Diagnosis: Multiplicity, Removal and Grey Areas

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Objectives

- To discuss:
- co-occurrence of neurodevelopmental conditions/disorders
- Diagnosis removal and 2nd opinions
- Reflect on 'Grey' areas regarding 'diagnoses'
- I will avoid statistics that won't be remembered and keep it simple.
- Give some tips
- NB This is not how to diagnose nor differentiate between specific diagnoses.

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ACAMH Touchstones

- Clinical practice

Neurodevelopmental conditions/disorders may resemble each other and co-occur. At times they require a re-evaluation, change or removal with development, changed presentation or new information. Sometimes there is uncertainty or lack of clarity regarding the validity of a 'diagnosis'.

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Multiplicity of NDCs

- Neurodevelopmental Conditions/Disorders relate to the development of the brain
- The brain has multiple functions which affect behaviours, skills-strengths and deficits
- These often share common pathways and areas of the brain
- Shared causes- genetics, environment, brain damage etc

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Multiplicity cont.

- Neurodevelopmental diagnoses are stereotypes with uncertain validity as separate conditions
- They commonly co-occur
- They often resemble each other and are differential diagnoses
- They may have a hierarchy and can exempt each other (though concepts change)

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Questions/discussion…

- NDCs may be on a spectrum of symptomatology and severity- not always reflected by diagnostic options so…
- Where does 'neurotypical' start and stop?
- What do we do about traits?
- Everyone neuro-develops, so what is disordered vs difference?

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Challenges

- How to differentiate between the different symptomatologies
- Recognising mixed symptomatology
- Treating 1 may remove another
- Keeping an open mind

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Co-occurrence with mental health/behavioural disorders

- Having a neurodevelopmental condition/disorder raises chances of mental health disorders
- Anxiety
- Depression/bipolar
- Psychosis
- catatonia
- Some have behaviour disorders as addition within their diagnostic code
- Some have behavioural issues as part of the diagnosis
- Increased incidence of behavioural issues
- sleep

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Questions / Discussion…

- Should we diagnose 1 condition 1st?
- Is there a hierarchy?
- Can you always co-diagnose?
- How do we avoid diagnostic overshadowing?

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Reasons for presenting symptoms/signs

- Self esteem
- Communication
- Genetics
- Physical health- neurological, chronic illness, disability
- Trauma, ACEs, abuse- differences in response, increased likelihood,
- Neurochemistry
- Resilience
- Understanding

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Management of co-occurring diagnoses

- Treating 1 may make another clearer, better or worse
- May require adaptation of psychological therapies
- May need altered medication approach- lower dose, slower changes, increased monitoring, off license,
- Consider STOMP-STAMP
- Approaches for the management of each may need to be combined- individualised
- Management strategies for 1 disorder may also help with others

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Removal of diagnoses

- Wrong diagnosis
- Change of clinical view:
- new information,
- change of presentation,
- new clinician
- Request for removal by person, family, carers, professionals
- Child develops- new or loss of symptoms/signs

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Questions / Discussion….

- Refusal to give up a diagnosis or refusal to be reassessed….
- What are your thoughts on the ethics of this?
- Professionals can refuse to diagnose, once given, if wrong should an individual/family be able to refuse to give it up?
- Should a diagnosis be removed, even if the evidence is present for its existence?

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Challenges

- Trust in the system
- Change of perception of the child and their needs
- Loss of identity
- Change of identity
- Loss/change of service
- Loss/change of benefits
- Change of parental/family support networks and/or identity

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Challenges cont.

- Removal of diagnosis may imply change of causality/nature of difficulties
- May coincide with a change if diagnosis- might not be wanted
- Conflicting past and current information

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2nd Opinions

- Following parent/individual not accepting 1st opinion
- Following 1st opinion wanting an expert opinion
- May confirm 1st opinion
- May contradict 1st opinion
- Often have more information (more gathered, extra tests/assessment, exaggeration of symptoms, more time has passed, life's challenges may increase with age expectations, more likely to have the information to make a diagnosis)

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2nd opinions cont.

- If no requested diagnosis made- what is the diagnosis/formulation?
- If diagnosis made, understand why not made the 1st time- often due to less info available.
- Explaining the above can maintain/renew trust in the system- often an individual may be returning to the original service
- When doing a 2nd opinion we are often in a luxurious position

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Questions / Discussion…

- Should there be a limit on how many extra opinions can be sought?
- How do we establish if the 2nd opinion is 'better' than the 1st or 'more willing'? ie Which do we believe?
- What do we do if evidence contradicts itself?

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Differential diagnoses

- Look similar, same presentation can have different underlying reasons, but also are the same conditions that can co-occur. eg
- ASD vs ADHD vs ID/LD
- ASD vs Attachment
- ADHD vs Conduct
- ASD vs psychopathy
- ASD vs Language Disorders
- ASD vs DCD
- DCD vs ADHD

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Eg ASD vs ADHD vs ID

- ASD- Communication, social communication, repetitive interests/behaviours
- ADHD- attention difficulties, hyperactivity, impulsivity
- ID- developmental delays- IQ <70, adaptive behaviour delays

- ID delays can resemble a younger child
- ADHD symptoms can resemble a younger child
- ASD symptomatology – many are normal at a younger age

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‘Grey’ areas- reflections/questions raised

- Controversial/non-mainstream diagnoses eg PDA, DAMP, SPD- separate or part of another disorder?
- Attachment difficulties in ASD- how to tell the difference accurately?
- ID/LD following head injury, neurodegenerative conditions- only if in developmental period, What about adults? When does the developmental period stop?
- ADHD symptomatology due to neglect, environment, foetal exposure to alcohol/valproate- to diagnose ADHD or formulate?
- Are traits normal?- should they be labelled?

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‘Grey’ areas cont.

- When conflicting views on causality, treatment, terminology, criteria, formulation- what/who is right?
- Transitioning to new terminology- what to do with old diagnostic terms? How to forward plan? How to manage loss of identity when a term changes?
- Trends in terminology despite ‘official’ diagnostic terms- How to manage these?
- Use of the same terminology to mean different things- What to do about this?
- Self diagnosis/ self identifying- What to do with this?

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Tips

- Know your diagnostic criteria
- Know your development
- Know the differential diagnoses
- Know the co-morbid / co-occurring conditions
- Have an open mind to change and complexity
- Be aware that 'life long' NDCs can change/get worse/reduce
- Diagnoses may be provisional

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Tips

- Be sensitive
- Explain why diagnoses are no longer correct
- Explain 'False' understanding is not helpful to an individual or services to meet needs
- Meeting needs, requires improved understanding
- Neurodevelopment means changes can/will occur in presentation
- Often removal of diagnoses, requires a replacement (diagnosis or formulation)

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Tips

- Sometimes using formulation can help explain a complex situation better than diagnoses
- Diagnostic accuracy may not be welcomed if it comes with blame, loss of status, benefits, rights, service- understand the position of the family/child, but don't shy away from accuracy.
- Removal of a diagnosis will often require a gold standard re-assessment
- Generate a needs based plan with any new diagnosis

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Tips

- Limit direct criticism of colleagues, we all make mistakes, or were right at the time based upon available evidence
- But, if a colleague has been negligent- report as appropriate
- Consider 'duty of candour' if harm done- admit and say sorry
- Allow families/individuals to express dissatisfaction and direct to support/complaints departments etc.
- Assist complaints procedures in explaining why a situation arose, rather than just apologising.

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Summary

- Neurodevelopmental diagnoses often co-occur
- Neurodevelopmental diagnoses have increased risks of mental health and behavioural issues
- Many of the differential diagnoses can be co-occurring conditions
- Removal of diagnoses may be a challenge
- 2nd opinions can be helpful

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•Any Questions?

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