Management of anxiety in children and young people with intellectual disability

Northern Sydney Intellectual Disability Health Service

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Learning objectives

1. Recognise signs of anxiety in children and young people with an intellectual disability
2. Determine the need for appropriate targeted anxiety intervention
3. Identify age appropriate referral pathways and services
4. Understand the role of psychology services in the management of anxiety
5. Assess the potential role of medication in the management of anxiety

- Deficits in intellectual function
  e.g. reasoning, problem solving, abstract thinking
  (Clinical assessment, IQ testing)

and

- Deficits in adaptive functioning
  e.g. independent living, communication, social participation

- Onset in developmental period – before age 18 years

DSM V, 2013

Anxiety in children and young people

- Signs of anxiety and indicated by changes in;
  - Physiology
  - Thoughts
  - Behaviours
- Children are less likely to be able to articulate that they are feeling anxious, and diagnosis is often made based on observation and parent report

Features of anxiety disorders

- “Anxiety disorders differ from developmentally normative fear and anxiety by being excessive or persisting beyond developmentally appropriate periods” (*DSM 5, 2013*)

- Typically persist beyond a period of 6 months. This is sometimes shorter in children e.g. with separation anxiety

- Different fears may be more likely to present at different ages/stages of development

(*DSM 5, 2013*)

Types of anxiety presentation

- Separation anxiety fears
- Selective mutism
- Specific phobia
- Social anxiety
- Panic
- Generalised anxiety

Anxiety in children with an ID

- 25% and 50% of youth with an Intellectual Disability (ID) meet criteria for a psychiatric disorder, compared to 6% to 17% of typically developing (TD) youth (Davis E, et al, 2008)

- 35% of 6-17 year olds with ID have a diagnosis of depression or anxiety (Whitney DG et al, 2019)

- Youth with ID and comorbid neurodevelopmental conditions, particularly autism spectrum disorder are at greater risk of depression and anxiety

Anxiety in children with an ID

- More likely to express symptoms of anxiety through externalising behaviour and non compliance due to difficulties with emotional regulation and expressive language skills

- Children with ID display rates of emotional and behavioural difficulties 3-4 times higher than TD children (Triple P- Positive Parenting Program)

- Youth with ID and anxiety are twice as likely to meet criteria for 1 or more disruptive behaviour disorders or Attention Deficit Hyperactivity Disorder (Green SA et al, 2015)

Case study - Tom

- 13 year old boy with a mild intellectual disability who moved to the area 12 months ago
- Tom's mother is a single parent and presents without Tom seeking help
- Tom refuses to leave the house and spends very little time outside of his room
- He enjoys gaming, watching movies and speaks to friends from previous school online
- Enrolled at a local high school but has not attended regularly, less frequently since period of home schooling because of Covid-19
- Says that he will go to school but each morning unable to leave his room
- Teacher made a home visit but Tom refused to speak with her or leave his room
- Resistant to mothers attempts to help him with school work provided by his teacher
- No physical activity and mother is concerned that he has gained weight
- Self restricted diet
- Sleeping well

Case study - Tom

- Previously at a mainstream primary school
- Separation from mother has been difficult from the beginning of school
- Tom would freeze and stop on the walk to school
- Long standing school refusal and partial enrolment, never achieved full attendance
- History of bullying, social isolation and peer conflict
- Struggled with academic demands
- Mother is considering applying for home schooling
- No regular medication
- No therapists currently involved but Tom is an NDIS participant with a current plan inclusive of funding for activities of daily living
- Tom will not attend the practice and mother is unsure if he will speak on the phone/videoconference

Case study - Tom

- It seems likely that Tom is experiencing anxiety and has been for some time
  1. What assists in making a reliable assessment and is it possible classify Tom's anxiety diagnosis?
  2. What psychological intervention is helpful for a child like Tom with anxiety and ID?
  3. Tom's mother wants him to see someone but has realised there are long waiting times to see a psychologist. What help can be provided in the meantime?
  4. When is additional medical specialist referral indicated? Is there a role for medication?

Strategies to help with assessment

- Flexible consultation options
- Use of social stories
- Use of calming strategies/objects
- Familiar support person for the child in addition to parent attendance
- Communicate with the young person before each step of the exam
- Recognise altered sensations and sensory issues e.g. touch
- Move slowly, performing exams distal to proximal
- Allow the child to remain in a sitting position rather than lying prone where possible

Assessment of anxiety in children with ID

- An assessment of Tom's anxiety is assisted by the following
  - Review of current physical health
  - Parent interview of anxiety presentation
  - Parent report of observations at home
  - Questionnaire
  - Feedback from teachers/allied health therapist/specialists where possible

- Ideally in a clinic or school setting, children are involved in the assessment as much as is possible (e.g. child interview and observations). Multiple informants also facilitate accurate assessment.

Assessment of anxiety in children with ID

Questions for parents (and those who know the child well)

- Presenting concerns and the nature of the problem
- Developmental history
- Current functioning - home and school
- Is there any family history of similar difficulties
- Previous/current intervention

Classification of Tom's diagnosis requires further information regarding the nature of his anxiety and underlying fears. Social fears and general worries are likely to be contributing.

Psychological interventions for anxiety

Cognitive Behaviour Therapy (CBT)

Key components include:

1. Psychoeducation about the nature of anxiety
2. Cognitive strategies - to encourage children to think more realistically about feared events
3. Behavioural strategies - gradual exposure to feared events and rewarding efforts

Psychological interventions for anxiety - considerations

- CBT strategies are modified
  - Cognitive strategies can be simplified
  - Parents are involved in supporting the implementation of graded exposure

- Targeted skill development – communication skills (such as assertiveness training) and social skills. This improves children's ability and confidence to engage in situations they find anxiety provoking).

Additional supports for Tom

Interim strategies to support Tom at home while he is waiting for a psychology service

- Continue to encourage Tom to be exposed to his fears rather than avoiding them. This may look like:
  - Spend increasing amounts of time outside of his room and house
  - Regularly engage in conversation with mum and visitors to the home as much as possible
  - At home talk about school and his teachers
  - Role play and modelling of skills
  - Reward/praise Tom for his efforts

Additional supports for Tom

- Interim supports while waiting for psychology may include
  - School counsellor assistance
  - Allied health practitioners
  - NDIS support coordinator and support staff

- Referral to paediatrician is warranted to assist in managing severe anxiety and school refusal, there is likely a role for medication.

Case Study - Belinda

- 12 years old with moderate ID and autism spectrum disorder
- Severe receptive and expressive language delay
  - Makes requests, can gain attention, can respond to questions
- Recently commenced high school at a school for specific purposes (ID)
- Lives with parents and younger sibling
- Menstruating
- History of anxious traits in primary school
  - Hyper vigilance, repetitive questioning, skin picking
  - Disrupted sleep
  - Increased separation anxiety

Case study - Belinda

Previous intervention

- Previously attended psychology services inclusive of cognitive behaviour therapy
- Parent report of limited benefit with Belinda's limited understanding and retention of strategies
- Emotional regulation still requires direct adult support
- Seen by a paediatrician who prescribed trial of an SSRI but no benefit reported and concern about further sleep disruption
- NDIS participant accessing regular speech pathology and an initial appointment with a behaviour support clinician

Case study- Belinda

Current concerns

- Belinda presents with:
- Daily episodes of rapid escalation to physical aggression at home and in the community, indiscriminately hitting out at people in the street
- Withdrawal in class and observation of reduced verbal skills
- Waking several times overnight with difficulty getting to sleep. Expressing worries and needing parent reassurance overnight
- Increased soiling, typically exacerbated with periods of high emotional stress
- Increased rigidity, reliance on obsessions, sensory seeking behaviour
- Vigilant about parents whereabouts in the home, unable to be alone

Case study - Belinda

1. Anxiety presentation in children with ASD

2. What does the family need to address the current situation and to meet Belinda's ongoing needs?

3. Is there a role for medication?

Anxiety in children with ID and ASD

- Social anxiety in youth with ASD but **without ID** 17%, reported up to 49% (Briot et al, 2020)

- Youth with ID and comorbid ASD and ADHD are more likely to experience depression and/or anxiety problems compared to
  - ID alone
  - ID with ASD
  - ID with ADHD (Whitney et al, 2019)

Contributors to anxiety in children with ASD

- Social skills difficulties
  - reduced social communication skills and social motivation
  - reduced assertiveness skills
  - previous negative social experiences (bullying and segregation)
- Resistance to change, preference for routine, insistence on sameness
- Thinking styles - e.g. black and white thinking styles, cognitive distortions
- Low tolerance for uncertainty and avoiding exposure – prevents learning experiences
- Difficulty communicating needs and wants
- Sensory processing difficulties

CBT for children with ASD and mild ID

Different interventions may be considered depending on the level of ID. For children with a mild ID the following may assist:

- Modifications to cognitive behavioural intervention
  - Includes building emotional skills and understanding, social skills, emotional regulation
  - Delivery incorporates increased use of visual supports, video role play, opportunities for practice (which should be encouraged across settings)

- Programs include
  - The Westmead Feelings Program – for children with ASD and mild ID
    (Ratcliffe B et al, 2019)

Interventions required to meet Belinda's ongoing needs

- Belinda is communicating through her behaviour a high level of anxiety and stress (hitting, increased soiling, withdrawal, increase in repetitive behaviours).

- Positive Behaviour Support interventions help identify what Belinda is trying to avoid/ finding overwhelming (what situations, why, with who). This is necessary in understanding her anxiety and developing targeted support strategies.

- Belinda's increase in repetitive behaviours is an attempt to self-soothe. She requires adult support with emotional regulation.

Interventions required to meet Belinda's ongoing needs

- Consider environmental adjustments – school placement, in home skilled support workers
  - Belinda has moved to a SSP where she is more supported
  - Support workers who know her well and understand her ASD specific needs
  - Availability of carers 1:1
  - Predictable environment
  - Communication of changes
  - Preparation for transitions (e.g. forewarning)

Interventions required to meet Belinda's ongoing needs

- Skill building
  - Communication skills development supports Belinda's wellbeing and growing need for independence as she enters adolescence. This includes:
    - Her understanding of routine, changes, instructions. Ability to communicate key messages such as I want, I don't want, I need a break.
    - This is supported by the development of her expressive and receptive language skills, use of visuals, social stories (with guidance of SP)
  - Social skills supports include helping her to gain others attention and join in
  - Emotional regulation skills require further support to help Belinda begin to understand her feelings and identify what she can do to feel better.

Interventions required to meet Belinda's ongoing needs

- Involvement of a multi-disciplinary team is required
  - Behaviour support practitioner/Psychologist
  - Occupational therapist
  - Speech pathologist
  - Paediatrician

- Interventions for Belinda aim to increase her ability to engage in daily activities in a positive way.
- This provides opportunities for Belinda to learn through experience that she can cope, and reduce anxiety over time.

Family well being

- Co occurring mental disorders in children and adolescents with ID are more predictive of:
  - Restricted access to education, vocation, community participation and social inclusion
  - Parent's personal experience of mental disorder

  than the severity of the ID

- Almost 1/3 of parents with a child with ID experience depression (Munir, K.M, 2016)
  - 31% of parents of children with ID had elevated levels of depression compared to 7% of parents of children without ID
  - 31% of parents of children with ID had elevated levels of anxiety symptoms compared to 14% of parents of children without ID

Family well being – Covid19

- UK study of Child Adolescent Mental Health Services for children with intellectual disability during Covid19 (Rauf, B et al, 2021)
  - Increase in medication interventions for behaviour or mental health issues
  - Some cases saw improvement with reduced demands (ADHD, sleep)
  - 4 fold per week increase in multidisciplinary team input

Family well being – Covid 19

- Regular communication amongst the MDT
- Increased monitoring of medication side effects
- Consider medication reduction or withdrawal when possible
- Increase access to psychosocial interventions
- Use of telehealth for regular review
- Consultation with specialist ID health services

Medication prescribing

- Only specialists with expertise in treating mental health problems in people with learning disabilities should **start** medication to treat a mental health problem in:
  - adults with severe or profound learning disabilities
  - children and young people with any learning disabilities (NICE Guidelines, 2016)

- Access to paediatric and psychiatry services is limited and takes time

- Adolescent patients in transition - consider GP management in consultation with specialist paediatric IDHS

Role of Medication

- Treatment indicated when function is compromised
- Used in combination with non pharmacological intervention
- Medication to support skill building or reduce impact of symptoms (e.g. arousal, anxiety, explosive episodes)
- Evidence based practice - heterogeneous group with at times difficult to treat symptoms
- Off-label prescribing is common
- Medication adjustments guided by feedback from family and therapists
- Realistic expectations of ongoing parent capacity to support behaviour
- Crisis support - maintaining young person in the family home/appropriate school placement

- **REGULAR REVIEW AFTER CIRCUMSTANCES CHANGE**

Medication management

- Adrenergic agents (Clonidine, propranolol)
  - α_2 agonists
  - β-adrenergic antagonists (Beversdorf DQ, 2020; Sagar-Ouriaghli I, et al, 2018)
  - Medical contraindications e.g. propranolol - asthma
- SSRI
  - Risk of activation
  - Be prepared to wait and trial multiple agents
  - Awareness of half life and cross tapering options
  - Theoretical increase in risperidone levels, effect and side effects
- Sleep
  - Melatonin 2-6mg at night, Slenyto (2-18yr ASD and insomnia)
  - Clonidine
  - Risperidone

Referral pathways and resources

- NSIDHS – consultation service and Triple P Parent training
- NDIS - ECEI providers, Local Area and support coordinators
- School counsellor
- Private psychology services – MHCP, recognising need for parent involvement in therapy
- Paediatrician – private or LHD community paediatric team
- Private child psychiatrist
- Child Youth and Mental Health Services (CYMHS) and Community MH
- Paediatric ID mental health hub – requires paediatrician referral

Referral pathways and resources

- Parent training programs and parent support groups

  http://resourcingparents.nsw.gov.au/

- State-wide Paediatric Mental Health Intellectual Disability Hub

  http://www.schoollink.chw.edu.au/mhid-hub-webinar-series/

- GP Social work program - NSLHD

  https://sydneynorthhealthnetwork.org.au/about us/commissioning/social-work-service-to-support-gps/

Contact Details

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