

TRAINING PACK FOR
SPECIALIST REGISTRARS AIMING TO BE
CONSULTANTS WITH SPECIAL RESPONSIBILITY
FOR PAEDIATRIC NEURODISABILITY

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Introduction

Paediatric Neurodisability is now recognised by the Specialist Training Authority as a subspecialty of Paediatrics (September 2003). There are increasing numbers of Consultant posts being advertised, where special responsibility for Paediatric Neurodisability is required.

This pack gives guidance about the skills a trainee might reasonably be expected to have acquired by the time of CCST, in order to be considered competent in Paediatric Neurodisability and be in a position to apply for and fulfil the duties of a Consultant post with special responsibility for Paediatric Neurodisability at secondary care level. Trainees who can demonstrate acquisition of these competencies will in the future be entered on the Specialist Register with the specialty (subspecialty) of Paediatrics (Neurodisability).

As with all training, the learning process will continue beyond CCST and become life-long.

We envisage the competencies described to be achievable over a two year training period, with the trainee working at least 50% of the time in Neurodisability, or equivalent. It is possible that in the future some of the competencies could be acquired by other paediatricians training in a modular fashion.

There is inevitably some overlap between Paediatric Neurology (tertiary specialist level) and Paediatric Neurodisability (secondary district level) but the training and final subspecialty recognition are different (see www.bpna.org.uk for further details of training programme in Paediatric Neurology). Currently the Paediatric Neurology training programme includes one year in Neurodisability. Whilst this training pack does not address the content of this one year programme or the expected levels of competence to be achieved, it is hoped that the materials in the pack will be of some use for this group of trainees and their trainers.

Some trainees will be aiming for Consultant posts in Paediatric Neurorehabilitation. This group will need to acquire the core competencies in Paediatric Neurodisability (2 years or equivalent), then further competencies specific to Neurorehabilitation (likely to involve a further year of training within the 5 year Higher Specialist Training programme). Trainees who can demonstrate acquisition of the additional competencies in Paediatric Neurorehabilitation as detailed in this Training Pack will be entered on the Specialist Register with the specialty (subspecialty) of Paediatrics (Neurodisability). There is NOT separate subspecialty recognition for Paediatric Neurorehabilitation.

Some trainees will be aiming for other subspecialty posts, for example in Paediatric Audiology, for which further specialist training will be required which may include specialist higher degree programmes.

In addition to defining core competencies within the field of Neurodisability and providing guidance on resources and literature, this pack includes a range of suggested assessment tools to help trainees and their clinical and/or educational supervisors to monitor progress. The assessment tools have not yet been formally validated. Guidance is also provided on what a training programme for Paediatric Neurodisability should have available in terms of personnel and facilities.

This competency model of training will be most beneficial to trainees who are self-motivated, enthusiastic and willing both to learn and also to direct their own learning using the available training opportunities. Trainees need to acquire core knowledge and competencies and to develop skills in self-assessment, critical evaluation of their own consultations and in keeping a record of the learning process.

The role of the trainer/educational/clinical supervisor is vital. S/he needs skills in evaluating consultations and clinic letters critically but positively using the assessment tools provided (Section 3), giving appropriate feedback and taking account of discussion with the trainee. In future, supervisors will also need to have these skills with respect to videoed consultations (starting with their own before going on to the trainees).

There should be regular opportunities for informal and formal supervision, as well as informal and formal appraisal. The training progress reports (Section 3, Tool 4) should be catalysts for discussions and the training programme should be sufficiently flexible to address the individual's identified training needs.

Trainees are encouraged to use their fellow trainees as an additional resource, sharing experiences and networking. The training schedule is evolving. Other trainees will be getting used to a new approach too. The syllabus in this Training Pack has evolved from one originally developed by the European Academy of Childhood Disability for transdisciplinary use within the field of childhood disability.

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SECTION 1

Programme requirements and Key texts

1.1: PROGRAMME REQUIREMENTS

The neurodisability programme will occupy two years of the Year 3,4,5 programme, either as a concentrated block or in modules. The trainee will be expected to have acquired competency in core general paediatric and community child health skills. The posts undertaken during the remaining year will be dependent on the eventual career goal of the trainee. Hence the neurodisability programme may be combined with a further year of general, community or specialty paediatrics, e.g. Paediatric Neurorehabilitation.

The overall objective of the training programme is for the trainee to work towards achieving the core competencies outlined in Section 2. The training programme should be “individualised” for the trainee, rather than consisting of fixed numbers of sessions in a particular balance. Completion and regular review of training progress reports (see Section 3) should allow opportunities for the trainee and supervisor to review the balance of the components of the training programme offered, to ensure that the trainee is appropriately directed towards achieving the required competencies.

There will be trainees wishing to have their retrospective experience recognised as equivalent to the new training programme in Paediatric Neurodisability. The assessment tools in Section 3 will be helpful in gauging the trainee’s level of competence. Evidence of competence is of greater importance in this regard than length of time spent in different posts. The CSAC for Neurodisability together with the trainee’s educational supervisor will need to take on the important role of assessing trainees on their individual merits where retrospective recognition of experience is sought.

Posts within the programme:

1. The trainee will be expected to spend the majority of the two year period based within a paediatric neurodisability service. At least one year should be spent within the same service, so that the trainee can have sufficient opportunity to form appropriate relationships within the multi-disciplinary team, to contribute to service developments and to gain experience of case management, patient follow-up and service audits.

There will be pros and cons in moving to a different service in the second year. Advantages include the opportunity to gain experience of a different team, with a different balance of staff members, access to different facilities and possibly a different patient population. The main disadvantage is a shorter time frame for follow-up of individual patients and / or projects, and a shorter relationship with other local agencies such as education and social services. Movement between different posts may be partly based on trainee choice, but will also be dependent on different models of programme management around the country.

Continuity in at least one clinic over a two year period would be encouraged.

2. Training in paediatric neurology may be undertaken in a block or as a regular sessional commitment whilst working within a community-based neurodisability team. As a guide, six months full-time equivalent is recommended, as part of the overall two year neurodisability programme.

The trainee should acquire outpatient experience including assessment, investigation and management of children with acute and chronic neurological disorders, especially epilepsy, and inpatient experience, including developing an understanding of the principles of acute care. There should be opportunities to attend neuroradiology and neurophysiology meetings.

3. Training in child and adolescent psychiatry is best undertaken as a regular sessional commitment whilst working within a neurodisability team, rather than in blocks, in order to allow adequate follow-up experience. As a guide, the equivalent of three months full-time equivalent is recommended, again as part of the two year overall neurodisability programme.

The trainee should gain outpatient experience including assessment, investigation and management of children and young people with a range of behavioural and neuropsychiatric conditions. If the local CAMHS service does not cater for children and young people with learning disabilities, access to learning disability psychiatry training opportunities is encouraged elsewhere.

4. Opportunities for observation of the following additional clinics should be available during the programme:

- Clinical genetics
- Paediatric gastroenterology / feeding clinic
- Paediatric ophthalmology
- Paediatric audiology / ENT
- Paediatric orthopaedics

Accessibility of these clinics, and the number that each trainee attends will vary according to local working practices, and trainee interest.

Requirements of neurodisability post:

The neurodisability post in which the trainee spends the majority of their placement should satisfy the following criteria:

Features of the service

- The service should provide for a total district population of at least 100,000 and should run new patient and follow up neurodisability clinics at least once a week.
- Standardised equipment should be available in all clinics, including examination couches, appropriate scales, Leicester Height measures, diagnostic equipment etc.
- Auxillary/nursing support should be available for all clinics, whatever the setting.
- The service must have clear access routes to investigation facilities, including haematology, biochemistry, specialist metabolic, immunology, microbiology and virology, cytogenetics, molecular genetics, x-ray, CT, MRI, EEG, ECG, Echocardiography etc.
- The location of the team will depend on the local service model and needs of the population served. There may be a hospital or community-based Child Development Centre where team members are co-located, in which case the trainee should have office space there to facilitate regular interaction with other team members.
- Whatever the local configuration and location of the team, the service must be able to demonstrate robust models of multi-disciplinary working, including regular clinical and service team meetings. Whilst staffing pressures exist across the country, there must be a core team comprising a range of therapists appropriate for the population served. This will most commonly include speech and language therapists, physiotherapists, occupational therapists, clinical psychologists, specialist health visitor, specialist social worker for children with disabilities etc.
- Depending on local models of care, a range of other services such as community children's nursing teams, children's learning disability nursing teams, behavioural management support teams, respite facilities and joint clinics with tertiary colleagues should be available and accessible to the trainee.

The service must also be able to demonstrate well-developed models of inter-agency working with other statutory and voluntary sector agencies.

Educational supervision

- Ongoing educational supervision should be provided by a paediatrician with special responsibility for neurodisability. This individual may be a paediatric neurologist, community or general paediatrician. Ideally the same individual should undertake educational supervision of the trainee throughout the duration of the 2-year neurodisability programme.
- The primary clinical supervisor may vary through placements within the programme, but s/he should directly supervise the trainee's work during a minimum of 1 clinic per week.

Educational content

- The trainee should be able to spend at least 50% day-time hours specifically in neurodisability with direct consultant clinical supervision. It is essential that regular clinical commitments and learning opportunities are not disrupted by 'on call' and days off as part of rotas.
- It is essential for the trainee to have the opportunity to assess and manage children of all ages with developmental problems from referral onwards over a period of time (preferably during the full two year training period), providing a long term perspective on the natural history of developmental disorders. This will also provide opportunities to work closely with locally based education, social services and other agencies.
- It is essential for the trainee to have the opportunity to experience and learn about a range of models of multidisciplinary team and inter-agency working and to understand the importance for families of coordinated care. Opportunities to lead team meetings and to explore new models of working effectively should be encouraged.
- The trainee should have the opportunity to directly observe and work jointly with specialist paediatric speech and language therapists, physiotherapists and occupational therapists, as well as to observe formal psychometric and functional assessment of children with a range of disabilities.
- Every trainee should have regular clinics in a range of special schools, as well as opportunities to see children who are included in mainstream educational settings. There should be opportunities to work with specialist teachers e.g. sensory impairment and to understand their role in advising schools.
- Trainees should also be working in an environment which enables them to gain an understanding of the rights of disabled children, services, benefits and allowances available and how these may be accessed, as well as an appreciation of local, national and web-based voluntary organisations and parent/carer support groups.

1.2: KEY TEXTS

Regular access to the following would be an advantage

i.e. worth buying yourself, or getting your local hospital department or library to buy

- Aicardi J. *Diseases of the Nervous System in Childhood*. Mac Keith Press, 2nd Ed. 1998.
- Hall D and Hill P. *The Child with a Disability*. Blackwell Science Ltd, 2nd Ed. 1996.
- Maria B L. *Current Management in Child Neurology*. BC Decker (available in UK via Harcourt Publishers Ltd), 2nd Edition (includes CD-ROM). 2002.
- Fenichel G. *Clinical Paediatric Neurology A Signs and Symptoms Approach*. Saunders. 1997.
- Capute A and Accardo P. *Developmental Disabilities in Infancy and Childhood*. Brookes Publishing Cp. 1996.
- Aicardi J. *Epilepsy in Children*. Raven Press, 2nd edition. 1994. (3rd edition due out soon)
- Wallace S. *Epilepsy in Children*. Chapman and Hall. Dec 1995.
- O'Donoghue NV. *Epilepsies of Childhood*. 3rd edition, Churchill-Heinemann Ltd. 1994.
- Stephenson J and King M. *Handbook of Neurological Investigations in Children*. Butterworth. 1989. (Out of print, but worth tracking down e.g. in Library. New edition due soon)
- Gillberg C. *Clinical Child Neuropsychiatry*. CUP. 1995.
- Reynolds C and Fletcher-Janzen E. *Clinical Child Neuropsychology*. Plenum Press. 1989.

Regular reading of the following journals is strongly recommended

- Developmental Medicine and Child Neurology ISSN 0012-1622
<http://journals.cambridge.org/>
- Child: Health, Care and Development ISSN 0305-1862
<http://www.blackwellpublishing.com/journals/cch/>

SECTION 2

Syllabus for Neurodisability Training and Core Competencies

2.1: SYLLABUS FOR NEURODISABILITY TRAINING

KNOWLEDGE REQUIRED	BASIC SCIENCES	ENVIRONMENTAL CONTEXT	CLINICAL PRACTICE	INTER-PROFESSIONAL
<p>Motor dysfunction including cerebral palsy, neuromuscular, musculoskeletal, neural tube defects, developmental coordination disorder</p> <p>Visual impairment (cortex, pathway, eye)</p> <p>Hearing impairment (cortex, pathway, ear)</p> <p>Communication disorders</p> <p>Disorders of social communication including autistic spectrum disorders</p> <p>Speech and Language disorders</p> <p>General learning disabilities (formerly mental retardation) including specific syndromes</p> <p>Specific learning disabilities including literacy and numeracy</p> <p>Epilepsy</p> <p>Neuropsychiatric disorders including attention deficit hyperactivity disorder, depression, Tourette Syndrome; Conduct disorder</p> <p>Associated medical/health/behaviour problems including diagnosis and management e.g. growth, feeding/nutrition, reflux, drooling, gastrostomy, continence (constipation, enuresis, neuropathic bladder), cardio-respiratory, orthopaedic problems, skin and shunt care, crying, attachment sleeping problems. Syndrome specific medical problems e.g. hypothyroidism in Down syndrome</p> <p>Skill regression</p> <ul style="list-style-type: none"> - Syndrome specific - Disease specific - Progressive disease 	<p>Normal and abnormal development</p> <p>Neuroanatomy, neurophysiology, embryogenesis</p> <p>Natural history of damage and disability from birth across lifespan</p> <ul style="list-style-type: none"> - Antenatal Health - Brain damage patterns - Aetiological evaluation - Symptoms - Signs early and late incl. Neonatal - Complications - Management - Genetics <p>Disease and disability</p> <ul style="list-style-type: none"> - Impairment - Disability/Function - Handicap/Participation <p>Relationship of pathology to phenotype in a number of areas of development e.g. congenital motor impairments, including secondary effects and co-morbidities</p>	<p>Condition in society</p> <ul style="list-style-type: none"> - Mortality and morbidity - Cultural issues - Social influences - Impact of poverty <p>Impact of disability on child and family</p> <p>Context of function and specific needs</p> <ul style="list-style-type: none"> - School - Home - Sibling/parent - Continuity of care - Transitional care incl. school entry and adult services <p>Service structure</p> <ul style="list-style-type: none"> - Multidisciplinary team - Interagency - Across levels of care: <ul style="list-style-type: none"> - primary - secondary - tertiary - Management skills - Business planning <p>Legislation/ Statutory Services</p> <p>Child protection</p> <p>Particular children</p> <ul style="list-style-type: none"> - Refugees - Adopted - Looked after <p>Ethical/legal issues</p>	<p>History taking, observation/examination at different ages</p> <p>Communication skills</p> <ul style="list-style-type: none"> - interdisciplinary - Child and family <p>Interviewing and evaluative tools including those of child psychology and psychiatry</p> <ul style="list-style-type: none"> - functional motor assessment - cognitive tests - behavioural syndromes/ neuropsychiatry <p>Diagnosis, differential diagnosis and co-morbidity</p> <p>Investigation (when and what) including Genetic investigation and counselling</p> <p>Standardised tests and interpretation</p> <p>Assessment and monitoring including protocols</p> <p>Management, aids and equipment</p> <ul style="list-style-type: none"> - prevention of deformity - communication systems - Neurodevelopmental programmes - Behaviour management including pharmacology - Mobility aids incl. chairs <p>Death and dying</p> <p>Acquired brain injury</p> <ul style="list-style-type: none"> - Rehabilitation 	<p>Understanding other professionals' roles</p> <ul style="list-style-type: none"> - overlap - respect for others' opinions <p>Co-working</p> <ul style="list-style-type: none"> - Mobility - Seating - Feeding and communication - Behaviour etc <p>Knowledge of key resources provided by other professionals and agencies, both statutory and voluntary</p> <p>Effective use of primary, secondary and tertiary services for diagnosis and management</p>

Syllabus evolved from one originally developed by the European Academy of Childhood Disability for transdisciplinary use in child disability. Ratified by RCPCH 2001. Also approved by BACCH and BPNA 2001.

COMPETENCIES IN NEURODISABILITY

2.2: CORE COMPETENCIES

It is assumed competence in basic skills will already have been acquired during Core SpR Training. Core competencies to be acquired in Neurodisability training are:

1. **Clinical assessment**
 - i. **Medical, family, developmental and functional history**
 - ii. **Physical examination**
 - iii. **Functional level**
2. **Formulate differential diagnosis**
3. **Formulate, apply and continue to reappraise an appropriate management plan**
4. **Communicate diagnoses and management plans effectively**
5. **Have the team-working skills to work in partnership with other professionals towards child-centred care**
6. **Identify and manage the functional consequences of impairments and associated medical conditions, including dying and death**
7. **Write relevant letters and reports understandable to parents, professionals and lay people**
8. **Anticipate and plan for transition stages and changes in environmental context**
9. **Give a balanced view on treatment options**
10. **Work in a variety of settings outside the health environment**
11. **Plan and evaluate services for populations of children with disabilities including prevention and health promotion**
12. **Teach and disseminate knowledge in health and non-health contexts**
13. **Undertake audit and understand the principles of research and development**

2.3: CLINICAL CONDITIONS IN WHICH THE NEURODISABILITY TRAINEE SHOULD ACQUIRE THE ABOVE CORE COMPETENCIES

- a. *Learning disabilities (mental retardation)*
- b. *Specific learning difficulties (dyspraxia, dyslexia, dysgraphia etc)*
- c. *Communication disorders*
- d. *Neuropsychiatric and behavioural disorders*
- e. *Motor disorders*
- f. *Sensory disorders*
- g. *Epilepsy*
- h. *Progressive neurological disorders*
- i. *Acquired neurological disorders*

For ease of expression throughout these documents, the term 'child' will be used as synonymous with 'child or young person' and the term 'parent' as synonymous with 'parent or carer'.

2.4: CORE COMPETENCIES

1. Clinical assessment

Skills and Abilities to Acquire

1. Taking detailed histories relevant to neurodisabling conditions
2. Correctly eliciting a range of physical including neurological signs as found in children with disordered development
3. Undertaking functional assessments of children including the domains listed below (knowledge section) and understanding the principles of quantitative assessment
4. Using skills of observation to interpret children's developmental levels and possible physical signs when they are not able to cooperate with formal assessments
5. Conducting anthropometric assessments in children with neurodisabling conditions
6. Constructing and interpreting family genograms
7. Distinguishing delayed and disordered development
8. Recognising a range of patterns of disordered development in neurodisabling conditions
9. Awareness of limitations of own expertise and when to refer on
10. Collecting information from other sources e.g. nursery and teaching staff
11. Maintaining a broad vision throughout clinical assessment, refocusing on new areas as required, towards multi-axial diagnosis

Basic Knowledge

- Broadly normal range of child development 0 – 19 years
- Common pathways of presentation of neurodisabling conditions including key pointers in histories
- Genetics and family patterns of neurodisabling conditions
- Broadly normal patterns of skill acquisition for the following areas in children from 0 – 19 years:
 - Mobility
 - Hand function
 - Personal care/self-help skills
 - Continence
 - Vision
 - Hearing
 - Speech, Language and Communication
 - Cognition
 - Behaviour
 - Social communication
- Patterns of skill acquisition for different functional areas in children 0-19 years with neurodisabling conditions
- Detailed neurological and general examination relevant to children with neurodisabling conditions at different ages
- Principles of anthropometric assessment in children with neurodisabling conditions

Resources

- Private study
 - standard texts of normal development, neurodevelopmental disorders, disability and neurology
 - appropriate journal articles
- Neurodisability clinics
- Neurology clinics
- Child Psychiatry clinics
- Observation of therapists
- Observation of formal psychometric assessment
- Observation of orthoptists and audiologists/audiological scientists
- Structured in-house teaching of adequate quality
- Approved courses e.g. Sheffield Distance Learning Course in Paediatric Neurodisability; RCPCH approved courses; Annual Meetings of RCPCH, British Paediatric Neurology Association, Child Development and Disability Group of BACCH etc
- Course/s on methodology of formal psychometric and developmental assessment
- Membership of learned societies e.g. British Paediatric Neurology Association, European Academy of Childhood Disability, British Association for Community Child Health etc

Additional Literature

- Illingworth RS. *Development in the Infant and Young Child Normal and Abnormal*. Churchill Livingstone. Aug 1987.

2. Formulate differential diagnosis

Skills and Abilities to Acquire

1. Collecting, reviewing, summarising and interpreting information from a range of sources about individual children
2. Conducting web-based and other literature and information searches about specific conditions
3. Reaching and documenting an appropriate (differential) diagnosis
4. Conveying breadth of diagnostic possibilities to parents/children
5. Requesting appropriate investigations

Basic Knowledge

- Sources of information about children and how to access these e.g. hospital case notes, community case notes, specialist reports (therapists, teachers, health visitor etc), statements of special educational needs, social work assessments, Children in Need assessments (joint framework), investigation results (laboratory, imaging etc)
- Which experts to discuss individual cases with, or to refer on to

Resources

- Hospital and University Libraries – books and journals, Dysmorphology and Neurogenetics Databases, on-line databases e.g. OMIM etc
- NHS Net and Internet
- Local, regional, national and international experts, within and outwith Health
- Evidence-based medicine course/s
- Critical appraisal course/s

Additional Literature

- Whiting K. Investigating the child with Learning Difficulty. *Current Paediatrics*. 2001;11(4):240-247
- Standard texts
- Condition specific journal articles
- Condition specific web resources

3. Formulate, apply and continue to reappraise an appropriate management plan

Skills and Abilities to Acquire

1. Formulating effective management plans for children of different ages with neurodisabling conditions, including planning and interpreting investigations, therapy needs and ongoing paediatric care needs
2. Appropriately liaising with colleagues to discuss or refer
3. Appropriately liaising with other agencies at relevant times
4. Seeking appropriate multi-disciplinary review

Basic Knowledge

- Knowledge of appropriate investigations for children suspected of having one or more neurodisabling conditions, including interpretation of results
- Knowledge of therapeutic options (including how to access; evidence of benefit in the specific condition; potential side effects; complications etc) for neurodisabling conditions, including:
 - Medical and pharmacological therapies
 - Other health-based therapies
 - Behavioural management options
 - Educational options
 - “Alternative” therapies
- Knowledge of objectives of paediatric follow-up for neurodisabling conditions. (What positive difference will Paediatric care make? How frequently does child need to be seen and why?)
- Knowledge of access to emergency health care for a range of potential emergency situations arising for children with neurodisabling conditions

Resources

- Observation of professional colleagues
- Discussion with clinical supervisor
- Local and national guidelines

4. Communicate diagnoses and management plans effectively

Skills and Abilities to Acquire

1. Establishing parent's and children's baseline understanding of the situation
2. Modifying language appropriate to the level of understanding of parents and children
3. Recognising, correctly interpreting and responding to verbal and non-verbal cues from parents and children
4. Preparing or adapting written material appropriate to the level of understanding, reading ability and language of parents and children
5. Confirming what parents and children have understood from what has been said and written and modifying as appropriate
6. Sharing difficult information according to agreed standards
7. Obtaining informed consent
8. Explaining about available benefits and other support including voluntary organisations

Basic Knowledge

- General principles of good communication
- Knowledge of different cultural belief systems and how these may impact on interpretation by others of information shared
- Knowledge of aetiology and pathophysiology of neurodisabling conditions
- Knowledge of functional consequences and prognosis of neurodisabling conditions, including impact on children, families, education and social life
- Knowledge of early signs of potential complications and secondary disabling factors to look out for in neurodisabling conditions

Resources

- Video on Communication with disabled children: *Two Way Street*. Triangle and NSPCC. 2001.
- Observation of professional colleagues
- Sheffield Distance Learning Course on Paediatric Neurodisability
- Other approved courses on Communication skills

Additional Literature

- Davies H and Fallowfield L (Eds). *Counselling and Communication in Health Care*. John Wiley and Sons. 1991.
- Corney R (Ed). *Developing Communication and Counselling Skills in Medicine*. Tavistock/Routledge. 1991.
- Kurz S. *Teaching and Learning Communication Skills*. Radcliffe Medical Press. Feb 1998.
- Davies H. *Counselling Parents of Children with Chronic Illness or Disability*. British Psychological Society Books. 1993.

5. Have the team-working skills to work in partnership with other professionals towards child-centred care

Skills and Abilities to Acquire

1. Working as part of a team in a child-centred way
2. Managing team tensions, keeping the focus on the child and their needs
3. Collecting information from other sources e.g. teachers, nursery staff etc
4. Explaining role of other professionals to parents
5. Working with other agencies e.g. case conferences, multi-agency meetings
6. Chairing meetings – clinical reviews, management
7. Fulfilling the duties of the Designated Doctor for Education for children with special educational needs
8. Case presentations

Basic Knowledge

- Roles and skills of other professionals who may be working with children with one or more neurodisabling conditions, to include:
 - Paediatric Neurodisability Specialist
 - Paediatric Neurologist
 - Neurosurgeon
 - Paediatric Gastroenterologist
 - Paediatric Orthopaedic surgeon
 - Paediatric Ophthalmologist
 - ENT Surgeon
 - Clinical Geneticist
 - Child Psychiatrist
 - Neuroradiologist
 - Neurophysiologist
 - Audiologist/Audiological Scientist
 - Community Children's Nurse
 - Specialist Nurse for children with learning disabilities
 - Specialist Nurse for children with epilepsy
 - Health Visitor
 - Specialist Social Worker for Children with Disabilities
 - Speech and Language Therapist
 - Physiotherapist
 - Occupational Therapist
 - Clinical Psychologist
 - Educational Psychologist
 - Specialist teacher for children with sensory impairment
 - Teachers, Nursery Nurses, Portage workers
 - Orthoptist
 - Orthotist
 - Paediatric Dietician
 - Benefits Advisor (Disabilities)
 - Voluntary Organisations
 - Etc
- Basic principles of team working, including potential difficulties and strategies to try to overcome them
- Basic principles of child-centred working
- Role and duties of the Designated Doctor for Education for children with special educational needs

Resources

- Observation of different models of multi-disciplinary teams in action
- Sheffield Distance Learning Course on Paediatric Neurodisability
- Attendance at multi-disciplinary team meetings
- Attendance at panel meetings with Education officers to consider children with potential special educational needs

Additional Literature

- McConachie H, Salt A et al. How do child development teams work? Findings from a UK national survey. *Child: Care, Health and Development*. 1999;25:157
- Robards M. *Running a team for disabled children and their families*. Clinics in Developmental Medicine. 130. 1994.
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- Ovretveit J. *Coordinating Community Care. Multidisciplinary teams and care management*. Open University Press. ISBN 0-335-19047-2. 1993.
- Stallard and Hutchison T. Development and satisfaction with individual programme planning. *Arch Dis Child*. 1995;73:43.
- *Special Educational Needs Code of Practice*. DfES Publications 581/2001. <http://www.dfes.gov.uk/sen/viewDocument.cfm?dID=260>

6. Identify and manage the functional consequences of impairments and associated medical conditions, including dying and death

Skills and Abilities to Acquire

1. Correctly identifying and managing functional consequences of impairments presenting in neurodisabling conditions
2. Correctly identifying (anticipating and preventing where possible) and managing associated medical conditions, mental health problems and difficult symptoms in neurodisabling conditions
3. Recognising indicators of stress/mental health problems in family members and communicating appropriately with General Practitioners
4. Presenting a balanced account of what is medically possible (or not), remaining supportive and offering comfort at all times
5. Preparing and discussing with parents, carers and other professionals “Do not attempt resuscitation” policies as appropriate, taking due account of the Human Rights Act (1998), ensuring that the best interests of the child are held as paramount at all times
6. Recognising and communicating about imminent death, ensuring dignity and comfort for the child at all times
7. Seeking consent for post-mortem examination as appropriate and communicating with the Coroner

Basic Knowledge

- Knowledge of functional consequences, prognosis and usual course of neurodisabling conditions, including impact on child, family, education and social life
- Knowledge of early signs of potential complications, secondary disabling factors, associated medical conditions and mental health problems to look out for in neurodisabling conditions
- Knowledge of appropriate and effective interventions to use towards the best possible quality of life for the child or young person, minimising the functional impact of impairments and preventing or managing associated medical conditions and mental health problems
- Knowledge of legislation, ethics, different religious and cultural practices and beliefs and their impact on decisions not to resuscitate, dying, death and post-mortem examination including when to discuss with the Coroner

Resources

- Observation of Neurodisability clinics
- Observation of Therapy sessions
- Observation of Child and Family Psychiatry sessions
- Sheffield Distance Learning Course in Paediatric Neurodisability
- Other approved courses
- Visits to Specialist Residential Schools and Treatment Centres e.g. Bobath, Conductive Education
- Specialist Clinics – orthotics, orthopaedics, audiology etc
- Children’s Community Nursing Teams
- Children’s Hospice Teams
- Local Ethics Committee
- Local Trust’s Legal Department

Additional Literature

- Wilson GN and Cooley WC. *Preventive Management of children with congenital anomalies and syndromes*. Cambridge University Press. ISBN 0 521 77673 2. 2000.
- Sister Frances Dominica, Woodward RN. Baum JD (Eds). *Listen, my child has a lot of living to do*. Oxford University Press. 1990.

7. Write relevant letters and reports understandable to parents, professionals and lay people

Skills and Abilities to Acquire

1. Writing reports understandable to parents, taking reading ability and language into account
2. Writing reports appropriate and understandable to other professionals, including:
 - a. Other health professionals
 - b. Education, including Medical Advice reports to inform statutory assessments where children have special educational needs
 - c. Social Services, as part of the joint assessment framework for Children in Need
 - d. Police and Courts

Basic Knowledge

- General principles of report writing for parents, professionals and lay people
- Knowledge of different cultural belief systems and how these may impact on interpretation by others of written information
- Knowledge of the requirements of the Education Act and Code of Practice for preparation of Medical Advice where children have special educational needs
- Knowledge of the Children in Need Joint Assessment Framework
- General principles of preparation of reports for Court

Resources

- Reports prepared by professional colleagues
- Approved courses on report writing, including for court

Additional Literature

- Crossley JGM. Howe A. Newble D. Jolly B. Davies HA. Sheffield assessment instrument for letters (SAIL): Performance assessment using outpatient letters. *Medical Education*. 2001;35(12):1115-1124.

8. Anticipate and plan for transition stages and changes in environmental context

Skills and Abilities to Acquire

1. Recognising, planning for and minimising adverse impact of times of transition and crisis
2. Discussing adult models of care with parents and children at appropriate times

Basic Knowledge

- Knowledge of key transition stages and potential crisis points, including “early warning” signs

Resources

- Long-term follow up of at least 20 children with neurodisabling conditions
- Adult Learning Disabilities Team
- Attendance at Annual Reviews of young people with Statement of Special Educational Needs prior to a Transition

Additional Literature

- Kurz Z and Hopkins A. *Services for Young People with Chronic disorders and their transition from childhood to adult life*. RCP. 1996.
- Bax M and Smyth D. *The Health and Social Needs of Young Adults with Physical Disabilities*. Clinics in Developmental Medicine 106. Mac Keith Press. 1989.
- Viner R Macfarlane A. Provision of age appropriate health services for young people has been ignored. *BMJ*. 2000;321(7267):1022.
- Viner R. Effective transition from paediatric to adult services. *Hospital Medicine* (London) 2000;61 (5):341-3.
- Viner R. Transition from paediatric to adult care. Bridging the gaps or passing the buck? *Arch Dis Child*. 1999;81(3):271-5.

9. Give a balanced expert view on treatment options

Skills and Abilities to Acquire

1. Critically appraising treatment/outcome papers
2. Performing web-searches on questions presented by families
3. Presenting a balanced account of the merits and demerits of particular treatment options for neurodisabling conditions

Basic Knowledge

- Knowledge of therapeutic options, including how to access; evidence of benefit in the specific condition; potential side effects; complications etc, for neurodisabling conditions, including:
 - Medical and pharmacological therapies
 - Other health-based therapies
 - Behavioural management options
 - Educational options
 - “Alternative” therapies
 - General principles of critical appraisal

Resources

- Observation of and discussion with Clinical supervisor
- Specialty therapy resources/attendance at therapy sessions
- Sheffield Distance Learning Course in Paediatric Neurodisability
- Specialty Clinics e.g. Botulinum Toxin, Pain etc

Additional Literature

- Evidence based medicine

10. Work in a variety of settings outside the health environment

Skills and Abilities to Acquire

1. Working flexibly in a range of settings
2. Understanding the challenges presented to education and social service professionals in settings outside health
3. Understanding the importance of “seamless care” for a child

Basic Knowledge

- Knowledge of the range of settings which children may experience, including statutory, private and voluntary
- Knowledge of how to access these settings for direct observational work, discussion with other carers and professionals

Resources

- Observation of clinical supervisor “in action” in a range of settings
- Special schools
- Mainstream schools with facilities for disabled children
- Social Services Respite/Short Break facilities
- Social Services Residential facilities
- School Nurse
- Health Visitor
- Teacher/Headteacher
- Educational Psychologist

11. Plan and evaluate services for populations of children with disabilities including prevention and health promotion

Skills and Abilities to Acquire

1. Planning and implementing population policies or strategies in the field of child disability
2. Critically evaluating own performance
3. Using routinely available information (e.g. on local child health information system, special needs register etc)
4. Consulting appropriately with other statutory/voluntary agencies
5. Understanding structured planning of services
6. Efficiently carry through plans formulated
7. Completing the Audit process

Basic Knowledge

- Structure of NHS
- Government and NHS strategies including National Service Framework for Children, Valuing People white paper
- Opportunities within government strategy for working in partnership with other agencies e.g. social services, including joint funding opportunities
- Local structure and organisation for planning children's services including those for children with disabilities
- General understanding of societal forces shaping the demand for health services

Resources

- Sheffield Distance Learning Course on Paediatric Neurodisability
- Local health and interagency planning meetings

Additional Literature

- Hall D. *Health for All Children*. 4th Edition. 2002.
- Polnay L. *Health Needs of School-Aged Children*.

12. Teach and disseminate knowledge in health and non-health contexts

Skills and Abilities to Acquire

1. Effectively teach a range of audiences
2. Critically evaluate own performance

Basic Knowledge

- Defining aims of teaching courses/programmes/lectures
- Targeting different audiences
- Preparation of teaching materials

Resources

- Hospital and University libraries – books and journals
- NHS Net and Internet
- Local, regional, national and international clinical expertise

13. Undertake audit and understand the principles of research and development

Skills and Abilities to Acquire

1. Leading multi-professional teams in audit projects aimed at contributing to change in practice
2. Understanding the value of audit as a driver of professional development and service development
3. Using audit explicitly in addressing current practice
4. Recognising the components of the audit cycle and the need sometimes to concentrate on only part of the audit cycle to ensure quality in audit
5. Completing tasks
6. Thinking in a structured way
7. Reporting clearly

Basic Knowledge

- The audit cycle
- Promoting change
- Basic principles of research

Resources

- Hospital audit department
- Local Clinical governance process
- RCPCH Booklet 1997
- Andy Mellon "Audit – Involving trainees in clinical audit: Report for College Tutors" posted by Mark Everard 24/01 on "Documents for Discussion" section of PIER website: www.pier.shef.ac.uk [Need to request a password if not logged in before]

NB It is important that some trainees are able to spend extended time (usually 3-4 years) in full-time research working for a higher degree.

2.5: CONDITION-SPECIFIC MINIMUM COMPETENCIES **FOR A SPECTRUM OF NEURODISABLING** **CONDITIONS**

Conditions in which the Neurodisability trainee should acquire competence are listed on page 2 of this section above.

The following guidance may be helpful towards further defining the required MINIMUM levels of condition-specific competence expected by the time of CCST.

Trainees should become familiar with multi-axial diagnoses and recognised patterns of co-morbidities; it will be necessary to cross-reference the different parts of this Section to take account of these.

Abilities NOT required at this level are also indicated.

Acquisition of these abilities will vary between individuals, their circumstances, opportunities for Continuing Professional Development etc.

Levels suggested are considered realistically achievable after 2 years of neurodisability training or equivalent.

a Child with a learning disability (mental retardation)

Skills and Abilities to Acquire

- Undertaking comprehensive paediatric assessments, reaching appropriate differential diagnoses and instituting appropriate management plans for children across the range of intellectual ability.
- Recognising when children's levels of cognitive functioning fall outside of the broadly normal range for age.
- Networking with colleagues (e.g. Educational and/or Clinical Psychologists) towards obtaining formal detailed cognitive profiles.
- Recognising indicators that children may be losing intellectual skills; networking with colleagues e.g. Paediatric Neurologists, towards appropriate investigation and expert assessment.

Skills and Abilities NOT required at this level

- Investigating and managing the whole range of neurometabolic and neurodegenerative disorders independently.

b Child with specific learning difficulties

Skills and Abilities to Acquire

- Undertaking comprehensive paediatric assessments of children with a range of specific learning difficulties including recognising indicators of same, and of common co-morbid conditions e.g. specific language disorders etc.
- Liaising with colleagues in Education regarding appropriate formal assessments for these children.
- Making appropriate paediatric management plans for this group (which may mean recognising that the Paediatrician does not have an active contribution to make, once co-morbid disorders have been excluded).
- Recognising indicators of significant organic disease, co-morbid neurobehavioural or developmental disorders and referring on as appropriate for further investigations/expert opinions.

Skills and Abilities NOT required at this level

- Conducting formal psychometric assessment or using specific diagnostic instruments for specific learning difficulties.

Additional literature

- Whitmore K, Hart H, Willems G (Editors) *A neurodevelopmental approach to specific learning disorders*. MacKeith Press 1999. ISBN 1898683115.

c Child with communication disorder

Skills and Abilities to Acquire

- Undertaking comprehensive paediatric assessments of children with a range of communication disorders, including making initial informal assessment of receptive and expressive language and of non-verbal communication in the context of intellectual ability.
- Taking social communication histories and recognising indicators of Autism Spectrum Disorders; undertaking Autism Spectrum diagnostic assessments, in conjunction with other professionals.
- Liaising with expert colleagues, including specialist Speech and Language Therapists and Psychologists, regarding further detailed assessments of communication skills including social communication skills.
- Recognising indicators of complex language disorders or where communication skills are regressing and liaising appropriately with colleagues regarding specialist investigations and management.

Skills and Abilities NOT required at this level

- Undertaking formal detailed assessment of speech and language.
- Using formal diagnostic instruments e.g. DISCO, ADOS.

Additional literature

- Rapin I. *Preschool children with inadequate communication*. MacKeith Press 1996. ISBN 1898683077.
- Gillberg C and Coleman M *The Biology of the Autistic Syndromes*. MacKeith Press 2000. 3rd Edition. ISBN 1 898683 22 0.

d Child with neuropsychiatric or behavioural disorder

Skills and Abilities to Acquire

- Undertaking comprehensive paediatric assessments of children with a range of neuropsychiatric and behavioural disorders; ability to recognise common behavioural syndromes and phenotypes e.g. Attention Deficit Hyperactivity Disorders, Tourette Syndrome, Conduct Disorder etc, including recognising co-morbidities.
- Arranging appropriate investigations, gathering information from other sources (e.g. school, nursery etc) and making appropriate management plans.
- Liaising appropriately with colleagues in Child and Adolescent Mental Health and Learning Disability Psychiatry services towards further detailed assessments/management advice.
- Recognising indicators of psychosis and depression and of complex neuropsychiatric disorders and arranging timely expert assessments and management advice.
- Recognising benefits and complications of commonly used psychopharmacological agents.

Skills and Abilities NOT required at this level

- Independently managing severe neuropsychiatric disorders, psychoses or depression.
- Initiating treatment with neuroleptic or antipsychotic medication.
- Independently using methodologies of Family Therapy, Psychotherapy etc.

Additional literature

- Graham P, Verhulst F and Turk J *Child Psychiatry – A Developmental Approach* OUP 1999 3rd Edition. ISBN 0-19-262864-X

e Child with motor disorder

Skills and Abilities to Acquire

- Undertaking comprehensive paediatric assessments of children with potential motor disorders, including detailed assessments of posture, mobility and function.
- Formulating appropriate differential diagnoses, investigations and management plans for children with a range of motor disorders including cerebral palsy, neuromuscular disorders, spina bifida, developmental coordination disorder, etc.
- Liaising with expert colleagues towards the specialist assessment and management of children with complex motor disorders.
- Recognising indicators of progressive motor disorders and liaising appropriately with expert colleagues e.g. Paediatric Neurology, regarding further assessment and management.

Skills and Abilities NOT required at this level

- Undertaking complex investigations e.g. muscle biopsy, nerve conduction studies.
- Undertaking gait analysis.
- Administering Botulinum Toxin injections.
- Independently assessing, investigating and managing the whole range of progressive motor disorders.

Additional literature

- Stanley FJ, Blair E, Alberman E. *Cerebral Palsies* MacKeith Press 2000
ISBN 1898683204
- Mayston M, Scrutton D *Management of the Motor Disorders of children with cerebral palsy* 2nd Edition due May 2003. ISBN 1898683328.

f Child with sensory disorder

Skills and Abilities to Acquire

- Undertaking comprehensive paediatric assessments on children with potential or confirmed hearing and/or visual impairments, including initial informal assessment of level of hearing/vision; arranging appropriate investigations and instituting management plans.
- Arranging appropriate formal testing of hearing and/or visual functioning, appropriate to cognitive level.
- Recognising indicators of potentially progressive or complex sensory disorders and arranging timely expert assessment/management advice.

Skills and Abilities NOT required at this level

- Undertaking formal audiometry or formal brain stem evoked response hearing testing.
- Undertaking formal refraction or formal neurophysiological assessment of visual pathway function.
- Independently assessing/managing the whole range of complex sensory impairment disorders.

g Child with epilepsy

Skills and Abilities to Acquire

- Undertaking comprehensive paediatric assessments of children who MAY have epilepsy, including obtaining detailed eye-witness accounts of each episode-type.
- Evaluating and forming a diagnostic opinion about episodes recorded on video or directly observed attacks.
- Formulating an appropriate differential diagnosis and demonstrating an awareness of the range of diagnostic possibilities.
- Formulating a diagnosis, including seizure type, epilepsy syndromic diagnosis; identifying possible aetiological factors and assessing impact of epilepsy on children/young people's level of functioning.
- Appropriately investigating children who MAY have epilepsy.
- Initiating treatment and demonstrating knowledge of the benefits and disadvantages of the range of treatment options for different epilepsy diagnoses.
- Recognising when children have an unusual presentation or evidence of refractory epilepsy which requires the expertise of an appropriate Paediatric Neurologist (with specific expertise in the field of epilepsy if possible).
- Recognising indicators from clinical evidence, EEG, neuroimaging and other investigations that further expert opinion/s are required.

Skills and Abilities NOT required at this level

- Interpreting EEGs in detail.
- Interpreting MRI/CT scans in detail.
- Managing refractory epilepsy which has not responded to first-line treatment with conventional anticonvulsants i.e. trials of any two drugs alone or in combination which have not resulted in improved seizure control.
- Managing work-up for consideration of Epilepsy Surgery.

Additional literature

- Stephenson JBP. *Fits and Faints*. MacKeith Press 1990. ISBN 0521411963.

h Child with progressive neurological disorder

Skills and Abilities to Acquire

- Undertaking comprehensive paediatric assessments of children and young people with potential and established progressive neurological disorders.
- Recognising indicators of progressive disorders and liaising appropriately with colleagues e.g. Paediatric Neurology, Paediatric Metabolic Medicine, towards timely assessment, investigation and management advice.

Skills and Abilities NOT required at this level

- Ability to independently investigate and manage all potential progressive neurological disorders.
- Ability to independently manage the palliative care of this group of children (there should be a clear network for expert advice and support).

i Child with acquired neurological disorder

Skills and Abilities to Acquire

- Undertaking comprehensive paediatric assessments of children of different ages who have acquired neurological disorders, taking into account pre-morbid cognitive, motor, behavioural and general levels of functioning.
- Assessing acquired impairments precisely and understanding the mechanisms and origins of impairments and their likely natural history.
- Establishing criteria by which progress could be recognised and negotiating general programme goals and specific intervention procedures that might help to achieve them.
- Engaging other key professionals in coordinating rehabilitation and care packages, linking with tertiary and primary health care, education, social services and the voluntary sector.
- Producing appropriate paediatric and inter-agency management plans, responsive to the changing needs of this group of children.
- Understanding and recognising indicators of complex behavioural and physical pathology e.g. epilepsy, movement disorders, orthopaedic complications, cognitive deficits, emotional and behavioural problems, dysphagia, communication difficulties etc which may require referral for timely expert assessment and management advice e.g. Paediatric Neurology, Paediatric Rehabilitation, Paediatric Neuropsychiatry etc

Skills and Abilities NOT required at this level

- Ability to independently manage all complications arising as a result of acquired neurological disorder.
- Ability to manage immediate i.e. PICU aspects of health care.

Additional Skills and Abilities to Acquire to achieve competence in Paediatric Neurorehabilitation sufficient to take on a Consultant Post with special responsibility for Paediatric Neurorehabilitation

NB This would need an extra FULL YEAR in the training programme, in addition to the 2 years required to achieve core competencies in Paediatric Neurodisability.

Some experience can be gained during an acute neurology placement, some during a Neurodisability placement, but further training with specialist team/s would be desirable e.g. services that provide comprehensive care from intensive care unit through to community integration with a team dedicated to paediatric rehabilitation, which uses agreed protocols for common conditions.

Relevant experience with rheumatology and oncology could be considered.

- *Early management* of children/young people with significant acquired defects to promote recovery and prevent complications. This could occur within an acute neurology placement and would include neuro-intensive care.
- *Intermediate management* of children/young people who may have on-going medical needs, with intensive therapy support. This may be in an acute hospital, a rehabilitation unit or as a staged discharge into the community.
- *Reintegration into the community* and specifically schooling
- *Organising the discharge* of children with on-going severe multiple and complex needs requiring multi-agency collaboration e.g. long term ventilation, severe challenging behaviour etc.
- *Long term follow up* and anticipation of latent effects of injury (particularly on cognition, emotion and behaviour) that often present in educational ways. Ideally a trainee should attend a regular follow-up clinic over 1-2 years.
- *Management of those children with severe medical or behavioural needs*, who may require a residential setting.
- *Child Psychiatry*, particularly behavioural therapy, recognition of depression and severe illness behaviour

There should be an option for some trainees to spend extended time (usually 3-4 years) in full time research working for a higher degree.

SECTION 3

Assessment tools

SECTION 3: ASSESSMENT TOOLS

- Suggested assessment tools are provided here (**TOOLS 1 to 4**).
These tools have not yet been formally evaluated but are suggested as possible methods to be used by trainees and clinical/educational supervisors to monitor learning progress throughout the training period. There is no set frequency for use of the tools – this should be agreed between trainee and supervisor/s. The trainee should complete the most, as a means of checking on progress towards acquisition of competencies; copies should be kept in the portfolio for discussion with supervisor/s, who will also complete reports from time to time.
 - **Tool 1.1** Checklist for assessing consultation skills for a new patient in the neurodisability clinic (direct observation or video)

 - **Tool 1.2** Checklist for assessing skills in sharing difficult information
 - **Tool 2** Checklist for assessing a clinic letter to parents relating to a new patient consultation in the neurodisability clinic

 - **Tool 3** Guide to reflective diary and portfolio

 - **Tool 4** Training progress reports

- **Table 3.1** gives guidance on best assessment tools for particular areas or skills. The competencies are listed down the side axis, the tools across the top axis.

- Some assessment tools may be better than others when looking at specific competencies. Some competencies are generic and may apply to a number of conditions; also, many children may have more than one of the conditions listed in **Section 2** on **page 11**. Thus a combination approach using different tools to give different views on the same competency is recommended.

- We suggest documenting in the training record/portfolio which conditions the trainee has been assessed on and by what method (clinic letter/s, observed consultation/s etc). In addition, training progress reports should provide evidence of training and, if completed by a range of professionals, should provide an even wider view of competency skills.

- The SAIL tool should be used to evaluate general letter writing skills. [Crossley JGM. Howe A. Newble D. Jolly B. Davies HA. Sheffield assessment instrument for letters (SAIL): Performance assessment using outpatient letters. *Medical Education*. 2001;35(12):1115-1124].

TOOL 1.1: CHECKLIST FOR ASSESSING CONSULTATION SKILLS FOR A NEW PATIENT IN THE NEURODISABILITY CLINIC (DIRECT OBSERVATION OR VIDEO)

Having the opportunity to be directly observed in clinic, with a critique discussed afterwards, is an invaluable contribution to training at any level.

Not everyone will have access to video equipment, but videoed consultations are to be encouraged, as it is the only way a trainee can see themselves in action.

If a consultation is to be videoed, it is essential that informed written consent is obtained from the young person (if possible), as well as the parent/carer. Consent is required (by the GMC) to include information about what the video will be used for, how long it will be kept for, how and where it will be stored, when/how it will be destroyed. Sample consent forms may be found on the GMC website.

This assessment tool can provide information about the following areas of clinical competence:

1. **Clinical assessment**
2. **Formulate differential diagnosis**
3. **Formulate management plan**
4. **Communicate diagnoses and management plans effectively**
5. **Have the team-working skills to work in partnership with other professionals towards child-centred care**
6. **Identify and manage the functional consequences of impairments and associated medical conditions, including dying and death**
8. **Anticipate and plan for transition stages and changes in environmental context**
9. **Give a balanced view on treatment options**

For some competencies, only limited assessment information will be gained requiring other tools to be used as well (e.g. assessment of clinic letters). The information should then be considered as a whole.

Scores of 1 or 2 are a significant cause for concern particularly if in the following domains:

- Detailed history
- Full systemic examination
- Detailed neurological examination
- Interpretation of documented findings
- Appropriate review and summary of available information about child
- Appropriate differential diagnosis
- Appropriate management plan
- Appropriate communication of diagnoses and management plan
- Appropriate identification of functional consequences of child's impairment
- Appropriate management of functional consequences of child's impairment

Consultations should be assessed over a period of time.

The trainee should also keep a reflective diary and record:

- What went well?
- What might I do better?

TOOL 1.1 [cont'd]: CHECKLIST FOR ASSESSING CONSULTATION SKILLS FOR A NEW PATIENT IN THE NEURODISABILITY CLINIC (DIRECT OBSERVATION OR VIDEO)

1 is poor, 5 is excellent and NR is not relevant/unable to assess.

Please tick the box that best describes the doctor's performance in each area listed.

Clinical assessment							
	NR	1	2	3	4	5	
Parents and child not put at ease/non-verbal cues missed							Parents and child put at ease/non-verbal cues recognised
Detailed medical history not taken							Detailed medical history taken
Detailed developmental history not taken							Detailed developmental history taken
Full systemic physical examination not carried out							Full systemic physical examination carried out
Physical signs not correctly elicited							Physical signs correctly elicited
Detailed neurological examination not done							Detailed neurological examination done
Neurological signs not correctly elicited							Neurological signs correctly elicited
Height not ascertained, percentile not plotted or recorded							Height correctly ascertained using standardised equipment and percentile correctly plotted and recorded
Weight not ascertained, percentile not plotted or recorded							Weight correctly ascertained using standardised equipment and percentile correctly plotted and recorded
Head circumference not ascertained, percentile not plotted or recorded							Head circumference correctly ascertained and percentile correctly plotted and recorded
Mobility not assessed or recorded							Mobility assessed and recorded
Hand function not assessed or recorded							Hand function assessed and recorded
Personal care function not assessed or recorded							Personal care function assessed and recorded
Continence not assessed or recorded							Continence assessed and recorded
Vision not assessed or recorded							Vision assessed and recorded
Hearing not assessed or recorded							Hearing assessed and recorded
Communication, speech and language not assessed or recorded							Communication, speech and language assessed and recorded, including non-verbal communication
Cognition not assessed or recorded							Cognition assessed and recorded
Behaviour not assessed or recorded							Behaviour assessed and recorded
Social functioning not assessed or recorded							Social functioning assessed and recorded
Clinical findings not appropriately interpreted							Clinical findings appropriately interpreted
Inappropriate interaction with child							Appropriate interaction with child
Inappropriate planning and organisation of clinic visit							Appropriate planning and organisation of clinic visit
Inappropriate or no clinical judgement made							Appropriate clinical judgement made

TOOL 1.1 [cont'd]: CHECKLIST FOR ASSESSING CONSULTATION SKILLS FOR A NEW PATIENT IN THE NEURODISABILITY CLINIC (DIRECT OBSERVATION OR VIDEO)

Formulate differential diagnosis							
	NR	1	2	3	4	5	
All available information about child not appropriately reviewed, summarised or interpreted							All available information about child appropriately reviewed, summarised and interpreted
Unable to give balanced view on differential diagnosis							Able to give balanced view on differential diagnosis

Formulate Management Plan							
	NR	1	2	3	4	5	
Effective management plan not prepared							Effective management plan prepared
Appropriate investigations not planned							Appropriate investigations planned
Investigation results not correctly interpreted							Investigation results correctly interpreted
Appropriate therapy needs, on-referrals and liaison with colleagues not identified or planned for							Appropriate therapy needs, on-referrals and liaison with colleagues identified and planned for
Ongoing Paediatric care needs not defined							Ongoing Paediatric care needs defined
Did not demonstrate ability to maintain broad vision throughout consultation. Unable to refocus on new areas							Demonstrated ability to maintain broad vision throughout consultation, refocusing on new areas as required, towards multi-axial diagnoses

Communicate diagnoses and management plans effectively							
	NR	1	2	3	4	5	
Did not establish parents' baseline level of understanding							Established parents' baseline level of understanding
Language used not appropriate to recipient and medical terms not clearly explained							Language used appropriate to recipient and medical terms clearly explained
Did not recognise, correctly interpret or respond to verbal and non-verbal cues from parent/child							Recognised, correctly interpreted and responded to verbal and non-verbal cues from parent/child
Account of diagnoses and management plans not appropriate							Account of diagnoses and management plans appropriate
Did not confirm what parent/child/ had understood and did not modify as appropriate							Confirmed what parent/child had understood and modified as appropriate
Did not share difficult information according to agreed standards							Shared difficult information according to agreed standards
Did not obtain informed consent							Obtained informed consent
Did not explain clearly about available benefits and other sources of support							Explained clearly about available benefits and other sources of support

TOOL 1.1 [cont'd]: CHECKLIST FOR ASSESSING CONSULTATION SKILLS FOR A NEW PATIENT IN THE NEURODISABILITY CLINIC (DIRECT OBSERVATION OR VIDEO)

Have the team-working skills to work in partnership with other professionals towards child-centred care							
	NR	1	2	3	4	5	
Did not clearly explain the role of other professionals							Clearly explained the role of other professionals

Identify and manage the functional consequences of impairments and associated medical conditions, including dying and death							
	NR	1	2	3	4	5	
Did not correctly identify functional consequences of child's impairments							Correctly identified functional consequences of child's impairments
Did not institute correct management for functional consequences of child's impairments							Instituted correct management for functional consequences of child's impairments
Did not correctly identify associated medical conditions							Correctly identified associated medical conditions
Did not correctly manage associated medical conditions							Correctly managed associated medical conditions
Did not correctly identify associated mental health problems							Correctly identified associated mental health problems
Did not correctly manage associated mental health problems							Correctly managed associated mental health problems
Did not correctly identify indicators of stress/mental health problems in family members							Correctly identified indicators of stress/mental health problems in family members
No appropriate communication with GP for family members with identified problems							Appropriate communication with GP for family members with identified problems

Anticipate and plan for transition stages and changes in environmental context							
	NR	1	2	3	4	5	
Did not recognise and plan transition times							Recognised, planned for and minimised the adverse impact of transition times

Give a balanced expert view on treatment options							
	NR	1	2	3	4	5	
Did not present balanced account of treatment options for the child's condition							Present ed balanced account of treatment options for the child's condition

TOOL 1.2: CHECKLIST FOR ASSESSING SKILLS IN SHARING DIFFICULT INFORMATION

This assessment tool can provide information about difficult but extremely important areas of clinical competence

- 4.6 Sharing difficult information according to agreed standards**
- 6.4 Presenting a balanced account of what is medically possible (or not), remaining supportive and offering comfort at all times**
- 6.5 Preparing and discussing with parents, carers and other professionals “Do not attempt resuscitation” policies as appropriate, taking due account of the Human Rights Act (1998), ensuring that the best interests of the child are held as paramount at all times**
- 6.6 Recognising and communicating about imminent death, ensuring dignity and comfort for the child at all times**

The trainee can score their own consultations; direct observation or video of consultations will allow the supervisor to score as well.

Scores of 1 or 2 are a significant cause for concern.

Consultations should be assessed over a period of time.
The trainee should also keep a reflective diary and record:

- What went well?
- What might I do better?

TOOL 1.2: CHECKLIST FOR ASSESSING SKILLS IN SHARING DIFFICULT INFORMATION

1 is poor, 5 is excellent and NR is not relevant/unable to assess.

Please tick the box that best describes the doctor's performance in each area listed.

Planning and organisation							
	NR	1	2	3	4	5	
Had not read case notes or made self aware of all the important facts							Had read case notes fully and knew all the facts before seeing the family
Did not arrange for privacy, allowed interruptions							Arranged for privacy during session (e.g. bleep free)
No attempt made to ensure both parents and/or other family member invited							Made sure that both parents and/or other family member invited
No additional staff member invited or inappropriate/too many staff present							Organised for appropriate additional staff member to be present

Valuing the child							
	NR	1	2	3	4	5	
Did not refer to the child by name during the consultation							Referred to the child by name throughout the consultation
Ignored or avoided the child during the consultation							Looked at/handled the child appropriately during the consultation
Newborn: did not allow parents to see and hold child before interview							Newborn: did allow parents to see and hold child before interview
Overly negative about the child or condition							Positive but realistic about the child or condition, gave hope

Use of Appropriate Language							
	NR	1	2	3	4	5	
Used jargon or complicated language							Used appropriate easy to understand language
Did not explain technical terminology							Clarified technical terminology
Used harsh or unkind words							Used kind words

Giving Information							
	NR	1	2	3	4	5	
Did not establish level of understanding							Established parental level of understanding
Did not give narrative of events so far							Gave a narrative of events so far
Did not check understanding at any point							Checked understanding periodically
Gave false/dishonest information or gave inaccurate information							Gave honest information

TOOL 1.2 [cont'd]: CHECKLIST FOR ASSESSING SKILLS IN SHARING DIFFICULT INFORMATION

Tuning in to parents							
	NR	1	2	3	4	5	
Did not elicit parental concerns							Elicited parental concerns
Did not answer parents' direct questions							Answered direct questions appropriately
Did not adapt the information given in response to parental culture and understanding							Adapted information given in response to parental culture and understanding
Overly negative about the child or condition							Positive but realistic about the child or condition, gave hope

Empathy							
	NR	1	2	3	4	5	
Lacked warmth							Showed warmth
Did not show respect for confidence in parents							Demonstrated respect for and confidence in parents
Failed to show understanding of parents							Showed understanding of parents
Failed to allow or enable parents to express their feelings							Allowed or enabled parents to express their feelings
Did not give chance for privacy after information sharing and not notified of follow up							Gave chance for privacy after information sharing and notified of follow up

Summary and plan							
	NR	1	2	3	4	5	
Did not arrange a review, or planned for too long ahead							Arranged for a review
Failed to give contact telephone number for further queries							Gave contact telephone number for follow up queries
Did not give, or make any plan to give, written information							Explained plan to give or gave written information
Did not explain plan to notify GP / HV / local Dr							Explained plan to notify GP / HV / local Dr
Failed to give any additional information re support groups etc.							Gave information re practical support/other agencies

TOOL 2: CHECKLIST FOR ASSESSING A CLINIC LETTER TO PARENTS RELATING TO A NEW PATIENT CONSULTATION IN THE NEURODISABILITY CLINIC

This assessment tool can provide information about the following areas of clinical competence:

1. **Clinical assessment**
2. **Formulate differential diagnosis**
3. **Formulate management plan**
4. **Communicate diagnoses and management plans effectively**
5. **Have the team-working skills to work in partnership with other professionals towards child-centred care**
6. **Identify and manage the functional consequences of impairments and associated medical conditions, including dying and death**
7. **Write relevant letters and reports, understandable to parents, professionals and lay people**
8. **Anticipate and plan for transition stages and changes in environmental context**
9. **Give a balanced view on treatment options**

For some competencies, only limited assessment information will be gained requiring other tools to be used as well e.g. formalised direct observation of consultation or videoed consultation, training progress reports. The information should then be considered as a whole.

The clinic letter itself should include an early clear statement about the diagnosis and proposed management plan then salient positive and negative parts of the history and findings. It should be possible to answer by extrapolation the assessment questions as below from reading the clinic letter, although additional details of the consultation may need to be extracted from the contemporaneous case notes. Different clinic letters will lend themselves to the assessment of different competencies.

Scores of 1 or 2 are a significant cause for concern particularly in the following domains:

- Detailed history
- Full systemic examination
- Detailed neurological examination
- Interpretation of documented findings
- Appropriate review and summary of available information about child
- Appropriate differential diagnosis
- Appropriate management plan
- Appropriate communication of diagnoses and management plan
- Appropriate identification of functional consequences of child's impairment
- Appropriate management of functional consequences of child's impairment

Consistent high scores across a number of clinic letters indicates a high level of competence in those areas.

Clinic letters should be assessed over a period of time

The trainee should also keep a reflective diary and record:

- What went well?
- What might I do better?

TOOL 2: CHECKLIST FOR ASSESSING NEW PATIENT CLINIC LETTER TO PARENTS FROM THE NEURODISABILITY CLINIC

1 is poor, 5 is excellent and NR is not relevant/unable to assess.
 Please tick the box that best describes the doctor's performance in each area listed.

Clinical assessment							
	NR	1	2	3	4	5	
Detailed medical history not taken							Detailed medical history taken
Detailed developmental history not taken							Detailed developmental history taken
Full systemic physical examination not carried out							Full systemic physical examination carried out
Detailed neurological examination not done							Detailed neurological examination done
Neurological signs not correctly elicited							Neurological signs correctly elicited
Height not ascertained, percentile not plotted or recorded							Height correctly ascertained and percentile correctly plotted and recorded
Weight not ascertained, percentile not plotted or recorded							Weight correctly ascertained and percentile correctly plotted and recorded
Head circumference not ascertained, percentile not plotted or recorded							Head circumference ascertained and percentile correctly plotted and recorded
Mobility not assessed or recorded							Mobility assessed and recorded
Hand function not assessed or recorded							Hand function assessed and recorded
Personal care function not assessed or recorded							Personal care function assessed and recorded
Continence not assessed or recorded							Continence assessed and recorded
Vision not assessed or recorded							Vision assessed and recorded
Hearing not assessed or recorded							Hearing assessed and recorded
Communication, speech and language not assessed or recorded							Communication, speech and language assessed and recorded, including non-verbal communication
Cognition not assessed or recorded							Cognition assessed and recorded
Behaviour not assessed or recorded							Behaviour assessed and recorded
Social functioning not assessed or recorded							Social functioning assessed and recorded
Documented findings not appropriately interpreted							Documented findings appropriately interpreted

TOOL 2 (contd): CHECKLIST FOR ASSESSING NEW PATIENT CLINIC LETTER TO PARENTS FROM THE NEURODISABILITY CLINIC

Formulate differential diagnosis							
	NR	1	2	3	4	5	
All available information about child had not been appropriately reviewed and summarised							All available information about child had been appropriately reviewed and summarised
Appropriate differential diagnosis not drawn up from the evidence available							Appropriate differential diagnosis drawn up from the evidence available

Formulate Management Plan							
	NR	1	2	3	4	5	
Appropriate investigations not planned							Appropriate investigations planned
Investigation results not correctly interpreted							Investigation results correctly interpreted
Appropriate therapy needs, on-referrals and liaison with colleagues not identified and planned for							Appropriate therapy needs, on-referrals and liaison with colleagues identified and planned for
Ongoing Paediatric care needs not defined							Ongoing Paediatric care needs defined

Communicate diagnoses and management plans effectively							
Write relevant letters and reports understandable to parents, professionals and lay people							
	NR	1	2	3	4	5	
Did not establish parents' baseline level of understanding							Established parents' baseline level of understanding
Language used not appropriate to recipient and medical terms not explained							Language used appropriate to recipient and medical terms clearly explained
Did not give clear account of diagnoses and management plans appropriate for recipient							Gave clear account of diagnoses and management plans appropriate for recipient
Ongoing Paediatric care needs not defined							Ongoing Paediatric care needs defined

Have the team-working skills to work in partnership with other professionals towards child-centred care							
	NR	1	2	3	4	5	
Did not explain role of other professionals							Explained role of other professionals

TOOL 2 (contd): CHECKLIST FOR ASSESSING NEW PATIENT CLINIC LETTER TO PARENTS FROM THE NEURODISABILITY CLINIC

Identify and manage the functional consequences of impairments and associated medical conditions							
	NR	1	2	3	4	5	
Did not correctly identify functional consequences of child's impairments							Correctly identified functional consequences of child's impairments
Did not institute correct management for functional consequences of child's impairments							Instituted correct management for functional consequences of child's impairments
Did not correctly identify associated medical conditions							Correctly identified associated medical conditions
Did not correctly manage associated medical conditions							Correctly managed associated medical conditions
Did not correctly identify associated mental health problems							Correctly identified associated mental health problems
Did not correctly manage associated mental health problems							Correctly managed associated mental health problems
Did not correctly identify indicators of stress/mental health problems in family members							Correctly identified indicators of stress/mental health problems in family members
No appropriate communication with GP for family members with identified problems							Appropriate communication with GP for family members with identified problems

Anticipate and plan for transition stages and changes in environmental context							
	NR	1	2	3	4	5	
Did not recognise and plan for transition times							Recognised, planned for and minimised the adverse impact of transition times

Give a balanced view on treatment options							
	NR	1	2	3	4	5	
Did not give a balanced view on treatment options appropriate to child's condition							Gave a balanced view on treatment options appropriate to child's condition

TOOL 3: GUIDE TO REFLECTIVE DIARY AND RECORDS FOR PORTFOLIO

It is essential for the trainee to keep careful records of learning experiences and progress.

For each letter and directly observed consultation/video assessed a copy of the relevant assessment sheet should be kept in the portfolio. The Clinical Supervisor will need to see these, along with the original letters and videos.

This section gives more ideas for recording learning experiences. Extra pages can be added as required.

The idea is for the trainee to drive their own learning, to reflect on and consolidate positive things learnt and to recognise, work at and improve those skills which prove more difficult.

The trainee will get more out of available learning opportunities by using this approach.

Additional information about consultation skills can be gained by using feedback forms completed by parents and young people. The local centre may use these already. If not, the trainee could devise one in conjunction with their supervisor.

TOOL 3.1: **REFLECTIVE NOTES FROM OBSERVED
CONSULTATION**

Clinic:

Date:

Person observed and specialty:

Number of patient/s seen:

Diagnoses/Active concerns of patient/s seen:

What went well?

What might I do better?

TOOL 3.2: **REFLECTIVE NOTES FROM OWN**
CONSULTATIONS

Clinic:

Date:

Number of patient/s seen:

Diagnoses/Active concerns of patient/s seen:

What went well?

What might I do better?

TOOL 3.3: **REFLECTIVE NOTES FROM MEETINGS,
PRESENTATIONS AND COURSES**

Event:

Date:

Presenter/s:

Subject:

Key Learning Points:

What value has this added to my training?

What will I change about my own practice as a result?

TOOL 3.4: REFLECTIVE NOTES FROM PRIVATE STUDY

Book/journal:

Date:

Title of paper/chapter:

Key Learning Points:

What value has this added to my training?

What will I change about my own practice as a result?

TOOL 4: TRAINING PROGRESS REPORTS

These training progress reports are for completion by a range of professionals with whom the trainee comes into contact and should be used in addition to the SpR training annual assessment tools, as found on the PIER website.

Reports can be requested from a range of professionals: Doctors, Nurses, Therapists, etc. The wider the range of feedback providers, the more complete the picture of progress.

Completed reports should act as a catalyst for discussion between trainee and supervisor on a regular basis, allowing time for training programmes to be modified to best meet the training needs of the individual.

TOOL 4.1: OVERALL TRAINING PROGRESS REPORT

Name of trainee:

Name of supervisor:

Name and profession of person completing report:

Date:

Year of training:

Please score the trainee for each area as follows:

NR - *Not relevant, unable to assess*

1 - *Very rudimentary level of competence*

2 - *Basic competence – not sufficient to be dependable*

3 - *Satisfactory competence – but always room to improve*

4 - *Above average competence*

5 - *Excellent competence – well done*

CLINICAL SKILLS

	SCORE
➤ History taking	NR 1 2 3 4 5
➤ Eliciting physical signs	NR 1 2 3 4 5
➤ Functional/developmental assessment	NR 1 2 3 4 5
➤ Anthropometric assessment	NR 1 2 3 4 5
➤ Genogram construction and interpretation	NR 1 2 3 4 5
➤ Appropriate on-referral/s	NR 1 2 3 4 5
➤ Appropriate investigation planning and interpretation	NR 1 2 3 4 5
➤ Appropriate management planning	NR 1 2 3 4 5
➤ Diagnostic ability	NR 1 2 3 4 5
➤ Overall clinical judgement	NR 1 2 3 4 5

COMMUNICATION

	SCORE
➤ Put child/parent at ease	NR 1 2 3 4 5
➤ Establish child/parent baseline understanding	NR 1 2 3 4 5
➤ Use appropriate language	NR 1 2 3 4 5
➤ Recognise, interpret and respond to non-verbal cues	NR 1 2 3 4 5
➤ Letter writing for parent/s	NR 1 2 3 4 5
➤ Letter writing for doctors	NR 1 2 3 4 5
➤ Letter writing for other professionals	NR 1 2 3 4 5
➤ Share difficult information	NR 1 2 3 4 5
➤ Obtain informed consent	NR 1 2 3 4 5

TEAM-WORKING

	SCORE
➤ Work as part of a team in a child-centred way	NR 1 2 3 4 5
➤ Manage team tensions, keep focus on child and their needs	NR 1 2 3 4 5
➤ Explain role of other professionals to parents	NR 1 2 3 4 5
➤ Work with other agencies e.g. case conferences, multi-agency meetings	NR 1 2 3 4 5
➤ Fulfil duties of Designated Doctor for Education (SEN)	NR 1 2 3 4 5
➤ Chair meetings – clinical reviews, management	NR 1 2 3 4 5

NON-CLINICAL

	SCORE
➤ Critically appraise treatment/outcome paper/s	NR 1 2 3 4 5
➤ Perform web-search on question/s presented by families	NR 1 2 3 4 5
➤ Understand challenges presented to education and social services' professionals in settings outside health	NR 1 2 3 4 5
➤ Understand importance of "seamless care" for a child	NR 1 2 3 4 5
➤ Plan and implement population policies or strategies in the field of child disability	NR 1 2 3 4 5
➤ Critically evaluate own performance	NR 1 2 3 4 5
➤ Use routinely available information e.g. on local child health information system, special needs register etc	NR 1 2 3 4 5
➤ Consult appropriately with other statutory/voluntary agencies	NR 1 2 3 4 5
➤ Structured planning	NR 1 2 3 4 5
➤ Efficiently carry through plans formulated	NR 1 2 3 4 5
➤ See through the Audit process	NR 1 2 3 4 5
➤ Effectively teach a range of audiences	NR 1 2 3 4 5

TRAINING PROGRESS REPORTS

Name of trainee:

Name of supervisor:

Name and profession of person completing report:

Date:

Year of training:

Please score the trainee for each area as follows:

NR - *Not relevant, unable to assess*

1 - *Very rudimentary level of competence*

2 - *Basic competence – not sufficient to be dependable*

3 - *Satisfactory competence – but always room to improve*

4 - *Above average competence*

5 - *Excellent competence – well done*

TOOL 4.2: Child with a learning disability (mental retardation)

SCORE

- For children/young people with mild/moderate learning disability
 - undertake comprehensive paediatric assessments **NR 1 2 3 4 5**
 - reach appropriate differential diagnoses **NR 1 2 3 4 5**
 - institute appropriate management plans **NR 1 2 3 4 5**

- For children/young people with severe/profound learning disability
 - undertake comprehensive paediatric assessments **NR 1 2 3 4 5**
 - reach appropriate differential diagnoses **NR 1 2 3 4 5**
 - institute appropriate management plans **NR 1 2 3 4 5**

- Recognise when children's levels of cognitive functioning fall outside the broadly normal range for age **NR 1 2 3 4 5**

- Network with colleagues e.g. Educational and/or Clinical Psychologist, towards obtaining formal detailed cognitive profiles **NR 1 2 3 4 5**

- Recognise indicators that children may be losing intellectual skills **NR 1 2 3 4 5**

- Network with colleagues e.g. Paediatric Neurologist, towards appropriate investigation and expert assessment and management **NR 1 2 3 4 5**

TOOL 4.3: Child with specific learning disability

SCORE

- Undertake comprehensive paediatric assessments on children with a range of specific learning disabilities **NR 1 2 3 4 5**

- Recognise indicators of specific learning disabilities, as well as indicators of common co-morbid conditions e.g. specific language disorders etc **NR 1 2 3 4 5**

- Liaise with colleagues in Education regarding appropriate formal assessment for these children **NR 1 2 3 4 5**

- Make appropriate paediatric management plans for this group (which may mean recognising that the Paediatrician does not have an active contribution to make, once co-morbid disorders have been excluded) **NR 1 2 3 4 5**

- Recognise indicators of significant organic disease, co-morbid neurobehavioural or developmental disorders and ability to refer on for further investigations/expert opinions as appropriate **NR 1 2 3 4 5**

TRAINING PROGRESS REPORTS

Name of trainee:

Name of supervisor:

Name and profession of person completing report:

Date:

Year of training:

Please score the trainee for each area as follows:

NR - *Not relevant, unable to assess*

- 1 - *Very rudimentary level of competence*
- 2 - *Basic competence – not sufficient to be dependable*
- 3 - *Satisfactory competence – but always room to improve*
- 4 - *Above average competence*
- 5 - *Excellent competence – well done*

TOOL 4.4: Child with communication disorder

SCORE

- Undertake comprehensive paediatric assessments of children with a range of communication disorders, including ability to make initial informal assessment of receptive and expressive language and of non-verbal communication in the context of intellectual ability
NR 1 2 3 4 5
- Take social communication histories and recognise indicators of Autism Spectrum Disorders
NR 1 2 3 4 5
- Undertake Autism Spectrum diagnostic assessments in conjunction with other professionals
NR 1 2 3 4 5
- Liaise with expert colleagues, including specialist Speech and Language Therapists and Psychologists, regarding further detailed assessments of communication skills including social skills
NR 1 2 3 4 5
- Recognise indicators of complex language disorders and disorders where communication skills are regressing, and liaise in a timely way with expert colleagues towards specialist investigations and management
NR 1 2 3 4 5

TOOL 4.5: Child with neuropsychiatric or behavioural disorder

SCORE

- Undertake comprehensive paediatric assessments on children with a range of neuropsychiatric and behavioural disorders
NR 1 2 3 4 5
- Recognise common behavioural syndromes and phenotypes e.g. Attention Deficit Hyperactivity Disorders, Tourette Syndrome, Conduct Disorder etc
NR 1 2 3 4 5
- Recognise co-morbidities
NR 1 2 3 4 5
- Arrange appropriate investigations, gather information from other sources e.g. schools, nurseries etc
NR 1 2 3 4 5
- Make appropriate management plans
NR 1 2 3 4 5
- Liaise appropriately with colleagues in Child and Adolescent Mental Health and Learning Disability Psychiatry services towards further detailed assessments/management advice
NR 1 2 3 4 5
- Recognise indicators of psychosis and depression and of complex neuropsychiatric disorders and arrange timely expert assessments and management advice
NR 1 2 3 4 5
- Recognise benefits and complications of commonly used psychopharmacological agents
NR 1 2 3 4 5

TRAINING PROGRESS REPORTS

Name of trainee:

Name of supervisor:

Name and profession of person completing report:

Date:

Year of training:

Please score the trainee for each area as follows:

NR - *Not relevant, unable to assess*

- 1 - *Very rudimentary level of competence*
- 2 - *Basic competence – not sufficient to be dependable*
- 3 - *Satisfactory competence – but always room to improve*
- 4 - *Above average competence*
- 5 - *Excellent competence – well done*

TOOL 4.6: Child with motor disorder

SCORE

- Undertake comprehensive paediatric assessments of children with potential motor disorders, including detailed assessment of posture, mobility and function
NR 1 2 3 4 5
- Formulate appropriate differential diagnoses, investigations and management plans for children with a range of motor disorders including cerebral palsy, neuromuscular disorders, spina bifida, developmental coordination disorder, etc.
NR 1 2 3 4 5
- Liaise with expert colleagues towards the specialist assessment and management of children with complex motor disorders
NR 1 2 3 4 5
- Recognise indicators of progressive motor disorders and liaise appropriately with expert colleagues e.g. Paediatric Neurology, towards timely further assessment and management
NR 1 2 3 4 5

TOOL 4.7: Child with sensory disorder

SCORE

- Undertake comprehensive paediatric assessments of children with potential or confirmed hearing and/or visual impairments, including initial informal assessment of hearing/vision levels
NR 1 2 3 4 5
- Arrange appropriate investigations
NR 1 2 3 4 5
- Institute management plans
NR 1 2 3 4 5
- Arrange appropriate formal testing of hearing and/or visual functioning, appropriate to cognitive level
NR 1 2 3 4 5
- Recognise indicators of potentially progressive or complex sensory disorders and arrange timely expert assessments and management advice
NR 1 2 3 4 5

TRAINING PROGRESS REPORTS

Name of trainee:

Name of supervisor:

Name and profession of person completing report:

Date:

Year of training:

Please score the trainee for each area as follows:

NR - *Not relevant, unable to assess*

1 - *Very rudimentary level of competence*

2 - *Basic competence – not sufficient to be dependable*

3 - *Satisfactory competence – but always room to improve*

4 - *Above average competence*

5 - *Excellent competence – well done*

TOOL 4.8: Child with epilepsy

SCORE

- Undertake comprehensive paediatric assessments of children who MAY have epilepsy, including obtaining detailed eye-witness accounts of each episode-type **NR 1 2 3 4 5**
- Critique and form diagnostic opinions about episodes recorded on video or directly observed episodes **NR 1 2 3 4 5**
- Formulate appropriate differential diagnoses, demonstrating an awareness of the range of diagnostic possibilities **NR 1 2 3 4 5**
- Formulate diagnoses, including seizure types and epilepsy syndromic diagnoses **NR 1 2 3 4 5**
- Identify possible aetiological factors **NR 1 2 3 4 5**
- Assess impact of epilepsy on child's level of functioning **NR 1 2 3 4 5**
- Appropriately investigate children who MAY have epilepsy **NR 1 2 3 4 5**
- Initiate treatment, demonstrating knowledge of the benefits and disadvantages of the range of treatment options for different epilepsy diagnoses **NR 1 2 3 4 5**
- Recognise when children have unusual presentations or evidence of refractory epilepsy which requires the expertise of a Paediatric Neurologist who has specific expertise in the field of epilepsy **NR 1 2 3 4 5**
- Recognise indicators from clinical evidence, EEG, neuroimaging and other investigations that further expert opinion/s are required **NR 1 2 3 4 5**

TOOL 4.9: Child with progressive neurological disorder

SCORE

- Undertake comprehensive paediatric assessments of children with potential and established progressive neurological disorders **NR 1 2 3 4 5**
- Recognise indicators of progressive disorders **NR 1 2 3 4 5**
- Liaise appropriately with colleagues e.g. Paediatric Neurology, Paediatric Metabolic Medicine, towards assessment, investigation and management advice **NR 1 2 3 4 5**

TRAINING PROGRESS REPORTS

Name of trainee:

Name of supervisor:

Name and profession of person completing report:

Date:

Year of training:

Please score the trainee for each area as follows:

NR - *Not relevant, unable to assess*

1 - *Very rudimentary level of competence*

2 - *Basic competence – not sufficient to be dependable*

3 - *Satisfactory competence – but always room to improve*

4 - *Above average competence*

5 - *Excellent competence – well done*

TOOL 4.10: *Child with acquired neurological disorder*

SCORE

Basic level for all Neurodisability trainees

- Undertake comprehensive paediatric assessments on children of different ages who have acquired neurological disorders, taking into account pre-morbid cognitive, motor, behavioural and general levels of function
NR 1 2 3 4 5
- Assess acquired impairments precisely and understand mechanisms and origins of impairments and their likely natural history
NR 1 2 3 4 5
- Establish criteria by which progress can be recognised
NR 1 2 3 4 5
- Negotiate general programme goals and specific intervention procedures which might help to achieve these goals
NR 1 2 3 4 5
- Engage other key professionals in coordinating rehabilitation and care packages, linking with tertiary and primary health care, education, social services and the voluntary sector
NR 1 2 3 4 5
- Produce appropriate paediatric and inter-agency management plans, responsive to the changing needs of this group of children
NR 1 2 3 4 5
- Recognise indicators of complex behavioural and physical pathology e.g. epilepsy, movement disorders, orthopaedic complications, cognitive deficits, emotional and behavioural problems, dysphagia, communication difficulties etc which may require referral for expert assessment and management advice e.g. Paediatric Neurology, Paediatric Rehabilitation, Paediatric Neuropsychiatry etc
NR 1 2 3 4 5

Advanced level for specialisation in Neurorehabilitation

- Proficient in early management of children with significant acquired defects, including ability to promote recovery and prevent complications
NR 1 2 3 4 5
- Proficient in intermediate management of children with ongoing medical needs, including co-ordinating intensive therapy support
NR 1 2 3 4 5
- Proficient in managing reintegration into the community including schooling, therapy services and voluntary organisations
NR 1 2 3 4 5
- Able to organise discharge of children with ongoing multiple and complex needs, requiring multi-agency collaboration e.g. long term ventilation, severe challenging behaviour
NR 1 2 3 4 5
- Proficient in long-term follow up, including ability to anticipate latent effects of injury e.g. on cognition, emotion, behaviour which may present in educational ways
NR 1 2 3 4 5