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# Health care services for adults with cerebral palsy

## Background

Increasing numbers of young adults with cerebral palsy (CP) are transitioning to adult services from coordinated multidisciplinary paediatric hospital services. Limitations on provision of adult services include inadequate funding, lack of trained staff, and fragmented medical, surgical and allied health teams.

## Objective

This article summarises changes in treatments for children with CP over the past 2 decades and the implications for adult health care services. A multidisciplinary clinic for adults with CP at a tertiary adult teaching hospital in Sydney (New South Wales) is described.

## Discussion

Over the past 2 decades, interventions such as botulinum toxin-A, intrathecal baclofen infusion, gastrostomy feeding and single event multilevel orthopaedic surgery have improved the lives of children with CP. These interventions are generally delivered within multidisciplinary rehabilitation programs in paediatric hospitals. As the most recent cohorts of children move into adulthood, they, and their carers, have expectations of similarly structured services in the adult health care sector. The Children's Hospital at Westmead and Westmead Hospital, together with The Spastic Centre of New South Wales, recognised this need and developed a multidisciplinary consultative clinic for adults with CP.

**Keywords:** rehabilitation, disabled persons



those patients for similarly structured adult services are not being met due to limited funding, lack of trained staff, and fragmented medical, surgical and allied health teams.

## Changes in the management of children with cerebral palsy

Over the past 2 decades, interventions such as botulinum toxin-A (BoNT-A), intrathecal baclofen infusion (ITB), single event multilevel orthopaedic surgery (SEMLS), and gastrostomy feeding have become readily available for children with CP. Botulinum toxin-A, an injected neurotoxin causing a localised chemical denervation of muscle, is now considered standard practice for the management of spasticity in children with CP, resulting in improvements in gait and upper limb function.<sup>4</sup> Intrathecal baclofen infusion is another relatively new treatment for spasticity and/or dystonia. Intrathecal baclofen infusion involves an implanted pump that delivers baclofen, an antispasticity drug, via a catheter to the intrathecal space. The pump is programmable and is refilled at 1–3 monthly intervals.<sup>5</sup> It is generally reserved for children who are more severely affected and where less invasive treatments such as BoNT-A have been ineffective. Gastrostomy feeding and a greater emphasis on bone health have led to improvements in nutrition status of those with more severe CP, although improvements in quality of life have proved elusive. Orthopaedic outcomes have also improved, with the SEMLS approach<sup>6</sup> and better understanding of the mechanics of gait from 3D gait analysis.<sup>4</sup>

Although there is an emphasis on using these treatments during the child's rapid growth in their first and second decades, many will continue to need physical therapy interventions which manage muscle tone and related complications, and enteral feeding in adulthood.

Cerebral palsy (CP) is the most common physical disability in childhood.<sup>1</sup> Over 33 000 Australians are estimated to have CP.<sup>2</sup> Many adults with CP have ongoing complex medical and therapy needs and continue to benefit from coordinated, multidisciplinary health care services. Increasing numbers of young adults with CP are transitioning to adult services from coordinated multidisciplinary paediatric hospital services.<sup>3</sup> The expectations of

## Transition for young adults with cerebral palsy

Although CP is the most common chronic physical disability of childhood, there is limited information on the health care needs of young Australian adults with CP. In a group of 66 people with CP aged 15–25 years, attending the Royal Children’s Hospital in Melbourne (Victoria), significant health problems including poor growth, gastrointestinal problems and orthopaedic conditions were identified.<sup>7</sup> Marked declines in contact with health practitioners after patients left school were also noted. A roundtable forum on aging and cerebral palsy listed the critical needs for this group as:

- management of reproductive health and menstruation
- facilities for physical examinations
- knowledge about cerebral palsy
- dental care
- nutrition
- speech/communication, and
- arthritis/joint pain.<sup>8</sup>

Lack of orthopaedic and allied health services have also been cited as major challenges for this patient group.<sup>7</sup> Overall, past studies have shown that the health status of adults with intellectual and physical disabilities is poor,<sup>9</sup> access to existing services is difficult, and new services need to be funded.<sup>3</sup>

The yearly financial cost of CP has been estimated at \$1.47 billion, with additional costs in reduced wellbeing of \$2.4 billion. This equates to a total financial cost per person with CP of \$115 000 per annum.<sup>2</sup>

There have been a number of reviews and position papers on the process of transition for young adults with chronic conditions.<sup>10,11</sup> Recommendations include a documented health care plan developed collaboratively between the patient and health care team in the paediatric setting, well before transition to adult services. Useful checklists have been developed to assist families and health professionals in this process.<sup>12</sup> In Victoria, funding has recently been provided to develop clinics for young adults with childhood onset disability. A review emphasised the importance of clear pathways into the adult sector, development of expertise in complex disabilities, transition processes within the paediatric setting and strong relationships between adult and paediatric health care providers.<sup>10</sup>

## The WHPDC

The Westmead Hospital Adult Physical Disability Clinic (WHPDC) was established in 2005 as a joint venture between The Spastic Centre of NSW and the Department of Rehabilitation Medicine at Westmead Hospital to provide continuity of care for patients discharged from The Children’s Hospital at Westmead, and additionally to offer consultation to adults with CP who had not previously accessed paediatric services. The clinic is staffed by a rehabilitation physician, physiotherapist and occupational therapist. Approximately 40 new patients are seen each year at a monthly outpatient clinic with a total of 117 patients seen since the clinic’s inception (Table 1). A recent audit of WHPDC patients found

that 88% had spastic quadriplegic CP, 82% had some degree of intellectual impairment, 62% had seizures, and 70% were wheelchair users or required assistance for walking. This suggests the clinic is attracting those with more severe CP, as CP population studies indicate only 20–30% of all patients with CP are more severely affected. Thirteen percent of patients had a gastrostomy tube, 16% were receiving BoNT-A injections and 5% had an ITB pump. Many associated conditions were diagnosed in patients attending the WHPDC (Table 2). Social factors were important with 57% overall still living with their parents and 25% living in group homes. Only 3% were in full or part time employment and 89% were in receipt of government benefit payments.

Table 1. Characteristics of 117 adults referred to the WHPDC

	N	% of cohort		N	% of cohort
<b>Gender</b>			<b>Botulinum toxin-A injections</b>		
Male	62	53	Currently receiving	19	16
<b>Motor disorder</b>			Never received	96	82
Quadriplegic spastic CP	72	62	Baclofen		
Quadriplegic spastic-dystonic CP	30	26	Currently taking oral baclofen	15	13
Diplegic spastic CP	8	7	Intrathecal baclofen pump	5	4
Hemiplegic spastic CP	6	5	Oral baclofen in the past	6	5
Erb palsy	1	1	Gastrostomy tube feeding	15	13
<b>Aetiology of the patient’s condition</b>			<b>Mobility status</b>		
Patient data available	98	84	Wheelchair	72	62
Perinatal cause	59	50	Walking with assistance	9	8
Genetic cause	29	25	Walking independently	36	31
Infective cause	6	5	<b>Accommodation status</b>		
Metabolic cause	4	3	Living with parents	67	57
<b>Referral source</b>			Living in a group home	29	25
Paediatric physical disability clinic	35	30	Independent living	16	14
Pathways service	48	41	Hostel	3	3
Other	34	29	Homeless	22	
<b>Cognitive function</b>			<b>Highest level of education</b>		
Normal	21	18	School	101	86
Mild impairment	18	15	TAFE	9	8
Moderate impairment	15	13	University	7	6
Severe impairment	52	44	<b>Vocational activity</b>		
Learning and communication	11	9	Government funded day program	75	64
<b>Epilepsy*</b>			Home	29	25
Antiepileptic medication	65	56	School	5	4
No previous seizures	44	38	University	4	3
Previous seizure/no medication	7	6	Full or part time employment	4	3
			<b>Age at referral</b>		
			Mean age at referral		27.2 years
			Median age at referral		23.0 years
* Missing data					

**Table 2. Associated conditions diagnosed in patients attending the WHPDC**

<b>Orthopaedic</b>	<b>Neurological</b>	<b>Gastrointestinal</b>	Irregular cycles
Scoliosis	Epilepsy	Dysphagia	Polycystic ovaries
Kyphosis	Migraine	Gastro-oesophageal reflux	Menorrhagia
Hip dislocation	Reflex sympathetic dystrophy	Barrett's	<b>Other</b>
Muscle contracture	Meige's	Cachexia	Hearing loss
Spinal canal stenosis	<b>Renal</b>	<b>Surgical</b>	Cataracts
Disc prolapse	Urinary tract infection	Inguinal hernia	Drug and alcohol abuse
<b>Respiratory</b>	Calculi	Undescended testes	Chronic fatigue syndrome
Asthma	Cystitis	Hydrocoele	
Pneumonia	Incontinence	Atrophic testes	
<b>Psychiatric</b>	<b>Dental</b>	<b>Metabolic</b>	
Autism	Malocclusion	Diabetes mellitus	
Psychosis	Temporo-mandibular joint pain	Diabetes insipidus	
Aggression	Dental caries	Hypothyroidism	
Depression	<b>Skin</b>	Osteopaenia/osteoporosis	
Panic attacks	Pressure ulcers	<b>Reproductive</b>	
Anxiety	Psoriasis	Amenorrhoea	

The cohort was divided into two subgroups: <20 and ≥20 years of age at referral, for further analysis. Seventy-six (41%) patients were ≥20 years when they were initially referred to the WHPDC. Trends were evident for use of BoNT-A (24% in <20 years vs. 12% in ≥20 years group), ITB (10% in <20 years vs. 1% ≥20 years group), and presence of a gastrostomy tube (20% <20 years vs. 9% ≥20 years group).

The main areas of health care need were neurological and musculoskeletal. Almost 60% of the group had a history of seizures and remained on anticonvulsant medication, requiring referral for review and management by neurologists. Patients who had spasticity and muscle contracture, spasms or dystonic movements and required evaluation for suitability or continuation of therapy with BoNT-A, oral baclofen, ITB or other medications were referred to either a Movement Disorders Clinic, a Spasticity Management Clinic or to neurologists in the private sector.

Loss of mobility, pain in the back or hips and contractures at the knee and ankle were frequent presenting complaints. Additional factors identified in this patient group were increasing muscle tone and spasms, poor balance, weight gain, depression and anxiety, osteoporosis and fractures, difficulty with transport, lack of equipment and inability to access therapy programs.

## Conclusion

Major risk areas identified in the literature for those with CP, consistent with our findings from

the WHPDC audit, include musculoskeletal deformity (contracture, scoliosis and hip subluxation), intellectual impairment, speech and communication impairment, vision and hearing impairments, problems with feeding and epilepsy. While there have been significant improvements in access to coordinated multidisciplinary teams and evidence based treatments in the paediatric setting, equivalent resources in the adult health care sector are lacking.

The WHPDC and similarly set up clinics in Victoria have allowed young adults with CP transitioning from paediatric services a more clearly defined pathway and access to specialist assessment and interventions. We acknowledge that staffing for the WHPDC is inadequate. An ideal interdisciplinary team for managing adults with CP would include not only the current staff but also a speech pathologist, social worker, psychologist, orthopaedic surgeon and clinical nurse coordinator. Funding for orthotics and equipment such as walking aides and wheelchairs is also essential.

The importance of the role of the general practitioner in managing overall care of such a complex group of patients can not be overstated. However, information on access to GPs for this group suggests it is too infrequent, with only 0.7 GP encounters per year per person with CP.<sup>2</sup> A recent initiative of The Royal Australian College of General Practitioners has been an online learning module for GPs on adults with developmental disabilities and intellectual impairment.<sup>13</sup> Further

work is needed to develop the role of the GP in coordinating care and working with specialised multidisciplinary clinics such as the WHPDC.

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