





## Acknowledgements

We acknowledge the traditional owners of the land on which we work and live, and respect Aboriginal people's ongoing custodianship of the land. We pay respect to Tasmanian Aboriginal people, and Elders past and present.

This Tasmanian Paediatric Rehabilitation Service Model of Care Project is a subproject of the Statewide Subacute Care Project (Geriatric Evaluation and Management and Rehabilitation), funded by the Australian Government under the National Partnership Agreement on Improving Health Services in Tasmania Schedule G: Improving the Management of Subacute and Acute Care.

The development of a Model of Care is one of the agreed actions of the Tasmanian Paediatric Rehabilitation Service Model of Care Project.

The Project team would like to thank the many consumers, families, carers, clinicians, individuals, groups and organisations who shared their stories, ideas and expertise with us so that we could develop this statewide Model of Care and set a vision for paediatric rehabilitation in Tasmania.

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## **Executive Summary**

Paediatric rehabilitation contributes to the health and wellbeing of the entire community. It provides care that optimises health outcomes and quality of life, reduces the impact of disability, and increases the inclusion and participation of children and their families in their community.

Children who experience health conditions such as illness or injury early in life are vulnerable to poorer long-term outcomes. Providing timely and effective rehabilitation care can significantly reduce the need for high-intensity crisis management and disability supports over time, and so reduce the current and future cost of delivering healthcare and social services.

Population data tells us that the rates of children with disabilities are higher in Tasmania than in Australia as a whole.<sup>2</sup> Furthermore, Tasmanian children experience higher than average socio-economic disadvantage;<sup>3</sup> pre-term birthrates are the highest in the nation;<sup>4</sup> and children are born at low birth weight at the second highest rate in the nation.<sup>5</sup> Together, this data tells us that the demand for paediatric rehabilitation care in Tasmania will remain high.

Specialised paediatric rehabilitation care has been available in Tasmania for many years. However, the service is not formally recognised, there is no Model of Care (MoC) to guide service delivery, and multidisciplinary paediatric rehabilitation care teams are not clearly identified. This means that paediatric rehabilitation care varies across the State and is often not offering best value to consumers.

Tasmanian children are not receiving the equivalent level of care that is provided to adults within the State, or to children who live in other states of Australia. The available data illustrates that most Tasmanian children who require intensive inpatient rehabilitation care access this care interstate. There is strong anecdotal evidence that this is a source of social and financial stress for families. Furthermore, this is adding to the overall health systemlevel cost of providing rehabilitation care.

If left unaddressed, the current state of play is very likely

to flow on to poorer health outcomes and negative longterm impacts for Tasmanian children, their families and their communities.

Change is imperative to ensure that paediatric rehabilitation services in Tasmania provide high-quality and effective care that is child- and family-centred and outcomes-focused.

This change can be achieved through this statewide MoC and accompanying recommendations, which were developed by the Project team and informed through an extensive co-design process with consumers and service providers. A detailed implementation plan will follow, which will step out key action areas and timeframes from 2020–2030.

This evidence-based MoC clarifies the important role that paediatric rehabilitation plays in the Tasmanian health system and is intended to align with the broader future directions of Tasmanian statewide subacute care services. It places the child and family at the centre and provides a framework for a quality, integrated paediatric rehabilitation service that is responsive to the health and wellbeing of the community.

When implemented, this MoC will ensure that Tasmanian children and their families have equitable access to rehabilitation care, regardless of where they live, when they need it most. This will bring paediatric rehabilitation care into line with the care that is currently available to adults within Tasmania, and with that available to children in other states of Australia.

This MoC is sufficiently high-level to enable a flexible response to emerging policy developments at a national level, changes in community needs, Tasmanian health service priorities, and available funding. This approach allows for the consideration of, and adaptation to, differences in service availability and provision across the State.

The core components of the Tasmanian Paediatric Rehabilitation Service MoC are described in detail in this document and are summarised on the following page.

## **Model of Care**



### VISION

All Tasmanian children have access to specialised child- and family-centred paediatric rehabilitation care.



### **MISSION**

To work in interdisciplinary, evidence-based and flexible ways in partnership with children and families to enable them to achieve the best possible outcomes.





**Collaboration** 

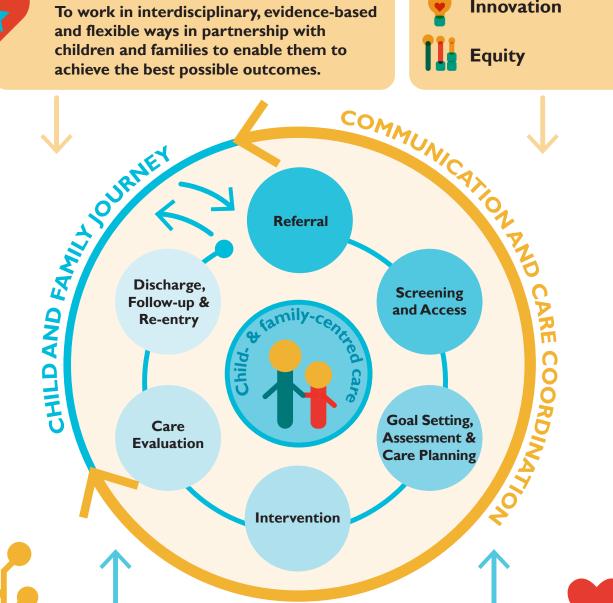


**Empowerment** 



**Innovation** 





### **ENABLERS**

- Workforce
- Data and Performance **Improvement**
- Integrated services
- Technology
- Infrastructure

#### **FLEXIBLE CARE DELIVERY**

- In-reach to Acute
- Admitted Inpatient
- Hub and Spoke Inpatient
- Same-day
- Outpatient
- Natural Settings

## Recommendations

These high-level recommendations will together support and sustain the implementation of the MoC:

Establish a statewide Tasmanian Paediatric Rehabilitation Service with formalised governance and leadership structures

This will enable the implementation of consistent statewide processes for patient flow, increase awareness of the service, facilitate equitable and timely access to the service, clarify the role of paediatric rehabilitation within the Tasmanian health system, and provide a framework for service accountability.

Allocate a sustainable funding source for paediatric rehabilitation

This will ensure that the service is adequately resourced to sustainably provide high-quality, safe and effective rehabilitation care to children and families across the State.

Create rehabilitation teams that take an interdisciplinary approach

Children and families who access paediatric rehabilitation have multiple and complex needs that are best met through an interdisciplinary approach in which different disciplines within a care team share resources and responsibilities and work in a coordinated fashion towards common goals.

Appoint regional care coordinators

Designated regional care coordination roles will facilitate a seamless journey through the service by improving local and statewide communication and links, preventing children with complex needs from falling through gaps, and reducing duplication and inefficiencies in care.

Design the paediatric rehabilitation service to be flexible and integrated

The establishment of core sites in line with agreed complexity levels will ensure rehabilitation care can be flexibly delivered across the continuum, at the right time and intensity based on individual needs. Statewide collaboration will increase access to specialist supports and build capacity for care to be provided locally.

Commit to ongoing statewide workforce development

A sustainable and skilled workforce is critical to the delivery of specialist paediatric rehabilitation care and will ensure access to the relevant expertise and support when and where it is needed.

Implement statewide data collection and quality improvement processes

A consistent statewide approach to data collection will allow for rehabilitation activities to be properly identified and funded. It will also enable participation in quality improvement, service evaluation and benchmarking activities in keeping with the principles of value-based healthcare.

8 Use accessible technology for communication and data collection

Accessible technology will enable timely and efficient access to specialist rehabilitation care across the State and facilitate effective data collection and information-sharing with consumers and external services.

Provide safe and appropriate infrastructure

Appropriate infrastructure that complies with the National Safety and Quality Health Service (NSQHS) standards will ensure that rehabilitation care is safe, effective and accessible for children and families.

Commit to ongoing consumer engagement

The experiences that consumers have when they receive rehabilitation services are a valuable source of information that will be used to evaluate and improve service delivery. Implementing the MoC through these overarching recommendations will have a positive flow-on effect. It will influence how paediatric rehabilitation care is provided across the State, how consumers experience their rehabilitation care, their treatment outcomes, and ultimately the health and wellbeing of the entire community.

### **IMPLEMENTATION OF THE MODEL OF CARE**



IMF	IMPACT ON THE PROVISION OF PAEDIATRIC REHABILITATION CARE			
Child- and family- centred treatment, education and care.	Goal-directed interdisciplinary teamwork.	Improved communication, collaboration and links.	Statewide consistency in service quality and standards.	Strong leadership and a sustainable and skilled workforce.
Increased awareness of the service and timely referrals.	Increased efficiency, reduced duplication and reduced reliance on interstate services.	Funding and resources that are matched to identified need.	Availability of care across flexible care settings across the care continuum.	Care that is aimed at child- and family-centred outcomes.



IMPACT ON THE CONSUMER EXPERIENCE WITH CARE				
A seamless journey with rehabilitation care.	Increased satisfaction and engagement with care.	Equitable access to specialist skills and support.	Access to care at the right time and at the right intensity.	Increased access to care closer to home and reduced hospital length of stay.



IMPACT ON TREATMENT OUTCOMES				
Empowerment of children and families.	Timely achievement of goals and optimised functional independence.	Increased whole- of-family social and emotional wellbeing.	Early identification and management of known complications.	Established links with ongoing supports.



HIGH-LEVEL IMPACTS			
Enhanced independence and quality of life for children and families.	Increased inclusion and participation of children with disability within their communities.	Optimised health outcomes and reduced current and future disease burden for children and families.	Reduced current and future cost of healthcare and social services.

# **Key Terms**

#### Care coordination

Care coordination helps children, families and service providers work together to improve health outcomes.

#### Care setting

A care setting is any location where healthcare is provided or accessed.

#### Tertiary care setting

Major acute specialist hospitals, where highly specialised medical care is provided.

#### Secondary care setting

A less specialised care setting that can function as a step-down from a major tertiary hospital, and/or a site where people can receive healthcare when they are referred by a primary care provider.

#### Primary care setting

The first point of contact for individuals accessing healthcare. This is where day-to-day health services are provided to the community, and includes general practice and child and maternal health

#### Community care setting

Healthcare provided to people in the setting of their everyday lives, where they work, play, learn and live. This is also referred to as 'natural settings' in the paediatric context.

#### Child- and family-centred care

Care that is respectful of, and responsive to, the cultural background, preferences, needs, and values of children and families.

#### Continuum of care

The child and family journey through the full range of health services, across all healthcare settings.

#### Co-design

An approach that enables staff and consumers to co-design services and/ or care pathways, in partnership. This approach also gathers experiences from consumers and staff through in-depth interviewing, observations and group discussions.<sup>6</sup>

#### Consumers

Children and their families/caregivers

who have accessed and/or are currently accessing paediatric rehabilitation care.

#### Equitable access

Ensuring all people have fair and socially just opportunities to access services, support and information.

#### Evidence-based healthcare

The use of current best evidence in making decisions about the care a person receives or the delivery of health services

#### Health condition

Disease (acute or chronic), disorder, injury or trauma. A health condition may also include other circumstances such as pregnancy, ageing, stress, congenital anomaly, or genetic predisposition.<sup>7</sup>

#### Functional impairment

A loss of functional capacity arising from a health condition. <sup>8</sup> This impairment may manifest in body function/structure, activity and/or participation, as described in the World Health Organization International Classification of Functioning, Disability and Health (ICF). <sup>9</sup>

#### Interdisciplinary approach

An approach in which different disciplines in a team share resources and responsibilities and work in a coordinated fashion towards common goals. 10,11 Under this approach, the care team works collaboratively with the child and family to undertake assessment, set goals, create a care plan and deliver interventions. 12

#### Integrated care

The provision of well-connected, effective and efficient care that takes account of, and is organised around, a person's health and social needs.

#### Model of care (MoC)

Broadly defines the way health services are delivered. It outlines best practice care and services for a person or population group as they progress through the stages of a condition, injury or event. It aims to ensure people get

the right care, at the right time, by the right team and in the right place. <sup>13</sup>

#### Multidisciplinary team

A group of healthcare professionals who are members of different disciplines (eg occupational therapists, social workers, physiotherapists), each providing specific services to the patient.

#### A 'no wrong door' approach

The staff of a service can connect children and families with the appropriate service(s) in a manner that is streamlined, effective and seamless for the child and family, even if that service(s) is not offered by their sector.

#### Rehabilitation

A set of interventions designed to optimise functioning and reduce disability in individuals with health conditions in interaction with their environment.<sup>7</sup>

#### Subacute care

Specialised care in which the primary need for care is optimisation of a person's functioning and quality of life. Subacute care comprises the defined care types of rehabilitation, palliative care, geriatric evaluation and management and psychogeriatric care. <sup>14</sup>

#### Tasmanian health system

Encompasses all aspects of healthcare service delivery across Tasmania, including public and private providers across all healthcare settings.

#### **Telerehabilitation**

The delivery of assessment and therapy services over telecommunication networks and the internet.

#### Value-based healthcare

Defined as the health outcomes achieved per dollar spent, with outcomes always centred around the person. It considers how the person perceives their treatment outcomes, how the treatment offers best technical value, and how the allocation of resources offers best value in line with the population's level of need.

# **Background**

This MoC was developed over a 12-month period by the Tasmanian Paediatric Rehabilitation Service MoC Project team. It was informed through an extensive co-design process with key stakeholders, including consumers (families of children who have accessed and/or are currently accessing paediatric rehabilitation services) and Tasmanian and interstate service providers. It is evidence based and takes account of key Tasmanian and national policy and planning documents. It is intended to align with the broader future directions of Tasmanian statewide subacute care services.

The Project team has developed several reports, which provide background and context and have been used to inform the MoC, including:

- » Introductory Report Part One The Context
- » Introductory Report Part Two Tasmania Service and Demand Review
- » Model of Care Co-Design Workshops Summary Report

A statewide steering committee provided oversight during this process and endorsed the MoC. The membership included the following roles:

- » Clinical Director of Women's & Children's Services (WACS), Royal Hobart Hospital (RHH), Tasmanian Health Service (THS)
- » Director of Paediatrics, North West Regional Hospital (NWRH), THS
- » Director of Paediatrics, Launceston General Hospital (LGH), THS
- » Director of Nursing and Group Manager WACS, RHH,THS
- » Executive Director of Allied Health, THS
- » Director of Allied Health Services North-West, THS
- » Director of Allied Health Services North, THS
- » Director of Allied Health Services South, THS
- » Community Paediatrician, THS
- » Adult Rehabilitation Services representative, THS
- » Consumer representative
- » Statewide Director of Victorian Paediatric Rehabilitation Service
- » Project Manager, Statewide Subacute Care (Geriatric Evaluation and Management and Rehabilitation), Health Planning, Planning Purchasing & Performance, Department of Health
- » Director of Disability and Community Services, Department of Communities
- » Director of Inclusion and Diversity Services, Department of Education

The Project team also received guidance from regional reference groups, with key allied health, medical, nursing and consumer representatives.

The MoC and key recommendations outlined in this document will be enabled through the development of a supporting implementation plan.





#### **Paediatric Rehabilitation**

The World Health Organization (WHO)<sup>7</sup> defines rehabilitation as a 'set of interventions designed to optimise functioning and reduce disability in individuals with health conditions in interaction with their environment. Health condition refers to disease (acute or chronic), disorder, injury or trauma. A health condition may also include other circumstances such as pregnancy, ageing, stress, congenital anomaly, or genetic predisposition.'

According to the NSW Agency for Clinical Innovation, <sup>15</sup> rehabilitation:

- » targets improvements in individual functioning
- » includes making changes to an individual's environment
- » reduces the impact of a broad range of health conditions
- » typically occurs for a specific time period, but can involve single or multiple interventions delivered by an individual or team
- » can be needed from the acute phase immediately following the recognition of a health condition through to post-acute and maintenance phases.

Paediatric rehabilitation is a sub-speciality of rehabilitation. The following factors distinguish it from rehabilitation support that is provided to adults:

- » Support is provided to children and adolescents (0–17 years). Throughout this document, the term 'children' will refer to both children and adolescents.
- » Paediatric rehabilitation incorporates the principles of functional intervention with components of growth and development, to ensure that care is child-focused and family-centred.
- » An event such as a stroke or an acquired brain injury is very different in a child than in an adult. It not only results in the potential loss of already acquired skills but can also inhibit the child's ability to learn new skills. This can have a profound impact on their ability to achieve functional independence over time. The functional outcomes for the child and family rely on highly specialised paediatric rehabilitation care. <sup>17</sup>
- » The needs of children are ever changing due to growth and development, educational transitions and transition to adulthood. Therefore, additional support is provided at strategic times to avoid or minimise preventable complications. 16

## The Impact of Paediatric Rehabilitation Care

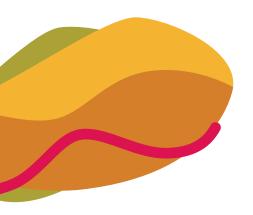
Research shows that early access to rehabilitation produces better functional outcomes for almost all health conditions associated with disability.<sup>15</sup> Rehabilitation aims to minimise or prevent disability, support people to improve their participation in life, and reduce the impact on families and communities.<sup>18</sup>

Children who experience health conditions such as diseases, disorders, injury or trauma early in life are vulnerable to poorer outcomes later in life. Providing the right support at the right time and in the right way can significantly reduce the demand for high-intensity and crisis health and social services over time. Accordingly, ensuring children have access to effective, targeted early intervention and support is a social and economic priority for Australia. <sup>19</sup>

Paediatric rehabilitation services contribute to the health and wellbeing of the entire community by:

- » enhancing independence and quality of life for children and their families
- » reducing the impact of disability and increasing inclusion and participation of children and their families in their community
- » optimising health outcomes and reducing current and future disease burden for children and their families
- » reducing the current and future cost of healthcare and social services.

Children who experience health conditions such as diseases, disorders, injury or trauma early in life are vunerable to poorer outcomes later in life.



Children and their families may require support to develop skills for the first time, recover from an illness, major trauma or injury, self-manage conditions and manage advocacy.

## Scope and Settings for Paediatric Rehabilitation

Paediatric rehabilitation is the combined and coordinated use of medical, social, educational and vocational methods for training or retraining the child to their highest possible level of function. It uses functional and social models rather than a predominantly disease-focused model. <sup>16</sup> Children and their families may require support to develop skills for the first time, recover from an illness, major trauma or injury, self-manage conditions and manage advocacy. <sup>20</sup>

Paediatric rehabilitation services typically support children with functional impairments that have arisen from complex health conditions. These children and their families typically present with a high burden of care and require coordinated support from multiple disciplines. The Australasian Rehabilitation Outcomes Centre (AROC) developed the following impairment groups for benchmarking paediatric rehabilitation activity: <sup>21</sup>

- » Neurological Disorders
- » Brain Dysfunction
- » Orthopaedic Conditions
- » Spinal Cord Dysfunction
- » Stroke
- » Functional Neurological Disorder
- » Amputation
- » Pain Syndromes
- » Burns
- » Arthritis
- » Reconditioning/restorative

Paediatric rehabilitation care is typically delivered through an interdisciplinary approach, in which members of a multidisciplinary team share resources and responsibilities and work in a coordinated fashion towards common goals. <sup>10,11</sup> Under this approach, the rehabilitation team works collaboratively with the child and family to undertake assessment, set goals, create a care plan, and deliver interventions. <sup>12</sup>

Paediatric rehabilitation support can be provided in a variety of ways, across a continuum of care settings. The main categories of paediatric rehabilitation care delivery are described below.

**Inpatient rehabilitation** is delivered by a multidisciplinary team of health professionals under the direction of a paediatric rehabilitation physician, while the child is accommodated overnight in a hospital.<sup>21</sup> Inpatient rehabilitation settings may include dedicated 'rehabilitation' beds on acute wards, rehabilitation wards in a children's hospital, or a paediatric unit in a general rehabilitation facility.<sup>22</sup>

**Ambulatory rehabilitation** does not involve an overnight stay. It may occur as the continuation of an inpatient episode of rehabilitation, or solely as an ambulatory rehabilitation program. Examples of ambulatory settings include day beds in a hospital or rehabilitation facility, outpatient departments, and community or natural settings for the child and family, such as home and school.<sup>21</sup>

**Same-day rehabilitation** is a subcategory of ambulatory rehabilitation and is also commonly referred to as 'day hospital' or 'day rehabilitation'. It is commonly used as a step-down from inpatient care and is typically defined by an increased intensity of therapy, usually several sessions a week, involving at least two disciplines.

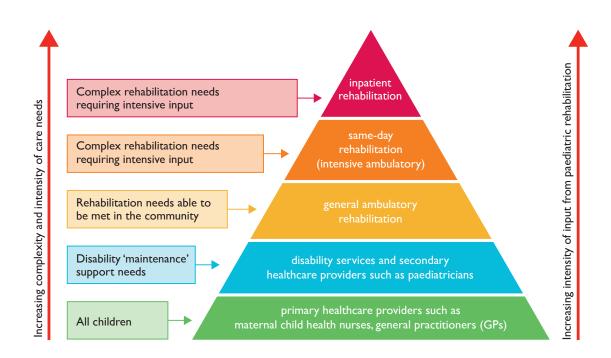
Rehabilitation services play an important role in bridging care that occurs across various healthcare settings and can help coordinate the care experience for children and their families across system boundaries.

Rehabilitation services play an important role in bridging care that occurs across various healthcare settings<sup>15</sup> and can help coordinate the care experience for children and their families across system boundaries.<sup>16</sup>

The complexity of care triangle depicted below has been adapted from the Victorian Paediatric Rehabilitation Service (VPRS) MoC.<sup>16</sup> It describes how children with the most complex care needs require more intensive and specialised paediatric rehabilitation care. As their care needs become less complex, children require less intensive paediatric rehabilitation care and there is increasing involvement from other services.

Accordingly, a paediatric rehabilitation service in the healthcare system typically provides care in the top three levels of the triangle: in the inpatient, same-day rehabilitation and general ambulatory rehabilitation categories. Other services are generally responsible for providing care in the bottom two categories of the triangle, including disability 'maintenance' supports and primary healthcare services. Rehabilitation care in the top three levels may be integrated across a variety of care settings depending on individual needs and circumstances, including tertiary, secondary, primary and community care settings.

#### Complexity of care triangle (adapted from the VPRS Model of Care)



## The Tasmanian Policy Context

The Tasmanian Government *One State, One Health System, Better Outcomes* (One Health) reform agenda<sup>23</sup> supports the development of a statewide health system where service delivery is aligned with community needs. Subacute care services (including rehabilitation) are identified as a priority area for change under this reform agenda.

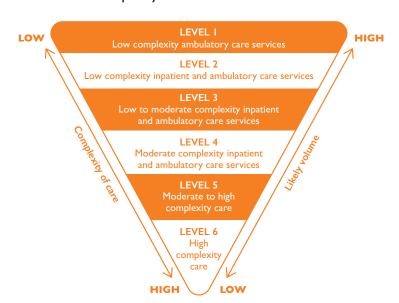
The Tasmanian Role Delineation Framework (TRDF) and Clinical Services Profile (CSP)<sup>10</sup> supports the One Health reform agenda and is the principal clinical service planning document for Tasmania's public health system. The TRDF describes health service levels to identify minimum support services, safety standards, skills and competencies, networking arrangements, and other service requirements. The TRDF complexity levels, which increase from level one (low) to level six (high), are shown below.

The CSP identifies which clinical and support services will be delivered at each hospital site. Paediatric rehabilitation as a sub-speciality is not specifically covered in the CSP. The table below depicts how approved levels for rehabilitation (adults) and paediatric medicine vary across the four major hospitals.

Tasmanian Hospital CSP for paediatric rehabilitation-related services <sup>10</sup>			
Current	Clinical Services Profile		
Approved Level	Rehabilitation (adults)	Paediatric Medicine	
RHH	5*	5*	
LGH	5	4	
NWRH	4	3	
The Mersey	4	I	

<sup>\*</sup> level 6 services are provided interstate

#### TRDF complexity levels from the TRDF and CSP 2018<sup>10</sup>



In 2016, the THS Tasmanian Rehabilitation MoC Working Group reviewed THS rehabilitation services across the State and developed the THS Statewide Rehabilitation Service Draft Model of Care<sup>24</sup> and the THS Statewide Rehabilitation Service Draft Business Case.<sup>25</sup> Paediatric rehabilitation was out of scope of this work, which focused on rehabilitation services for adults. This provided impetus for the current Project to develop a statewide paediatric rehabilitation MoC that aligns with priorities for Tasmanian rehabilitation services articulated through the Statewide Subacute Care – Rehabilitation Project.

The Statement of Purchaser Intent (SoPI) 2019–20<sup>26</sup> outlines Government priorities and the Department of Health response to health needs across the State. It provides a framework against which a MoC can be developed and benchmarked, service design can be guided, and decisions on policy or funding can be made. The SoPI combines core components which together support the planning and commissioning of peoplecentred care. These core components are:

- » Priority Conditions several chronic health conditions are identified which together significantly contribute to the overall disease burden in Tasmania. Neurological conditions are one of the top three identified priority conditions. A high proportion of the functional impairments in children who access paediatric rehabilitation care arise from neurological conditions, most commonly cerebral palsy and acquired brain injury.
- » Complexity Model this model supports people-centred care by accounting for service providers' ability to alleviate therapeutic burden and facilitate consumer engagement with care, as well as consumers' physical and mental health and vulnerability to poor outcomes. It is well accepted that children who require paediatric rehabilitation have complex care needs, experience a high burden of care, and are particularly vulnerable to poor outcomes. Paediatric rehabilitation provides a people-centred, coordinated, and integrated approach to support children and families with complex care needs.
- » Capability Framework the TRDF and CSP will sit under the Health System Capability Framework which will support service delivery across the full continuum of care and ensure that all care type sectors can contribute equitably to the delivery of care, in an integrated manner. Paediatric rehabilitation care, as a component of the subacute care type sector, forms an integral part of the health system and can be provided across a continuum of care settings from tertiary to community.

The SoPI 2019–20 signals a move towards **value-based healthcare**, defined as the health outcomes achieved per dollar spent, with outcomes always centred around the person. Value-based healthcare considers the person's experience of receiving their treatment/care (Patient-Reported Experience Measures – PREMs) and how the person perceives their treatment outcomes

(Patient-Reported Outcome Measures – PROMs). Value-based healthcare also considers how the treatment offers best technical value, and how the allocation of resources offers best value in line with the population's level of need. In the context of paediatric rehabilitation, functional assessments are conducted on admission and discharge, along with other measures including PREMs, PROMs and length of stay, to enable service evaluation and benchmarking against other services through AROC.

## The National Policy Context

The National Disability Insurance Scheme (NDIS) represents a significant change in the delivery of funded supports to Australians living with disability. The NDIS introduced consumer-driven access to services, with greater flexibility, choice and control. It aims to support the independence and social and economic participation of people with disability. Early Childhood Early Intervention (ECEI) is the way the NDIS supports children aged 0–6 years who have a developmental delay or disability, and their families/carers. The ECEI approach supports families to help children develop the skills they need to take part in daily activities and achieve the best possible outcomes throughout their lives.<sup>27</sup>

In 2015, the Council of Australian Governments released the Applied Principles and Tables of Services<sup>28</sup> to assist with decision-making on whether a support is most appropriately funded by the NDIS (including ECEI) or other systems such as health. This document stipulates that health systems are responsible for funding timelimited, recovery-oriented services and therapies (including rehabilitation) aimed primarily at restoring the person's health and improving the person's functioning after a recent medical or surgical treatment intervention. This includes where rehabilitation is required episodically. The NDIS is responsible for supports required due to the impact of a person's impairment/s on their functional capacity and their ability to undertake activities of daily living. This includes 'maintenance' supports where the person has reached a point of stability in their functional capacity. Furthermore, the document makes it clear that health services and NDIS services may be delivered concurrently, and that both systems will need to work together at the local level to plan and coordinate streamlined care and ensure a smooth transition from one system to the other.

States and territories are continuing to negotiate the boundaries and the criteria that will determine responsibility for disability and health services, including rehabilitation. The *THS NDIS Implementation Policy* is in draft and has not yet been released.

While the NDIS has undoubtedly introduced new opportunities for Australians with disability, the interface between health and disability has the potential to increase the burden of care experienced by children and their families. Families are negotiating multiple systems, often at the same time, in order to seek and secure the right treatments, services and equipment for their child. It is therefore important that a 'no wrong door' approach is taken by service providers, to reduce barriers and provide seamless support to ensure that children and their families do not fall through the gaps. Health is often the first system that children and families interact with before they engage with disability services. Therefore, the health system – as a first responder to disability – is uniquely positioned to support families.<sup>29</sup>

## International Agreements with Implications for Rehabilitation

It is estimated that 75 per cent of the total number of years lived with disability in the world are linked to health conditions for which rehabilitation is likely to be beneficial. However, historically rehabilitation services have been a low priority for many governments.<sup>7</sup>

In 2017, the WHO called for coordinated global action at the *Rehabilitation 2030:A Call for Action* meeting.<sup>7</sup> A diverse group of rehabilitation stakeholders met to develop a plan of action to address unmet rehabilitation needs and to scale up rehabilitation services to meet future demand.

Participants committed to 10 areas of action. These included building comprehensive rehabilitation service delivery models to progressively achieve equitable access to quality services for all; improving the integration of rehabilitation into the health sector; and strengthening rehabilitation planning and implementation.

Tabled at this meeting was the Rehabilitation in Health Systems Report,<sup>30</sup> which provided evidence-based recommendations for the expansion and extension of rehabilitation services. Relevant recommendations are:

- » rehabilitation services should be integrated into and between primary, secondary and tertiary levels of health systems
- » a multidisciplinary rehabilitation workforce should be available
- » both community and hospital rehabilitation services should be available
- » hospitals should include specialised rehabilitation units for inpatients with complex needs
- » financial resources should be allocated to rehabilitation services to implement and sustain the recommendations on services delivery
- » where health insurance exists or is to become available, it should cover rehabilitation services.

### The Evidence Context

A multi-method approach was taken during the Project to develop a strong evidence base for best-practice rehabilitation care. Key methods and findings are summarised below.

## Literature, policy and interstate service review

Requirements for the delivery of best-practice paediatric rehabilitation care were identified from a review of relevant literature, policy, guidelines, and interstate paediatric rehabilitation services as:

- » coordinated care provided at the right time, at the right intensity, close to home, and in natural settings whenever possible
- » clear entry pathways that support early identification, referral, and access
- » meaningful partnerships with children, families, and communities
- » co-located rehabilitation teams providing care through an interdisciplinary approach, in flexible care settings across the continuum
- » collaborative goal setting centred around child and family priorities and focused on participation, inclusion, and quality of life
- » collection of outcomes data for service planning and benchmarking, including functional assessments on admission and discharge and PREMs and PROMs
- » support for whole of family to optimise social and emotional wellbeing
- » alignment with cultural respect principles in all aspects of service development and delivery
- » use of accessible technology for transparent communication and information-sharing

- » provision of increased support at times of transition, particularly during transition to adult services
- » clearly defined leadership and clinical governance structures in the rehabilitation service
- » formalised workforce development processes and structures
- » participation in, and engagement with, research to ensure excellence and innovation in care
- » partnerships to foster collaboration across the whole system, particularly education and disability.

#### Co-design workshops

The experiences that patients, the public, and health professionals have when they receive or deliver healthcare services are a valuable source of information that can be used to improve care and transform services.<sup>31</sup>

At co-design workshops held during the Project, 34 consumers and 104 service providers were asked to describe what the future paediatric rehabilitation service model in Tasmania should look like, in the ideal world. Ideas put forward by participants centred around the following eight themes:

- » Child- and family-centred care
- » Coordinated care
- » Continuum of care
- » Collaborative teamwork
- » Holistic and integrated
- » Informative and empowering
- » Equitable and consistent
- » Innovative and best practice

Refer to the Model of Care Co-design Workshops Summary Report for further details.



This section summarises the current situation for paediatric rehabilitation practice in Tasmania. It provides an overview of available service-use data and a summary of feedback received from consumers and service providers.

## Paediatric Rehabilitation Practice in Tasmania

In-depth interviews and service mapping activities were conducted with service providers directly involved in the provision of paediatric rehabilitation care. These have informed the following overview of current paediatric rehabilitation practice in Tasmania.

Specialised paediatric rehabilitation care has been available in Tasmania for many years. However, the service is not formally recognised, there is no MoC for service delivery, and there are no formalised leadership and governance structures to oversee and guide services. This means that the delivery of paediatric rehabilitation care varies across the State and there is an absence of statewide processes to coordinate patient flow, undertake assessments and care planning, and guide decisions on the scope of the service. By comparison, adults in Tasmania have access to a recognised and formalised multidisciplinary rehabilitation service that is available across the State.

There is a full-time statewide paediatric rehabilitation consultant position in THS, WACS - South. This position provides support to all regions through periodic outreach clinics, and is supported by a part-time general paediatrician and a rotating senior paediatric registrar position, both employed by WACS - South. Multidisciplinary paediatric rehabilitation therapy teams are not clearly identified, there is no defined coordinator role to manage patient flow, and the approach to rehabilitation care is not interdisciplinary.

There is no dedicated inpatient ward or beds for the delivery of paediatric rehabilitation care in Tasmania. Tasmanian children requiring inpatient rehabilitation care are supported by the paediatric rehabilitation consultant in a general paediatric medical ward. During these admissions, the acute medical team continues to provide day-to-day medical support and the general hospital paediatric allied health team delivers rehabilitation therapy. There are few formal processes to guide service delivery in this setting. For example, there are no consistent formalised processes for functional assessment, coordination of care, care planning, goal setting and outcomes measurement. Furthermore, care type changes are not always implemented, which means that paediatric rehabilitation activities are not always identified and appropriately funded. The availability of allied health

support is often limited due to concurrent demands from the acute caseload, which impacts on the intensity of intervention provided and the scope of the service.

Most children access inpatient rehabilitation in Tasmania following acute inpatient treatment for a medical condition or injury. There is currently limited scope for planned inpatient rehabilitation admissions. This particularly affects children who are undergoing complex orthopaedic surgeries or have experienced exacerbations of chronic conditions with further loss or limitation in function. These children commonly travel interstate to access inpatient rehabilitation services.

The provision of ambulatory rehabilitation care also varies across the State, and intensive same-day rehabilitation is currently not available in Tasmania. As with the inpatient setting, there are few formal processes to guide service delivery. Allied health support is drawn from publicly funded paediatric allied health teams across the State, as per the current children's therapy services model in Tasmania. In the North and South of the State, allied health support is accessed via St Giles, a not-for-profit allied health therapy and disability provider. In the North-West of the State, allied health support is accessed via THS North-West. This support is largely provided by physiotherapists and occupational therapists, with very limited access to other disciplines.

There are strong links with interstate services including rehabilitation, orthopaedics, plastics, urology, and neurosurgery. These links are essential to ensure that Tasmanian children have access to specialised interventions that are not available due to insufficient critical mass to safely provide highly specialised care within the State. This particularly refers to:

- » complex orthopaedic surgery to maximise functional mobility and manage complications in children with congenital and acquired conditions (mainly cerebral palsy)
- » specialised gait laboratory analysis to assist planning for interventions such as complex orthopaedic surgery to maximise functional mobility and minimise pain and dysfunction in children with congenital and acquired conditions (mainly cerebral palsy)
- » neurosurgical treatment for children with complex movement disorders, such as intrathecal baclofen, deep brain stimulation and selective dorsal rhizotomy
- » plastic surgery to manage complications and maximise function in children with congenital and acquired conditions (mainly cerebral palsy)
- » urology to optimise management of neurogenic bladder and bowel in children with congenital and acquired conditions (mainly spinal cord disorders).

### Paediatric Rehabilitation Service-Use Data

Tasmania does not yet participate in paediatric AROC benchmarking and there is no consistent statewide approach to data collection or care type changes for paediatric rehabilitation activities. This means that children requiring specialist paediatric rehabilitation care are not always identified through existing reporting mechanisms. It is therefore likely that available data underestimates the true demand for services.

#### Inpatient rehabilitation data

Five years of Tasmanian hospital separation data identified 11 episodes of inpatient rehabilitation care over a total of 383 bed days, all at the RHH. It should be noted that six of these episodes were seen by the adult rehabilitation team in an adult ward (all were 16 or 17 years old). During the same period, Tasmanian children received 31 episodes of inpatient rehabilitation care over a total of 431 bed days through VPRS at tertiary hospitals in Melbourne. The table below provides an overview of identified inpatient rehabilitation episodes of care for Tasmanian children between June 2014 and June 2019.

Episodes of inpatient rehabilitation care for Tasmanian children 2014–2019

Location	Episodes (bed days)	Average length of stay
RHH	11 (383)	34.8
VPRS	31 (431)	13.9

The average length of stay in Tasmania was high at 34.8 days, compared to 13.9 days at VPRS. However, this finding should be interpreted with caution due to the small number of identified episodes and the differences in presentations seen at each site. All identified inpatient episodes at the RHH were related to complex acute presentations, most with complicating psychosocial factors. By comparison, 19 of the VPRS episodes were planned admissions following elective complex orthopaedic surgery.

The available data illustrates that most Tasmanian children who require intensive inpatient rehabilitation care access this care interstate. As a result, Tasmanian children and their families are spending significant time away from their usual supports while they access rehabilitation care. There is strong anecdotal evidence that this is a source of social and financial stress (outlined in more detail in the following section). Furthermore, this travel is adding to the overall health system-level cost of providing rehabilitation care.

#### Ambulatory rehabilitation data

Reliable data is only available for medically led outpatient clinics at this time. Data pertaining to allied health activity cannot be reported due to differences in the collection and reporting of data across the State. In the 2018–2019 financial year there were 533 recorded attendances at outpatient clinics, including general paediatric rehabilitation clinics and several sub-specialist clinics (spinal, combined orthopaedic and rehabilitation, acquired brain injury and neuromuscular clinics); 135 of these attendances were new referrals. There were an additional 75 attendances at Botulinum Toxin injecting clinics.

As of the 23rd January 2020, there were 344 children and adolescents on the statewide paediatric rehabilitation caseload. This caseload is heavily skewed towards children with congenital conditions, while children with acquired conditions are the minority. The largest proportion of children on the caseload live in the South (65 per cent), followed by the North (18 per cent), and the North-West (17 per cent). When this caseload distribution is compared with the regional distribution of the 0–17 year-old population (South 51 per cent, North 27 per cent, and North-West 22 per cent), it is clear that children in the South are being identified for paediatric rehabilitation support at a higher rate than children who live in the North and North-West.

## The Consumer Experience

Despite the commitment and dedication shown by Tasmanian service providers, there is strong evidence that paediatric rehabilitation care in Tasmania is often not meeting consumer expectations.

In-depth interviews were conducted with 12 consumers (parents and caregivers of children who access paediatric rehabilitation support) to explore their past experiences with paediatric rehabilitation and their ideas for service improvement. The main findings are summarised below.

There is frustration and confusion relating to the lack of clarity about the role of rehabilitation and how it interfaces with other services.

"Nobody really understands the system, everyone says somebody else can do it... This is incredibly frustrating and confusing and I feel righteously indignant on behalf of my child."

There is a need for more timely and accessible information about rehabilitation services.

"If we had just been informed it would have been a really great journey for us and our child, you feel so much more able to handle things when you have information."

Families often feel they need to be powerful advocates in order to get the right care for their child.

"We got some support when we came home from surgery because we jumped up and down and made a big noise because we weren't getting what we needed."

Families are often experiencing unwarranted treatment burden during their care journey.

"You feel like you are fighting for things all the time, it's frustrating. I am always following things up, I can think of three things right now. It is exhausting."

There is a need for better coordinated care and improved communication processes.

"One of the biggest problems that we had was interactions between services, there was none! The left hand wasn't talking to the right hand."

There is a need for a more collaborative and coordinated approach from the rehabilitation team.

"More therapy available would be helpful. I feel like I spent a lot of time getting recommendations but not the follow-up."

"It has always been separate appointments for different people, they don't work together. We can never get an OT and physio on the same day, so it is multiple days off school." The need to travel interstate and the lack of coordination is adding to the overall burden of care.

"We were pretty desperate to get home, you don't want to be in a situation where you can't access your family and supports and there was money stress too."

"The transition between the Victorian hospital and Tasmania is mind bogglingly bad. Post-surgery it all fell apart."

There is a need for more socio-emotional support for families during their journey with paediatric rehabilitation care.

"We need a social worker — so that when I was falling apart and breaking down trying to manage the complex and stressful situations I experience at home, I had some support. I started asking for help and contacting our specialist. I shouldn't be speaking to the specialist as it is not a good use of their time."

#### Service Provider Feedback

Feedback was sought from service providers regarding perceived strengths, weaknesses and priority areas for improvement for paediatric rehabilitation service delivery in Tasmania. In-depth interviews were conducted with 16 service providers directly involved in paediatric rehabilitation service delivery, and 65 responses were received to an online survey that was widely distributed to Tasmanian service providers. The main findings are summarised below.

Perceived strengths expressed by service providers related to individuals rather than the paediatric rehabilitation service or system. These included strong informal relationships and dedicated staff.

Perceived weaknesses far outweighed strengths in the feedback received. Concerns raised included:

- » poor awareness of the service
- » lack of clarity regarding service scope and entry pathways
- » lack of care coordination and communication processes
- » lack of resources to support rehabilitation service delivery including staffing, infrastructure, and equipment
- » lack of support for workforce development
- » lack of clarity about the interface between NDIS and rehabilitation.

### The Imperative for Change

A shift in thinking is required to develop a new approach to better meet the needs of Tasmanian children who require rehabilitation care and their families. Without a designated service, Tasmanian service providers have attempted to provide the best possible paediatric rehabilitation care within the resources and skills available to them. There are significant issues with how paediatric rehabilitation care is currently provided in Tasmania. If left unaddressed, these issues are highly likely to flow on to poor outcomes and negative long-term impacts for Tasmanian children, their families, and their wider communities. This flow-on effect is detailed below:

#### Identified issues, likely outcomes and long-term impacts

#### **ISSUES**

- » Service is not formalised or recognised, inconsistent processes across the State.
- » Unclear clinical governance and leadership structures.
- » Lack of clearly identified funding for paediatric rehabilitation.
- » Rehabilitation teams are not clearly defined and approach to care is not interdisciplinary.
- » Insufficient access to specialist skills and professional roles, particularly allied health and nursing.
- » Lack of coordination of care and inconsistent communication processes.
- » Care is not available across the continuum (limited settings).
- » Lack of processes to develop and retain a skilled workforce.
- » Lack of clarity about service scope and access pathways.
- » Lack of processes to support goal setting and outcome measurement.
- » Lack of access to appropriate space and infrastructure.
- » Confusion about the interface with other services.
- » Activity is not being identified through existing reporting and data-collection processes.

## **→**

### **OUTCOMES (SHORT TERM)**

- » Poor awareness of the service.
- » Delayed access to rehabilitation care.
- » No access to rehabilitation care (gaps in care).
- » Fragmented patient journey.
- » Increased reliance on interstate services and increased financial cost associated with travel.
- » Insufficient intensity of care.
- » Inequitable access to care.
- » Consumer dissatisfaction and disengagement.
- » Variation in the quality of clinical services.
- » Lack of support for social and emotional wellbeing.
- » Duplication and inefficiencies in service delivery.
- » Increased length of stay/ prolonged hospital admissions.
- » Poor treatment outcomes and unwarranted clinical variation.
- » Delayed recovery.
- » Increased treatment burden and family stress, impacting on social and emotional wellbeing.



### **IMPACTS (LONGER TERM)**

- » Reduced independence and quality of life for children and their families.
- » Reduced inclusion and participation of children with disability in their communities.
- » Poor health outcomes and increased current and future disease burden for children and their families.
- » Increased current and future cost of healthcare and social services.



## The Tasmanian Paediatric Rehabilitation Service Model of Care

A MoC broadly defines the way health services are delivered. It outlines best practice care and services for a person or population group as they progress through the stages of a condition, injury, or event. It aims to ensure people get the right care, at the right time, by the right team, and in the right place.<sup>13</sup>

This statewide paediatric rehabilitation MoC has been developed through a co-design process with Tasmanian consumers and service providers. It is informed by the best available evidence and Tasmanian and national policy directions and reforms. It is intended to align with the broader future directions of Tasmanian statewide rehabilitation services.

This MoC clarifies the important role that paediatric rehabilitation plays in the Tasmanian health system and aims to:

- » place the child and family at the centre
- » build system and service capacity and capability to provide specialised paediatric rehabilitation care
- » provide a quality, integrated paediatric rehabilitation service that is responsive to the health and wellbeing of the community

» reduce the need for families to travel where services can be safely provided closer to home.

This MoC describes:

- » service vision, mission, and values
- » the scope of the service
- » enablers to support MoC implementation
- » models and care settings for service delivery
- » core sites and service requirements
- » service and clinical support requirements
- » standards of practice to guide service delivery at each of the key steps in the child and family journey.

This MoC has been developed to be high level and practical to enable a flexible response to emerging policy developments at a national level, changes in community needs, Tasmanian health service priorities, and available funding. This approach allows for the consideration of, and adaptation to, differences in service availability and provision across the State.

This MoC should be read in conjunction with the 10 recommendations provided at the beginning of this document. These recommendations will support and sustain the implementation of the MoC.





All Tasmanian children have access to specialised child- and family-centred paediatric rehabilitation care.



## Mission

To work in interdisciplinary, evidencebased and flexible ways in partnership with children and families to enable them to achieve the best possible outcomes.

#### **Values**

The core values of empowerment, collaboration, equity and innovation have been chosen by Tasmanian consumers and service providers to shape our identity, guide our behaviours and keep us accountable to each other and the people we support. These core values and what they mean are described below using direct quotes from consumers and service providers, as articulated during the MoC co-design workshops.



#### **Empowerment**

Providing informative care and treating children and families as active members of the rehabilitation team to empower them to achieve their best potential.

"Equip us to be part of the solution, give us the tools and information we need." (consumer)

"Respect parents and families as a valued source of knowledge." (consumer)



#### Collaboration

Working collaboratively to optimise locally delivered care and to provide coordinated and connected care throughout the rehabilitation journey.

"Create a genuine partnership with the family." (service provider)

"We need better communication between teams, cross sectoral between health, rehab, disability, all of the different services." (consumer)



#### **Equity**

Supporting children and their families across the continuum of care, based on their individual needs, regardless of their location, personal and social circumstances.

"Support should be made available, no matter which part of the State people are from." (service provider)

"Access and timeframes should be fair and consistent." (consumer)



#### Innovation

Encouraging innovation and flexibility to provide high-quality care that creates new possibilities for children and their families. "The service should always be striving to be better." (service provider)

"We see the rehab team as the experts." (consumer)

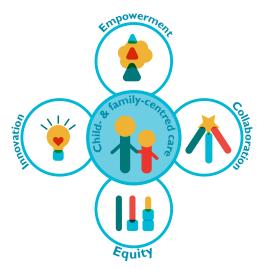
"Use the best available evidence to make decisions." (service provider)

Together these values will support the delivery of **child-and family-centred care** that is respectful of, and responsive to, the cultural background, preferences, needs, and values of children and families.

"Support the wellbeing of our family; think about the whole family not just the child." (consumer)

"Keep the child and family at the centre." (service provider)

"Prioritise opportunities for our child and our family to live a normal life." (consumer)



## The Scope of the Service

The service is integrated, statewide, and provides publicly funded specialised rehabilitation care to children with complex healthcare needs and functional impairment who may require support from multiple disciplines. Provision of care is overseen by a paediatric rehabilitation physician.

Access to the service is based on functional impairment rather than clinical diagnosis.

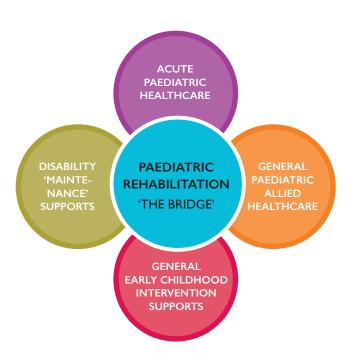
The service supports children and families who will benefit from a program of time-limited, goal-focused, interdisciplinary rehabilitation that is aimed at improving functional status and reducing the impact of the health condition. This includes children with health conditions such as diseases (acute or chronic), disorders (congenital and acquired) and injury, and/or children following medical or surgical intervention, who have goals amenable to a defined period of rehabilitation.

The service provides supports that aim to assist children and their families to:

- » achieve their highest possible level of independence physically, psychologically and socially
- » optimise their health-related quality of life
- » take part in everyday activities that are important to them, including educational, vocational, and recreational activities
- » facilitate the early detection and management of known complications arising from their congenital or acquired condition, accounting for growth and development
- » transition seamlessly across different settings through cross-sectoral collaboration.

The service does not provide acute paediatric healthcare, general paediatric allied healthcare, general early childhood intervention supports that are provided by other systems and services (such as ECEI and the Early Childhood Intervention Service), or disability 'maintenance' supports that are provided by the NDIS.

It is acknowledged that at times there will be some overlap between these different service areas and paediatric rehabilitation is often the bridge between these services. The service will follow a 'no wrong door' approach to reduce barriers, provide seamless support, and ensure that children and their families do not fall through the gaps. The service will provide coordinated support for children and their families across service and system boundaries and locations by working collaboratively with existing supports and services.



The service supports children and families who will benefit from a program of time-limited, goal-focused, interdisciplinary rehabilitation that is aimed at improving functional status and reducing the impact of the health condition.

### **Enablers**

The following section provides a summary of the key focus areas and elements that will enable the implementation of the MoC. The five enabler categories broadly align with the Draft Tasmanian Subacute Care Framework<sup>33</sup> and supporting documents.

## **Enabler I: Workforce**

FOCUS AREA	ESSENTIAL ELEMENTS
Governance and leadership	<ul> <li>» Overarching statewide leadership.</li> <li>» Close collaboration with key regional stakeholders to develop and support a shared vision.</li> <li>» Clinical governance provided as perTHS guidelines.</li> <li>» Collaboration in recruitment and workforce development across regions with relevant discipline leads.</li> </ul>
Regional teams that take an interdisciplinary approach to care provision	<ul> <li>» Identified rehabilitation teams that take an interdisciplinary approach and are supported by an overarching statewide peer network.</li> <li>» Regional team skill mix and availability to be determined by the demand for services.</li> </ul>
A skilled and sustainable workforce	<ul> <li>» Adequate staffing in each region to allow access to time-limited intensive therapy when clinically indicated.</li> <li>» Statewide clinical competencies and processes to achieve and maintain them.</li> <li>» Statewide interdisciplinary peer support, supervision and mentoring network, underpinned by a clear grade structure and senior clinical roles.</li> <li>» Accreditation for registrar in paediatric rehabilitation medicine.</li> <li>» Strong links with interstate services for peer support and networking.</li> <li>» Workforce flexibility with the capacity to move staff to areas of need.</li> </ul>

## **Enabler 2: Data and Performance Improvement**

FOCUS AREA	ESSENTIAL ELEMENTS
Engagement with	» Consumer engagement in ongoing service development and evaluation.
consumers	» Collection of PREMs and PROMs.
Data recording, reporting and analysis	» Consistent statewide processes to support data collection, care type classification and reporting as per relevant funding models.
, ,	» Upskilling staff in data analysis.
Evidence-based	» Measurable service goals with agreed key performance indicators.
evaluation and practice	» Participation in national benchmarking through AROC.
	» Staff training and accreditation in relevant, valid, and reliable functional assessments and
	outcome measures.
	» Staff engagement in reflective practice for continual quality improvement.
Compliance with	» Compliance with NSQHS standards.
national standards	
Research and education	» Promotion of research and education within the service to facilitate innovative and evidence-based care.

## **Enabler 3: Integrated Services**

FOCUS AREA	ESSENTIAL ELEMENTS
Child- and family-	» Active participation of children and families in all aspects of the journey.
centred care	» Advocacy for child and family needs.
	» Viewing the child in the context of their family and natural environment.
Coordinated care and interdisciplinary	» Designated regional coordinator to manage patient flow, oversee local team processes, and link with local services and the statewide network.
teamwork	» Regular region-based and statewide interdisciplinary team meetings.
Access to care	» Equitable and transparent entry and exit pathways.
	» Consistent processes for early identification, screening, and prioritising referrals.
	» Readily available information about the service.
	» Staff actively promoting community awareness of the service.
Care close to home	» Timely access to services in the community, to reduce the need for children and families to travel, and for safe transition across care settings.
Interconnected	» Strong networks and links across care settings and systems.
services	» Formalised links with adult services to support transition to adult care when ongoing needs are identified.

## **Enabler 4: Technology**

FOCUS AREA	ESSENTIAL ELEMENTS	
Access to technology	» Videoconferencing resources to facilitate statewide collaboration and to support the delivery of telerehabilitation. This will ensure timely access to consultations and specialist interventions across the State, when clinically appropriate.	
Information and communication systems	» Shared statewide software to support the transfer of patient information and care plans between care settings and regions and to facilitate data collection for reporting and benchmarking purposes.	
	» Systems to facilitate effective collaboration and information-sharing with consumers and external service providers.	

## **Enabler 5: Infrastructure**

FOCUS AREA	ESSENTIAL ELEMENTS
Environment	» Safe and accessible space for children and families that is compliant with NSQHS standards.
	» Access to space for interdisciplinary activities such as team meetings.
	» Access to an accessible community-based space (within the primary, secondary or community care settings) for appointments and therapy.
Clinical equipment and resources	» Access to specialised and child-appropriate rehabilitation equipment.
Transport	» Statewide processes for patient transfers between facilities and interstate, when care cannot be safely provided close to home.
	» Access to infrastructure to support statewide staff travel when required.

## Flexible Care Delivery and Settings

The availability of services across flexible settings is a foundational requirement for integrated rehabilitation care. <sup>15</sup> A child may move between different care settings and models of care at different stages of their paediatric rehabilitation journey. The Tasmanian Statewide Subacute Care Project Advisory Committee has agreed to the NSW Rehabilitation <sup>15</sup> care settings. These have been adapted to suit the paediatric rehabilitation context in Tasmania.

Inpatient care will only be available in tertiary care settings. Specific models of inpatient care delivery are described below.

INPATIENT CARE (TERTIARY CARE SETTINGS)				
Care Model	Who is it for?	How will it be delivered?		
In-reach to Acute	Children with functional impairment and rehabilitation goals who can participate in a rehabilitation program and require close support from the acute team due to an acute or unstable health condition.	Early rehabilitation is provided while day-to-day care needs are managed by the acute care team in a paediatric ward in a tertiary hospital.  » Integrated pathway from acute to subacute care.  » Screening for eligibility for inpatient rehabilitation.  » Shared care model between medical specialist groups.		
Admitted Inpatient	Children with functional impairment and rehabilitation goals who can participate in intensive rehabilitation therapy and require the safety of a structured inpatient environment.	A subacute paediatric rehabilitation care type is allocated in a paediatric ward in a tertiary hospital. Rehabilitation care is delivered by a team that takes an interdisciplinary approach, under the direction of a paediatric rehabilitation physician. Care is evidenced by an individualised interdisciplinary management plan that includes negotiated time-limited goals and formal assessment of functional ability.		
Hub and Spoke Inpatient	Children with functional impairment and rehabilitation goals who can participate in intensive therapy and have care needs that can be safely managed in a tertiary hospital that is closest to their home.	One tertiary hospital is the specialist 'hub' and another tertiary hospital in another region is the 'spoke'. Rehabilitation care is delivered via a collaborative model where the hub and spoke hospitals work together to deliver the rehabilitation program. Consultations may be face to face or via telerehabilitation. Care is evidenced by an individualised interdisciplinary management plan that includes negotiated time-limited goals and formal assessment of functional ability.		

Ambulatory paediatric rehabilitation care may be delivered across multiple care settings, depending on individual needs and the availability of local services and facilities. In the context of paediatric rehabilitation, ambulatory care is most likely to be provided in either tertiary, secondary, primary or community care settings.

AMBULATORY CARE – TERTIARY, SECONDARY, PRIMARY AND COMMUNITY CARE SETTINGS				
Care Model	Who is it for?	How will it be delivered?		
Same-day	Children with functional impairment and rehabilitation goals who can participate in intensive therapy but do not require the safety of a structured inpatient environment. May be accessed as a 'step-down' from inpatient care.	Intensive rehabilitation care delivered in a tertiary hospital ward or outpatient department by a team that takes an interdisciplinary approach, under the direction of a paediatric rehabilitation physician. An intensive rehabilitation program (several sessions a week) involving at least two disciplines that are working towards common goals. Care is evidenced by an individualised interdisciplinary management plan that includes negotiated time-limited goals and formal assessment of functional ability.		
Outpatient	Children with functional impairment and rehabilitation goals who require specialist rehabilitation intervention that is not intensive in nature.	Delivered in an outpatient facility (in either a tertiary, secondary or primary care setting) by various multidisciplinary team members depending on individual needs. Varying intensity of care and varying level of coordination and collaboration between disciplines.		
Natural Settings	Children with functional impairment with rehabilitation goals that can be most effectively addressed in natural environments.	Delivered in natural settings for the child and their family by different multidisciplinary team members depending on individual needs. Varying intensity of care and varying level of coordination and collaboration between disciplines. Natural settings might include home, community, and educational settings. Also commonly referred to as home- or community-based rehabilitation.		

## **Core Sites and Service Requirements**

There will be one core site in each region. In line with CSP approval levels for adult rehabilitation and paediatric medicine and regional demand for services, level 5 complexity paediatric rehabilitation services will be delivered in the South, and level 4 complexity services will be delivered in the North and North-West. Level 6 services will continue to be delivered interstate through a collaborative partnership with VPRS. It is proposed that the following delineations in the availability of care models across regions will apply:

CARE MODELS		SOUTH (LEVEL 5)	NORTH (LEVEL 4)	NORTH- WEST (LEVEL 4)
INPATIENT	In-reach to Acute	<b>✓</b>	<b>✓</b>	X
	Admitted Inpatient	<b>✓</b>	X	X
	Hub and Spoke Inpatient (Hub = South, Spoke = North, North-West)	×	<b>✓</b>	<b>✓</b>
AMBULATORY	Same-day	✓	✓	✓
	Outpatient	✓	✓	✓
	Natural Settings	<b>✓</b>	✓	✓

The proposed service and workforce requirements that correspond with level 4 and 5 complexity levels have been adapted from the existing TRDF for adult rehabilitation<sup>10</sup> and are described below:

COMPLEXITY	SERVICE REQUIREMENTS	WORKFORCE REQUIREMENTS
LEVEL 4	Designated rehabilitation team that takes an interdisciplinary approach to care provision.  Care coordination.  Designated therapy areas and equipment.  Access to clinical support services and post-hospital services to facilitate ongoing community management.  Access to manufacture and provision of specialist aids and equipment.	Access to paediatric rehabilitation physician from level 5 site.  Onsite coordinator providing leadership in rehabilitation.  Onsite access to core allied health roles and specialty roles accessed from level 5 site.
LEVEL 5	As for level 4, plus:  Dedicated rehabilitation team that takes an interdisciplinary approach to care provision.  Responsible for leadership, liaison, research, and support for other sites.  Accredited training site for registrar in paediatric rehabilitation medicine.  Additional infrastructure and equipment to meet rehabilitation needs of complex patients.	As for level 4, plus:  Consultant paediatric rehabilitation physician onsite.  Paediatric rehabilitation registrar.  Neuropsychologist.  Clinical nurse coordinator.

## Service and Clinical Support Requirements

Paediatric rehabilitation service delivery will be supported by the establishment of a statewide service, overseen by a high-level clinical leadership position. This position will have clinical oversight, establish connections, drive the implementation of the service in collaboration with regional leadership positions, identify funding opportunities, be responsible for service evaluation activities, and inform future service directions.

A program manager position will support the high-level clinical leadership position and help develop and implement statewide processes, program development, data management, quality improvement and statewide education and peer support.

A regional coordinator position will be based at each core site to coordinate local service provision, manage patient flow, support the successful transition of children across sites and care settings, establish links with ongoing supports when indicated, and provide a point of contact for families.

The statewide interdisciplinary clinician network will include, but not be limited to, the following core roles:

- » Rehabilitation Consultant
- » Paediatrician
- » Paediatric Rehabilitation Registrar
- » Physiotherapist
- » Occupational Therapist
- » Nurse/Clinical Nurse Coordinator
- » Social Worker
- » Speech Pathologist
- » Clinical Psychologist
- » Neuropsychologist
- » Allied Health Assistant
- » Education Liaison Role (or formalised links with education stakeholders)

Senior clinicians will develop a clinical network across the service that will involve collaboration and communication between all sites. This will ensure a level of consistency across the service, upskilling of local service providers, and the development and maintenance of specialist skills across Tasmania.

There will be established pathways to support access to/collaboration with the following Tasmanian professional groups or services when indicated:

- » GPs/Paediatricians
- » Medical and Surgical specialties
- » Child and Adolescent Mental Health Services
- » Orthotist and Prosthetists
- » Dietitians
- » Allied health private providers
- » Persistent Pain Service
- » Vision and Hearing services
- » Interpreter services
- » NDIS/ECEI partners
- » Aboriginal Liaison Officers
- » GP Liaison Officers
- » Child Safety Liaison Officers

There will continue to be strong links with interstate specialist services to ensure that Tasmanian children have access to specialised interventions that are not available in Tasmania due to insufficient critical mass to safely provide highly specialised interventions within the State.



## The Child and Family Journey

All children who access an intensive rehabilitation program will progress through each of the following steps during their journey: Referral; Screening and Access; Goal Setting, Assessment and Care Planning; Intervention; Care Evaluation; and Discharge, Follow-up and Re-entry. Communication and Care Coordination will support integrated service delivery across the care continuum. This will provide an individualised and seamless journey for children, families and their supports.

This journey may begin at any care setting, and a child and family may move across multiple care settings and models of care delivery at different points in this journey.

There will be set processes to manage and respond to unexpected or unintended clinical variations and interruptions to the child and family journey. These will be managed collaboratively within the regional site with support from statewide clinical leadership. A no-blame culture will be fostered throughout, and there will be set processes to facilitate team reflection and peer support.

The following activities will be undertaken at each step to ensure that care provision aligns with the service vision, mission, and values, and that children and families are well supported throughout their journey.

#### I. Referral

- » Information about the service will be accessible to families and service providers, including guidelines and processes to identify children who would benefit from rehabilitation.
- » Families and service providers will be able to initiate contact with the service before the formal referral is made. This may be just to seek information, or lead to a formal referral to the service, or the referral may be redirected to a more appropriate service ('no wrong door' approach).
- » There will be a single entry point and a clearly defined referral process in each region, with overarching statewide consistency in processes and documentation templates.
- » Referral will occur in a timely manner to facilitate early rehabilitation intervention and reduce functional decline.

#### Child and Family Journey



### 2. Screening and Access

- » Soon after the initial referral, a screening conversation will be carried out with the family and their relevant supports to acknowledge the referral and start the individual care plan. The conversation will include gathering background information, providing information about the service, setting expectations, and identifying family priorities.
- » This screening process may be supported by a clinical handover from other services or care settings, to support continuity of care and patient safety.
- » Depending on the individual situation, screening may occur face to face or via phone/videoconference.
- » The start of the service will be timed and planned based on screening and referral information. This decision will be communicated to the family and referrer.
- » Appropriate screening and prioritisation tools will be identified or developed and consistently implemented across the service.

#### 3. Goal Setting, Assessment and Care Planning

- » An initial assessment will occur once the child has been accepted into the service and initial needs have been identified through the screening process.
- » The assessment is a clinical process that may involve different members of the rehabilitation team, depending

- on the complexity of the child's needs. A child with more complex needs may require an interdisciplinary assessment, whereas a child with less complex needs may require single discipline assessment/s with one or more members of the team.
- » Wherever possible, recognised and validated assessment tools and outcome measures will be used. This will improve consistency of practice and allow participation in service evaluation and benchmarking activities.
- » Care planning will be informed by the assessment and will be centred around child and family priorities.
- » The care plan will be documented with agreed goals that are linked to interventions.
- » Resources will be identified or developed to support child and family participation in goal setting.
- » Goals will be developed through collaboration with the child and family and written down in the family's own words.
- » Goals will have a focus on participation, inclusion, quality of life, and everyday activities and routines.
- » The child and family will be provided with the names and roles of their rehabilitation team, a contact number/email for a key team member or coordinator, and a copy of their care plan once it has been developed.
- » The care plan will be shared with relevant service providers with the consent of the family.
- » A team member will follow up with the family following the initial assessment and provide the opportunity to ask questions.

#### 4. Intervention

- » Intervention will be well coordinated, evidence based and provided by a skilled and competent workforce.
- » Intervention will be engaging for the child and family and focused on function, activities, and participation.
- » The setting, location, and intensity of the intervention will be the most appropriate to meet the individual child and family needs and priorities. The safety of the rehabilitation care team and that of the child and family will also be considered when deciding the setting and location of the intervention.

- » Where possible, the options will be presented to the family and they will be empowered to make a choice. When appropriate, priority will be given to intervention close to home and in natural settings to facilitate participation and translation of skills to everyday settings.
- » Telerehabilitation will be considered when appropriate.
- » Interdisciplinary (joint) appointments will be offered whenever possible.
- » The team will make time to celebrate success and review progress towards goals during the intervention period.

#### 5. Care Evaluation

- » The location and timing of the care evaluation will be flexible. Sometimes a formal review appointment will be required and sometimes a phone call will suffice.
- » The team will collect PREMs and PROMs and complete standardised functional assessments on completion of the intervention.
- » The team will check in with the family to see how things have worked in their own environment.

#### 6. Discharge, Follow-up and Re-entry

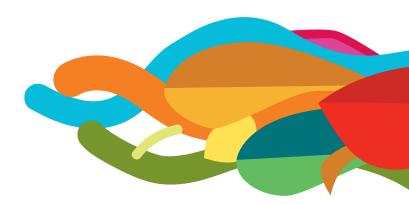
- » The timing of discharge will be decided by the team, in collaboration with the family and child when appropriate.
- » The family and their usual supports, including their GP or paediatrician as appropriate, will be informed.
- » When ongoing needs are identified, the family will be assisted to link in with other services.
- » Information will be given to families and their usual supports about key transition points and possible triggers that may indicate a need to re-enter the service.
- » The family will leave the service with details on who and how to contact if questions arise.
- » When it is deemed that follow-up is required, this may involve a face-to-face review, phone call or videoconference. The method and timing of the followup will be identified with the family before discharge.

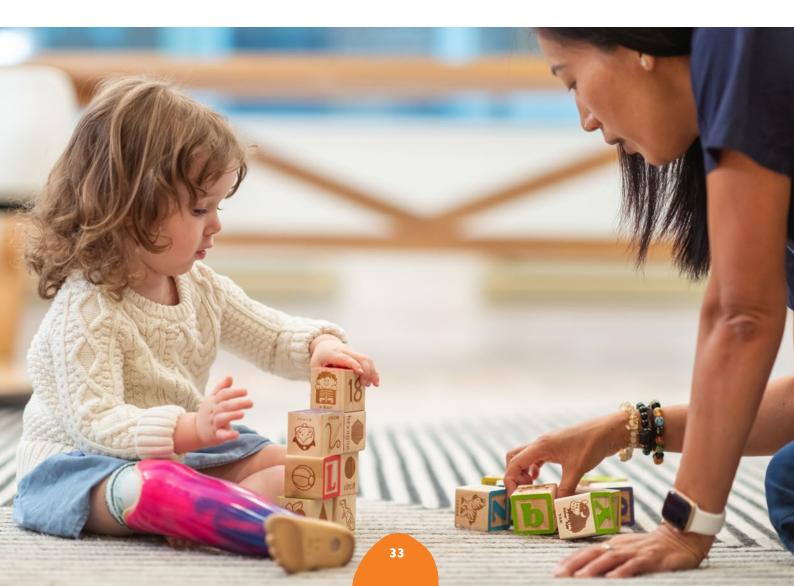
## **Next Steps and Implementation**

This MoC and the accompanying high-level recommendations will be taken forward to an Implementation Plan that will step out key action areas with suggested timeframes from 2020–2030.

The Project team will collaborate with key regional stakeholders to ensure the Implementation Plan allows for regional differences in service availability and care provision and will meet the needs of children and families across the State.

Some recommendations and key action areas may be implemented within existing resources, or through reallocation of existing resources. When it is determined that new resources are required, a business case will be developed in parallel.





## **Abbreviations**

AROC Australasian Rehabilitation Outcomes Centre

**CSP** Clinical Services Profile

**ECEI** Early Childhood Early Intervention

**LGH** Launceston General Hospital

MoC Model of Care

NDIS National Disability Insurance Scheme

NSQHS standards National Safety and Quality Health Service standards

**NWRH** North West Regional Hospital

PREMs Patient-Reported Experience Measures
PROMs Patient-Reported Outcome Measures

**RHH** Royal Hobart Hospital

SoPI Statement of Purchaser Intent

THS Tasmanian Health Service

TRDF Tasmanian Role Delineation Framework

VPRS Victorian Paediatric Rehabilitation Service

WACS Women's and Children's Services

WHO World Health Organization

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