

Intellectual Disability (ID), Autism & Epilepsy



GOOD PSYCHIATRIC PRACTICE CR203

Management of epilepsy in adults with intellectual disability

COLLEGE REPORT

Presented on behalf of the ID Epilepsy Strategy Working Committee

Context

- * People with ID (~25% of all PWE) are more susceptible to being in the higher risk groups of treatment resistance but have less defined treatment outputs
- * Mild ID – 8 -10% Moderate – profound ID - 50%
- * 60% of people with ID and epilepsy will be treatment resistant
- * Seizures 2nd most common reason for premature mortality in ID
- * Deaths - 43% with epilepsy - 31% had had a seizure in the previous 5 years
- * SUDEP 3 -9 times her risk of SUDEP
- * Misdiagnosis rates

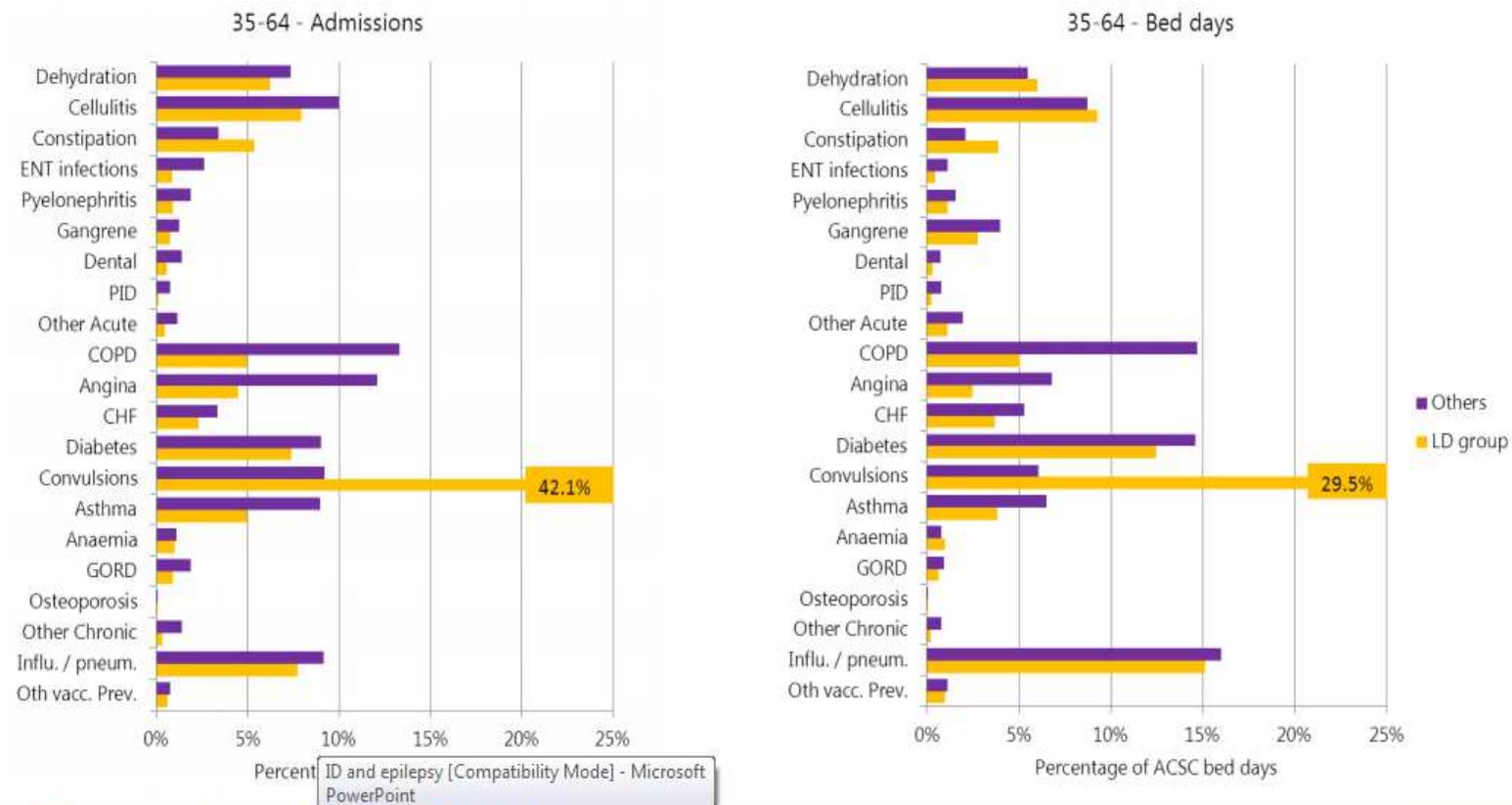
ID Specific issues

Ambulatory care sensitive conditions

- * English Hospital Episode Statistics (HES) data; 2005 to 2009 inclusive
- * crude rate of emergency admissions for ACSCs is 76 admissions/1000/year for adults with ID.
- * This is roughly five times the rate for other people (15 per 1000)
- * 5.8 days/admission for ID compared to 3.7 for others

Hospital Admissions which should not happen

Figure 2 Comparison of the causes of emergency admissions for ACSCs admissions for people with and without LD or associated conditions (cont).



Autism & it's spectrum

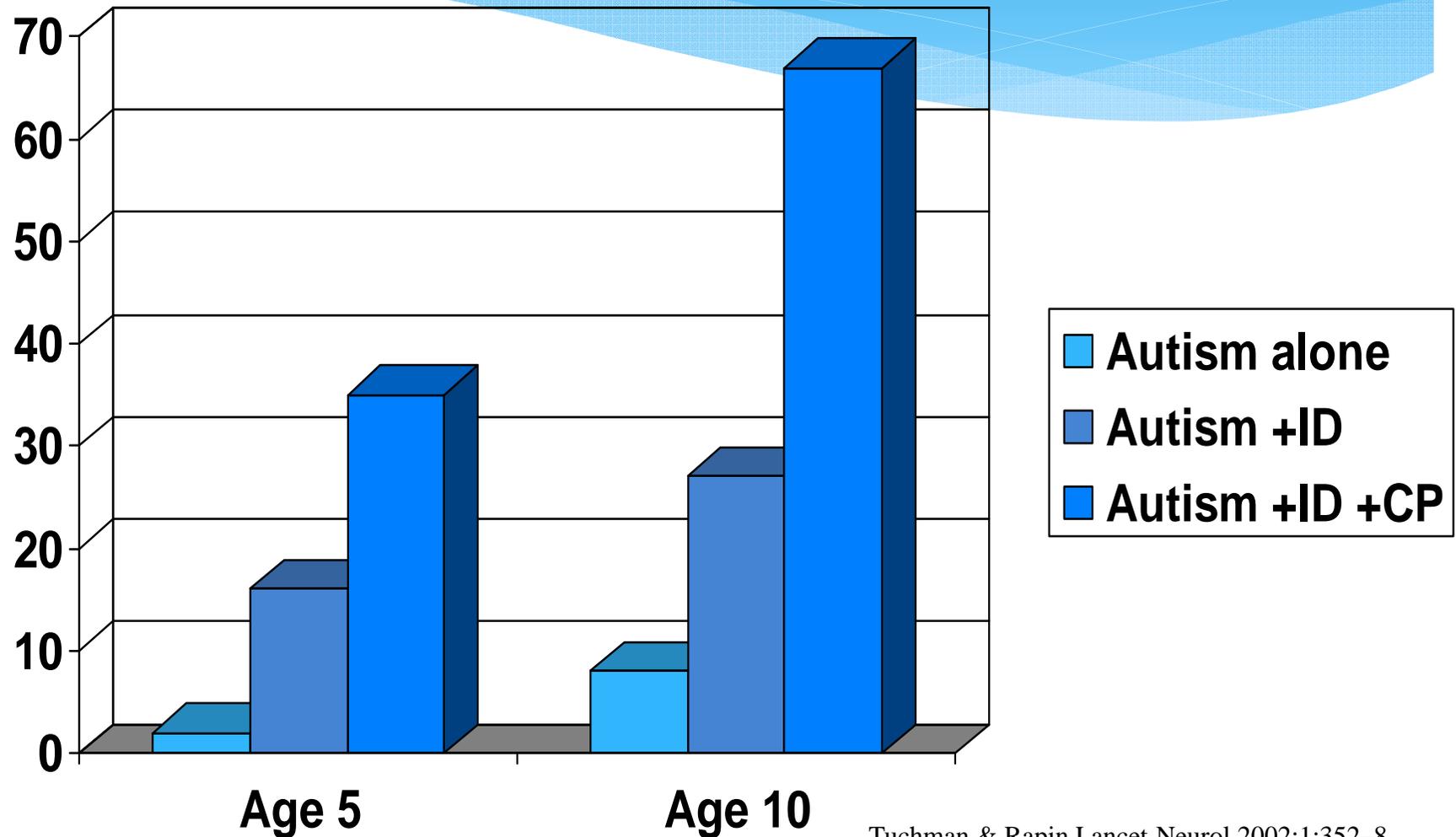
- * Up to 38% may develop epilepsy
- * Two peaks
 - * 0-5 years
 - * 10 years +
- * Seizures have low remission rate (16% in adulthood)

Rossi et al. Brain Develop 1995;17:169–74

Volkmar & Nelson J Am Acad Child Adolesc Psychiatry 1990;29:127–9

Danielsson et al. Epilepsia 2005;46:918–23

Risk of epilepsy in autism and ID



ASD subtypes & epilepsy

(Tuchman & Rapin 2002)

- * Core autism (autistic disorder, AD)
 - * About 30% show AR
 - * About 30% develop a clinical epilepsy by adolescence
- * Asperger syndrome
 - * ~5-10% develop epilepsy in early childhood
- * Pervasive Developmental Disorder NOS
 - * Increased risk of epilepsy linked to severity of brain dysfunction
- * Disintegrative Disorder
 - * up to 70% develop epilepsy
- * Rett syndrome
 - * >90% develop epilepsy

Table 1

Characteristics of the individuals with or without epilepsy

	Epileptics (<i>n</i> = 33)	Non-epileptics (<i>n</i> = 97)
Gender (M/F)	25/8	81/16
Birth weight (g)	3227 ± 374	3172 ± 457
Head circumference (cm) ^a	33.5 ± 1.0	33.5 ± 1.7
Age when walking alone (months)	14.4 ± 7.0	13.7 ± 3.6
Diagnosis of DSM- IV		
Autistic disorder	26	75
Atypical autism	7	22
Speech loss in infancy (+/-)	7/26	17/80
Cognitive level ^{***}		
Normal–mildly retarded	1 (3.1%)	31
Moderately retarded	6 (20.0%)	24
Severely retarded	8 (22.2%)	28
Profoundly retarded	18 (56.3%)	14
Adaptive level (SQ) ^{b,**}	42.1 ± 16.8	59.4 ± 20.6
Psychotropic drugs (+/-) [*]	21/12	39/58

^a Six data points were not available.

^b Two data points were not available.

^{*} *p* = 0.026 (Fisher, both side).

^{**} *p* < 0.05.

^{***} *p* < 0.001.

Current prescribing practices in ID

- * Current approach – is this working?
- * Can strategies that work in the general population apply directly to ID?
- * Are we tailoring available AEDs using a person-centred approach?



I know the way through the minefield,
step exactly where I do!

Managing anti-epileptic drug treatment in adult patients with intellectual disability: a serious conundrum

Z. Doran^a, R. Shankar^{a,b}, M. R. Keezer^c, C. Dale^a, B. McLean^d, M. P. Ken^e, J. Devapriam^f, J. Craig^g and J. W. Sander^{g,h,i}

^aCornwall Partnership NHS Foundation Trust, Cornwall, UK; ^bExeter Medical School, Truro, UK; ^cNHR University College London Hospitals Biomedical Research Centre, UCL Institute of Neurology, London, UK; ^dRoyal Cornwall Hospital, Truro; ^eCardiff University, Cardiff; ^fLeicestershire Partnership NHS Trust, Leicester; ^gBelfast Health and Social Care Trust, Belfast, UK; ^hStichting Epilepsie Instellingen Nederland (SEIN), Heemstede, The Netherlands; and ⁱEpilepsy Society, Chalfont St Peter, Buckinghamshire, UK

* Side effects: behavioural, mental, and physical

* Relevant co-morbidities

* Evidence base of individual AEDs

Keywords: adult intellectual disability, antiepileptic drugs, epilepsy, review

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Background and purpose: About a quarter of people with epilepsy have intellectual disability (ID). This group has communication issues, premature mortality, more treatment resistance, difficulties in making informed choices and greater risks of physical and mental health comorbidities. There is no specific prescribing guidance for this large and vulnerable group. The literature on prescribing for epilepsy in this group was reviewed, in particular examining how antiepileptic drugs (AEDs) work regarding their side effect profiles, effects on specific epilepsy syndromes associated with ID and their individual strengths and weaknesses based on the nature and degree of ID.

Method: This is a narrative review for which a comprehensive search was conducted to identify evidence for prescribing commonly used AEDs to people with ID including genetic syndromes specifically associated with epilepsy.

Results: A detailed analysis of the results has highlighted the urgent requirement for suitable and reliable evidence in AED prescribing amongst adults with epilepsy and ID as no studies taking account of the response to AEDs of the ID populations based on the WHO *Diagnostic and Statistical Manual of Mental Disorders* criteria of clinical severity of ID were identified.

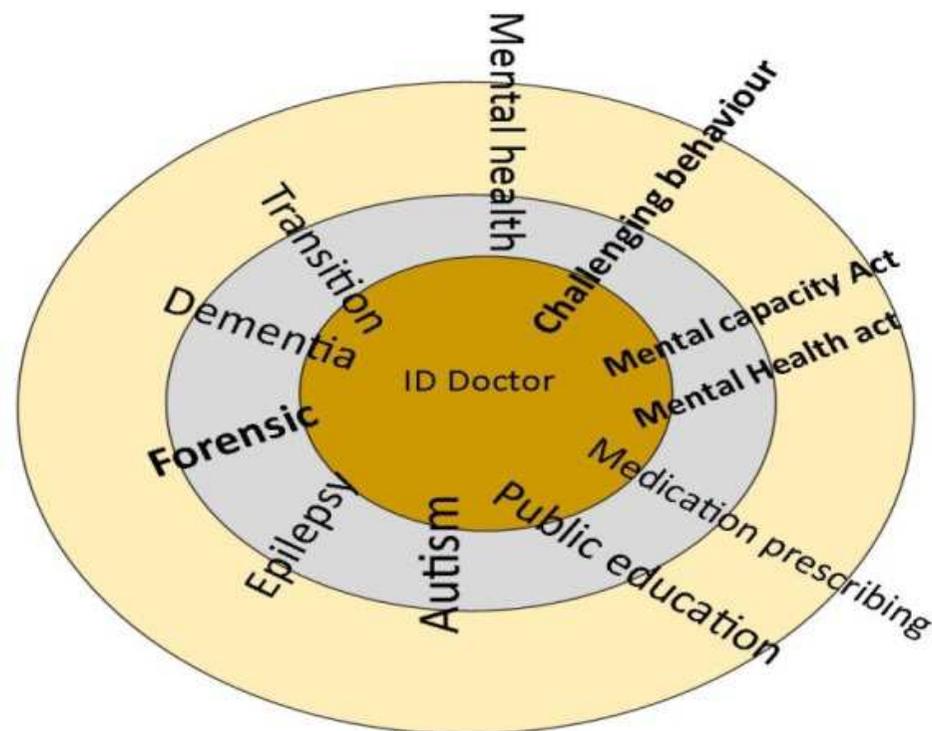
Conclusion: There is a significant shortfall in suitably powered studies to provide sufficient evidence for safe prescribing of AEDs to people with ID.

Drug Name	ID specific evidence	Type of evidence	Comments
Carbamazepine	Kaski et al 1991	Improved efficacy using slow release preparation vs. standard	No direct evidence of tolerance or efficacy
Gabapentin	Crawford et al	Add on comparative open study with Lamotrigine – no difference	Power side effects of aggression?
Lamotrigine	Motte et al 1997	LGS specific, RCT using placebo	power, specific syndrome
	Buchanan 1995	N =34 majority showed > 50% improvement	Power
	Gidal et al 2000	N=44, 45% > 50% improvement 20% worsening	Power, who's who?
	McKee et al 2006	N =22 sub analysis of a larger study	Power
LEV	Kelly et al. 2004	N = 64 Observational study of adjunct LEV 38% seizure free	Improved seizure control in majority and carer satisfaction
	Brodtkorb et al 2004	n =184 ID n = 56 equally effective	Study focus was on behaviour - worse in ID
Topiramate	Kerr et al 2005	RCT Double blind to placebo n=57 28/29 32% reduction in seizure frequency vs. 1%	No negative impact on behaviour Power
Sodium V	SANAD?	Sub analysis of difficult to treat	Multiple issues
Lacosamide	Flores et al 2012	Real world cohort N =403 18% ID sub analysis No differences between ID vs. non ID	Case selection

Conclusions

- * Concept of ID – nebulous – all lumped into one!
- * No specification of the nature or degree of ID, even when ID is mentioned
- * Poor descriptions of co-morbidities, such as PDD/autism
- * The newer AEDs possibly tend to be better tolerated and affect cognitive functioning to a lesser degree than older AED options. However the evidence base for safe use is extremely weak
- * No Concept of what is ‘Challenging Behaviour’

Why should a psychiatrist working with people with ID have a knowledge of epilepsy?



The development of standards and initiatives

- Enhance diagnosis, pathways to investigation
- Guidelines for treatment
- Improve links among different stakeholders between primary care, MDT, social services and patient centred clinical consultations

SPECIAL REPORT

A White Paper on the medical and social needs of people with epilepsy and intellectual disability: The Task Force on Intellectual Disabilities and Epilepsy of the International League Against Epilepsy

*Mike Kerr, ††Christine Linehan, ‡Rose Thompson, #Marco Mula, **Antonio Gil-Nagel, †††Sameer M. Zuberi, and §§Mike Glynn

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SUMMARY

This White Paper builds on the publication of the International League Against Epilepsy (ILAE) and International Bureau for Epilepsy (IBE) report "Listening for a change—medical and social needs of people with intellectual disability who have epilepsy" (Listening for a change the medical and social needs of people with epilepsy and intellectual disability, ILAE, 2013). The Paper presents an overview of the recommendations of the report, which aim to improve the health and social care of this important population of people with epilepsy worldwide. Actions in four domains are indicated: (1) the development of standards and initiatives that would enhance diagnosis, pathways to investigation, and treatment; (2) the development of guidelines for treatment, specifically best practice in the management of antiepileptic drugs including rescue medication; (3) the development of standards for primary care, multidisciplinary teamwork, and clinical consultations, with emphasis on the need to enhance communication and improve access to information; and (4) the enhancement of links among different stakeholders including medical services, educational establishments, employment services, organizations providing opportunities for social engagement, and family members. The breadth of needs of this population is a challenge to the epilepsy world, spanning all the professional groupings, care providers, and the research modalities in epilepsy.

KEY WORDS: Intellectual disability, Families, White Paper, Health care, Social care.



Mike Kerr is Professor of Learning Disability Psychiatry at Cardiff University, the leading University in Wales.

Recommended Actions

Investigations and diagnosis in individuals with complex needs

- A Working Group to develop
- the diagnosis of epilepsy
 - educational initiatives to improve clinician communication
 - identify a pathway to investigation for complex needs

Medication

- Establish a Task Force to develop
 - guidelines for the treatment & establishing best practice for the identification and management of AED side effects
 - Audit templates
 - Rescue medication

Enhancing medical services

- Guidance on
 - Accessible & exchangeable information in clinic settings
 - Minimum standards on MDTs primary care, shared decisions, person centred patient care etc.
 - epilepsy specialist nurse provision
 - training manuals to support non-specialist services

BRONZE	<ul style="list-style-type: none"> 4. That adults with epilepsy have an agreed and comprehensive written care plan 6. That adults with a history of prolonged or repeated seizures have an agreed written emergency care plan 8. That adults with epilepsy who have medical or lifestyle issues that need review are referred to specialist epilepsy services 9. That young people with epilepsy have an agreed transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services
SILVER	<ul style="list-style-type: none"> 1. That adults presenting with a suspected seizure are seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation 2. That adults having initial investigations for epilepsy undergo the tests within 4 weeks of them being requested 3. That adults who meet the criteria for neuroimaging for epilepsy have an MRI 5. That adults with epilepsy are seen by an epilepsy specialist nurse who they can contact between scheduled reviews <p>The above are in addition to all of Bronze level indicators</p>
GOLD	<ul style="list-style-type: none"> 6. That adults who meet the criteria for referral to a tertiary care specialist are seen within 4 weeks of referral <p>The above is in addition to all of Bronze and Silver level indicators</p>

Patient with ID and epilepsy,
seen in psychiatric context

Psychiatrist has no
input into epilepsy
management

Psychiatrist has
epilepsy management
role

Bronze

- Identify and manage epilepsy needs
- Assess impact of disease and treatment on mental disorder
- Able to treat NEAD
- Support use of rescue medication

Silver

- Additional skills in:
- drug change
 - seizure classification
 - understanding EEG/ MRI
 - rescue plans
 - side-effect assessment
 - SUDEP risk

Gold

- Additional skills in:
- diagnosis
 - new AEDs
 - VNS
 - surgical assessment

Epilepsy in People with an ID - Core Knowledge, Skills and Attitude Framework

Adapted from framework developed by Skills for Health, Skills for Care and Health Education England

Gold

- Knowledge, skills & attitudes for those who are providing **expert** epilepsy care
- example: ID psychiatrists & neurologists who diagnose & manage complex epilepsy

Silver

- Knowledge, skills & attitudes for those who are providing epilepsy support & care
- example ID psychiatrists, neurologists, GPs managing the epilepsy.

Bronze B

- Knowledge, skills and attitudes for roles that will have **regular contact** with epilepsy
- example general practice, psychiatry trainees in all specialities particularly ID

Bronze A

- Knowledge, skills & attitudes for roles that require **general awareness** of epilepsy in ID
- For example medical students, ED doctors

Implementing Strategy

Next Steps

Links with other Stakeholders

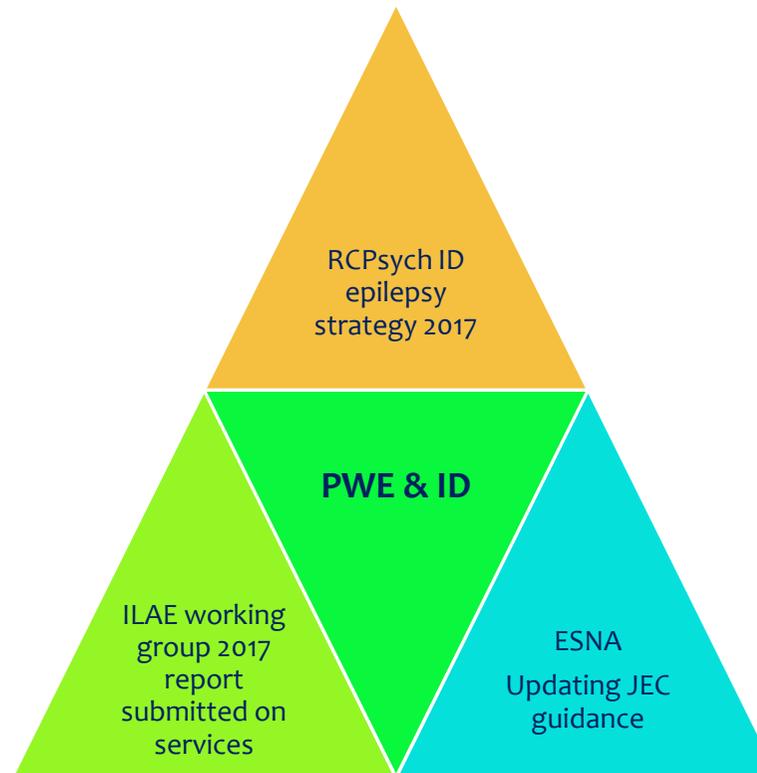
Links with training structure

Competencies & CPD

Better evidence of mortality causes - ? LeDer link

Assess current evidence base for service provision - ? Link with NASH/LD –observatory

Position paper from RCPsych of prescribing modelling STOMP



Working Group

Chairs

Dr Rohit Shankar

Dr Mogbeyiteren Eyeoyibo

Committee Members

Dr Mark Scheepers

Dr Jennifer Dolman

Dr Lance Watkins

Dr Rajnish Attavar

Dr Elizabeth Carmody

Dr Fabian Haut

Advisors

Professor Mike Kerr

Dr Regi Alexander

Dr John Devapriam

Dr Ashok Roy



GOOD PSYCHIATRIC PRACTICE CR203

Management of
epilepsy in adults
with intellectual
disability

COLLEGE REPORT

“Life for people with major disabilities supported by good services will often look quite ordinary, but this ordinariness will be the product of a great deal of careful planning and management”

Mansell 2007