UNIVERSITY OF CAMBRIDGE

NHS

The Cambridge Centre for Paediatric Neuropsychological Rehabilitation

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

Cambridgeshire and Peterborough NHS
NHS Foundation Trust
Understanding mental health, understanding people

The Oliver Zangwill Centre

NHS
Cambridgeshire Community Services

Cambridgeshire Community Services is responsible for providing a range of NHS and social care services in the Cambridgeshire area, commissioned by and accountable to Cambridgeshire Primary Care Trust

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.

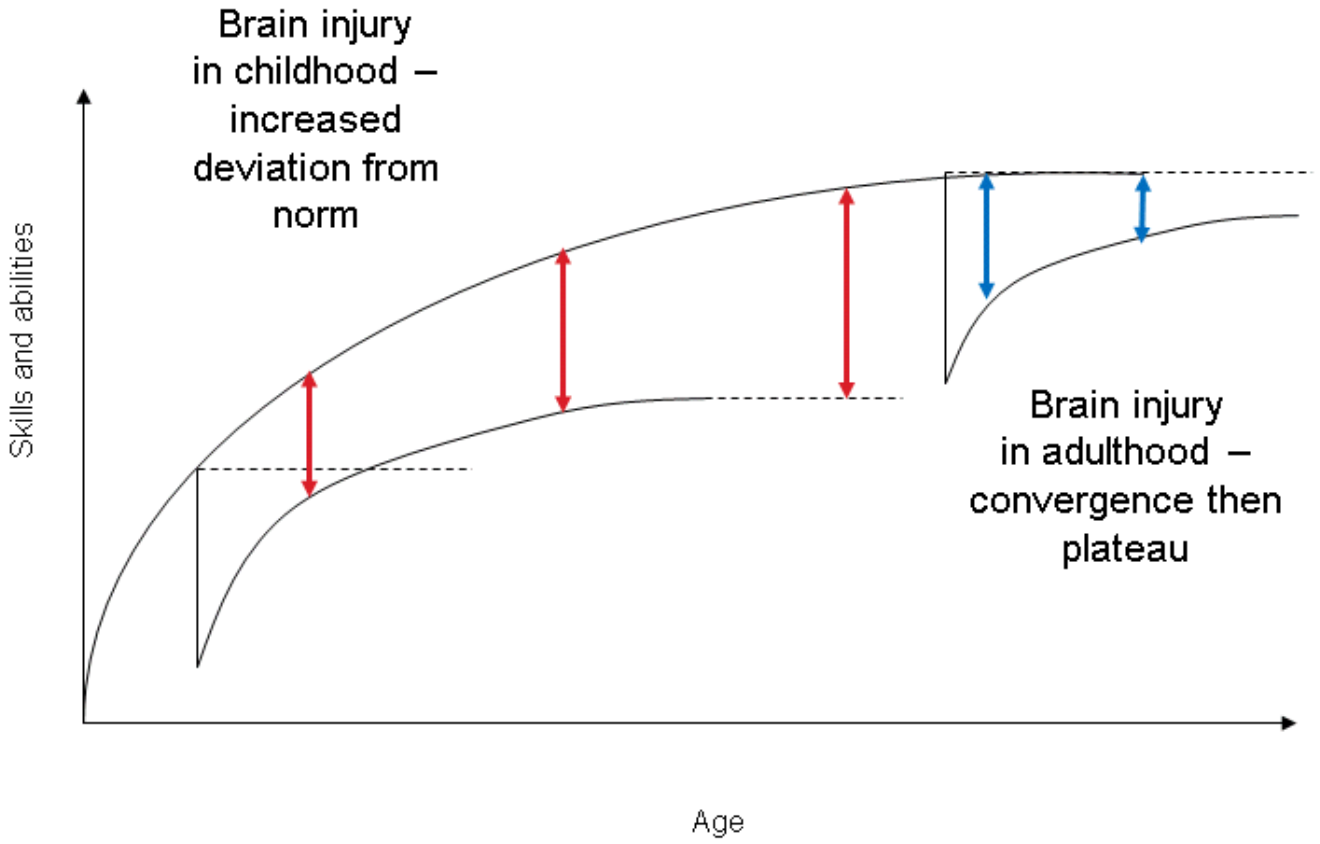
(NICE, Head Injury. 2014; Appleton and Baldwin, 2006)

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

L

Acute

Community

- 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

Local Innovation in the NHS

2003-2007

- *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

2007-2008

- *Sharing the knowledge, sharing the vision AND bringing in the business*
  - Director of Business, Cambridge and Peterborough Foundation Trust/ University of Cambridge

Local Innovation in the NHS

2008-2009

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

Local Innovation in the NHS

2008-2009

- *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

2008-2010

- *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

Local Innovation in the NHS

2010

The Cambridge Centre for Paediatric Neuropsychological Rehabilitation (CCPNR)

T

Acute

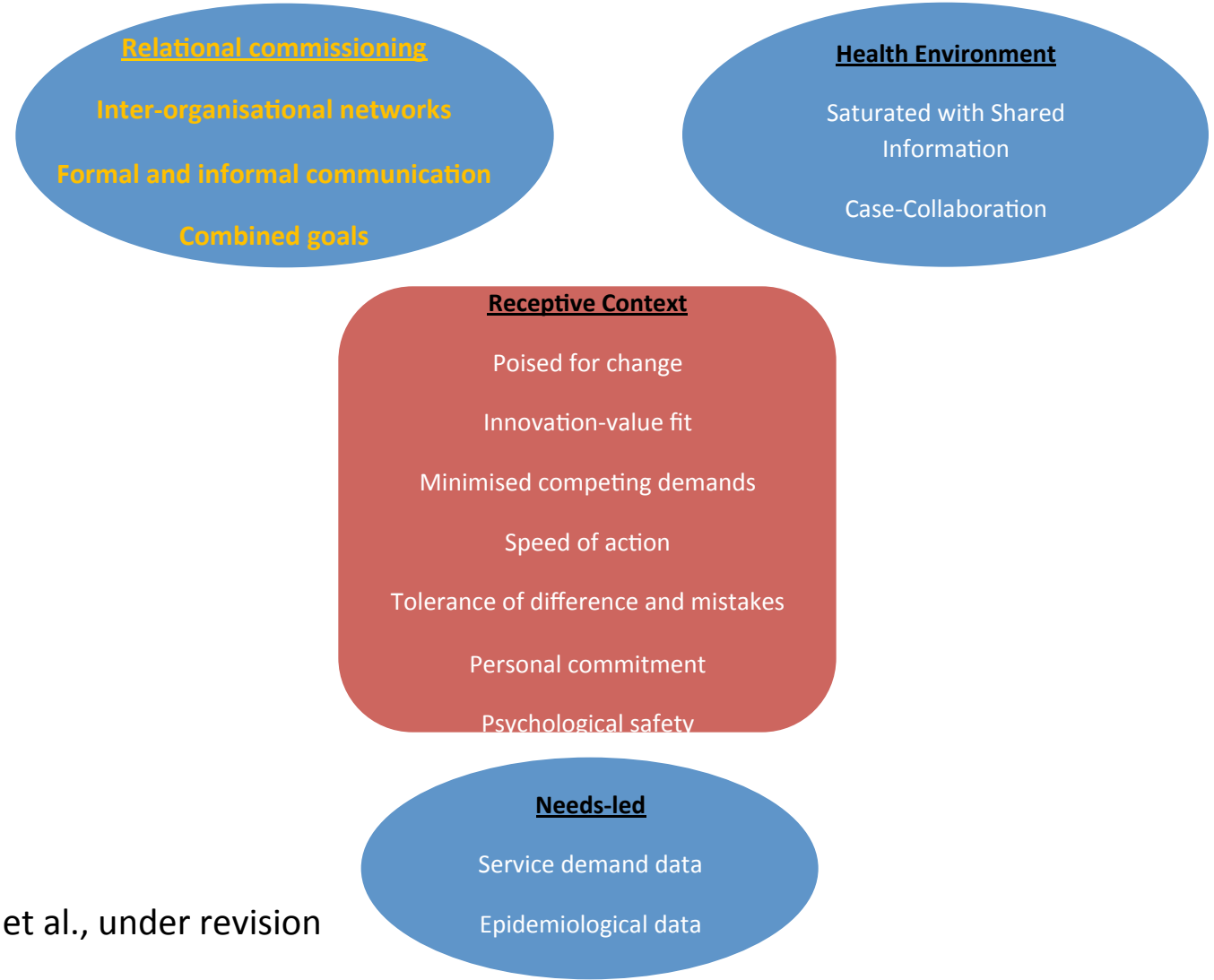
Community

4 months post injury

3 years post injury

- 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

What We Could Have Done Better

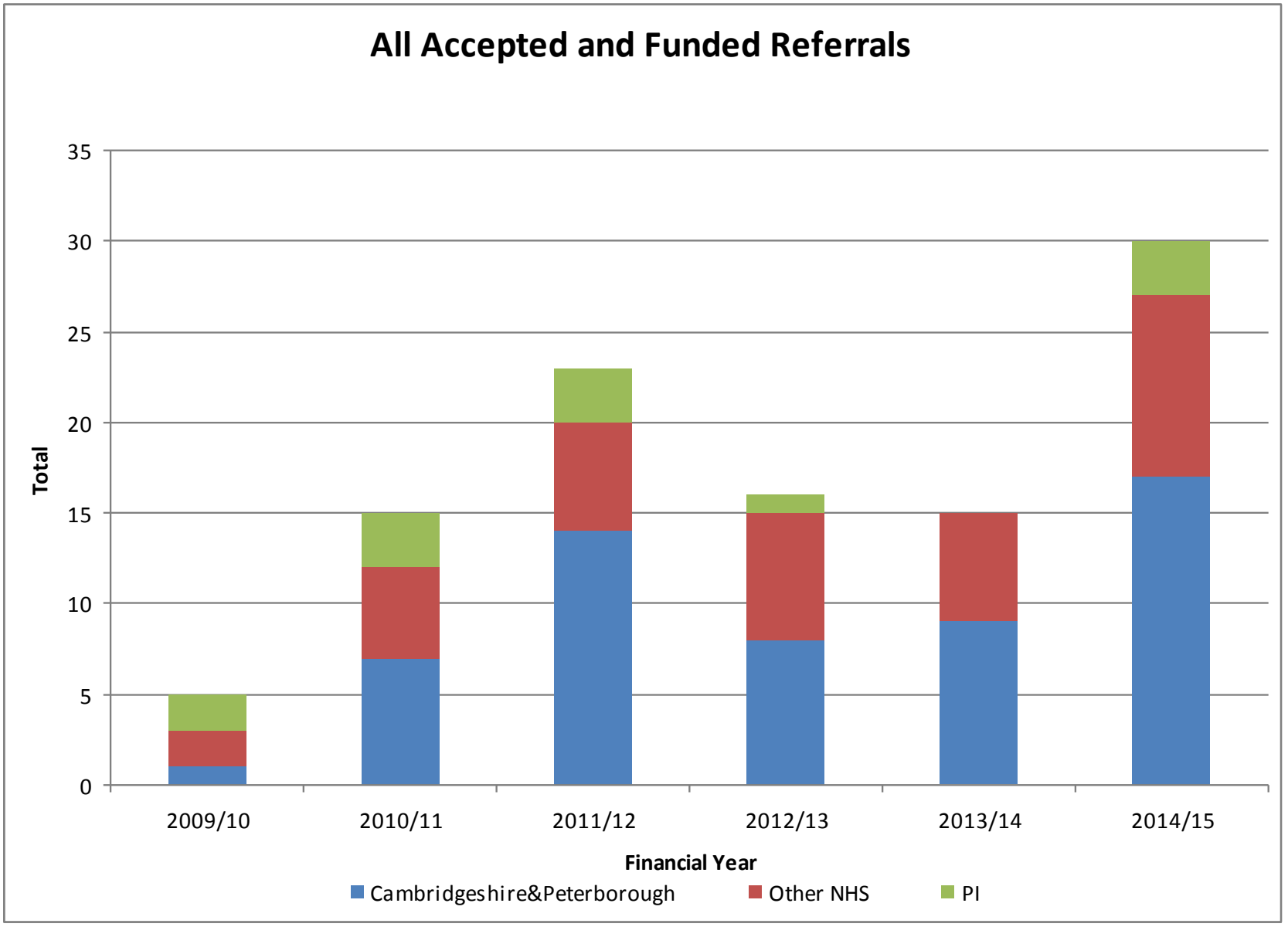


Humphrey et al., under revision

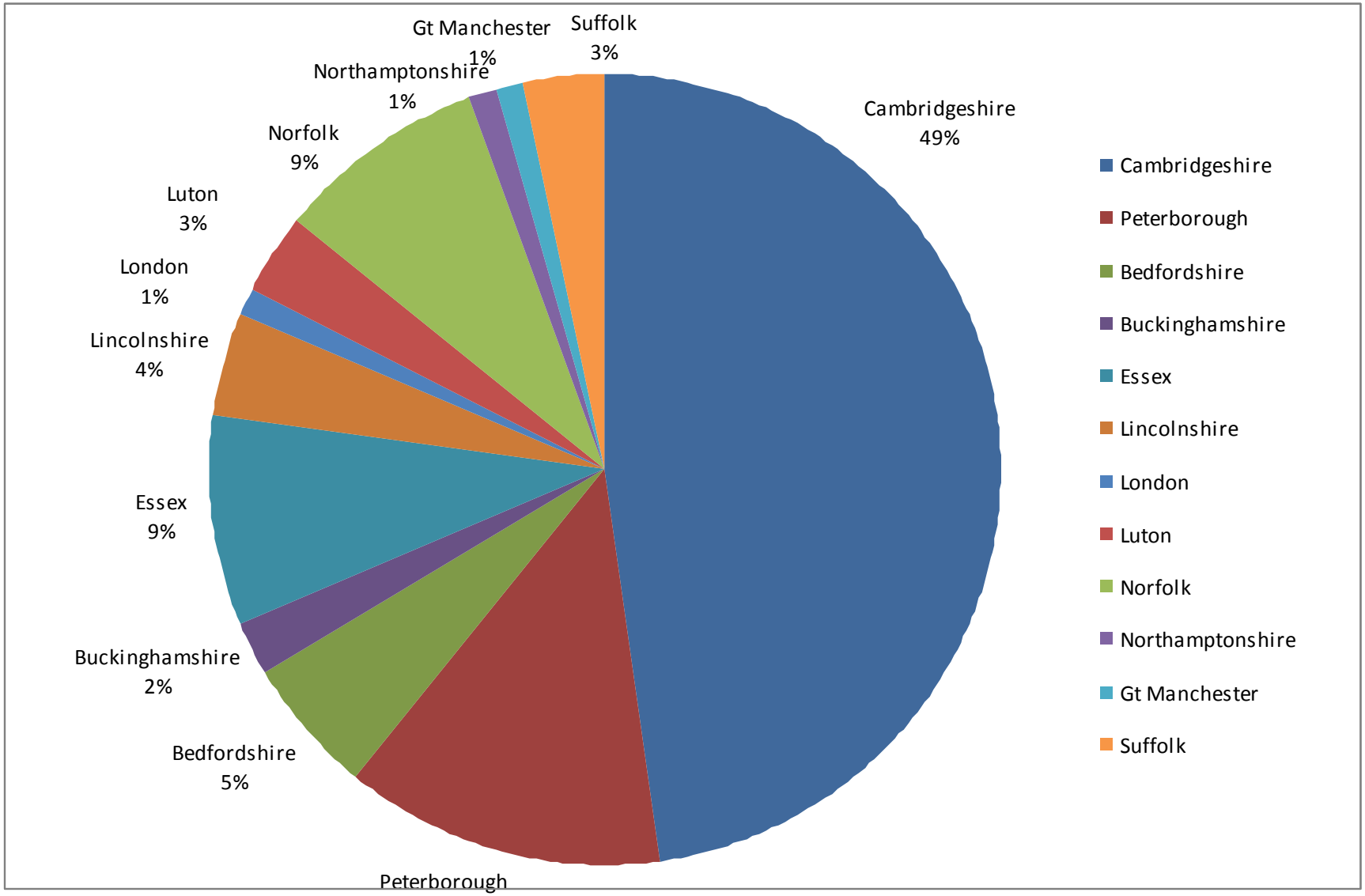
"the best performing systems are characterised by integration of commissioning and provision"

Kelly, E. (2008). *Forward to health care commissioning in the international context: Lessons from experience and evidence*. Birmingham: University of Birmingham, Health Services Management Centre. www.hsmc.bham.ac.uk

Acting Clinical Lead Clinical Psychologist	Dr Suzanna Watson	0.5 WTE
Team Co-ordinator	Jenny Cahill	0.8 WTE
Consultant Clinical Neuropsychologist	Dr Fergus Gracey	0.05 WTE
Consultant Paediatric Neurologist	Dr Anna Maw	0.05 WTE
Consultant Child and Adolescent Psychiatrist	Dr Jo Holmes	0.05 WTE
Paediatric Neuropsychologist	Dr Catherine Harter	0.1 WTE
Specialist Teacher	Lorraine Austin	0.6 WTE
Specialist OT	Patty Van Rooij	0.4 WTE
Specialist OT	Stella Parry	0.2 WTE
Highly Specialist SLT	Gillian Shravat	0.4 WTE + 0.2 CLAHRC
Clinical Psychologist	Dr Aafke Ninteman	1 WTE
Assistant Psychologist	Meghan Mc-Hugh-Harvey	0.4 WTE
Research Associate from UEA	Dr Darren Dunning	0.1 WTE

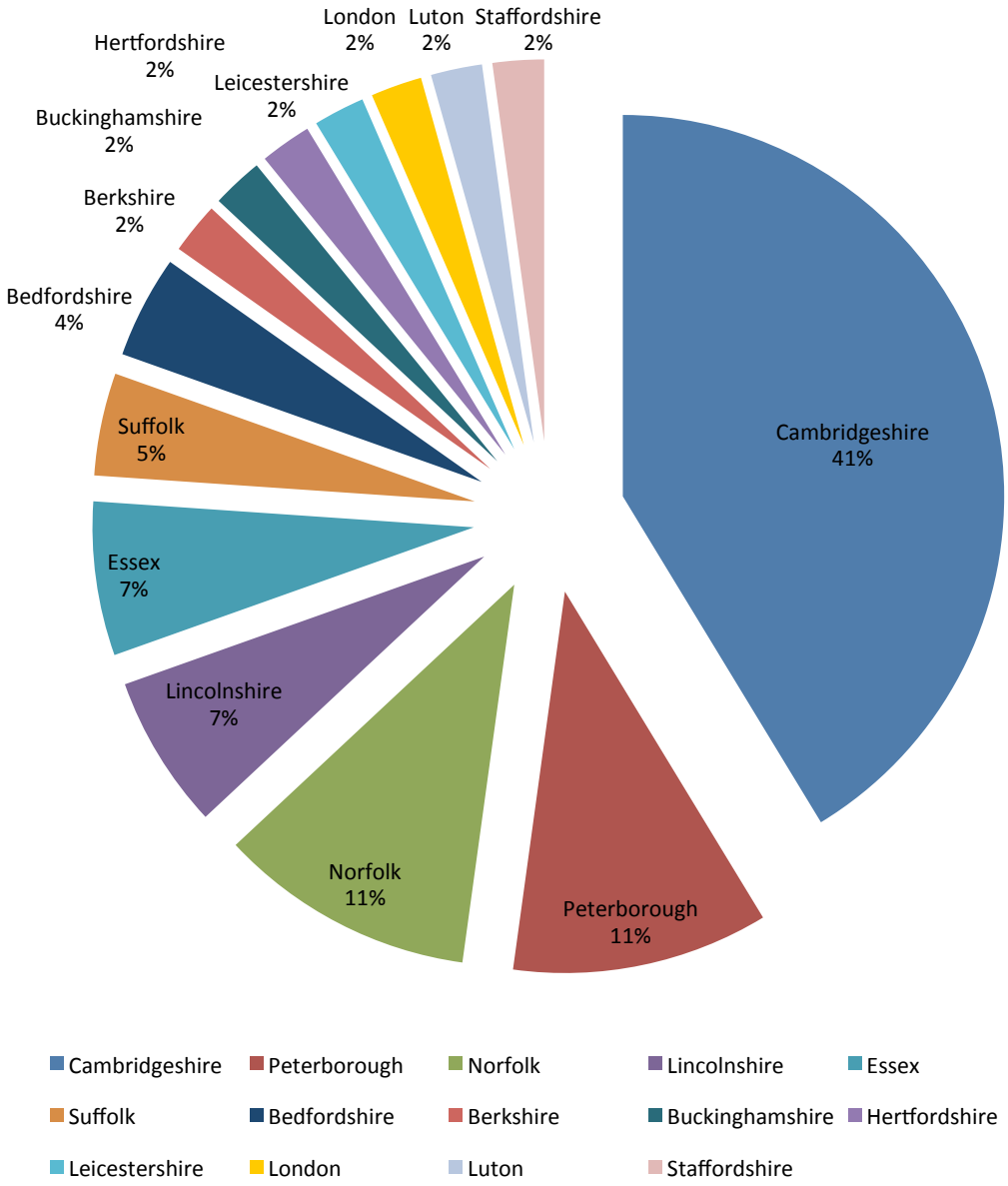

All Accepted and Funded Referrals
35
30
25
20
15
10
5
0
Total
2009/10
2010/11
2011/12
2012/13
2013/14
2014/15
Financial Year
Cambridgeshire&Peterborough
Other NHS
PI

All Accepted and Funded Referrals 2009-2015



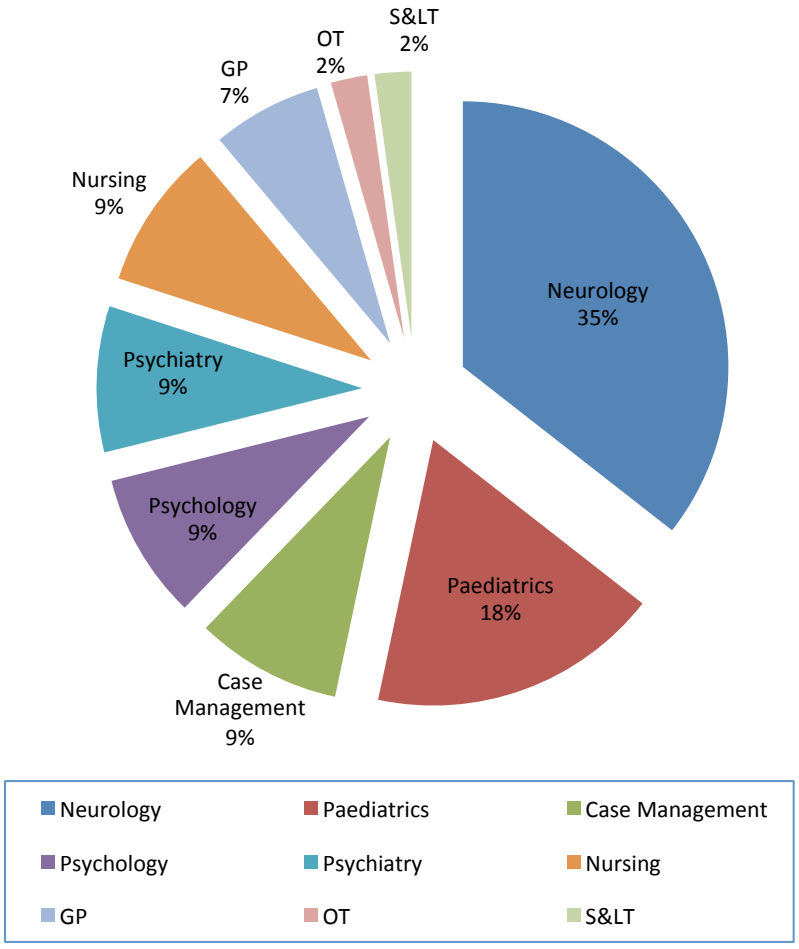
CCPNR:
All Referrals December 2013-December 2014

Referrals	46
Accepted	38
% Male	59
Average age	11.6 years *(2.5 - 17.6 years)*
Average number of years post injury	3.7 years *(15 days – 14.6 years)*

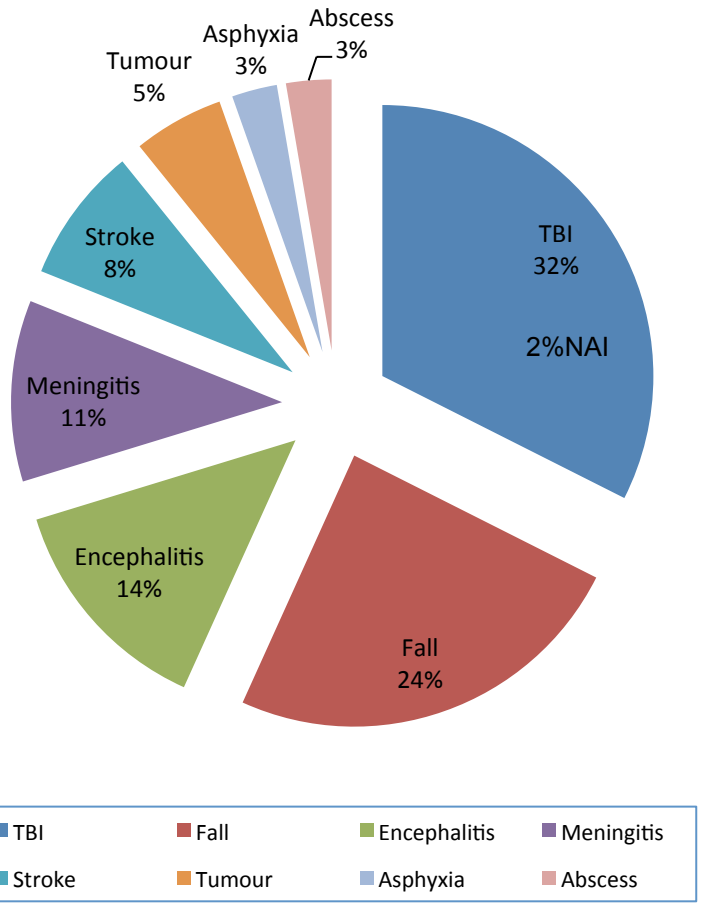


CCPNR: Accepted Referrals (December 2013-December 2014)

Referral Source

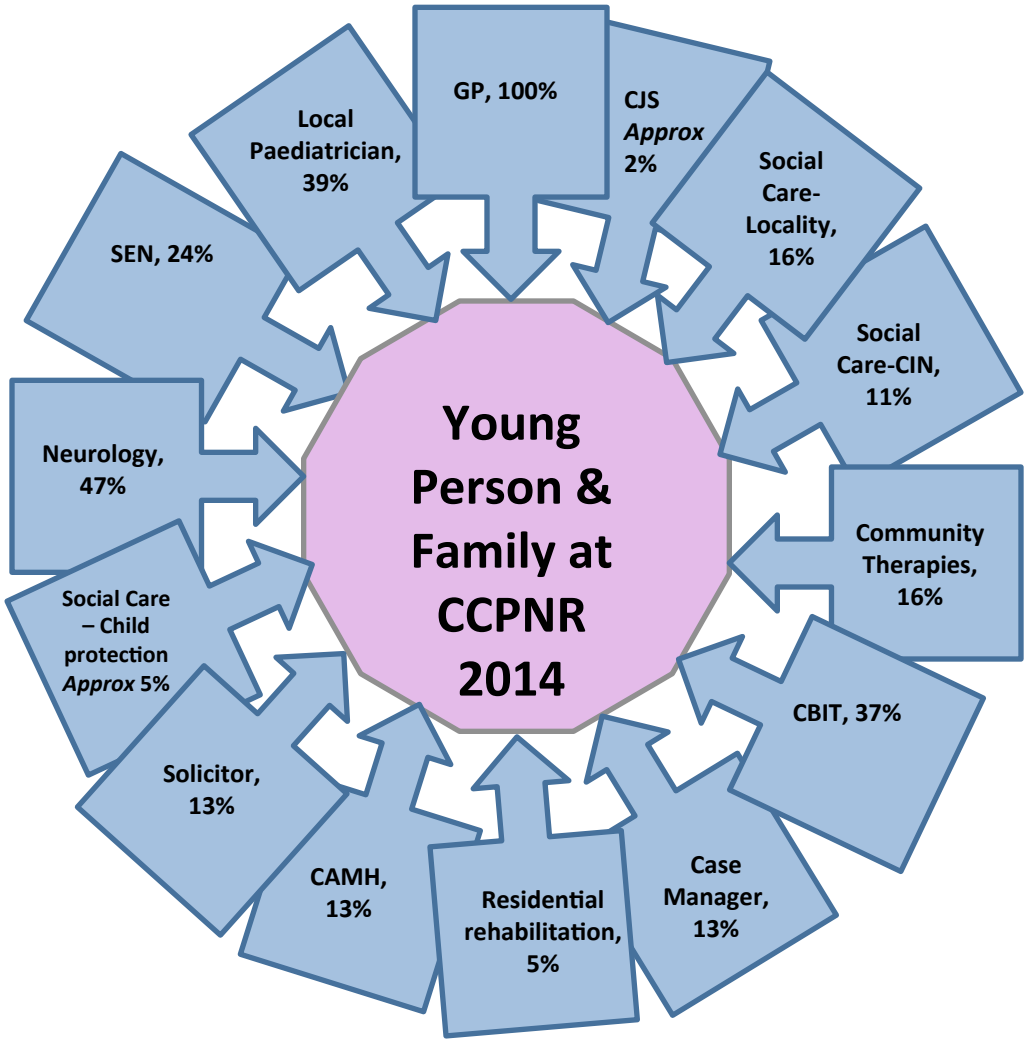


Injury



CCPNR: Multiagency working

(Accepted referrals, December 2013-December 2014)



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 , Apahsia (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

Transferred to PICU.

Scan & inter-cranial pressure monitored

Email alert for new brain tumour diagnosis & admission

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).

Surgery takes place.

If required, commence discussion with commissioners

Admitted to ED with temperature / sickness/ NAI/ Stroke

Scan carried out – parents informed suspected encephalitis

Diagnosis confirmed

Treatment process begins

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, Physo, play) provided for **all** brain injured children as required + hospital school. PTA Screening (GCS >15)

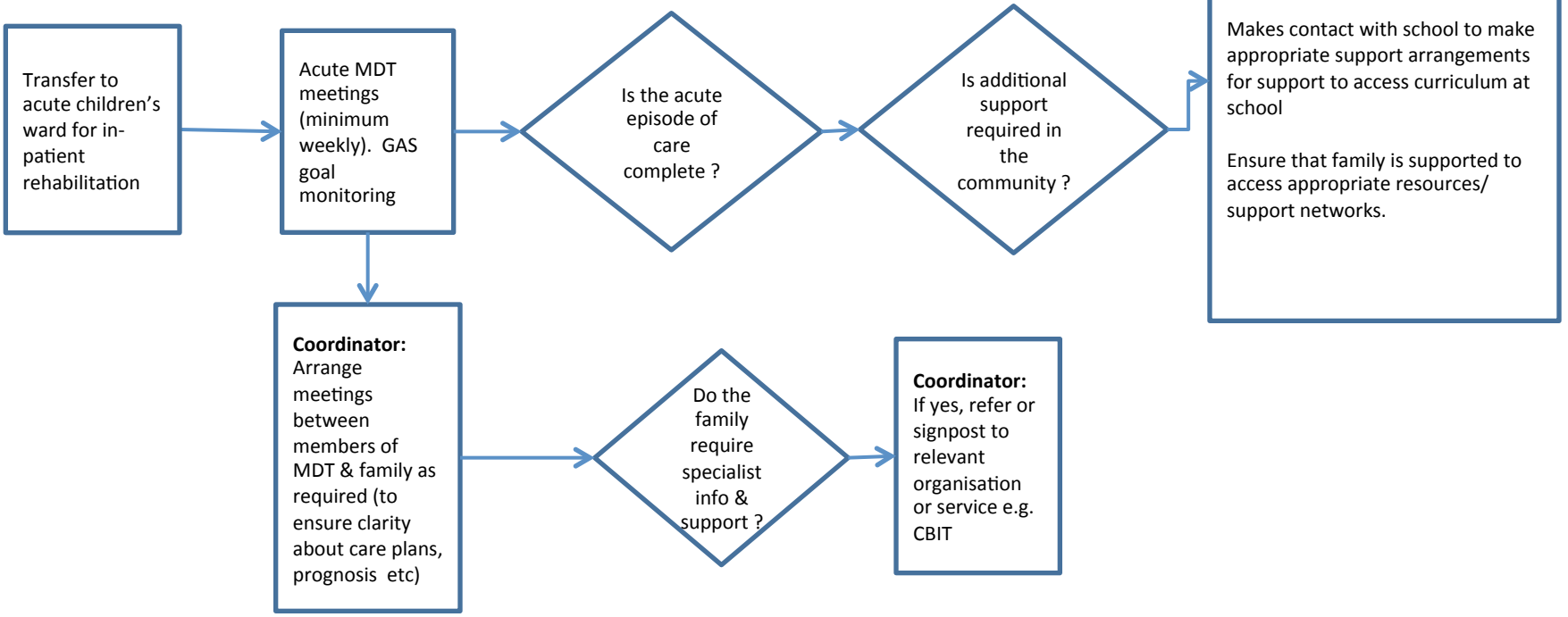
Paediatric Rehabilitation Pathway: 2. Acute Rehabilitation Phase

Psychology involved when emotional or behavioural difficulties.

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

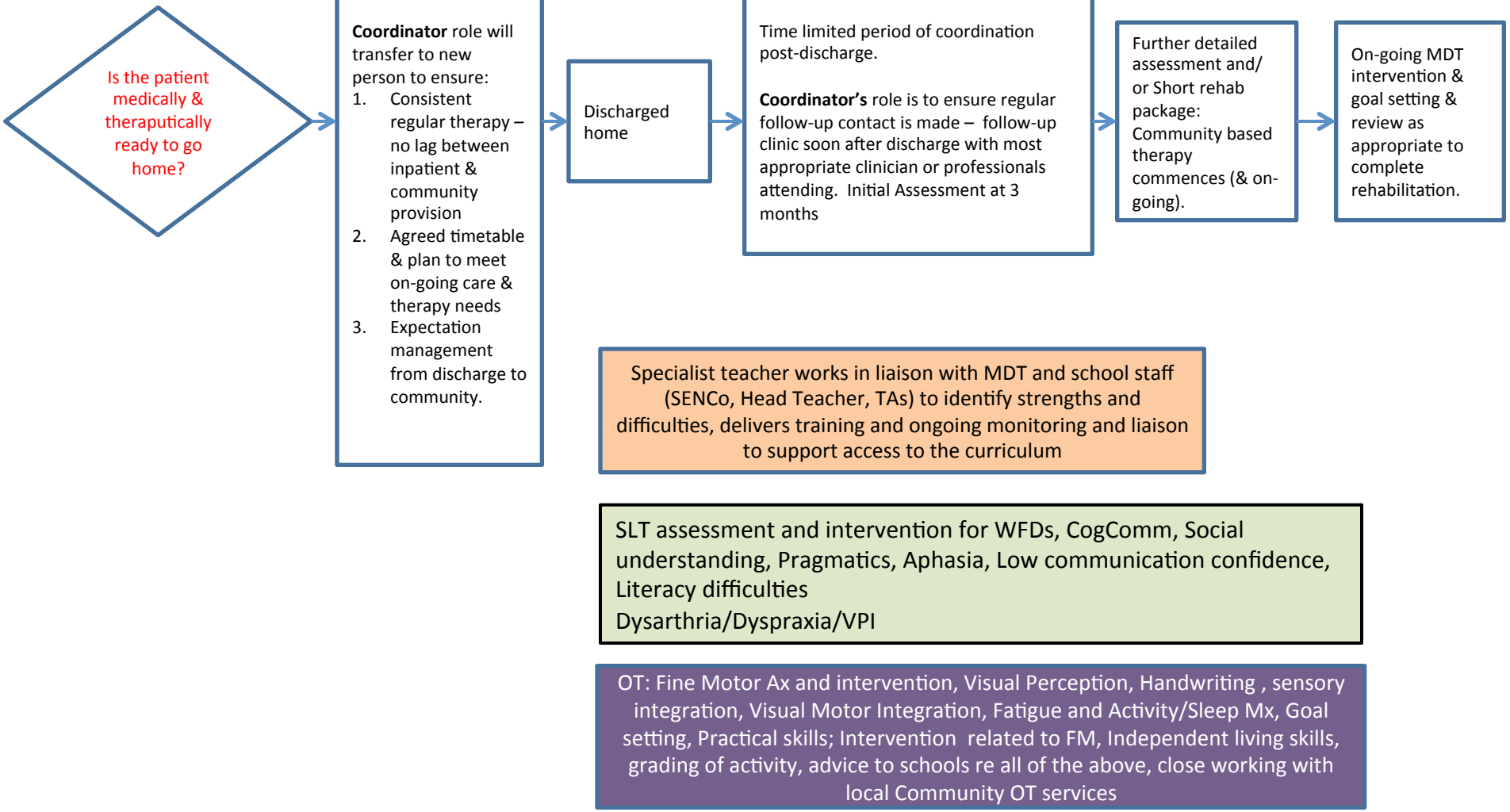
SLTs: Dysfluency, Dysphagia, Dysarthria/Dyspraxia/ VPI, AAC , Aphasia (anomic common), WFD, Echo and palilalia

FIM/FAM +Cognitive screen to support discharge



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



Thank You

Any thoughts or questions are very welcome to

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