Epilepsy and Disability
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Epilepsy Top of Mind 2011
• Definitions
• Epidemiology
• Impact of epilepsy
• Is Epilepsy a disability?
• Does epilepsy cause disability?
• Does disability cause epilepsy?
Disability

- Disabilities is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Thus disability is a complex phenomenon, reflecting an interaction between features of a person’s body and features of the society in which he or she lives.

World Health Organisation
Is epilepsy a disability?

- Epilepsy can be considered a disability because people with epilepsy face barriers similar to those faced by people with other disabilities:
  - in getting an education,
  - in finding employment,
  - in finding housing, and
  - in gaining respect from others due to stigma and prevailing myths about this condition.
- Some people with epilepsy do not consider themselves as having a disability.

Epilepsy Ontario
Does epilepsy cause disability?

- A single short seizure does not cause disability
- A prolonged seizure (status epilepticus) may cause disability
- Recurrent seizures may cause weakness or deficits in learning and attention
- In the majority of cases the epilepsy does not cause the disability
- The disability is due to the underlying cause
Complex relationship!

- Epilepsy
- Physical disability
- Learning Disability
• Some people with epilepsy will have a learning disability but not all.
• Some people with a learning disability will have epilepsy but not all.
• Some people with physical disability have epilepsy but not all.
• Some people with epilepsy have a physical disability but not all.
Statistics of people with physical disability in Australia

- One in five people in Australia (3,958,300 or 20%) had a reported disability in 2003.
- A further 4,149,000 (21%) had a long-term health condition that did not restrict their everyday activities.
- The remaining 11,703,800 (59%) had neither a disability nor a long term health condition.

ABS - Disability, Ageing and Carers, Australia. 2003
Developmental Disability

- Developmental disability is an umbrella term that includes intellectual disability but also includes physical disabilities.
- Some developmental disabilities can be strictly physical, such as blindness from birth. Some individuals have both physical and intellectual disabilities stemming from genetic or other physical causes (e.g., Down Syndrome, fetal alcohol syndrome).
• Of those with a reported disability, 86% (3,387,900) had a specific limitation or restriction, that is were limited in the core activities of self care, mobility or communication, or restricted in schooling or employment.

• Most people with a disability (76%) were limited in one or more of these core activities.¹

¹Australian Bureau Statistics - disability, ageing and carers, Australia.
Intellectual Disability

- A disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before the age of 18.

= Learning Disability

American Association on Intellectual and Developmental Disabilities
American Psychiatric Association
Epidemiology

- 1/5 of the population with intellectual disability have epilepsy.
- Lifetime prevalence of epilepsy in those with mild to moderate learning disability (IQ 50–70) is 15%, whereas in those with severe or profound learning disability (IQ<50) mean lifetime prevalence is 30%.
Epilepsy and Developmental Delay

- The prevalence of epilepsy in this group of children is 30–50% and is higher compared to the general population [Sunder, 1997].
- In the majority of cases, the pathological process causing the developmental disability is also the cause for the epilepsy.
- Consequently, the more severe and extensive the cerebral pathology, the higher the likelihood the child will have epilepsy [Holmes, 2002].
Epilepsy and Developmental Delay

- Some learning disability syndromes are associated with a relatively high prevalence of epilepsy, including conditions with a defined genetic abnormality such as tuberous sclerosis, Rett syndrome and fragile X, as well as autism.

- Other such as Down Syndrome and Prader Willi do not have increased rates of epilepsy.
# Epilepsy and Intellectual Disability

<table>
<thead>
<tr>
<th>Study</th>
<th>Sample</th>
<th>Prevalence rate (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Corbett et al. (1975)</td>
<td>Children &lt;14 years of age in the community with severe ID</td>
<td>20.0</td>
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<tr>
<td>Richardson et al. (1981)</td>
<td>Children ≥22 years of age in the community:</td>
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<tr>
<td></td>
<td>mild ID</td>
<td>24.0</td>
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<tr>
<td></td>
<td>severe ID</td>
<td>44.0</td>
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<tr>
<td>Mariani et al. (1993)</td>
<td>Institution</td>
<td>32.0</td>
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<tr>
<td>Steffenburg et al. (1995)</td>
<td>Children between 6 and 13 years of age in the community:</td>
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<tr>
<td></td>
<td>mild ID</td>
<td>14.0</td>
</tr>
<tr>
<td></td>
<td>severe ID</td>
<td>24.0</td>
</tr>
<tr>
<td>Welsh Office (1995)</td>
<td>Adults based in the community (all with ID)</td>
<td>22.1</td>
</tr>
<tr>
<td>C. Morgan (personal communication)</td>
<td>All ages, record-linked health data</td>
<td>18.3</td>
</tr>
</tbody>
</table>

Epilepsy developed in 22% of participants. In the majority, seizures began after 10 years of age.

Generalised tonic–clonic seizures predominated (88%).

In over a half (19/33), seizures occurred weekly or less frequently and in the majority of individuals (28/31) they were controlled with the prescription of one to two anticonvulsants.

Epilepsy was associated with gender (female), intellectual disability and poorer verbal abilities.
Cerebral Palsy and Epilepsy

- The prevalence of epilepsy is five times more common in patients with CP compared to normal children.
- Data combined from several studies involving 1,918 children [Ashwal et al., 2004] found that on average 43% (range 35–62%) of children with CP develop seizures.
Cerebral Palsy and Epilepsy

- The epilepsy onset is often within the first year of life, many had history of neonatal seizures, and there is an increased incidence of status epilepticus.

- Patients had a lower chance of becoming seizure free, and treatment with an additional second-line antiepileptic drug is more likely [Ashwal et al., 2004].
TREATMENT
Challenges

- Epilepsy can be difficult to treat and prove resistant to medications.
- Frequent seizure clusters and status
- Underlying brain malformations
- Diagnosis can be difficult as non-epileptic events can occur
- Data may be poorly recorded
- Multiple seizure types can occur
Aims of Treatment

- Individualised
- Improving Quality of Life
- Seizure reduction
- Acceptable seizure control
- Seizure freedom may be an unrealistic goal
- Limit drug side – effects
- Optimise cognition
- Limit drug load
Minimising Side-Effects

- AED-related cognitive and behavioral adverse effects tend to occur more frequently in children with developmental disabilities.
- The risk could be minimized by selecting the appropriate AED for the individual patient, titrating slowly to the lowest effective dose, and avoiding polypharmacy.
Other challenges

- Getting support from other agencies (DSQ, Centrelink, Education Queensland)
- Acknowledgement from others that epilepsy can have an impact (Education Queensland, Centrelink, DSQ)
LOCAL COMMUNITY SUPPORTS
NATIONAL CENTRE FOR YOUNG PEOPLE WITH EPILEPSY
National Centre for Young People With Epilepsy
- Based on a 60 acre rural campus in Surrey with residential special school and FE college
- Provides specialist services for young people with epilepsy
- Multidisciplinary assessments
- EEG services
The Neville Childhood Epilepsy Centre
CONCLUSIONS
Conclusions

- Epilepsy commonly coexists with disability
- The disability is commonly the cause of the epilepsy
- When it does it can be difficult to treat
- Treatment goals should be individualised