Structuring Epilepsy Services:
Why psychology is vital in the management of childhood epilepsy.

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Epilepsy is more than just seizures!!!
The Disability Complex

• Epilepsy should be understood as a Disability Complex (Neville, 1999) - Epileptic Seizures and an increased risk for:
  • Cognitive Arrest or Regression (Global or Specific)
  • Symptoms of Neurodevelopmental Disorders – ADHD and ASD
  • Symptoms of Emotional Disorders (Anxiety and Depression)
  • A range of Motor Impairments
  • Academic Underachievement

• The additional impairments frequently constitute the major disability of children with epilepsy
• It is vital that the range of impairments are assessed and managed/treated to improve quality of life.
Manifestation of the Disability Complex

• The Impairments are often partially expressed (Borderline symptoms)

• Many individuals have multiple impairments.

• Difficulties in at least one of the main cognitive, behavioural and motor domains are the norm not the exception in childhood epilepsy.

• The treatment of the impairments is similar as for children without epilepsy.
The Unique Contribution of the Psychologist in the Management of the Disability Complex

1. Clear Identification of problems
2. Provide evidenced based interventions
3. Provide understanding as to the nature and impact of the disability complex
Cognitive Impairments

• Global cognition problems - 30% of children with epilepsy functioning in the learning disabled range (Berg, 2011).

• Specific - memory problems and processing speed problems more common in children with epilepsy (Sherman, 2012).

• Identification - Only psychologists can identify the level of global cognitive functioning and cognitive profiles (specific strengths and weaknesses) and advise on interventions.

• Interventions:
  – Educational placement, differentiation of the curriculum, appropriate learning resources.
  – Working memory strategies, working memory training (Westerberg et al. 2006), processing speed accommodations.

• Outcome - Appropriate educational provision, motivated learners, less behaviour problems, efficacious interventions.
Symptoms of ADHD

- Many children have difficulties with inattentive symptoms of ADHD (Sanchez-Carpintero & Neville, 2003) and 1 in 6 will reach full criteria for ADHD (Reilly, 2011).
- Many have subclinical symptoms which are impairing (CHESS, 2012 - 70% of parents reported difficulties and 70% reported difficulties at 80th percentile or more on an ADHD rating scale).
- **Identification** - Observe in class, analyse behaviour checklists, cognitive profiles.
- **Interventions** - Medication and Behavioural interventions best for ADHD symptoms (MTA, 2009), classroom accommodations, monitor effects of medication.
- **Outcome** - Lower level of symptoms, better school performance, less chance of secondary mental health problems and antisocial behaviour.
Symptoms of ASD

- Prevalence of ASD is 1 in 3 for children with epilepsy and intellectual disability (e.g., Steffenburg et al. 1996).
- Significant minority of children without LD have ASD type difficulties even if don’t reach full criteria (CHESS, 2012)
- **Identification** – Aid with screening, observations, and contribute to diagnostic assessment.
- **Interventions** – Evidence for Intensive behavioral Interventions, structured teaching, Picture Exchange Communication (PECS) (Research Autism, 2012)
- **Outcome** – Improvement in skill acquisition and reduction in behaviours of concern
Emotional Disorders

- 16-17% of children with epilepsy ‘had an emotional disorder’, compared with 6% of children with diabetes and 4% of children in the general population (Davies et al. 2003).
- CHESS(2012): 34 screened for depression - 11% 2SD and 17% 1SD above mean
- Identification - Aid in identification using screening instruments/interviews and taking history
- Intervention - Consensus statement on treatment of people with epilepsy (Barry et al. 2008) and NICE guidelines on paediatric depression emphasise psychological interventions and/or use of medication.
- Outcome - Psychological Interventions lead to a lower level of symptoms, and prevent development of full-blown depression (e.g. Martinović et al. (2006)).
Motor Impairments

- Disability complex involves a range of motor difficulties (Neville, 1999)
- CHESS (2012) – 58 children screened on DCD-Q – 70% in at-risk category. 1% previous diagnosis!
- Identification – Screen and provide important information on fine motor skills (e.g. Handwriting and processing speed)
- Intervention – Advise on classroom and exam accommodations.
- Outcome – Increase in supports, better school performance and reduction in potential of self-esteem and self-efficacy problems.
Family Functioning

• Up to 50% of mothers at risk for depression (Ferro and Speechley, 2009) and a negative relationship exists between such symptoms and child health outcomes and quality of life.

• Rodenburg et al. (2005) - family related factors, particularly quality of child parent relationship and parental rejection are pivotal in psychopathology of children with epilepsy.

• Identification – Screen for depression in adults and identify unhelpful relationships within the family.

• Intervention – Treat depression in adults and can also promote positive relationships within families.

• Outcome – Reduction in parental stress, improvement in parental well-being, family functioning and greater understanding of self, child and family.
Problems of childhood epilepsy?

• CHESS population based study (2012)
• What are the difficulties reported by parents?
  – Academic Difficulties - 78%
  – Behavioural Difficulties - 71%
  – Seizure Management Difficulties - 34%

• On psychological assessment, significant difficulties are found across a range of cognitive (e.g., working memory) and behavioural (e.g., attention, symptoms of anxiety) domains and children often present with multiple issues and partial expression.
Problems of childhood epilepsy?

• 62% of parents and 48% of teachers reported significant emotional-behaviour problems based on the SDQ.

• 50% of parents of children without a statement reported that their child was experiencing academic difficulties.

• 62% of parents of children without a statement reported that their child was experiencing behavioural difficulties.

• Only 9% of children had received any formal psychological input and only 7% had been reviewed by a psychiatrist.

• Only 6% of students assessed had no concerns identified in psychological assessment - 94% required follow up!
What do we want to improve?

• **Quality of Life (QOL)** should be considered the most important variable in treatment of children with epilepsy (Clary et al. 2010)

• **QOL in childhood epilepsy predicted by**
  – Age of seizure onset
  – Presence of cognitive problems
  – Presence of emotional-behavioural difficulties (Clary et al. 2010)

• Many children with epilepsy have problem before the onset of seizures (Berg et al. 2005) and continue to so after they have become medication and seizure free (Silanpaa et al. 1998)
The Current Situation?

• NICE Guidance

– For some people with epilepsy it is important to assess learning disabilities, speech and memory. Specialist centres should include psychology.

– Epilepsy Specialist Nurse should be involved in your care; they can provide information about epilepsy, make sure you are getting the right help and support from other healthcare professionals.
• **Bradley and Lindsay (2007)**
  - No evidence that specialist epilepsy nurses improve outcomes for people with epilepsy.
  - Important outcomes (e.g., seizure frequency, psychosocial functioning, knowledge of epilepsy, general health status, depression and anxiety scores showed no significant improvement)
  - It is not possible to describe specialist epilepsy nurses as effective in improving epilepsy care for people with epilepsy.

• **Epilepsy 12 Audit**
  - Majority (54%) of children not referred to an epilepsy specialist nurse
  - 82% of parents and young people responded positively about their experiences
  - Main complaint - lack of collaboration with schools and nurseries
Case Study 1

• 15 year old female - JME - Lamotrigine
• School no concerns, parents worried – what is wrong?

• **Identification**
  – FSIQ - High average
  – Childhood Depression Inventory (98th Percentile); suicidal ideation
  – Spence Children’s Anxiety Scale (Generalised Anxiety. Social Phobia); School Refusal?
  – Attention and memory problems
  – Coordination difficulties
  – Above at risk cut-off on ASD screen
  – Bullied?

• **Intervention** - Emergency referral to CAMHS – monitoring, psychoeducation and ongoing support, assertiveness course, social skills awareness.

• **Outcome** – Attending school, reduction in symptoms of depression and anxiety, increased parent and student understanding.
Case Study 2

- 9 year old female - focal seizures - Zonisamide
- School No Concerns, Parent No Concerns

Identification
- Average FSIQ
- Mild Anxiety on behavioural screening
- Academic scores - Maths 8th percentile, Spelling 10th percentile

Intervention - Put on special educational needs register at ‘School Action’ level. Increased support at home and school in both subject areas

Outcome - 6 month follow up - Maths 27th percentile, Spelling 21st percentile. Lower anxiety.

SENCO - “Psychological assessment made us aware of the academic underachievement issue, potential impact of this on well-being and allowed us to target supports in the right places”.
Conclusion

• Epilepsy is a disability complex. Key disabling factors are cognitive and behavioural impairments.

• The role of the psychologist is crucial in the identification of cognitive and behavioural issues as well as in the design, implementation and monitoring of effective interventions.

• Psychologists can identify subclinical problems and prevent the development of serious issues further down the line.

• The accurate assessment and treatment of cognitive and behavioural problems are key to enhanced quality of life in childhood epilepsy.

• A nurse may be helpful but a psychologist is essential and the role a psychologist plays in the management of this disability complex is unique.