

Core principles for services for children and young people with cerebral palsy in Northern England

Overarching principles

For each individual child or young person with cerebral palsy:

- The views and wishes of the child or young person and their family will be ascertained, listened to and taken into account at all times.
- Decisions about all aspect of care should be made with full involvement of the child or young person and their family in the decision-making process. This includes provision of appropriate written information and any necessary support or advocacy to assist decision-making.
- Goals of interventions should be clearly linked to improved participation and quality of life for individuals and their families as perceived by them, rather than improved body structure or function as perceived by professionals.

For the population of children and young people with cerebral palsy:

- It is the responsibility of ALL practitioners to work towards providing high quality, holistic services that are delivered according to each individual's assessed needs and context, working towards goals that matter to each individual and their family.
- Generic services across agencies should be accessible for all children and young people with cerebral palsy, with clear signposting arrangements and referral pathways into specialist services as required.
- Complete reporting of all children and young people with cerebral palsy to the North of England Collaborative Cerebral Palsy Survey (NECCPS) will mean this can be used as a tool to underpin excellence and equity in aspects of clinical care and research. All practitioners should promote the Survey and ensure that families understand the benefits of linking with it.
- If barriers to the core principles or to the participation or quality of life of individuals or their families are identified, these should be documented and professionals should work in partnership with families and advocate for them to overcome these wherever possible.
- Any unresolved issues should be brought to the attention of the commissioners.
- These core principles should be reviewed every three years and updated in the light of new information from rigorous research.

Children and young people with cerebral palsy and their families should expect of services:

- Holistic management with practitioners competent in the assessment and management of children and young people with cerebral palsy, including, as appropriate for the individual:
 - Paediatric physiotherapist.
 - Paediatric speech and language therapist with competence in the assessment and management of communication, feeding and swallowing.
 - Paediatric occupational therapist.
 - Paediatric dietician.
 - Paediatrician competent in neurodisability.
 - Orthopaedic surgeon competent in paediatric disability.
 - Spinal surgeon competent in paediatric disability for all children and young people with identified spinal curvatures or anomalies.
- Paediatric review at intervals tailored to individual needs, to identify the cause of the cerebral palsy as far as this can be ascertained, and to troubleshoot for any associated medical issues or complications, as prompt identification and appropriate management may reduce impact on quality of life and participation.

The following may be useful areas to consider:

- *Personal factors*
 - Strengths and achievements.
 - Concerns.
 - Experience and effects of pain.
 - Emotional well-being.
 - Self reported experience of wellbeing/quality of life.
- *Body structure and fitness*
 - General health enquiry.
 - Specific health enquiries e.g. pain, breathing, cough, teeth, drooling, reflux, vomiting, bowels, seizures, abnormal movements etc.
 - Height/length and weight, using standardised, calibrated equipment wherever possible with percentiles plotted on appropriate growth charts.
 - Nutritional status, e.g. comment on skin integrity, pressure areas etc.
 - Pubertal status.
 - Posture.
 - Hips e.g. range of movement, dislocatable, dislocated etc.
 - Spine e.g. straight, scoliosis (curve to the side), kyphosis (curve to the back) etc.
 - Systems examination, including skin, mouth and teeth, chest, abdomen, nervous system, bones and joints etc.
 - Magnetic Resonance Imaging (MRI) of brain +/- spine (to define as precisely as possible brain structure, including any evidence of developmental anomaly or damage that may predict function or have implications for management or for the wider family).
 - Other investigations or expert opinions tailored to the individual's needs.

- *Function*
 - Gross motor function classification system (GMFCS) level.
 - Gait pattern.
 - Manual Ability Classification System (MACS) level.
 - Personal care: dressing, washing, toileting etc.
 - Vision, including results of formal tests.
 - Hearing, including results of formal tests.
 - Speech and communication.
 - Feeding, swallowing and drooling.
 - Behaviour.
 - Social communication and relationships.
 - Learning.
 - Sleep.

- *Environmental factors*
 - Parent/carer concerns or issues.
 - Other's concerns or issues e.g. staff at children's centres, nurseries, schools, short breaks etc.
 - Accessibility of environment e.g. home, children's centres, nurseries, schools, leisure activities etc.
 - Continuing professional development across all agencies and the voluntary sector about disability issues.
 - Equipment, aids, orthoses etc. and any issues with these.
 - Opportunities to practice activities for independence e.g. food preparation, cooking, cleaning, bed changing etc.
 - Assistance required e.g. for lifting, transfers etc.
 - Barriers to participation.
 - Respect from others for the need to live ordinary and private lives
 - 24 hour postural management plan in place (If GMFCS III to V)
 - Emergency Health Care Plan in place to facilitate communication in the event of a health emergency (for those with the most complex needs).
 - Easy access to information and support across agencies:
 - all reports and correspondence written to/copied to families with medical/technical terms fully explained
 - in decision-making about choices in education
 - to inform times of transition in a timely way
 - to participate in relevant research studies that may be of benefit
 - about:
 - accessible leisure activities, short breaks, before and after school clubs etc.
 - support groups or voluntary organisations
 - confidential counselling for individuals or family members