also presents challenges associated with infrastructure and community access. Many remote communities are exposed to harsh weather conditions and can be cut off for extended periods during the wet season. Lack of suitable infrastructure, including housing, public buildings and transport can also restrict community participation of people with disabilities (6). Assistive equipment and technology, such as wheelchairs, are not built to withstand the tough conditions in remote areas and require frequent servicing and replacement. Children with a disability face particular challenges in accessing school, due to limited special education support, as well as issues with the school environment and accessible transport.

There is a huge, unmet need for disability services and supports in remote Northern Territory, with only a handful of providers working in this area. Services are often 'fly in fly out' and costly to deliver, with infrequent access to specialist medical and allied health professionals. A 2013 audit by the MJD foundation found that residential care, allied health services, mental health services, home modifications, community transport and respite were the largest unmet needs in a number of NT remote communities (10). Children with disabilities in remote areas are a particularly vulnerable population, with risks compounded by lack of access to early intervention.

## Office of Disability – Top End Remote

Office of Disability – Top End Remote (OoD-TER) is one of a small number of disability services available in regional and remote areas of the Top End. The team covers a large geographical area outside of Darwin, including remote Aboriginal communities and outstations in the Darwin, Katherine and East Arnhem regions. The team also service a number of larger regional centres, including Jabiru, Katherine and Nhulunbuy. The model of service delivery differs depending on the location. Services to remote communities are provided by a fly-in-fly-out or drive-in-drive-out model, whereas appointment-based services and home visits are provided in regional centres. The OoD-TER team has offices in Darwin, Katherine and Nhulunbuy.

The team provide a service to eligible clients across the lifespan and has a range of functions, including disability case management, aged care assessment, community allied health and equipment provision. In remote communities, OoD-TER services are provided primarily through a 'Key Worker' model. The team's key workers are referred to as community 'Key Contacts' and function in a trans-

disciplinary role, acting as the primary point of contact for their allocated community or communities. In the OoD-TER team, the Key Contact role is performed by Physiotherapists or Occupational Therapists. The team also employ a small number of Speech Pathologists and Disability Coordinators, who work across a larger number of communities in more consultative roles.

## Advantages of 'Key Worker' model

The key worker model has a number of advantages in the remote context, some of which have been highlighted in the broader disability literature (11). The majority of OoD-TER services are provided through a key worker model for a number of reasons, including a geographically dispersed population, limited resources, economies of scale and importance of relationships in remote service delivery. The OoD-TER Key Contact is responsible for a small number of communities and through their orientation process gain an understanding of local community context, issues and history. Through regular visits, the Key Contact is able to establish relationships with local structures and service providers, such as schools, health clinics, aged care facilities and other local service providers. These networks enable referrals into the program and regular communication between the large number of providers that can be involved in supporting clients and families. As a single point of contact for clients and families, Key Contacts are able to develop trusting relationships and be available on a regular basis, either in person or by phone. The Key Contact is able to help families understand and navigate the system, as well as coordinating their care across different sectors. Key Contacts work in a family and community centred model of care, with the emphasis being on supporting clients and families to address their priorities.

## Challenges – Key worker model and paediatrics

It has been recognised that 'the simplicity of the idea of key working stands in stark contrast to the complexity of implementation' (11). The breadth of the Key Contact role within OoD-TER highlights some of these complexities. Key Contacts manage a large caseload of clients across the lifespan and perform a number of functions, including case management, case coordination and allied health intervention. In the remote context, service delivery is time intensive and inherently more complex, particularly in the area of paediatrics. For Key Contacts (Physiotherapists or Occupational Therapists), paediatrics is a specialist area in which most staff have had had little or no experience prior to commencing in the role. Managing paediatric clients can be challenging not only because of the skills and knowledge required, but the need for timely intervention during the early years of a child's life. In the Top End, paediatric practice is further complicated by language barriers, limited special education support, complex family and community dynamics, co-morbidities associated with social disadvantage (i.e. otitis media, trachoma, malnutrition, bronchiectasis, scabies) and limited access to specialists, such as psychologists, behaviour educators and social workers. Despite the complexity and time intensity required to support families, paediatrics comprises only 30% of most Key Contacts total caseload and is one of many competing demands.

## Pilot model – Remote Paediatric Therapy Program (RPTP)

The Remote Paediatric Therapy Program (RPTP) was developed in response to growing inequities in service provision between urban and remote areas of the Top End and increasing recognition of the need to support Key Contacts in this area of practice. RPTP was established as a pilot program in 2010 with the aim of providing intensive, multi-disciplinary intervention for children with complex needs. The team consisted of a Physiotherapist, Occupational Therapist and Speech Pathologist, all with significant training and expertise in paediatric practice. The team's brief was to provide intensive therapy for complex clients, in collaboration with family and Key Contacts. Over the past 5 years, evaluations have revealed that the model posed both benefits and challenges for clients, families and Key Contacts.

Evaluations were completed with Key Contacts in 2010, 2012 and 2014, to assess the impact of RPTP, in terms of service provision for children and families and effectiveness in supporting the work of Key Contacts. The earlier evaluations highlighted that the major benefits of the RPTP model were improved access to services for clients with complex needs and services that were more timely, comprehensive and able to be provided more intensively at critical periods during a child's life. The most significant limitation of the model was identified as capacity of the team to meet the needs of more than a handful of complex cases, due to a widely dispersed population and significant travel

requirements. Consequently, timely follow up was also an issue, as was adequate support on the ground to implement programs, support school attendance and follow up new equipment.

## Where we're at now

A more recent evaluation (2014) asked Key Contacts to identify what aspects of the RPTP model were most effective, with responses grouped into themes. The top three themes were all based on support provided for Key Contacts, rather than direct therapy intervention for clients *(1: informal support and advice, 2: mentoring and training, 3: joint visits and sessions)*. These results reflect the way in which the program has evolved over the past 5 years, with the role of RPTP staff members shifting from therapist to capacity builder.

The past 5 years have seen a significant shift in the RPTP model, with a change in focus from 'intensive therapy' to 'capacity building'. Capacity building occurs at a number of levels, including the individual client, family, school and broader community. RPTP exists primarily as a support structure for Key Contacts, who function as link between the specialist allied health professional (RPTP) and family. The joint work of RPTP and Key Contacts is a two-way learning process, with transfer of specialist skills from the paediatric therapist and sharing of knowledge about family, community and local context from the Key Contact. Key Contacts are encouraged to take an active role with paediatric clients and are trained to understand normal development, complete basic paediatric assessments, set functional goals and work successfully in schools. RPTP time and resources are now shared more equitably across the region, with strategies such as videoconferencing, mentoring of Key Contacts, multi-disciplinary case conferences, video assessments and 'in-reach' blocks when clients travel to Darwin.

## Key learnings

Despite its challenges, the key worker model is an effective way of providing disability services to a culturally diverse population, over a large geographical area. In recent years, this model has been strengthened by the availability of a specialist paediatric team (RPTP), which has evolved from a therapy program to a support structure for Key Contacts. Key learnings that could be identified as critical success factors for other programs attempting to replicate this service delivery model are:

### Relationships are the foundation for success

Regular visits enable the Key Contact to build strong relationships with clients and families, which often happens slowly, over a number of visits to community. Being a presence in community, having regular contact with family and understanding family and community dynamics are all factors that contribute to the development of successful relationships. This can be challenging for an infrequent visitor, who has less understanding of the reality of each family's situation and local contextual factors. Key Contacts are in the best position to develop these relationships, both with families and other service providers. They are then able to act as a facilitator during initial contact between a family and specialist therapist/ team, with the visitor orientated to each situation and family aware of what the specialist is able to offer.

### Specialist knowledge needs to be shared effectively and appropriately

In order for this model to be effective, RPTP staff must have specialist knowledge and expertise in the areas of paediatric disability and remote practice. As capacity builders, mentors and consultants for a large number of staff, it is important that the RPTP staff have relevant knowledge of evidence-based paediatric practice and the ability to translate this knowledge into the remote context. To work effectively, it is essential for members of this team to have high level interpersonal, communication and coaching/mentoring skills. These skills are essential for success in sharing specialist skills and knowledge, as well as empowering families to take a lead role in decision making. This approach recognises families as the experts around their child's needs and Key Contacts as best placed to provide in-community support for children and families.

### Key Contacts are an important link between family and specialist

A visiting specialist team, such as RPTP, is not able to work effectively in isolation. Being infrequent visitors to each community and unfamiliar with the local context, it is essential that a partnership

approach be taken with key workers. The OoD-TER Key Contacts are an established presence in community and have more in-depth knowledge of community dynamics, local infrastructure and cultural factors. As a specialist therapy team, RPTP have the technical skills to manage each situation, but this alone is not enough. Key Contacts have the important role of assisting clients and families to articulate their priorities and in consultation with family, drawing in specialist teams if and when required. Without this important link, there is a high risk of miscommunication and misunderstanding between clients, families and visiting specialists, despite the best of intentions. Following a consultation with specialist services, such as RPTP, the missing link is often support for families in applying therapy programs or recommendations. Working with RPTP, Key Contacts can support families to incorporate opportunities for their child's learning and development in the local context, using whatever resources are available in community. The generalist allied health skills and local knowledge of the Key Contact complement the specialist knowledge and skills of RPTP, which can be drawn upon when required.

### Staff values and attitudes are fundamental

Delivering a client and family centred service requires a partnership approach, with client, family, Key Contact and other service providers. Experience has shown that the ability of a Key Contact to develop successful partnerships depends largely on their attitudes and values, rather than specific technical skills. For a Key Contact to be effective, some baseline competencies in remote Allied Health are required. However, equal importance needs to be placed on their attitudes and values, with respect, flexibility, self-awareness and open mindedness all paramount. Research has highlighted characteristics that are important for non-Aboriginal health professionals practicing in Aboriginal health, including 'awareness of cultural identity, recognition of one's own position and an awareness of Aboriginal history' (12). With this awareness and a baseline level of competency, more specialised expertise can be drawn upon when required. In practice, recruiting Key Contacts with broad and high level technical skills across a number of areas, including paediatrics, is often unrealistic. With values that are a good match for the role and access to support structures like RPTP, Key Contacts are able to function effectively in the remote context. Likewise, attitudes of visiting specialists, such as RPTP, are just as critical for successful outcomes.

### Service delivery needs to be flexible

A model of service delivery for remote paediatrics needs inbuilt flexibility. There needs to be acknowledgement that the remote context can be inherently more complex and additional time needs to be invested in developing relationships, understanding family and community dynamics, assisting families to navigate the system and coordinating services. This translates into a need for involved providers (Key Contact or RPTP) to be flexible in a number of areas of service delivery, such as time allocated to review clients, location for client reviews, involvement of family and significant others, communication style, creative use of resources (i.e. equipment, community facilities, respite), information sharing and capacity to change or cancel plans, often at short notice.

## Policy recommendations

The following recommendations are suggested as best practice guidelines when providing disability services in the remote context:

- The key worker model is an effective and economical way of delivering disability services to remote and very remote areas. Key workers are best placed to build relationships in communities, develop an understanding of local contextual factors and through self-reflection, become culturally responsive practitioners.
- Key workers need access to support structures, such as RPTP, to function effectively in a broad and demanding role. Teams like RPTP need to have capacity to provide training and guidance for key workers in specialist areas of practice, such as Paediatrics.
- This model of service would be greatly strengthened by employing community based workers to work in partnership with visiting key workers and act as community/cultural advisors. With training, these individuals would be better placed to provide regular, on the ground support for

people with disabilities in their local community and help key workers to navigate the local context.

- Service providers working in remote communities must have rigorous cultural orientation and ongoing support to ensure that practices are culturally responsive and meet the needs of clients, families and communities.

- Service coordination plays a critical role in achieving positive outcomes. In order to navigate complex systems and processes, clients and families need ongoing assistance and support from the key worker. It is imperative for future service delivery models to consider the longer time frames required for service coordination and delivery in the remote context

- There is an urgent need for development of more culturally appropriate information about disability and related concepts, which enables children and families to make informed decisions and engage meaningfully with visiting service providers.

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## Presenters

**Hannah Johnston** graduated from La Trobe University in 2006 with a Bachelor of Physiotherapy (Honours). She spent her graduate years working in acute paediatrics and paediatric rehabilitation. In 2008 she moved to Malawi as an AVI volunteer and spent the next two years working in community based rehabilitation. Hannah relocated to Darwin in 2011 and joined the Top End Remote Disability team. She currently works as a specialist paediatric physiotherapist in this team and provides support to colleagues, as well as clients, families and schools across the Top End Remote Region. Hannah is currently completing a Masters in Public Health through Flinders University. Hannah is passionate about service delivery for children and families in remote areas and tailoring services to meet the diverse needs of communities across the Top End.

**Claire Pilkington** graduated from the University of Newcastle in 2001 with a Bachelor of Health Science (Occupational Therapy) (Honours). Claire has experience working with paediatric and adult clients in numerous parts of Australia including country NSW, Newcastle, Kimberley Region in Western Australia and in the Northern Territory. Since moving to Darwin in 2010, Claire has been working in the Top End Remote Office of Disability team. This has involved working as an occupational therapist and clinical leader providing specialist support in the area of paediatric disability. Claire is passionate about disability services and the provision of quality services in remote regions. Claire completed a Graduate Certificate in Social Change and Development in 2012 and Certificate IV in Frontline Management in 2014.