The Cambridge Centre for Paediatric Neuropsychological Rehabilitation (CCPNR)

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University of Cambridge and CPFT

A specialist service for children and families affected by acquired brain injury
Cambridge Centre For Paediatric Neuropsychological Rehabilitation (CCPNR)

Who we are:

- Specialist inter-disciplinary team
- Provide specialist assessment and neuropsychological rehabilitation for children with an acquired, non-progressive brain injury
- We support children and their family to make sense of the injury, learn helpful ways to cope and realise their full potential

Who we see:

- Up to the age of 16, or 19 if still involved in further education
- With complex interacting cognitive, emotional and communication difficulties
- Where working with school and family systems, across age and ability ranges is required
- Referrals from any professional

What we offer:

- Specialist assessment and intervention to young people, families, health, social care and education services
- Delivered by a multidisciplinary team
- Direct intervention with child, family and their system
- Indirect intervention training others
- Work alongside other services
CCPNR’s story from conception to date: a work in progress

• Development of CCPNR
  - What services were there for children with ABI and how did we get what was needed?

• What does the service look like now?
  - Who are we and what do we do?

• Interdisciplinary assessment and intervention
  - Initial Assessment, Detailed Assessment, Short Rehab packages and Full programmes

• What next?
Epidemiology

• 1.4 million people/year attend A and E with traumatic brain injury

• Approximately 50% are young people under the age of 15.

• 5-6% of children admitted with closed head injury every year.

(NICE, Head Injury. 2014; Appleton and Baldwin, 2006)
What Was/Is missing

• Local generic services as currently configured in the UK will, and indeed should, struggle to meet these children’s needs. If they are not struggling, they are probably not recognising them.

Terms of reference for the Rehabilitation Working Party of the Standing Committee on Disability of Royal College of Paediatrics and Child Health, 2003
Quick thought about trajectory of development for young people with brain injuries: the longer we delay intervention the bigger the gap.
What is Needed

- To fund a clinician and administrator to act as co-ordinators for an initial term of 3 years.

- To decide on their catchment population’s need (numerically and intensity) for rehabilitation in co-ordination with surrounding areas and the National Steering Group.

- To access the local strengths, which could contribute to a rehabilitation service.

- To set up a population based clinical team, whose brief is to provide a rehabilitation service between the tertiary hospital, and secondary level and community services.

- To work with NHS and charitable rehabilitation units where possible to develop services.

- To work with the national steering group (see section) on the development of locally based paediatric rehabilitation services (see section).

- To develop a business plan for the population based service, which will be in a form which can be audited annually (see section on audit). This plan may include an inpatient unit.

- To develop research, both locally and contribute to national research priorities.

- To assess training needs.

- To develop joint working practices with social services and education services
2007 Provision

• Nationally: in-patient provision for children with acquired brain injury

• Locally: No specialist provision for children and teens with acquired brain injury
Acute

- TBI in RTC aged 9
- Emergency Neurosurgery
- Transferred to PICU
- Return to DGH for acute rehab
- Referred to community paediatrician and CAMHS
- Referred back to DGH to reveal significant damage to frontal lobe
- Significant difficulties in return to home/school due to violent behavior
- EP recommends Brain Injury Service
- Re-referral to CAMHS: intervention from psychiatry and psychology
- Referral to CCPNR
- Statement/ EHCP process initiated
- Referred to specialist inpatient adolescent brain injury unit (funded by social, education and health services)
- CCPNR integrated with inpatient unit to support transition home

Community

- 12 months post injury
- 4 years post injury
- 6 years post injury
- 7 years post injury
Local Innovation in the NHS

- *Sharing the knowledge, sharing the vision*
  
  - Child and Adolescent Psychology Lead, Cambridge and Peterborough Foundation Trust/University of Cambridge
  
  - Manager Neuropsychologist, Oliver Zangwill Centre,
  
  - Founder, Oliver Zangwill Centre,
Local Innovation in the NHS

- *Sharing the knowledge, sharing the vision AND bringing in the business*

2007-2008

— Director of Business, Cambridge and Peterborough Foundation Trust/University of Cambridge
Local Innovation in the NHS

- Demand/Capacity Planning, Demand/Capacity Planning, Demand/Capacity Planning,
  - Hospital figures
  - Solicitor figures
  - Insurance figures

2008-2009
Local Innovation in the NHS

• *Knowing the market*
  – Needs families have identified
  – Needs have commissioners identified and what costs do they want to save
  – Market cost (£30k)
Local Innovation in the NHS

• *Meeting the need*
  – What models are already working?
  – In what context are they working?
  – What will resource (cost and care) sustain?
  – Iterative shaping of the service model

2008-2010
Local Innovation in the NHS

2010

The Cambridge Centre for Paediatric Neuropsychological Rehabilitation (CCPNR)
**Acute**
- TBI in RTC aged 15 years
- Emergency Neurosurgery
- Transferred to PICU
- Transferred to acute children’s ward
- Further neurosurgery and trauma surgery
- Acute MDT rehab
- CCPNR at Discharge Planning Meeting
- Referred to community services (SLT, OT, Physio)
- CCPNR assessment
- Specialist teacher liaison with school: graded return
- Family support, psychoeducation and adjustment. Cognitive rehab begins
- Change to appropriate college course - EP
- Training for all those supporting in college and community to understand injury and integrate cog rehab into contacts
- Referral and supported transition to adult community TBI service

**Community**
- 4 months post injury
- 3 years post injury
What We Could Have Done Better

**Relational commissioning**
- Inter-organisational networks
- Formal and informal communication
- Combined goals

**Health Environment**
- Saturated with Shared Information
- Case-Collaboration

**Receptive Context**
- Poised for change
- Innovation-value fit
- Minimised competing demands
- Speed of action
- Tolerance of difference and mistakes
- Personal commitment
- Psychological safety

**Needs-led**
- Service demand data
- Epidemiological data

Humphrey et al., under revision
“the best performing systems are characterised by integration of commissioning and provision”

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<table>
<thead>
<tr>
<th>Position</th>
<th>Name</th>
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<tbody>
<tr>
<td>Acting Clinical Lead Clinical Psychologist</td>
<td>Dr Suzanna Watson</td>
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<tr>
<td>Team Co-ordinator</td>
<td>Jenny Cahill</td>
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<td>Consultant Clinical Neuropsychologist</td>
<td>Dr Fergus Gracey</td>
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<tr>
<td>Consultant Paediatric Neurologist</td>
<td>Dr Anna Maw</td>
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<tr>
<td>Consultant Child and Adolescent Psychiatrist</td>
<td>Dr Jo Holmes</td>
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<td>Paediatric Neuropsychologist</td>
<td>Dr Catherine Harter</td>
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<tr>
<td>Specialist Teacher</td>
<td>Lorraine Austin</td>
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<td>Specialist OT</td>
<td>Patty Van Rooij</td>
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<td>Specialist OT</td>
<td>Stella Parry</td>
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<tr>
<td>Highly Specialist SLT</td>
<td>Gillian Shravat</td>
<td>0.4 + 0.2 CLAHRC</td>
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<tr>
<td>Clinical Psychologist</td>
<td>Dr Aafke Ninteman</td>
<td>1</td>
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<tr>
<td>Assistant Psychologist</td>
<td>Meghan Mc-Hugh-Harvey</td>
<td>0.4</td>
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<tr>
<td>Research Associate from UEA</td>
<td>Dr Darren Dunning</td>
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CCPNR: All Referrals December 2013-December 2014

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<tr>
<th>Category</th>
<th>Value</th>
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<tr>
<td>Referrals</td>
<td>46</td>
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<tr>
<td>Accepted</td>
<td>38</td>
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<tr>
<td>% Male</td>
<td>59</td>
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<tr>
<td>Average age</td>
<td>11.6 years</td>
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<td>(2.5 - 17.6 years)</td>
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<tr>
<td>Average number of years post injury</td>
<td>3.7 years</td>
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<td>(15 days – 14.6 years)</td>
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- Cambridgeshire: 41%
- Peterborough: 11%
- Norfolk: 11%
- Lincolnshire: 7%
- Essex: 7%
- Suffolk: 5%
- Bedfordshire: 4%
- Berkshire: 2%
- Buckinghamshire: 2%
- Hertfordshire: 2%
- London: 2%
- Luton: 2%
- Staffordshire: 2%
CCPNR: Accepted Referrals (December 2013-December 2014)

**Referral Source**
- Neurology: 35%
- Paediatrics: 18%
- Case Management: 18%
- Psychology: 9%
- Psychiatry: 9%
- Nursing: 9%
- GP: 7%
- OT: 2%
- S&LT: 2%

**Injury**
- TBI: 32%
- Fall: 24%
- Encephalitis: 14%
- Meningitis: 11%
- Stroke: 8%
- Tumour: 5%
- Asphyxia: 3%
- Abscess: 3%

Legend:
- Neurology
- Paediatrics
- Case Management
- Psychology
- Psychiatry
- Nursing
- GP
- OT
- S&LT
- TBI
- Fall
- Encephalitis
- Meningitis
- Stroke
- Tumour
- Asphyxia
- Abscess

2% NAI
CCPNR: Multiagency working
(Accepted referrals, December 2013-December 2014)

Young Person & Family at CCPNR 2014

- GP, 100%
- CJS Approx 2%
- Social Care- Locality, 16%
- Social Care-CIN, 11%
- Community Therapies, 16%
- CBIT, 37%
- Residential rehabilitation, 5%
- Case Manager, 13%
- CAMH, 13%
- Solicitor, 13%
- Social Care – Child protection Approx 5%
- Neurology, 47%
- SEN, 24%
- Local Paediatrician, 39%
- Social Care, 2%
- SEN, 24%
- CJS Approx 2%
Interdisciplinary assessment

• Based on the application of the WHO-ICF framework to rehabilitation (Wilson, Gracey and Evans 2009)

• with a developmental and systemic perspective (e.g. PEDS model: Physical, Executive, Developmental and Systems from Reed, Byard and Fine 2011)
Interdisciplinary intervention

Short rehabilitation package
20 hours direct contact: 20 hours indirect

Full programme
60 hours direct and indirect

PNI model
Goals planned with child family and system
Mediators of intervention?

• Pre-morbid mental health
• Pre-morbid family functioning
• Executive functioning predicts indirect contact (and DNA rate in mental health services) Cocksedge, Gracey and Wagner, 2014
• Complexity (Stacey Matrix)
What next?

Development of neurorehabilitation services from acute to community.
Paediatric Rehabilitation Pathway: 1. Acute Care / Inpatient Phase

SLTs: Dysfluency, Dysphagia, Dysarthria/Dyspraxia/VPI, AAC, Apraxia (anomic common), WFD, Echo and Palilalia

Is the child stable enough to step down to acute? Does the family require support? Is acute rehab required?

Child sustains TBI – Admitted to ED

Email alert for new brain tumour diagnosis & admission

Admitted to ED with temperature / sickness/ NAI/ Stroke

First person who is aware of a new case sends this email alert to group email. Instruction to start intervention sent to appropriate professionals / teams. Case file created.

Pre-op assessments undertaken including outcome measures. Conducted by physio, OT or SLT (ideal would be to have a single assessment tool/record).

Scan & intercranial pressure monitored

Surgery takes place.

If required, commence discussion with commissioners

Professionals involved liaise to allocate coordinator (often Specialist Nurse) with daily contact Role to be defined but must include:
1. Rehab prescription or Initial formulation started (trauma only)
2. Visual timetable (Play or OT)
3. Expectation management
4. Checklist of tasks/ information for coordinator
5. Information on physical/ mental health issues
6. Arrange dedicated social worker &/ or dedicated therapy input required
7. Information that can be provided for the family.
8. Letter to GP, Paediatrician and school
NB: Person who acts as coordinator will change as child moves through the pathway.

Coordinator: Liaison/ handover with acute children’s ward

Regular MDT meetings with family - significant info to be shared prior to the meeting itself to allow time to process

Coordinated MDT assessment to identify goals & develop acute rehab care plan.

Counsellors at ward round + neurology mtg available for families

Therapy input (OT, SALT, dietitian, Physio, play) provided for all brain injured children as required + hospital school. PTA Screening (GCS >15)
Paediatric Rehabilitation Pathway: 2. Acute Rehabilitation Phase

**Psychology involved when emotional or behavioural difficulties.**

**Hospital teachers carry out basic assessment of academic attainment, liaise with school and structure support accordingly.**

**SLTs: Dysfluency, Dysphagia, Dysarthria/Dyspraxia/ VPI, AAC , Aphasia (anomic common), WFD, Echo and palilalia**

**FIM/FAM +Cognitive screen to support discharge**

Transfer to acute children's ward for in-patient rehabilitation

Acute MDT meetings (minimum weekly). GAS goal monitoring

*Coordinator:* Arrange meetings between members of MDT & family as required (to ensure clarity about care plans, prognosis etc)

Is the acute episode of care complete?

Is additional support required in the community?

Do the family require specialist info & support?

*Coordinator:* If yes, refer or signpost to relevant organisation or service e.g. CBIT

*Coordinator:* Ensures Referrals to CCPNR, OT, S&LT, Physio & Comm. Paeds., as required.

Makes contact with school to make appropriate support arrangements for support to access curriculum at school

Ensure that family is supported to access appropriate resources/support networks.

Therapy input (OT, SALT, dietitian, Physio, play) provided for all brain injured children as required + hospital school. PTA Screening (GCS >15)
Paediatric Rehabilitation Pathway: 3. Community Rehabilitation Phase

**Is the patient medically & therapeutically ready to go home?**

- **Discharge meeting:**
  - Attended by all involved with the child including CCPNR, social care & education.
  - **Coordinator** role will transfer to new person to ensure:
    1. Consistent regular therapy – no lag between inpatient & community provision
    2. Agreed timetable & plan to meet on-going care & therapy needs
    3. Expectation management from discharge to community.

- **Psychologists provide Neuropsychological assessment (e.g. IQ, attention, memory, executive functioning, academic attainment)**
  + Psychological (emotional/behavioural) assessment and intervention for child and family (emotional/behavioural/cognitive rehabilitation)

- **Further detailed assessment and/or Short rehab package:**
  - Community based therapy commences (& on-going).
  - Time limited period of coordination post-discharge.
  - **Coordinator's** role is to ensure regular follow-up contact is made – follow-up clinic soon after discharge with most appropriate clinician or professionals attending. Initial Assessment at 3 months

- **On-going MDT intervention & goal setting & review as appropriate to complete rehabilitation.**

- **Specialist teacher works in liaison with MDT and school staff (SENCo, Head Teacher, TAs) to identify strengths and difficulties, delivers training and ongoing monitoring and liaison to support access to the curriculum**

- **SLT assessment and intervention for WFDs, CogComm, Social understanding, Pragmatics, Aphasia, Low communication confidence, Literacy difficulties, Dysarthria/Dyspraxia/VPI**

- **OT: Fine Motor Ax and intervention, Visual Perception, Handwriting, sensory integration, Visual Motor Integration, Fatigue and Activity/Sleep Mx, Goal setting, Practical skills; Intervention related to FM, Independent living skills, grading of activity, advice to schools re all of the above, close working with local Community OT services**
Thank You

Any thoughts or questions are very welcome to Suzanna.watson@cpft.nhs.uk (01223 884433) and ayla.humphrey@cpft.nhs.uk