



Gillbergcenterum  
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GÖTEBORGS UNIVERSITET

# ESSENCE-DAG 1 "Vad säger forskningen?"

## ESSENCE och epilepsi

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# What is Epilepsy?

- Epilepsy (or the epilepsies)
  - Two or more unprovoked epileptic seizures.
- 1 in 26 people will develop epilepsy
  - Most common neurological disorder in childhood
- 70% of patients with childhood-onset epilepsy enter periods of remission of at least 5 years **But**
  - An increased risk for a wide spectrum of cognitive, behavioural and psychiatric disorders.



# Cognitive and Psychiatric Problems in Epilepsy

- Intellectual Developmental Disorder (IDD) -21% to 38%
  - The majority with IDD and epilepsy have IQ scores below 50
- Behaviour/Psychiatric
  - Rutter et al. (1970)- 29% children with 'uncomplicated epilepsy' and 58% with 'complicated epilepsy' had psychiatric disorder (6.6% Controls).
  - Davies et al. (2003) – 37% of children with epilepsy had DSM-IV disorder **but** Diabetes 11% and 9% control children.
  - Steffenburg et al. 1996 - 53% of children with IDD and epilepsy had at least one psychiatric diagnosis.



# Children with Epilepsy in Sussex Schools (CHESS)

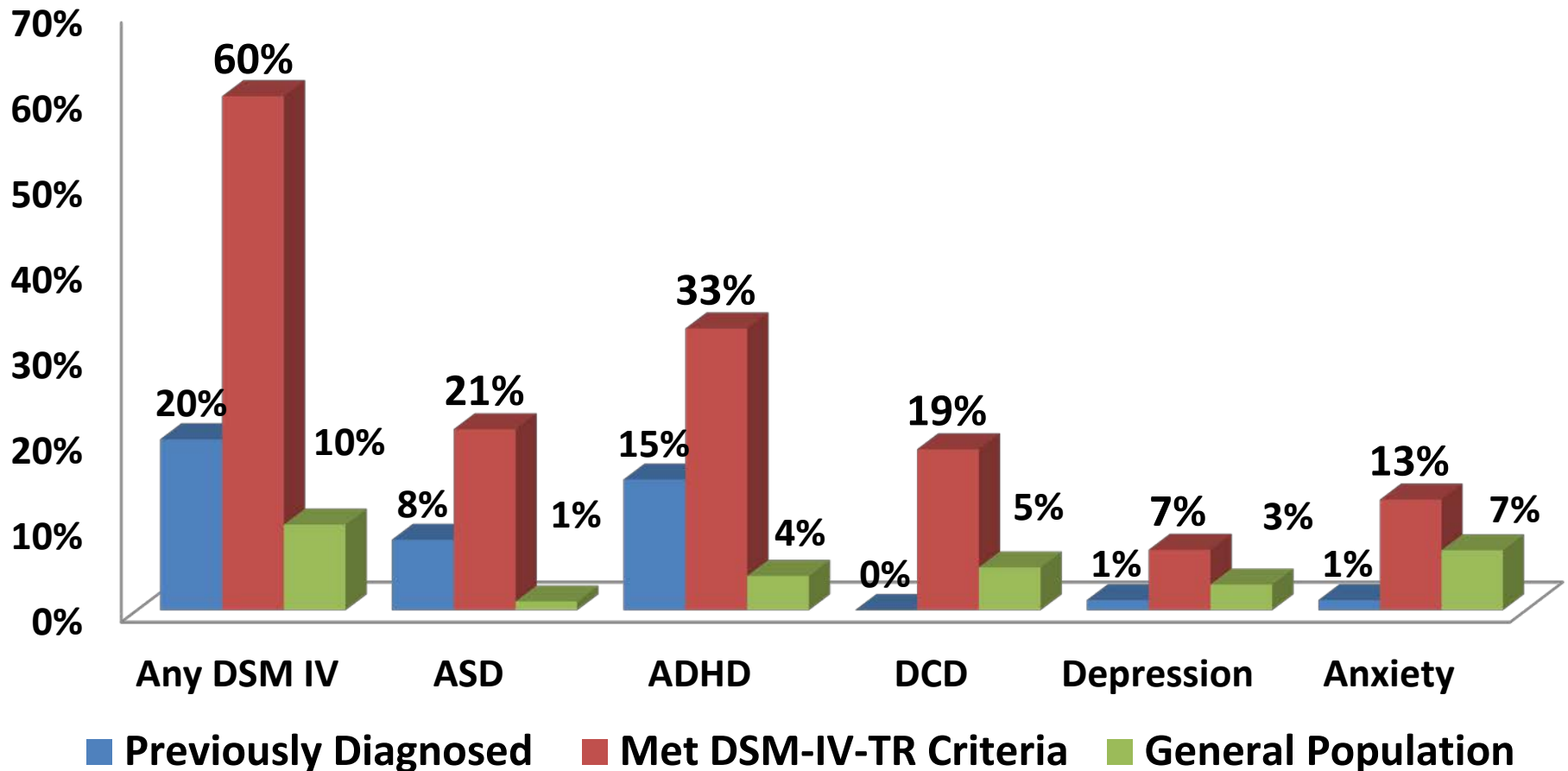
- Aim was to characterise the prevalence and spectrum of difficulties in 'active' epilepsy (children aged 5-15 years)
  - *Cognition (global and specific difficulties)*
  - *Academic Achievement*
  - *Behaviour (neurodevelopmental, psychiatric and motor)*
- 85 Children (74% of eligible population) underwent assessment.
- DSM-IV-TR consensus clinical diagnoses



## CHES Study – Main Findings

- Cognition/Academic Achievement
  - 24% below IQ 50, 40% below IQ70 (IDD) 55% below 85.
  - Memory + Processing Speed problems (approximately 50%)
  - 42% displayed academic underachievement
- Behaviour/Psychiatric
  - 60% had DSM-IV behavioural or motor disorder.
  - Only 33% of these had previously been diagnosed.
  - 80% had at least one DSM-IV and/or or cognitive impairment.
  - 34% had IQ below 85 and 1 or more DSM-IV disorder.

# Behaviour/Psychiatric/Motor Diagnosis





## CHES Study – ASD in Epilepsy

- 18(21%) of Children met DSM-IV criteria for ASD but only 7 had previously been diagnosed.
  - Of those with ASD
    - 61% had IDD
    - 33% had ADHD
    - 33% had DCD
    - 11% had Depression
    - 17% had an Anxiety Disorder



## Quality of Life- Primary outcome in epilepsy

- Improving quality of life rather than just reducing seizures, should be the principal goal in comprehensive epilepsy management.
- In the treatment of epilepsy it is important to weigh seizure control with possible side-effects of antiepileptic treatments.
- **But** - It is also important that resources are also available need to treat the often associated cognitive and behavioural impairments as well as the seizures as these impairments often have the greatest impact on quality of life (Baca et al. 2011; CHES study 2014).





# What is Epilepsy?

- Epilepsy should be understood as a **Disability Complex** (Neville, 1999) - Epileptic Seizures **and** an increased risk for
  - **Cognitive difficulties** (Global or Specific)
  - Symptoms of **Neurodevelopmental Disorders** – ADHD and ASD
  - Symptoms of **Emotional Disorders** (Anxiety and Depression)
  - A range of **motor difficulties** including DCD
  - **Academic Underachievement**
- The additional difficulties frequently constitute the major disability of children with epilepsy
- For many epilepsy is an Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations (ESSENCE) disorder



## Epilepsy and ESSENCE

- The concept of ESSENCE refers to the likely coexistence of disorders or sharing of symptoms in children with neurodevelopmental concerns, including symptoms of cognitive impairment, ASD, ADHD and DCD.
- In childhood epilepsy children often have problems across a range of cognitive and behavioural domains as per ESSENCE.
- These difficulties
  - often precede the onset of epilepsy.
  - are often present before 5 years of age.
- The concept of ESSENCE is important in Epilepsy as it alerts clinicians to the likelihood of a child having difficulties in more than one domain of functioning which may well be the norm in childhood epilepsy.



## What is Needed?

- Screening/Assessment for ESSENCE type difficulties should be an integral part of management in children with 'active' epilepsy
  - Behaviour/Psychiatric (ASD, ADHD, Depression and Anxiety)
  - DCD/Motor
  - Cognition (Specific and Global)
  - Language
  - Academic Achievement
- Interventions that work in non-epilepsy population are also likely to work in epilepsy population.
- But there is also a need to support parents and staff in schools - increase knowledge, reduce fear and stigma.