

ACTION POINTS FOR LEAVING PAEDIATRIC HEALTH SERVICES FOR ADOLESCENTS AND YOUTH WITH CEREBRAL PALSY

ABOUT THIS WORK

The Paediatric Society of New Zealand Cerebral Palsy Clinical Network recognises there are significant differences throughout New Zealand in the health transition of young people with cerebral palsy (CP) from paediatrics to adult services. The variation in the transition process may be due to many factors, including differences in the availability of resources, geographical location, regional policies and models of care across Aotearoa. This document is specifically aligned to people with cerebral palsy however we acknowledge the value and importance of transition services for all people with disability.

Since the inception of the Cerebral Palsy Clinical Network, three years ago, the Transition Workstream has undertaken significant work in reviewing the literature around the transition of adolescents and young adults (AYA) to adult care in cerebral palsy; and available transition models from around the world. This is essential, as AYA with CP have specific and complex needs that are not represented in other population groups and have high prevalence. AYA and adults with CP are expected to live a fulfilling life as adults, however current literature suggests there are significant discrepancies in their health outcomes compared to the general population, with earlier and greater co-morbidities.

A summary and commentary of transition models was published here: <https://starship.org.newzealand/health-professionals/international-guidelines-and-resources-for-transition-in-cerebral-palsy/>

The primary outcome of this work has been the further development of the **Action Points for Leaving Paediatric Health Services for Adolescents and Youth with Cerebral Palsy**. The checklists reflect the literature available on the subject at the time of researching, and some of the recommendations within may be described as aspirational in a New Zealand context. The checklists will provide healthcare professionals and service planners with a guide for consideration of what to consider in the transition care of AYA with CP within New Zealand and what to include in the review of adults with CP.

There are limitations within these documents within a New Zealand context, where there was a lack of research into bicultural transition models, and minimal research specific to the New Zealand population. The transition workgroup aims to collaborate with other groups researching transition around New Zealand and with tangata whenua to create a model relevant to the local context.

The Action Points for Leaving Paediatric Health Services for Adolescents and Youth with Cerebral Palsy is the original work of collaboration between the CPCN Transition Workstream members and those from within the health sector that provided feedback prior to publishing.

“Tamariki in Aotearoa flourish in health and wellness”

ACTION POINTS FOR ADOLESCENT AND YOUNG ADULT (AYA) MOVING INTO ADULT HEALTH SERVICES IN CEREBRAL PALSY (CP)

Philosophy/Principles:

AYA (Adolescent and Young Adult) living with CP and disability are empowered to transition from paediatric services to adult services through a structured, standardised process, with input from their whānau.

KEY PRINCIPLES	ACTIONS		
	Essential for current services	Important to incorporate	Ideal to incorporate
Partnership	Equal partnership with the young person living with CP to foster independence, confidence, health self-efficacy and sense of wellbeing. All processes involve the young person's views and needs in decision making in a way that is meaningful to them.		
Cultural safety	Commitment to eliminating inequities and bias for young people living with CP. Commitment to ongoing professional development and training for cultural safety for those caring for young people living with CP.	Awareness of other cultural groups (e.g. Asian and Pacific peoples) and concepts of disability (e.g. medical, social, and biopsychosocial model)	

	<p>Utilise Māori and other culturally appropriate health advisors.</p> <p>The application of kaupapa māori principles that promote:</p> <ul style="list-style-type: none"> -<i>Manaakitanga</i> (respect and kindness with emphasis on responsibility and reciprocity) -<i>Whanaungatanga</i> (relationships and connections within/ across services and define responsibilities) -<i>Rangatiratanga</i> (leadership, confidence, self-determination) -<i>Whakatoi</i> (curiosity and confidence) 		
<p>Information provision</p>	<p>Provide information about entitlements for young people living with CP to transition including:</p> <ul style="list-style-type: none"> -WINZ allowances and grants -Equipment needs and provisions -Parking permits (CCS Disability Action) -Driver assessments (Enable) <p>Needs Assessment Service Coordinator (NASC) Assessments:</p> <ul style="list-style-type: none"> -Respite -Home and Community Support Services (personal cares, household management) -Community Day Programmes -Supported Living -Community residential Support Services 		<p>Liaise with Ministry of Education (MOE)</p> <p>Liaise with local CCS Disability Action</p>

<p>Support and Services into Adulthood Support Agencies</p>			<p>Based on needs and interests of the young person living with CP including:</p> <ul style="list-style-type: none"> -Participation in physical activity: Parafed, Halberg Trust -CP Society -New Zealand Standards and Monitoring Service - CCS Disability Action Supported Lifestyles programme -Workbridge supported employment agency -Intensive Wraparound Service through MOE -Welfare Guardianship (for those with Intellectual Disability)
<p>Support and Services into Adulthood Vocational skills and independent living services</p>		<p>Consider referral to an occupational therapist where necessary for the young person with CP to increase independence in home, work, or leisure.</p>	<p>Engage with schools and disability support agencies to seek local community opportunities.</p>
<p>Barriers for Accessing Care</p>			<p>Consider accessible transport, physical space, and communication needs of the young person living with CP. Include whānau when appropriate in accessing care. Utilise other professionals where necessary e.g. social workers.</p>

<p>Healthcare Reviews</p>	<p>All people with CP should be enrolled with a GP. Offer regular healthcare reviews tailored to persons needs and preferences including allowing for longer appointments. Ideally these reviews should be offered at least yearly.</p>	<p>Annual review with expert in neurodisabilities if the young person living with CP is:</p> <ul style="list-style-type: none"> -GMFCS IV and V -Experiences persistent communication difficulties -Lives with an intellectual disability -Lives in a long-term care facility -Lives with comorbidities <p>Refer to multidisciplinary or community allied health team if:</p> <ul style="list-style-type: none"> -Ability to carry out daily activities deteriorates -Orthopaedic or neurosurgical procedure is being considered that may affect functional abilities 	
<p>Details of Health Care Reviews Health issues more frequent in CP</p>	<p>Regular assessment for health issues more frequent in CP including:</p> <ul style="list-style-type: none"> -Pain/fatigue -Spasticity. See Management of Abnormal Tone. -Contractures, scoliosis, early onset arthritis, bone mineral density, fractures -Mental health -Fatigue and Depression -Seizures / Epilepsy -Nutrition -Constipation -Gastroesophageal reflux -Respiratory monitoring in GMFCS IV and V. NICE Recommendations CP in adults section 1.4.22 to 1.4.35 	<p>Offer vaccinations such as influenza and COVID.</p> <p>Discussions of age-appropriate cancer screening (includes risks, benefits, and practical considerations).</p>	

	<ul style="list-style-type: none"> -Saliva management - Hearing or vision Loss - Hypertension - Kidney stones 		
Details of Health Care Reviews Pain	Pain of the young person with CP should be assessed and managed at each healthcare review.	Consider different pain scales based on communication needs. Where appropriate, include whānau and caregivers.	Consider effects of: <ul style="list-style-type: none"> -Muscle tone -Bladder problems -Constipation -Emotional distress -Posture -Seating -Medication -Sleep quality -Nutrition/feeding regime
Details of Health Care Reviews General health			Consider all aspects of health including: <ul style="list-style-type: none"> -Preventative health screening e.g., breast and bowel cancer -Sexual health -Encourage physical activity. See Infographic for Physical Activity in CP -Screening for drug and alcohol misuse -Increased cardiometabolic risk in CP -Premature and accelerated aging in CP <p>See: Surrey Place Questionnaire</p>

Note: GMFCS IV-V – Gross motor function classification system, Level IV – young people are able to walk with wheeled mobility with physical assistance in the home environment short distances only, use a manual or powered mobility for school. outdoors and community settings, Level V – young people are transported in a manual wheelchair in all settings

AYA: Adolescent and Young Adult

ACTION POINTS FOR HEALTH PROFESSIONALS FOR LEAVING PAEDIATRIC SERVICES IN CEREBRAL PALSY (CP)

Philosophy/Principles:

AYA (Adolescent and Young Adult) living with CP and disability are empowered to transition from paediatric services to adult services through a structured, standardised process, with input from their whānau.

KEY PRINCIPLES	ACTIONS		
	Essential for current services	Important to incorporate	Ideal to incorporate
Partnership AYA living with CP and disability, parents, and caregivers	Equal partnership with the AYA (in a way that is meaningful to them and their whānau) to foster independence, confidence, health self-efficacy and sense of wellbeing. All processes involve AYA's views and needs in decision making.		
Cultural safety	Commitment to eliminating inequities and bias for the young person living with CP. Commitment to ongoing professional development and training for cultural safety with those who provide care to the young person living with CP.	Awareness of other cultural groups (e.g. Asian and Pacific peoples) and concepts of disability (e.g. medical, social, and biopsychosocial model)	

	<p>Collaborate with Māori and other culturally appropriate health advisors.</p> <p>The application of kaupapa māori principles that promote:</p> <ul style="list-style-type: none"> -<i>Manaakitanga</i> (respect and kindness with emphasis on responsibility and reciprocity) -<i>Whanaungatanga</i> (relationships and connections within/ across services and define responsibilities) -<i>Rangatiratanga</i> (leadership, confidence, self-determination) -<i>Whakatoi</i> (curiosity and confidence) 		
<p>Timing Establishing the starting point</p>	<p>Begin formal planning at age 13-14 years with the young person living with CP. Establish a time frame for transfer based on age and development.</p>	<p>Facilitate skill acquisition to be able to navigate adult health service and self-manage their condition. Applicability will differ based on level of functioning.</p>	<p>Liaise with the Ministry of Education (MOE) to ensure education transition planning is occurring.</p>
<p>Timing Point of transfer</p>	<p>Comprehensive health summary of the young person living with CP must be completed by the young person's Paediatric Health Team prior to transfer.</p>	<p>A handover case conference. This must include AYA and all adults identified by the AYA as important in the transition process.</p>	<p>Not based on age but time of stability for AYA.</p>
<p>Logistic Planning Transition planning and handover meetings</p>			<p>Annual (or more frequent) transition planning meetings involving all people involved in AYA's transition including GP.</p>

<p>Logistic Planning Period of shared care between paediatrician and adult specialists or GP</p>	<p>The AYA meets a practitioner from the adult team before transfer.</p>	<p>There is a period of shared care between the paediatric and adult team.</p>	<p>All team members work together to reduce repeat assessments on young person living with CP.</p>
<p>Transition follow-up recommendations Continue transition after the point of transfer to adult system</p>	<p>Discharge from paediatric services only when transfer successfully completed.</p>	<p>Named health professional follows AYA for at least six months after transfer to ensure engagement with adult services. Develop systems for monitoring engagement with adult services.</p>	<p>Communication and shared responsibility between all services to ensure AYA is engaging with health services. Follow up should occur regularly until aged 25.</p>
<p>Clinician Role and Responsibilities Transition worker role</p>		<p>Each AYA needs a named health professional to help navigate services, advocate, plan and facilitate transition</p>	<p>Direct AYA to other sources of support and advice. Help AYA attend appointments. Determine AYA abilities and gaps in managing the transition. Prepare AYA to develop their own plan. Facilitate AYA's access to peers for information and support.</p>
<p>Clinician Role and Responsibilities Clinician in adult services</p>	<p>Named clinicians in adult services (including named GP). Adult practitioners must develop an understanding of: CP, childhood development, disability, family centred care, communication needs and special education needs.</p>		

Clinician Role and Responsibilities Advocates			Advocates are important for support and communication. Health and Disability Advocacy Services are available throughout Aotearoa New Zealand, for example: CCS Disability Action, CP Society.
Clinician Role and Responsibilities Parents and carers	Ask the AYA regularly how they would like their parents and caregivers involved. Information content, needs and delivery are different between AYA and their whānau.		Parent support groups offered to assist with transition
Transition Planning Documented individualised transition plan for the young person living with CP	Use a structured, written transition plan, which matches the AYA’s short- and long-term goals.		A transition plan to include: -Education and employment -Community inclusion -Health and wellbeing including emotional health -Independent living and housing options Ensure MOE has an Individual Career Plan (ICP) in place.
Transition Planning Further resources			Useful resources include: - Northern Regional Alliance: Youth Health Toolkit - Transition to Adult Care: Ready Steady Go - NSW Transition Readiness Checklist

<p>Medical Information and Referral Medical summary and referrals</p>	<p>A comprehensive health summary must be provided to the AYA, GP and adult services. All documentation should go to the AYA including letters from their new adult clinicians.</p>	<p>Medical information should include:</p> <ul style="list-style-type: none"> -Medical diagnoses -List of up-to-date medication -The timing and outcome of any medical and surgical interventions -Co-morbidities -Functional and developmental abilities, including mobility -Preferred way of communication -What equipment was provided and was useful -Ongoing care plans -A list of health, care and emergency contacts 	
<p>Medical Information and Referral Patient held folder</p>	<p>AYA should hold a personal folder, in a format that suits them and their whānau, containing:</p> <ul style="list-style-type: none"> -Health, education, employment, social participation needs -Preferences about parent and caregiver involvement -Emergency care plans -Strengths, achievements, hopes for future and goals 		
<p>Medical Information and Referral Legal issues – guardianship, informed consent, health care power of attorney, end of</p>		<p>Discuss and document all legal issues collaboratively. Can refer to social worker</p>	<p>If appropriate, Young person’s capacity to give informed consent should be assessed and documented before transition is complete. A psychology assessment may be needed</p>

life, emergency planning			Complete functional competency assessment (Needs Assessment and Service Coordination survey) or equivalent prior to transition to establish support needed.
Medical Information and Referral Information for consumers			Individualise information and provide in a format that suits the AYA. Provide information face to face to the AYA and not via parents.
Medical Information and Referral Transition process and supports	Provide information about services and funding including: -Transition process -Support available before and after transfer -Role of parents and caregivers in adult healthcare system -Access to benefits and financial support		Provide information about finding employment and housing

AYA: Adolescent and Young Adult

ACTION POINTS FOR SERVICE PLANNING FOR LEAVING PAEDIATRIC SERVICES IN CEREBRAL PALSY (CP)

Philosophy/Principles:

Adolescents and young adults (AYA) living with CP and disability are empowered to transition from paediatric services to adult services through a structured, standardised process, with input from their whānau.

KEY PRINCIPLES	ACTIONS		
	Essential for current services	Important to incorporate	Ideal to incorporate
Consumer Involvement/Engagement AYA with CP and a disability, parents, caregivers	AYA living with CP and whānau involved in service design (including policy and protocol development), delivery, evaluation. AYA at the centre, directing their future.		Youth groups to feedback and highlight transition service gaps. Include the feedback in ongoing service planning. Parent/caregiver support groups for transition preparation and information exchange.
Cultural safety	Integrate cultural responsiveness into the process. Commitment to eliminating inequities for the young person living with CP (Indigenous child health in Australia and Aotearoa New Zealand) .	Awareness of other cultural groups (e.g. Asian and Pacific peoples) and concepts of disability (e.g. medical, social, and biopsychosocial model)	

	<p>Ensure health professionals have access to training and/or ongoing support when caring for those with CP.</p> <p>Access to Māori and other culturally appropriate health advisors.</p> <p>The application of kaupapa māori principles that promote:</p> <ul style="list-style-type: none"> -<i>Manaakitanga</i> (respect and kindness with emphasis on responsibility and reciprocity) -<i>Whanaungatanga</i> (relationships and connections within / across services and define responsibilities) -<i>Rangatiratanga</i> (leadership, confidence, self-determination) -<i>Whakatoi</i> (curiosity and confidence) 		
Collaborative work between paediatric and adult services	<p>Plan and develop transition services together.</p> <p>Support from institution and management to collaborate.</p>	<p>Establish connections between paediatric services and adult specialty health services.</p> <p>Joint adult/paediatric appointment prior to transfer of health care.</p>	<p>Standalone transition clinic.</p> <p>Involve a Ministry of Education representative to collaborate on the transition plan and transition goals.</p>
Policy and protocol development	<p>Written policy for provision of transition for young people living with CP.</p> <p>A named senior person in the service is responsible for transition strategy and policy development.</p>	<p>Map transition process into all service delivery protocols.</p> <p>Be guided by the New Zealand Standards and Monitoring Service</p>	

	<p>Formulate specific referral pathways and incorporate them into guidelines / policies.</p> <p>When there is no equivalent adult service, there is a written pathway for this group of young people, outlining how they can get their needs met as adults.</p> <p>Consider and incorporate the Children, Young Person's, and Their Families Act (1989) and the Vulnerable Children Act (2014) and the Human Rights Act (1993)</p>		
The process of implementation		Transition is planned and timing can be adjusted to suit individual circumstances.	<p>Transition Coordinator is appointed for the young person with CP and the health services. Needs Assessment Service Coordinator (NASC) and program providers work together to ensure all the necessary supports are available.</p> <p>Provide ongoing transition training for stakeholders.</p>
Adult service needs	<p>Ensure an adequately resourced and accessible environment (e.g., physical environment, people who may need to assist).</p> <p>Allow time in adult service for complex care.</p>	Develop an adult multidisciplinary team for neurodisability care.	<p>Connect General Practitioners (GP) with an inter-professional team including equipment, rehabilitation and specialists.</p> <p>Have access to knowledge of local support networks.</p>

Data collection and analysis	Both qualitative (lived experience) and quantitative to use for quality improvement and best practice guidelines.	Yearly audit e.g. NICE (UK) assessment tool	Gap analysis to determine needs.
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AYA: Adolescent and Young Adult