Open discussion document

Considered representation - long term residential care strategies for persons living with cerebral palsy

Cerebral palsy (CP) is the term used for a group of nonprogressive disorders of movement and posture caused by abnormal development of, or damage to, motor control centers of the brain. CP is caused by events before, during, or after birth. The abnormalities of muscle control that define CP are often accompanied by other neurological and physical abnormalities[1].

Cerebral palsy is an abnormality of motor function (the ability to move and control movements) that is acquired at an early age, usually less than 1 year, and is due to a brain lesion that is nonprogressive. CP is frequently the result of abnormalities that occur while a fetus is developing inside the womb. Such abnormalities may include accidents of brain development, genetic disorders, stroke due to abnormal blood vessels or blood clots, or infection of the brain.

In rare instances, obstetrical accidents during particularly difficult deliveries can cause brain damage and result in CP. CP can take three forms: spastic, choreoathetoid, and hypotonic (flaccid). In spastic CP, there is an abnormality of muscle tone in which one or more extremities (arms or legs) are held in a rigid posture. Choreoathetoid CP is associated with abnormal, uncontrollable writhing movements of the arms and/or legs.

Treatment may include the use of casting and braces to prevent further loss of limb function, speech therapy, physical therapy, occupational therapy, the use of augmentative communication devices, and the use of medications or botulism toxin (botox) injections to treat spasticity.

[1] https://medical-dictionary.thefreedictionary.com/cerebral+palsy

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Items for consideration:

1. Partnership and alliances with SA associations, societies and residential facilities such as the United Cerebral Palsy Association of South Africa http://ucpa.za.org/ ; Prevensey place http://pevenseyplace.co.za/ ; Western Cape Cerebral Palsy Association https://wccpa.org.za/contact/, Forest Town
2. Public private partnership with supernumerary appointments;
3. State resources deployed into care facilities and paid for out of private funds and settlement trusts
4. Allocation of persons into residential care facilities through a committee structure with WHODAS related functional levels
5. Care orientation using 'mixed care' models – ref. 'being mortal' Atul Gawanda
6. Access to state formulary
7. Primary healthcare and reboarding / scripting through local day clinics
8. Preferred admission into 2nd care facilities on 'state patient' preauthorization basis;
9. Creation of a settlement trust vehicle for CP (as per guardian trust) to fund care for individuals and vocational employment for parents
10. Geocentricity approach to identifying parcels of land in each province based on incidence and impact of CP to individuals, families and communities
11. Alignment with skills development programs for parents, relatives and potential caregivers
12. Alignment with residency and internship programs at tertiary healthcare and social services educational facilities for healthcare providers and for care givers
13. Alignment with NEHAWU

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