PHYSICAL HEALTH AND LEARNING DISABILITY

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OVERVIEW

- Present an introduction physical health in LD
- A little plug for Genetics
- Epilepsy - SUDEP
- Sleep Disordered Breathing
- MOST IMPORTANT – Getting the basics right
  - Annual Health Checks
  - Reasonable Adjustments
  - Being aware of diagnostic overshadowing

INDIVIDUALLY RARE/COLLECTIVELY COMMON

- There are many different reasons why someone may have a Learning Disability
  - Ranging from a genetic syndrome to childhood traumatic brain injury
  - There are physical health concerns common to many people with LD regardless of aetiology
  - Some concerns will be syndrome specific
    - E.g. Down Syndrome: Thyroid Disease, Coeliac Disease, - recommendations for a screening Echo in early adulthood
    - Prader-Willi Syndrome: propensity for Gastric Rupture (inability to vomit, vomiting as a sign of severe likely surgical pathology)
    - Fragile-X: Aortic Dilation, Mitral Valve Prolapse, Scoliosis

‘LD PHYSICIAN’? – IT’S US

- As GPs we are “experts in our own patients” and so it’s vitally important that if we have a patient with a rare or unusual condition that we help support others to understand these disorders and contribute to the formation of their hospital passport.
- For Children- Community Paediatricians can serve as expert clinician for these patients.
- There have been calls for the establishment of a specialty of ‘Learning Disability Medicine’.
  - until the day that happens- we’re it.
- Skills: #1 – is “Time”, Beware of ”Diagnostic overshadowing”, “Communication is Key”, “Proactive not just Reactive”, “Thoughtful Data Gathering”,
  - “staff didn’t think it was consistent with partial epilepsy” (it likely was)
  - “carer didn’t think he could tolerate the scan” (he did)

A BRIEF WORD ON TRANSITIONS

- This can be a particularly difficult time for young adults
- Consider starting Transition Annual Health Checks in teenage years – current funding for AHCs only from 18.
- These preliminary visits can be really helpful for young adults and their carers to think about what might be needed in the future.
- Have shown a role in decreasing the amount of crisis contacts when not managed well
- This is a big topic: RCGP E LEARNING TRANSITIONS
- RCGP Youtube Channel: Transitions from Paediatric to Adult care - the role of general practice https://www.youtube.com/watch?v=GaePEuZ5ne0

GENETIC DIAGNOSIS

- Genetics: we are discovering ever more genetic syndromes as science and data sharing progress.
- It is likely that many of your adult LD patients had only limited Genetic Testing in the past.
- Clinical Genetics is actively interested to see these patients, and have a very short waiting list.
  - Currently a pilot scheme is starting within the Belfast trust to systematically invite patients with an LD for genetic screening. But no need to wait.
- "This means so much for me. Finally, it shows I wasn't just a 'bad parent'"

PHYSICAL HEALTH ISSUES IN LD

- LeDeR Report https://www.england.nhs.uk/publication/university-of-bristol-leder-annual-report/
- All deaths in patients with LD in England and Wales are reported to LeDeR who publish an annual report into the causes and allow us to examine the potentially preventable causes.
- Most common cause of death- bacterial pneumonia (24%), and Aspiration Pneumonia (16%)
- Most common treatable cause of death were Pneumonia, **Epilepsy**, then Cardiovascular Disease.

COMMON PHYSICAL HEALTH ISSUES IN LD

- Dysphagia – (can be due to behavioural, coordination, tone, dental issues)
  - If any concerns please get speech and language involved. Some great resources on safe eating practices
  - Dental care important here too.

- Constipation – at least 25% of patients with LD are on laxatives
  - Can be a contributing factor for increased hospitalizations, and even death in this population
  - Contributing factors (dehydration, dietary preferences, genetics, lack of activity, medication side effects)
  - "Question what we think is behavioural"

COMMON PHYSICAL HEALTH ISSUES IN LD

- GORD
  - Up to 70% of patients with ID have reported GI disturbances, on the differential for Behavioural change.
  - H. Pylori can be very prevalent especially in group home, care home settings.
  - GI cancers more prevalent in this group – be careful not to assume someone won't tolerate endoscopy
- Low Bone Density/Osteoporosis
  - Growing area of research. Higher than usual fracture risk.
  - Less sun exposure. Nutritional issues. Many antiepileptics also decrease your Vitamin D. Antipsychotics increase your prolactin.
  - PAIN
- Extremes of weight – obesity and malnutrition
  - British Dietetic Association- great resources

COMMON PHYSICAL HEALTH ISSUES IN LD

- Dental
  - Special Care Dentistry can be really helpful – via call management
  - https://brushmyteeth.ie/ - extremely good resource
- Hearing
  - Significant issue – estimates are that at least 1 in 10 people with a Learning Disability have hearing loss- most undiagnosed
- Vision
  - https://www.seeability.org/

EPILEPSY AND SUDEP

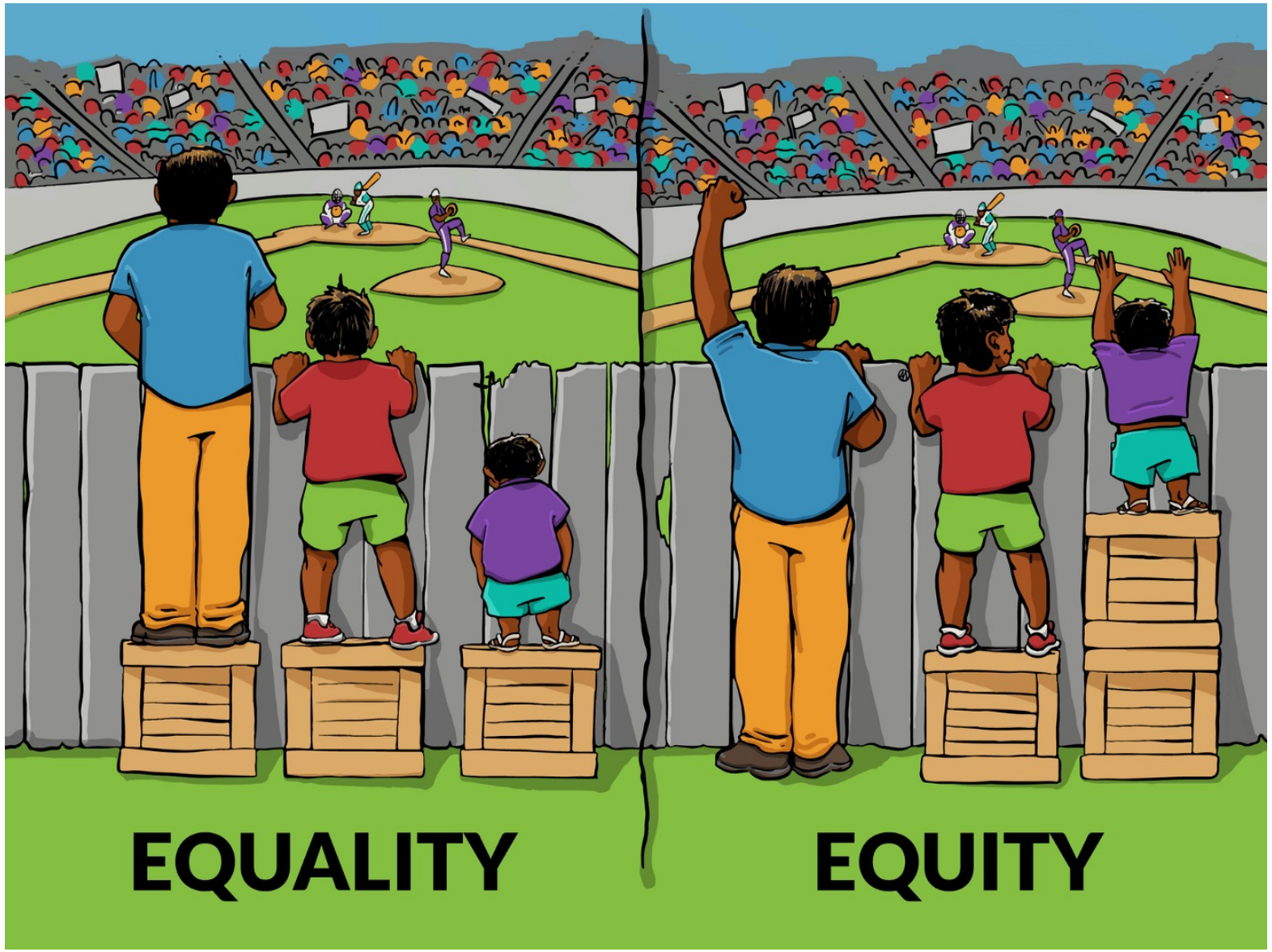
- Epilepsy - Roughly 30% of patients with ID have epilepsy, where roughly 1% of general population
  - Increases with severity of LD. Behaviour changes and Seizures management issues can be significantly difficult to tease out
  - Many antiepileptics can contribute to behaviour disturbance, so can uncontrolled seizures, or pre-seizure activity
  - Most trusts have LD Epilepsy Specialist Nurses who can be a wonderful link into appropriate Neurology care
- SUDEP (Intellectual Disability is independent risk factor)
  - https://sudep.org/checklist

OBSTRUCTIVE SLEEP APNOEA (OSA) SLEEP DISORDERED BREATHING

- Needing to rethink OSA– beyond Occupational Risks
- Sleep Apnoea (especially poorly controlled) increases risk of SUDEP (Sudden Unexpected Death in Epilepsy)
  - May 2021 article in SLEEP suggests screening for OSA in all patients with epilepsy
- There is a non epilepsy risk of Sudden Death in untreated Sleep Apnoea although low, it is increased with increasing age and poorly controlled cardiovascular disease.
- Can have significant effects on quality of life, contribute to behaviours that challenge, lead to missed life opportunities.
- LD is an independent risk factor for OSA apart from Obesity (tone, anatomy).
- NICE Guidance suggests screening Epworth sleepiness scale – not validated in LD populations
  - STOP BANG Tool - also recommended by NICE - has some validation in Down Syndrome and LD populations
- May need to help our Sleep consultant colleagues with understanding the importance in our population "doesn't drive so not a problem"
- Overnight oximetry easy and generally well tolerated.

ANNUAL HEALTH CHECK

- Great starting point- but these patients need good year round access
- Relationship Building – Health Facilitators are vital but the GP role is vital too
  - Some practices use Locums for this- best not to
  - might be good to have an LD lead for the practice
- Large spectrum of LD- some with mild range LD may not always be apparent- but still need significant support and reasonable adjustments
- Access: I called 73 times without getting through to my GP 2 weeks ago- I don't have a Learning Disability


EQUALITY
EQUITY

SUMMARY

- Pneumonia and Aspiration Pneumonia – leading cause of treatable/preventable death – SWALLOW ASSESSMENT
- Epilepsy- and SUDEP
  - Utilise your LD Specialist Epilepsy Nurses
- Annual Health Checks
  - Why are some of our patients not being seen? What can we do to improve this?
  - AHCs start the conversation, but what about the rest of the year?
- Diagnostic Overshadowing: Constantly question ourselves when we suggest that something is ”behavioural”.
- Currently- we are IT – no ‘Adult Community Paediatricians’.
  - We can continue to educate ourselves about the conditions our patients face and advocate for them to have the same level of access to care as anyone else.