Learning and Behaviour in NF1 – We know what the research says, but how can we help?

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What we already know

- **Academic Skills**
  - Up to 65% children with NF1 impaired in at least one area of academic functioning
  - North et al, 1995

- **Language**
  - Some evidence of lower scores on measures of expressive and receptive language
  - Mixed picture
  - Maybe some speech production issues
  - More research needed
  - Lehtonen et al, 2012
What we already know

• **Visuospatial Functioning**
  – One of the most robustly established areas of difficulty for children with NF1
  – Difficulties with judgements of lines
  – Visuomotor integration problems
  – Eliason, 1986

• **Motor Control/Co-ordination**
  – Not well researched, but frequently observed/reported clinically
  – Related to visuo-spatial functioning
  – Difficulties with gross and fine motor skills
  – Difficulties with handwriting, clumsiness and poor co-ordination
  – Levine et al, 2006
What we already know

• General Intellectual Functioning (IQ)
  – VERY general, therefore doesn’t always tell us much
  – Majority of children with NF1 within the average range, but roughly 10 points lower
  – 6% of children with NF1 have IQ below 70 compared with 2% of general population
What we already know

• Memory
  – Mixed research
  – Visual memory tests seem to be more problematic than verbal memory

• Executive Functioning and Attention
  – Includes working memory, planning, organization, inhibitory processes, categorization, flexibility, rule deduction, and divided and sustained attention
  – Seem to be difficulties even after accounting for IQ
  – High levels of ADHD – a third to a half of NF population compared to 3-5% of general population
What we already know

• Behaviour, emotionality and social competence
  – Behaviour in part related to high rates of ADHD
  – Little research in some areas
    • Sleep and feeding problems frequently reported clinically but little research
  – Children with NF1 generally under-report difficulties and over-estimate own abilities
What we already know

- Behaviour, emotionality and social competence
  - Perceived by both teachers and peers as more sensitive and isolated, less well liked, displayed less leadership behaviour
    - But not self report
    - Children with NF1 did not have lower self-ratings than children without NF1
  - Higher levels of Autistic Spectrum Disorder (ASD)
    - As measured by questionnaire measures
    - Further research needed
What do I do about it all?!

- Neuropsychological assessment
  - Long assessments looking at domains of functioning
  - Help to identify specific areas of difficulties in order to offer advice to schools and parents about how to support children
  - Advice is variable depending on specific areas of strengths/weaknesses
  - Can help inform statementing process if appropriate
What do I do about it all?!

- Talking therapies
  - Low mood, anxiety, visible difference concerns
  - 1:1 work with children/young people
    - i.e. CBT for anxiety:
What do I do about it all?!

- Parenting work
  - Includes supporting parental adjustment/mood/cognitions relating to child
    - i.e. parent who feels responsible for NF may feel guilty, guilt makes it difficult to be consistent with boundaries, parents feel they need to compensate
    - Anxious parents produce anxious children – can be necessary to spend time exploring and developing strategies to manage anxiety
  - Much of my work is in supporting parents who are struggling with managing their child’s behaviour
    - Can be 1:1 or group
What do I do about it all?!

- **Family work**
  - For more complex problems involving the family dynamics and wider systems
  - Complex and can be long term
    - Not always possible for families to attend regularly

- **Referral onwards**
  - ADHD assessment and pharmacological treatment
    - I can identify when children are struggling, but if pharmacological treatment may be useful referral to local psychiatry services is useful
  - ASD assessment
  - Family therapy or other specific issues less connected with NF1
    - Not always appropriate or necessary for children/families to travel to Manchester for interventions
But we don’t have a psychologist!

• Neuropsychological assessment
  – Can be difficult to access
    • If children have additional difficulties (epilepsy, brain tumour etc) they can often access specialist neuropsychological services within the hospital they are treated for the condition
  – Educational Psychologists can do assessments
    • However, often it is the school who determine priorities and EPs may have very limited time with individual children
    • Unlikely they will be able to complete in same level of detail
  – Useful to consider, why do you want it, what do you hope it will achieve?
    • Assessment is not a sure fire method of receiving a statement
    • Clinical psychologists have no statutory role in statementing process and although assessments are often welcomed by schools/EPs, they do not have to act on them
But we don’t have a psychologist!

- Neuropsychological assessment
  - For statementing process EPs are key but often only do general IQ and achievement tests
    - Can be useful to speak to EP about known difficulties in NF1
    - I am happy to liaise with Educational Psychologists if appropriate
  - Statements are not always necessary
    - Different levels of support – school action, school action plus
    - Different authorities manage things differently, but it can be possible to get sufficient support for children with significant learning difficulties without needing a statement
But we don’t have a psychologist!

• Talking Therapies
  – Children and young people who are low in mood are able to access Child and Adolescent Mental Health Services (CAMHS) in their local areas
  – Useful to frame referrals in terms of what the mental health concern is (depression, anxiety etc)
    • Also, what is the functional impact on school, home, family etc
  – For older children, there are often counsellors available within high schools – can be a very useful (and quick) access to support for young people with less severe problems
  – If children are under the care of tertiary health care they may be able to access psychological care via the hospital
But we don’t have a psychologist!

- Parenting Groups
  - **Should** be available within most localities
    - Sometimes co-ordinated through CAMHS
    - Sometimes via local authorities or Sure Start centres
    - Not always necessary to be referred in (can self refer)
  - Useful for tantrums, feeding problems, non-compliance, low self esteem, anxiety, general behaviour difficulties etc!
  - Group interventions are recommended by NICE (NICE, 2006)
    - First line treatment for ADHD in **all** pre-school children and school age children with mild to moderate difficulties
    - Very strong evidence base in managing “conduct disorder” in children under 12
    - Useful in addition to medication for older children with ADHD
Parenting Groups

- 2 main approaches specifically recommended by NICE
  - Webster-Stratton
  - Triple-P Positive Parenting Programme
- Both based on ideas of Social Learning Theory
  - Children learn in social situations – observation and modelling are key
- Should be 8-12 sessions
- Can do parenting work in a 1:1 setting, but evidence is it is less effective!
- A referral to CAMHS may be useful for more intensive support if problems persist
Parenting Groups

- Need to make sure parenting groups are introduced to parents sensitively
- Not about blame (although it can easily be perceived in this way)
- Being a parent is one of the toughest jobs out there! Even harder in the context of chronic health problems, learning problems and uncertainty of NF1
- Experience of running groups for parents of children with NF1 suggests parents value specific advice relevant for NF1
  - Need to emphasise that strategies are the same regardless of presence of NF1 - we would be recommending the same things
Parenting Pyramid

Webster-Stratton (2006)
When to refer to CAMHS?

- **Risk Assessment**
  - If you are worried about a child or young persons mental state, risk of harm to self or others

- **Therapy**
  - Low mood
  - Anxiety
  - Appearance related concerns
  - Family Therapy
    - Often particularly useful when there are complex issues which are perpetuated by dynamics within a family
  - Parenting work
    - If problems are severe
    - If parents have attended a group, but problems still persist
When to refer to CAMHS?

- ADHD assessment
  - If medication is a consideration this is normally co-ordinated through a local CAMHS psychiatrist
  - In some areas, community paediatricians may diagnose and treat ADHD
  - Can be a useful label in helping schools as it is something they will be familiar with
  - Remember, for pre-school children, first line treatment should be parenting groups
    - A lot of attentional problems resolve once children are in full time education
When to refer to CAMHS?

- ASD (autistic spectrum disorder) assessment
  - Useful to think about what is hoped to be achieved by this
  - If a child already has a statement, what is the added value?
  - Useful for helping parents and children access appropriate support (National Autistic Society, post diagnosis workshops, educational advice etc)
  - ASD assessment should be multi-agency and involve health, education, psychology (educational and/or clinical), speech and language therapy
  - Particularly useful when children have significant problems but not receiving support or very distressed by difficulties
Parental mental health

- Can have a huge impact on both children’s well being and parent’s ability to cope with and manage challenges of parenting
- Can be exacerbated by presence of chronic health condition particularly if there are issues of guilt/responsibility relating to children’s diagnoses
- Adult mental health services often have long waits
- Counselling may be available via GPs or charities
- Always useful to consider – if parents are depressed it may be that other interventions are ineffective until parental depression is addressed
Common Assessment Framework

• Worth thinking about for children with NF1
• Aims to integrate services
  – Get health, education and social care working together
• Can be initiated because of concerns about:
  – Health, development, welfare, behaviour or learning
• Must have informed consent from parents
References


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