Early Interventions in ASD for community paediatricians

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BACCH ASM
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Newcastle

Early Interventions in ASD for community paediatricians:

• Background
  – incl. update on DSM-5 changes
• NICE CG 128 (142) 170; QS 51
• Recognition, diagnostic assessment & devm’t of care plan of needs incl. access to effective interventions for ASD & co-existing conditions
• Transition (to young adulthood)
• Concluding comments

Background:

• Autism/ASD occurs in ~1% children & young people
• Diagnosis less commonly made in girls & individuals with severe Learning Disability
• One of the most imp causes of lifelong disability
• Individual presentations vary as do associated functional impairments
• Core features of autism: Persistent Impairments in
  – Social communication
  – Restricted repetitive patterns of behaviours, interests & activities (incl sensory sensitivities)
  – Occur across ability range; typically present from early childhood
• Co-occurring problems & co-morbidities are common
Early diagnosis is not usual practice

- ASD diagnosis before 3.0 yrs stable in clinic & community ascertained samples***
- Diagnosis not made until approx. 4.0yrs
- Age at ASD diagnosis in UK
  - ASD-UK & Daslne; 2134 c’s
  - Median age of diagnosis 55 months
  - No evidence that age at diagnosis has decreased between 2004 -2014 (Brett et al, 2016)


- New revisions of the classification systems
- Removal of subgroups of ASD because of poor agreement between professionals & often assoc w severity, lang level or intelligence (rather than features of the disorder
- Social interaction and social communication to become one domain
- **ASD must meet criteria A, B, C, & D**
  - Severity specifiers
  - Co-existence w other diagnoses allowed

A. Persistent deficits in social communication & social interaction across contexts, not accted for by dev delays & manifest by all 3 of the following:
  - Deficits in social-emotional reciprocity
  - Deficits in nonverbal communicative behaviours used in Social Interaction
  - Deficits in dev & maintaining relationships
B. Restricted, repetitive patterns of behaviour, interests, or activities as manifested by at least 2 of the following:

- Stereotyped or repetitive speech, motor mim's or use of objects
- Excessive adherence to routines, ritualised patterns of behaviour (V & N/V), or excessive resistance to change
- Highly restricted, fixed interests
- Hyper-or hypo reactivity to sensory input or unusual interest in sensory aspects of environment

ASD must meet criteria A, B, C, & D

C. Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities)

D. Symptoms together limit and impair everyday functioning

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**DSM-5 Severity specifiers**

<table>
<thead>
<tr>
<th>Severity level for ASD</th>
<th>Social communication</th>
<th>Restricted interests &amp; repetitive behaviours</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level 3: requiring very substantial support</td>
<td>Severe impairment; v little initiation &amp; min response to soc overtures from others</td>
<td>RRBs markedly interfer functioning f all spheres. Mixed distress; v diff to redirect</td>
</tr>
<tr>
<td>Level 2: substantial support</td>
<td>Impairment apparent even with support</td>
<td>RRBs obvious to casual observer. Distress &amp; frustration apparent if interrupted</td>
</tr>
<tr>
<td>Level 1: requiring support</td>
<td>Noticeable impairment</td>
<td>RRBs cause interference in one or more contexts; resists attempts to interrupt/redirect</td>
</tr>
</tbody>
</table>
DSM5 Specifiers
- With or without accompanying intellectual impairment
- With or without accompanying language impairment
- Associated with known medical or genetic condition or environmental factor
- Additional neurodevelopmental, mental or behavioural conditions

NICE 128 GDG decisions
- Use ICD10 and DSM IV but have regard to the future changes in ICD11 and DSM 5
- Use the term autism as an ‘umbrella term for autism/Asperger’s syndrome/ASD/ASC/PDDs etc
- Conceptualise diagnostic assessment as a process that is more than ‘attaching a label’ but considers differential diagnosis, co-existing conditions, and construct a profile of the CYPs strengths/skills and needs/impairments
  - so that a plan of needs, taking into account family & educational context, can be developed.

NICE CGs: 128; [142]; 170 & QS 51: KEY THEMES
- Autism strategy group
- Multi agency training about autism and the impact of autism
- Autism Team
- A quality integrated assessment for diagnosis and care plan including needs based interventions
- Key worker approach
- Personalised care/Involvement of individual and family
- Support and information for individual and family
- Co-existing conditions/ co-morbidities
- Behaviours that challenge NG 11 & QS 101 (2015)
- Transition NG 43 (Feb 2016) QS Dec 2016
The Autism Team (which may be virtual)

Has the skills and competencies (or access to the skills and competences through a regional team) to:

- carry out an autism diagnostic assessment including in those with special circumstances such as severe visual and hearing impairments, motor disorders including cerebral palsy, severe intellectual disability, complex language disorders or complex mental health disorders and looked-after children and young people
- communicate with children, young people and adults with suspected or known autism, and with their parents and carers, and sensitively share the diagnosis with them

The Autism Team

Should provide (or organise) the interventions and care

- specialist care and interventions for children and young people with autism, incl. living in specialist residential accommodation
- advice, training and support for other health and social care professionals and staff
- advice and interventions to promote functional adaptive skills including communication and daily living skills
- assessment and management of behaviour that challenges & coexisting conditions
- Reassessment of needs throughout c’hood & adolescence & transition to adult services

The local Autism team has a key role in the delivery and coordination of

- Supporting access to leisure and enjoyable activities
- Supporting access to and maintaining contact with educational, housing and employment services
- Providing support for families (including siblings) and carers, including offering short breaks and other respite care
- Producing local protocols for:
  information sharing, communication and collaborative working among healthcare, education and social care services, including arrangements for transition to adult services
  shared care arrangements with primary care providers and ensuring that clear lines of communication between primary and secondary care are maintained
  a single point of referral to the team & the autism diagnostic assessment should be started within 3 months of the referral to the autism team
Core team members

Core team members for Children and Young People are:
• paediatrician and/or child and adolescent psychiatrist
• speech and language therapist
• clinical and/or educational psychologist.
• and regular access to an occupational therapist

For adults core team members are:
• clinical psychologists
• nurses
• occupational therapists
• psychiatrists
• social workers
• speech and language therapists
• support staff (for example, supporting access to employment, further education, residential services, financial advice, and personal and community safety skills)

NICE CG128: multidisciplinary autism diagnostic assessment
• detailed questions about parent’s or carer’s concerns and, if appropriate, the child’s or young person’s or adult’s concerns
• details of the person’s experiences of home life, education and social care
• a developmental history (where possible if an adult), focusing on developmental and behaviourial features in different contexts consistent with ICD-10 or DSM-IV criteria (consider using an autism-specific tool to gather this information e.g. ADI-R, DISCO, 3Di although evidence does not indicate any specific tool)
• assessment (through interaction with and observation of the person) of social and communication skills and behaviours, focusing on features consistent with ICD-10 or DSM-IV/DSM-5 criteria (consider using an autism-specific tool such as the ADOS to gather this information)

The multidisciplinary autism diagnostic assessment:
• a medical history, including prenatal, perinatal and family history (where possible), and past and current health conditions
• a physical examination including hearing and vision tests (if not done)
• consideration of the differential diagnosis
• systematic assessment for conditions that may coexist with autism including mental and behaviour problems, medical and functional conditions
• functioning at home, in education or in employment
• assessment of risk including self-harm, harm to others, harm from others including exploitation; rapid escalation of problems, self-neglect, breakdown of family or residential support
• communication of assessment findings to the parent or carer and, if appropriate, the individual/ a written report
• Follow up appointment at 6 weeks post assessment
Diagnostic assessment: 'what not to do'

- Diagnosis should not be based on one tool alone. History and observation are necessary and diagnosis remains a clinical judgment after synthesising all sources of information. If there is discrepant information, further assessment including other contexts (and other opinions) may be necessary.

- Biological tests, genetic tests or neuroimaging should not be used routinely for diagnostic purposes but genetic tests, as recommended by the regional genetics centre, should be considered in individual circumstances based on clinical judgment and physical examination e.g. if there are specific dysmorphic features, congenital anomalies and/or evidence of intellectual disability and electroencephalography considered if there is suspicion of epilepsy.

NICE 170 Management, intervention and care

A care PLAN (including risk management plan):
Strengths, skills, impairments and needs

Key Principles:
- Improve the knowledge and competence of all who are involved in the care of those with autism
- Make adjustments to the physical (sensory) and social environment
- Provision of specific Interventions for autism and co-existing conditions
- Enable full access to all health and social care including mental health with adjustments as needed to the processes of care eg timing of appointments, anticipating problems with hospital admission, having a health passport

ASD: Social communication intervention

- Joint attention, engagement, & reciprocal communication.
- For preschool children: parent, carer, or teacher mediation
- School aged children: peer mediation
- Strategies:
  - Individual’s developmental level
  - Increase the parents’, carers’, teachers’, or peers’ understanding of and sensitivity and responsiveness to the individual’s patterns of communication and interaction
  - Techniques of therapist modelling and video interaction feedback
  - Techniques to expand the individual’s communication, interactive play, and social routines

Evidence from meta-analyses with blinded outcome assessment for small to moderate effects

- No specific recommendations for management of RRBs
Evidence base for interventions for ASD

- Most studies compare intervention w TAU
- Report a positive outcome particularly with JA, communication; social imitation; & ASD symptoms
- Parents (Oono et al 2013), therapists, teachers & peers
- Interventions include: Early State Denver Model (ESDM)(Dawson et al 2010; Waddington et al 2016); Learning Experiences & alternative programme (LEAP)(Strain & Bovery 2011); Preschool Autism Communication Trial (PACT)(Green et al 2010); Treatment & Education for Autistic & Related Communication Handicapped Children (TEACCH)(Virues-Ortega et al 2013)……

Developmentally targeted interventions- some early work on associated mediation eg PACT trial (Pickles et al 2015) & vulnerable gps (Kasari et al 2014)
- Longer term impact (Anderson et al 2013; Estes et al 2015; Pickles et al. in press (PACT 7-11))

Design
- First large RCT of an early psychosocial treatment 3 site 2 arm, N=152
  2-4,11 yrs; core autistic disorder (ADOS-G/ADI-R)
  Testing a model deliverable in the NHS
  Cost effectiveness analysis
- Pre-specified primary outcome and analysis plan
- Blinded rating of outcomes
- Testing mediating mechanisms
  Use of RCT design to test basic science hypotheses
How effective is early intervention?

**We know:**
- Efficacy of some elements and types of early intervention:
  - Structured teaching
  - Value of specific training—Joint attention, play skills
  - Use of specific strategies such as Visual cues
  - Build social—communication skills
  - Role of parent training & educational staff
  - Peer support….

**We know less:**
- Long term impact? 3RCTs including PACT follow up (Pickles et al, in press)
- How to generalise the impact for ASD PACT-G new study recruiting from Jan 2017 (3 sites; ASD aged 2-11 yrs)
- Which approaches for which parents & children—indiv variability within and between individuals
- How to combine communication intervention and management of difficult behaviours
ASD: What not to do:

- Secretin, chelation, or hyperbaric oxygen therapy should never be used to manage autism in any context because there is no clear evidence that these are effective and because there is harm associated with their use

- [based on moderate to very low quality randomised controlled trials (RCT) for secretin, low to very low quality RCT for chelation and hyperbaric oxygen therapy, & the experience & expert opinion of the GDG]

ASD: What not to do:

- Antipsychotics, antidepressants, anticonvulsants, and exclusion diets (such as gluten-free or casein-free diets) should not be used to manage the core features of autism because the balance of risks (especially with anticonvulsants and exclusion diets) and benefits did not favour their use

- [based on moderate to very low quality RCT for antipsychotics, antidepressants & anticonvulsants; low to very low quality RCTs for exclusion diets; & the experience & expert opinion of the GDG]

ASD: What not to do:

- Neither neurofeedback or auditory integration training should be used to manage speech and language problems in children and young people with autism

- Emerging data (not sufficient for endorsement) yoga, acupuncture & horseback riding (Koenig et al 2012; Lee et al 2012; Ward et al 2013)
Co-existing problems/conditions

Mental and Behavioural disorders.
- ~70% of individuals with autism also meet diagnostic criteria for at least one other (often unrecognised) mental and behavioural disorder
- 40 % meet diagnostic criteria for at least two disorders, mainly anxiety, ADHD and ODD
- these coexisting mental and behavioural conditions further impair psychosocial functioning

Behaviours that challenge (NG 11 QS101)
- aggression (to objects or people)
- destructiveness and self injury (e.g. head-banging, hand or wrist biting, or skin picking)
- more common in autism than in other conditions with similar levels of intellectual impairment

Co-existing conditions

Intellectual disability (IQ<70)
- ~ 50% of young people with autism.
- Delays in Adaptive functioning (communication, socialisation and daily living/self-care skills )

Neurodevelopmental disorders
- Language disorders and specific learning difficulties (literacy, numeracy and other academic skills) 10% of people with autism fail to develop speech.
- Developmental Coordination Disorder (DCD) ~ 50-73% of children with autism have significant motor delays Handwriting is a particular frustration for many

Functional problems.
- 40%-86 % sleep problems affecting sleep onset, frequent waking for longer periods and reduced sleep duration.
- Eating difficulties - restricted and rigid food choices
- Gastrointestinal problems- diarrhoea, abdominal pain and constipation

Co-existing conditions

- Psychosocial and pharmacological interventions for the management of coexisting mental health or medical problems in people with autism informed by existing NICE guidance for the specific disorder
  - CBT (adapted) for verbally and cognitively able individuals
  - Psycho social interventions based on behavioural principles for all young people and adults who need help with daily living and participation in leisure activities
  - stepped approach for sleep problem
Behaviour that Challenges (NG 11 QS101)

• Factors that may increase risk
• Possible triggers or maintaining factors:
  – Impairments in communication that may result in difficulty understanding situations or expressing needs and wishes
  – Coexisting physical disorders (such as pain or gastrointestinal disorders), mental health problems (such as anxiety or depression), and other neurodevelopmental conditions (such as ADHD)
  – Physical/sensory environment, such as lighting and noise levels
  – Social environment, including home, school, employment and leisure activities
  – Changes to routines or personal circumstances
  – Developmental change, including puberty
  – Exploitation or abuse by others
  – Absence of predictability and structure

Mental health interventions & management in ASD:

● Co-morbidities/Co-occurring conditions
  ● Epilepsy & other medical conditions
  ● ADHD** (Miodovnik et al 2015)
  ● Anxiety
  ● Mood disturbance/Depression/emotional well being

● Maladaptive behavioural disturbance
  ● ODD & CD
  ● Behaviours that challenge
  ● Sleeping, eating, toileting problems
(Simonoff et al 2008; 2013; Van Steensel et al., 2011; Salazar et al., 2015; Maskey et al 2013)
ASD and Anxiety

- Many children, YP and adults with ASD experience anxiety ****
- Various types of anxiety: generalised, social, specific phobia, separation, OCD…
- Interventions:
  - Psychoeducation (ASD, anxiety, ADHD)
  - Psychosocial interventions for child/YP +/- family- modified for ASD
  - Virtual reality (Maskey et al 2014)
  - medication

Growing evidence base for CBT with ASD

- Case studies (Ozsivadjian and Knott, 2011)
- Group studies (Chalfant et al, 2007; Reaven et al, 2012)
- RCT’s (Sofronoff et al., 2005; Chalfant et al., 2007; Reaven et al., 2012; Storch et al., 2013; McConachie et al., 2014)
- Meta-analysis (Sukhodolsky et al., 2013)**

Encouraging evidence that adapted CBT is effective for children with ASDs and anxiety disorder
ASD & Anxiety: medication

- Medication should be managed by child or adolescent psychiatrist
- Selective Serotonin Reuptake Inhibitor (SSRI) medications
- No RCTs in CYPs & 1 small study in adults w ASD
- Follow NICE CG recommendations but aware of modifications for children & YP with ASD
- Consideration of the potentially differing causes & mechanisms

ADHD

- Common co-occurring condition
- Multiagency working: child health & mental health
- NICE CG recommendations
  - Psycho-educational interventions
  - Psychosocial interventions
  - Medication
- Likely to require modifications for ASD

ADHD: medication

- Methylphenidate- across all studies ES 0.2- 0.7
- Significant effect but lower than for TD
- Recent study of atomoxetine ES 1.0
- BUT ATX may show less clinical impact (CGI-I)
- MPH and ATX signif better than placebo
- BUT increased risk of side effects
Treatment of ADHD: Reported adverse effects

MPH: 10-15% withdrawal due to AEs
- Irritability
- Lethargy
- Sadness
- Dullness
- Social withdrawal
- Stereotyped behaviour
- Upset stomach
- Sleep problems
- Emotional lability

ATM
- Weight loss
- Fatigue
- Tachycardia

General principles: Identifying targets for intervention

- Identify the most problematic behaviours
- Are these realistic to treat?
- Elicit antecedents and consequences (A,B,C)
- Link behaviours to relevant psychiatric symptoms/disorders
- Draw on available evidence base to initiate treatment

Monitoring outcomes

- Systematic
- Obtain baseline
- Cross-situation and different informants
- Goal-oriented
- Strategy for identifying adverse effects
- Consider poor communication of CYPs with ASD
- Consider the possible communicative intent
- Consider functional goals and outcomes
In summary- current clinical trends for use of medication in CYP with ASD for CAMH/CYPS teams

- Choose target behaviour(s) and outcome measure
- Initiate medication at a low dose
- Increase dose slowly
- Monitor more frequently for side effects
- Review effectiveness
- Stop medication if no response
- Be prepared to revisit formulation and hypotheses

Increasing awareness of transition

- Some examples of promising interventions in health services e.g. Transition co-ordinators, joint clinics, young adult clinics (Crowley et al., 2011)
- Scoping Review (Watson et al. 2012): limited literature evaluating health services for young people with diabetes or cerebral palsy
  - No models found for autism
- Urgent need for more research and evaluation, particularly focussing on the experiences of people with ASD
- NG 43 : TRANSITION Feb 2016 (QS Dec 2016)

Does s/he attend appointments with GP or practice nurse on own?
UK Transition research

  - Transition from CAMHS to Adult Mental Health Services
- SPRU
  - Sloper et al., 2011: Transition to adult services for disabled young people and those with complex health needs
  - Beresford et al, 2013: Transition to Adult services and adulthood for young people with autistic spectrum conditions
- TRANSITION Research Programme (NIHR) (2017)

NG43 Implementation: 4 Challenges for commissioners, managers & practitioners

- adults’ services take joint/equal responsibility w c’s services
- joint planning, dev’nt & commissioning of services involved in transition across c’s & adults’ health and social care
- improving front line practice w. YP thro’ training in Developmentally Appropriate (DAH) services and person-centred practice
- maximising opportunities for YP who have become disengaged or who are not eligible for adults’ services to access care & support

Early Interventions in ASD for community paediatricians

- Our roles in early identification & diagnosis – likely to change over time especially as we gain further understanding about ASD & co-occurring conditions alongside evidence for interventions
- Effective treatments, opportunities & interventions
  - Build on skills, strengths & interests
  - Meet current and anticipate lifetime social, emotional, health & mental health needs
  - With finite resources how do we increase opportunities for social inclusion/ ‘ASC’ friendly environments
  - Education, employment, accommodation & leisure opportunities
Thank you
Questions?
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Dr Sarah Mills
ST8 Paediatrics

Though not part of the core symptoms of ASD, children often have sensory, eating, sleep or behaviour difficulties when presenting to the assessment service for ASD

“Secondary Behavioural Difficulties”

- Prof Amanda Richdale, Dept Psychology and Intellectual Disability studies, Victoria, Australia

The level of functional impairment and the presence of maladaptive behaviours appear to contribute specifically to parental stress.

Tobing and Glenwick, 2002

have a significant impact on behaviour management, learning acquisition and the development of social relationships.

Pearson et al. 2006

Definitions and parental reporting may vary but this data demonstrates the difficulties families perceive at ASD diagnosis.
The Service

Demographic details of Newcastle

Population 0-4 year olds:
Office for National Statistics 17,400
GP Registered 16,404 (2014)
Stable population

Population based ASD assessment service
Preschool Age

Defined population
• During diagnostic interview secondary behavioural difficulties are sought through specific questioning

• Screening for comorbidities

• Enabled data collection for project

• Assessed 84 children in 2015

• 64 diagnosed at initial assessment
Prevalence of Secondary behavioural difficulties:
- Sensory difficulties
- Restricted eating
- Poor sleep
- Aggressive behaviour

Aims…

Methods…
- Retrospective case notes analysis of 64 pre-school children
- Diagnosed with ASD between 1st January and 31st December 2015
- Aged: 18 months - 4 ½ Years (Median age: 2 years 11 months)

Data gathered…
Sensory sensitivities

- Not a full sensory profile
  - e.g.:
    - Tactile or auditory aversion
      - Food/ messy play/ clothing/ labels
      - Household items: hoover
      - Hand dryers

Restricted eating

‘Do they eat the same as the rest of the family?’

If not:
- Record specific list of what they do eat, usually very limited

Poor sleep

‘Do they have any problems with sleep?’

- e.g.:
  - Difficulty settling
  - Night waking
Aggressive behaviour

‘Do they have any aggressive or challenging behaviour?’

e.g:
• Kick/bite/punch others
• Self injurious

Methods...

At Diagnostic Interview, Caregiver’s specifically asked about Secondary Behavioural Difficulties

If:
• Affected daily functioning
• Required professional intervention
• Viewed as problematic by the parents

Data gathered for this study

The Results
Results...

- 55 (85%) Children had at least one difficult secondary behavior at diagnosis
- 18 (30%) children presented with difficulties in all four areas

Sensory Difficulties

33% Sensory difficulties

Reported prevalence

Typically developing children

Reported prevalence ASD children

Sensory difficulties

33% Up to 94%

Significantly more and concurrent

Now a specific diagnostic criteria: DSM-5

ASD children

Sensory difficulties

33% Up to 94%

73% (47)

Restricted eating
Reported prevalence for Typically Developing children:

Sensory difficulties: 33%

Restricted eating: 18.9%

Reported prevalence for Autism Spectrum Disorder (ASD) children:

Sensory difficulties: 33%

Restricted eating: 18.9% - up to 94%

Significant impacts:
- Limited diet ~ 5 foods
- Food texture affects choice in 70% ASD children

Citations:
### Poor Sleep

<table>
<thead>
<tr>
<th>Difficulty</th>
<th>ASD Prevalence</th>
<th>Typically Developing Prevalence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensory difficulties</td>
<td>33%</td>
<td>Up to 94%</td>
</tr>
<tr>
<td>Restricted eating</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor Sleep</td>
<td>30%</td>
<td>44-83%</td>
</tr>
</tbody>
</table>


### Sensory difficulties

<table>
<thead>
<tr>
<th>Reported prevalence in Typically Developing children</th>
<th>Reported prevalence in ASD children</th>
<th>Prevalence in Our ASD population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensory difficulties</td>
<td>33%</td>
<td>75%</td>
</tr>
<tr>
<td>Restricting eating</td>
<td>14.6%</td>
<td>67.7%</td>
</tr>
<tr>
<td>Poor Sleep</td>
<td>30%</td>
<td>44-83%</td>
</tr>
</tbody>
</table>

\[36\]

### Aggressive behaviour

Reported prevalence for Typically Developing children

<table>
<thead>
<tr>
<th>Condition</th>
<th>Typically Developing</th>
<th>ASD Children</th>
<th>Known associations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensory difficulties</td>
<td>33%</td>
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<td>Restricted eating</td>
<td>18.9%</td>
<td>41.7%</td>
<td></td>
</tr>
<tr>
<td>Poor Sleep</td>
<td>30%</td>
<td>66-83%</td>
<td></td>
</tr>
<tr>
<td>Aggressive behaviour</td>
<td>16.6%</td>
<td>30%</td>
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- Aggression and self-injury begin after the second or third birthday
- Aggressive behaviour is linked to low IQ and poor language ability

Sensory Sensitivities and Aggressive behaviour

- The distress caused by particular sensory inputs can cause severely disturbed and aggressive behaviour in those with ASD who cannot explain their distress.


Sensory Sensitivities and Aggressive behaviour in Our Population

- Yes 33 (70%)
- No 14

Prevalence of aggression and sleep difficulties

- In children with developmental delay, sleep problems are more common in younger children and are often associated with self injury, aggression and other behavioural problems.

Those with Aggressive behaviour who have Sleep difficulties in Our Population

Yes 24 (63%)
No 14

Associations...

- Crucially sleep abnormalities in ASD children increase the lifetime risk for major depression

Discussion...
What makes this data relevant?

• Population based, not self selecting
• The way the question is asked…

Why high prevalence…

• Youngest
• Often more severely affected
• Undiagnosed language and IQ deficits

Limitations

• Point Prevalence: Some difficulties may be fleeting, follow up data shows some haven’t developed yet
• Haven’t looked at IQ or level of language
• Not a full assessment of difficulties e.g. sensory profile, useful yield but could even under estimate problem
• We didn’t look at anxiety found by Davis 2010 to be very prevalent in ASD pre-schoolers.
What this means for service planning...

Pre-school, Population based services

- Demonstrate need
- Compete for limited resources

- Services need adequate input from allied health professionals: psychology, OT

- Families need access to support post diagnosis

- Wider Service Evaluation project incorporated Parent Feedback
The future…

- Service Evaluation Project
- Improving post diagnostic support
- Expanding the service

The early onset, severity, persistent course and frequent occurrence of atypical behaviours brings into clearer focus what a difficult and stressful period very early childhood is for children with ASD and their parents.

Dominick et al. 2007

The case for providing tailored support and early intervention for these difficult behaviours is strengthened in a bid to help families cope with their future.
Questions…

With Thanks…
To my Supervising Consultant
Dr Helen Leonard
To the Families for sharing their experiences
Clinicians’ knowledge of our Trust’s safeguarding proformas and body maps – but do we know where to find them?

Dr Jennifer Ho
ST1 Paediatric Trainee at North Middlesex Hospital
Dr Susie Gabbie
Paediatric Consultant at The Royal Free Hospital

Problem

- Incomplete documentation in safeguarding cases
- Incomplete knowledge of the accessibility of the safeguarding proformas and body maps
- Frequently rotating junior doctors

Unsafe management of children with safeguarding concerns

Recommendation – The RCPCH Child Protection Companion 2013
The documentation of a clinician’s findings should be clearly and contemporaneously documented on a proforma

Aim:

- To increase paediatric clinicians’ knowledge of the accessibility of the safeguarding proformas and body maps on the hospital’s intranet
Method

- 4 question audit proforma
- Data
  - Paediatric clinicians
- Time period
  - November 2015 - March 2016
  - 1st cycle [pre-interventions] - 23 cases
  - 2nd cycle [post-interventions] - 16 cases

Results - Demographics

1. What level of doctor are you?
Results

2. Do you know how to access the safeguarding proforma on the Royal Free’s Freenet?

- Yes: 48% (11)
- No: 52% (12)

Consultant: 1
Paediatric trainee: 5
GP trainee: 9
FY doctor: 4
Results

3. Do you know how to access the MASH forms?

- Yes (13)
- No (8)

87% (26)

4. Have you ever/in the last three years made a referral to social care either using CAF or MASH forms?

- Yes (35)
- No (65)

Interventions

- ‘How to’ quick guidesheet
  - Email
  - Person
  - Induction pack
  - Doctors office
- Consultants’ meeting
- Departmental induction for junior doctors
- Pop up workshop
Re-audit results - Demographics

What level of doctor are you?

Consultant  Paediatric trainee  GP trainee  FY doctor  Physician assistants

0 1 2 3 4 5 6

Re-audit results - Do you know how to access the safeguarding proforma?

BEFORE INTERVENTION

AFTER INTERVENTION

100%

Re-audit results

Graph showing the increase in clinician's knowledge of where to access the safeguarding proformas

% of clinicians who know how to access the safeguarding proformas

Before  After  Before  After  Before  After  Before  After  Before  After

Before  After

Level of clinician
Re-audit results

3. Do you know how to access the MASH forms?
- Yes: 19% (3)
- No: 81% (20)

3. Do you know how to access the MASH forms?
- Yes: 23% (3)
- No: 77% (20)

Re-audit results

4. Have you ever/in the last three years made a referral to social care either using CAF or MASH form?
- Yes: 81% (13)
- No: 19% (3)

4. Have you ever/in the last three years made a referral to social care either using CAF or MASH form?
- Yes: 65% (15)
- No: 35% (8)

Recommendations
1. The absolute importance of completing the mandatory safeguarding paperwork
2. The need for regular updates especially with a high turnover of clinicians
3. Quick guides are an effective method of disseminating knowledge
4. Face-to-face workshops consolidate knowledge
Thank you!

- Any questions?
Health needs of unaccompanied asylum seeking CHILDREN: A descriptive analysis

Dr. Georgie Siggers, Designated Dr LAC Kent
Dr. Rachel Coyle, Specialist Registrar in Public Health
Nancy Sayer, Designated Nurse for LAC, Kent & Medway
Dr. Ana Draper, CAMHS

The Kent experience

• May-Oct 2016, large surge in numbers; 213 children in May 15, 1000 by Oct 16
• End of Dec 2015, 600 who had not received IHA
• Historic arrangement with GP practice for 4 per week
• Range of health and safeguarding concerns

National transfer

• Effective from 1st July
• Voluntary system at present
• YP arriving in Kent – request new region
• Aim to move them in 5 days
• Fitness to travel screening to deal with immediate health issues
Where do they go?
- Foster care
  - in and out of county
- Reception centres
- Independent living

Health
- Massive vulnerabilities and risks
- Experiences in country of origin
- Traumatic journeys
- Exposure to diseases not common in UK
- Effect of malnutrition
- Unmet screening and immunisation needs

The study
- 154 IHAs analysed
- Completed by GPwSI & Comm Paeds
- Dr. Rachel Coyle, Specialist Registrar in Public Health
- Need for TB screening, prevalence of Hep B & parasitic infection modelled
Health Needs

- Psychological signs/symptoms (41%)
- Physical complaints common
- Dental (43%)
- Vision (35%)
- High risks for TB & Hep B

The Detail

- Range of chronic health conditions – asthma, diabetes, epilepsy
- Acute Hep B, TB
- Burns, fractures, infected wounds

Gastro-intestinal Issues

- Almost universal complaint
- Pain, bloating, reflux
- Refeeding?
- Nutrition training & advice
Mental health issues

- 16% PTSD
- Acute distress, aggression
- Self harm
- Action research project
- Hope work

Sleep

- Body clock reversal
- Sleep training – staff & YP
- Sleep packs
- Sleep prescription

www.uaschealth.org
Thank you for listening

UASCs are children first, asylum seekers second
Early Interventions in ASD for community paediatricians

Ann Le Couteur
BACCH ASM
15th September 2016
Newcastle

Early Interventions in ASD for community paediatricians:

• Background
  – incl. update on DSM-5 changes
• NICE CG 128 (142) 170; QS 51
• Recognition, diagnostic assessment & devm’t of care plan of needs incl. access to effective interventions for ASD & co-existing conditions
• Transition (to young adulthood)
• Concluding comments

Background:

• Autism/ASD occurs in ~1% children & young people
• Diagnosis less commonly made in girls & individuals with severe Learning Disability
• One of the most imp causes of lifelong disability
• Individual presentations vary as do associated functional impairments
• Core features of autism: Persistent Impairments in
  – Social communication
  – Restricted repetitive patterns of behaviours, interests & activities (incl sensory sensitivities)
  – Occur across ability range; typically present from early childhood
• Co-occurring problems & co-morbities are common
Early diagnosis is not usual practice

- ASD diagnosis before 3.0 yrs stable in clinic & community ascertained samples***
- Diagnosis not made until approx. 4.0yrs
- Age at ASD diagnosis in UK
  - ASD-UK & Daslne ; 2134 c’s
  - Median age of diagnosis 55 months
  - No evidence that age at diagnosis has decreased between 2004 -2014 (Brett et al, 2016)


- New revisions of the classification systems
- Removal of subgroups of ASD because of poor agreement between professionals & often associated with severity, lang level or intelligence (rather than features of the disorder)
- Social interaction and social communication to become one domain
- ASD must meet criteria A, B, C, & D
- Severity specifiers
- Co-existence w other diagnoses allowed

A. Persistent deficits in social communication & social interaction across contexts, not accted for by dev delays & manifest by all 3 of the following:
  - Deficits in social-emotional reciprocity
  - Deficits in nonverbal communicative behaviours used in Social Interaction
  - Deficits in dev & maintaining relationships
B. Restricted, repetitive patterns of behaviour, interests, or activities as manifested by at least 2 of the following:

- **Stereotyped or repetitive speech**, motor mmt's or use of objects
- Excessive adherence to routines, ritualised patterns of behaviour (V & N/V), or excessive resistance to change
- Highly restricted, fixed interests
- Hyper-or hypo reactivity to sensory input or unusual interest in sensory aspects of environment

ASD must meet criteria A, B, C, & D

C. Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities)

D. Symptoms together limit and impair everyday functioning

**DSM-5 Severity specifiers**

<table>
<thead>
<tr>
<th>Severity level for ASD</th>
<th>Social communication</th>
<th>Restricted interests &amp; repetitive behaviours</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level 3: requiring very substantial support</td>
<td>Severe impairment; v little initiation &amp; min response to soc overtures from others</td>
<td>RRBs markedly interfer w functioning i all spheres. Mixed distress; v diff to redirect</td>
</tr>
<tr>
<td>Level 2: substantial support</td>
<td>Impairment apparent even with support</td>
<td>RRBs obvious to casual observer. Distress &amp; frustration apparent if interrupted</td>
</tr>
<tr>
<td>Level 1: requiring support</td>
<td>Noticeable impairment</td>
<td>RRBs cause interference in one or more contexts; resists attempts to interrupt/ redirect</td>
</tr>
</tbody>
</table>
DSM5 Specifiers

- With or without accompanying intellectual impairment
- With or without accompanying language impairment
- Associated with known medical or genetic condition or environmental factor
- Additional neurodevelopmental, mental or behavioural conditions

NICE 128 GDG decisions

- Use ICD10 and DSM IV but have regard to the future changes in ICD11 and DSM 5
- Use the term autism as an “umbrella term for autism/Asperger’s syndrome/ASD/ASC/PDDs etc
- Conceptualise diagnostic assessment as a process that is more than ‘attaching a label’ but considers differential diagnosis, co-existing conditions, and construct a profile of the CYPs strengths/skills and needs/impairments
- so that a plan of needs, taking into account family & educational context, can be developed.

NICE CGs: 128; [142]; 170 & QS 51: KEY THEMES

- Autism strategy group
- Multi agency training about autism and the impact of autism
- Autism Team
- A quality integrated assessment for diagnosis and care plan including needs based interventions
- Key worker approach
- Personalised care/Involvement of individual and family
- Support and information for individual and family
- Co-existing conditions/ co-morbidities
- Behaviours that challenge NG 11 & QS 101 (2015)
- Transition NG 43 (Feb 2016) QS Dec 2016
The Autism Team (which may be virtual)

Has the skills and competencies (or access to the skills and competencies through a regional team) to:
• carry out an autism diagnostic assessment including in those with special circumstances such as severe visual and hearing impairments, motor disorders including cerebral palsy, severe intellectual disability, complex language disorders or complex mental health disorders and looked-after children and young people
• communicate with children, young people and adults with suspected or known autism, and with their parents and carers, and sensitively share the diagnosis with them

The Autism Team

Should provide (or organise) the interventions and care
• specialist care and interventions for children and young people with autism, incl. living in specialist residential accommodation
• advice, training and support for other health and social care professionals and staff
• advice and interventions to promote functional adaptive skills including communication and daily living skills
• assessment and management of behaviour that challenges & coexisting conditions
• Reassessment of needs throughout c’hood & adolescence & transition to adult services

The local Autism team has a key role in the delivery and coordination of
• Supporting access to leisure and enjoyable activities
• Supporting access to and maintaining contact with educational, housing and employment services
• Providing support for families (including siblings) and carers, including offering short breaks and other respite care
• Producing local protocols for:
  information sharing, communication and collaborative working among healthcare, education and social care services,
  including arrangements for transition to adult services
  shared care arrangements with primary care providers and ensuring that clear lines of communication between primary and secondary care are maintained
  a single point of referral to the team & the autism diagnostic assessment should be started within 3 months of the referral to the autism team
Core team members

Core team members for Children and Young People are:
• a paediatrician and/or child and adolescent psychiatrist
• speech and language therapist
• clinical and/or educational psychologist.
• and regular access to an occupational therapist

For adults core team members are:
• clinical psychologists
• nurses
• occupational therapists
• psychiatrists
• social workers
• speech and language therapists
• support staff (for example, supporting access to employment, further education, residential services, financial advice, and personal and community safety skills)

NICE CG128: multidisciplinary autism diagnostic assessment

• detailed questions about parent’s or carer’s concerns and, if appropriate, the child’s or young person’s or adult’s concerns
• details of the person’s experiences of home life, education and social care
• a developmental history (where possible if an adult), focusing on developmental and behavioural features in different contexts consistent with ICD-10 or DSM-IV criteria (consider using an autism-specific tool to gather this information eg ADI-R, DISCO, 3DI although evidence does not indicate any specific tool)
• assessment (through interaction with and observation of the person) of social and communication skills and behaviours, focusing on features consistent with ICD-10 or DSM-IV/DSM-5 criteria (consider using an autism-specific tool such as the ADOS to gather this information)

The multidisciplinary autism diagnostic assessment:

• a medical history, including prenatal, perinatal and family history (where possible), and past and current health conditions
• a physical examination including hearing and vision tests (if not done)
• consideration of the differential diagnosis
• systematic assessment for conditions that may coexist with autism including mental and behaviour problems, medical and functional conditions
• functioning at home, in education or in employment
• assessment of risk including self-harm, harm to others, harm from others including exploitation, rapid escalation of problems, self-neglect, breakdown of family or residential support
• communication of assessment findings to the parent or carer and, if appropriate, the individual/ a written report
• Follow up appointment at 6 weeks post assessment
Diagnostic assessment: ‘what not to do’

• Diagnosis should not be based on one tool alone. History and observation are necessary and diagnosis remains a clinical judgment after synthesising all sources of information. If there is discrepant information, further assessment including other contexts (and other opinions) may be necessary.

• Biological tests, genetic tests or neuroimaging should not be used routinely for diagnostic purposes but genetic tests, as recommended by the regional genetics centre, should be considered in individual circumstances based on clinical judgment and physical examination e.g. if there are specific dysmorphic features, congenital anomalies and/or evidence of intellectual disability and electroencephalography considered if there is suspicion of epilepsy.

NICE 170 Management, intervention and care

A care PLAN (including risk management plan):
Strengths, skills, impairments and needs

Key Principles:
• Improve the knowledge and competence of all who are involved in the care of those with autism
• Make adjustments to the physical (sensory) and social environment
• Provision of specific Interventions for autism and co-existing conditions
• Enable full access to all health and social care including mental health with adjustments as needed to the processes of care eg timing of appointments, anticipating problems with hospital admission, having a health passport

ASD: Social communication intervention

• Joint attention, engagement, & reciprocal communication.
• For preschool children: parent, carer, or teacher mediation
• For school aged children: peer mediation
• Strategies
  – individual’s developmental level
  – increase the parents’, carers’, teachers’, or peers’ understanding of and sensitivity and responsiveness to the individual’s patterns of communication and interaction
  – techniques of therapist modelling and video interaction feedback
  – techniques to expand the individual’s communication, interactive play, and social routines

[Evidence from meta-analyses with blinded outcome assessment for small to moderate effects]

• No specific recommendations for management of RRBs
Evidence base for interventions for ASD

- Most studies compare intervention w TAU
- Report a positive outcome particularly with JA, communication; social imitation; & ASD symptoms
- Parents (Oono et al 2013), therapists, teachers & peers
- Interventions include: Early State Denver Model (ESDM) (Dawson et al 2010; Waddington et al 2016); Learning Experiences & alternative programme (LEAP) (Strain & Bovery 2011); Preschool Autism Communication Trial (PACT) (Green et al 2010); Treatment & Education for Autistic & Related Communication Handicapped Children (TEACCH) (Virues-Ortega et al 2013) ……
- Developmentally targeted interventions - some early work on associated mediation eg PACT trial (Pickles et al 2015) & vulnerable gps (Kasari et al 2014)
- Longer term impact (Anderson et al 2013; Estes et al 2015; Pickles et al. in press (PACT 7-11))

Clinician referral
Full baseline assessment
Diagnostic, cognitive, interaction
Randomisation
PACT + TAU
Fortnightly SALT sessions
TAU Community services
7m: Brief midpoint assessment
PACT + TAU
Monthly boosters
TAU Community services
13m: Full endpoint assessment

Design
- First large RCT of an early psychosocial treatment
  3 site 2 arm, N=152
  2-4,11 yrs; core autistic disorder (ADOS-ADOS-R)
  Testing a model deliverable in the NHS
  Cost effectiveness analysis
- Pre-specified primary outcome and analysis plan
- Blinded rating of outcomes
- Testing mediating mechanisms
  Use of RCT design to test basic science hypotheses
Attenuation of treatment effect on generalisation across interaction and context

### Parent interaction with Child
- **Parental synchrony:** ES=1.22 (0.85, 1.59)
- **Child initiations:** ES=0.40 (0.16, 0.64)

### Child interaction with Parent

### Child interaction with Assessor

### Child in School

### CONTEXT

**How effective is early intervention?**

**We know:**
- Efficacy of some elements and types of early intervention:
  - Structured teaching
  - Value of specific training- Joint attention, play skills
  - Use of specific strategies such as Visual cues
  - Build social -communication skills
  - Role of parent training & educational staff
  - Peer support....

**We know less:**
- Long term impact? 3RCTs including PACT follow up (Pickles et al, in press)
- How to generalise the impact for ASD PACT-G new study recruiting from Jan 2017 (3 sites; ASD aged 2-11 yrs)
- Which approaches for which parents & children- indiv variability within and between individuals
- How to combine communication intervention and management of difficult behaviours
ASD: What not to do:

- Secretin, chelation, or hyperbaric oxygen therapy should never be used to manage autism in any context because there is no clear evidence that these are effective and because there is harm associated with their use

- [based on moderate to very low quality randomised controlled trials (RCT) for secretin, low to very low quality RCT for chelation and hyperbaric oxygen therapy, & the experience & expert opinion of the GDG]

ASD: What not to do:

- Antipsychotics, antidepressants, anticonvulsants, and exclusion diets (such as gluten-free or casein-free diets) should not be used to manage the core features of autism because the balance of risks (especially with anticonvulsants and exclusion diets) and benefits did not favour their use

- [based on moderate to very low quality RCT for antipsychotics, antidepressants & anticonvulsants; low to very low quality RCTs for exclusion diets; & the experience & expert opinion of the GDG]

ASD: What not to do:

- Neither neurofeedback or auditory integration training should be used to manage speech and language problems in children and young people with autism

- Emerging data (not sufficient for endorsement) yoga, acupuncture & horseback riding (Koenig et al 2012; Lee et al 2012; Ward et al 2013)
Co-existing problems/conditions

Mental and Behavioural disorders.
• ~70% of individuals with autism also meet diagnostic criteria for at least one other (often unrecognised) mental and behavioural disorder
• 40% meet diagnostic criteria for at least two disorders, mainly anxiety, ADHD and ODD
• these coexisting mental and behavioural conditions further impair psychosocial functioning

Behaviours that challenge (NG 11 QS101)
• aggression (to objects or people)
• destructiveness and self injury (e.g. head-banging, hand or wrist biting, or skin picking)
• more common in autism than in other conditions with similar levels of intellectual impairment

Co-existing conditions

Intellectual disability (IQ<70)
• ~50% of young people with autism.
• Delays in Adaptive functioning (communication, socialisation and daily living/self-care skills)

Neurodevelopmental disorders
• Language disorders and specific learning difficulties (literacy, numeracy and other academic skills) 10% of people with autism fail to develop speech.
• Developmental Coordination Disorder (DCD) ~50-73% of children with autism have significant motor delays. Handwriting is a particular frustration for many

Functional problems.
• 40%-86% sleep problems affecting sleep onset, frequent waking for longer periods and reduced sleep duration.
• Eating difficulties - restricted and rigid food choices
• Gastrointestinal problems - diarrhoea, abdominal pain and constipation

Co-existing conditions

• Psychosocial and pharmacological interventions for the management of coexisting mental health or medical problems in people with autism informed by existing NICE guidance for the specific disorder
  – CBT (adapted) for verbally and cognitively able individuals
  – Psycho social interventions based on behavioural principles for all young people and adults who need help with daily living and participation in leisure activities
  – stepped approach for sleep problem

Co-existing conditions

• "Co-existing problems/conditions"
**Behaviour that Challenges (NG 11 QS101)**

- Factors that may increase risk
- Possible triggers or maintaining factors:
  - Impairments in communication that may result in difficulty understanding situations or expressing needs and wishes
  - Coexisting physical disorders (such as pain or gastrointestinal disorders), mental health problems (such as anxiety or depression), and other neurodevelopmental conditions (such as ADHD)
  - Physical/sensory environment, such as lighting and noise levels
  - Social environment, including home, school, employment and leisure activities
  - Changes to routines or personal circumstances
  - Developmental change, including puberty
  - Exploitation or abuse by others
  - Absence of predictability and structure

---

**Mental health interventions & management in ASD:**

- Co-morbidities/Co-occurring conditions
  - Epilepsy & other medical conditions
  - ADHD** (Miodovnik et al 2015)
  - Anxiety
  - Mood disturbance/Depression/emotional well being
- Maladaptive behavioural disturbance
  - ODD & CD
  - Behaviours that challenge
  - Sleeping, eating, toileting problems

(Simonoff et al 2008; 2013; Van Steensel et al., 2011; Salazar et al, 2015; Maskey et al 2013)
ASD and Anxiety

- Many children, YP and adults with ASD experience anxiety ****
- Various types of anxiety: generalised, social, specific phobia, separation, OCD…
- Interventions:
  - Psychoeducation (ASD, anxiety, ADHD)
  - Psychosocial interventions for child/YP +/- family- modified for ASD
  - Virtual reality (Maskey et al 2014)
  - medication

Growing evidence base for CBT with ASD

- Case studies (Ozsivadjian and Knott, 2011)
- Group studies (Chalfant et al, 2007; Reaven et al, 2012)
- RCT’s (Sofronoff et al., 2005; Chalfant et al., 2007; Reaven et al., 2012; Storch et al., 2013; McConachie et al., 2014)
- Meta-analysis (Sukhodolsky et al., 2013)***

Encouraging evidence that adapted CBT is effective for children with ASDs and anxiety disorder
ASD & Anxiety: medication

- Medication should be managed by child or adolescent psychiatrist
- Selective Serotonin Reuptake Inhibitor (SSRI) medications
- No RCTs in CYPs & 1 small study in adults with ASD
- Follow NICE CG recommendations but aware of modifications for children & YP with ASD
- Consideration of the potentially differing causes & mechanisms

ADHD

- Common co-occurring condition
- Multiagency working: child health & mental health
- NICE CG recommendations
  – Psycho-educational interventions
  – Psychosocial interventions
  – Medication
- Likely to require modifications for ASD

ADHD: medication

- Methylphenidate- across all studies ES 0.2- 0.7
- Significant effect but lower than for TD
- Recent study of atomoxetine ES 1.0
- BUT ATX may show less clinical impact (CGI-I)
- MPH and ATX signifi better than placebo
- BUT increased risk of side effects
Treatment of ADHD: Reported adverse effects

MPH: 10-15% withdrawal due to AEs
- Irritability
- Lethargy
- Sadness
- Dullness
- Social withdrawal
- Stereotyped behaviour
- Upset stomach
- Sleep problems
- Emotional lability

ATM
- Weight loss
- Fatigue
- Tachycardia

General principles:
Identifying targets for intervention

- Identify the most problematic behaviours
- Are these realistic to treat?
- Elicit antecedents and consequences (A,B,C)
- Link behaviours to relevant psychiatric symptoms/disorders
- Draw on available evidence base to initiate treatment

Monitoring outcomes

- Systematic
- Obtain baseline
- Cross-situation and different informants
- Goal-oriented
- Strategy for identifying adverse effects
- Consider poor communication of CYPs with ASD
- Consider the possible communicative intent
- Consider functional goals and outcomes
In summary - current clinical trends for use of medication in CYP with ASD for CAMH/CYPS teams

- Choose target behaviour(s) and outcome measure
- Initiate medication at a low dose
- Increase dose slowly
- Monitor more frequently for side effects
- Review effectiveness
- Stop medication if no response
- Be prepared to revisit formulation and hypotheses

Increasing awareness of transition

- Some examples of promising interventions in health services e.g. Transition co-ordinators, joint clinics, young adult clinics (Crowley et al., 2011)
- Scoping Review (Watson et al., 2012): limited literature evaluating health services for young people with diabetes or cerebral palsy
  - No models found for autism
- Urgent need for more research and evaluation, particularly focussing on the experiences of people with ASD
- NG 43: TRANSITION Feb 2016 (QS Dec 2016)

Does s/he attend appointments with GP or practice nurse on own?
UK Transition research

  - Transition from CAMHS to Adult Mental Health Services
- **SPRU**
  - Sloper et al., 2011: Transition to adult services for disabled young people and those with complex health needs
  - Beresford et al., 2013: Transition to Adult services and adulthood for young people with autistic spectrum conditions
- **TRANSITION Research Programme (NIHR)** (2017)

NG43 Implementation: 4 Challenges for commissioners, managers & practitioners

- Adults’ services take joint/equal responsibility w c’s services
- Joint planning, dev’mt & commissioning of services involved in transition across c’s & adults’ health and social care
- Improving front line practice w. YP thr’ training in Developmentally Appropriate (DAH) services and person-centred practice
- Maximising opportunities for YP who have become disengaged or who are not eligible for adults’ services to access care & support

Early Interventions in ASD for community paediatricians

- Our roles in early identification & diagnosis – likely to change over time especially as we gain further understanding about ASD & co-occurring conditions alongside evidence for interventions
- Effective treatments, opportunities & interventions
  - Build on skills, strengths & interests
  - Meet current and anticipate lifetime social, emotional, health & mental health needs
  - With finite resources how do we increase opportunities for social inclusion/ASC friendly environments
  - Education, employment, accommodation & leisure opportunities
Thank you
Questions?
a.s.le-couteur@ncl.ac.uk
The Challenges of Eating, Sleeping, Sensory Aversion and Aggressive Behaviour: 
Parental reporting of secondary difficulties in a population of pre-school children with Autism Spectrum Disorder (ASD)

Dr Sarah Mills
ST8 Paediatrics

Though not part of the core symptoms of ASD, children often have sensory, eating, sleep or behaviour difficulties when presenting to the assessment service for ASD

“Secondary Behavioural Difficulties”

Prof Amanda Richdale, 
Dept Psychology and Intellectual Disability studies, Victoria, Australia

The level of functional impairment and the presence of maladaptive behaviours appear to contribute specifically to parental stress

Tobing and Glenwick, 2002

have a significant impact on behaviour management, learning acquisition and the development of social relationships

Pearson et al. 2006

Definitions and parental reporting may vary but this data demonstrates the difficulties families perceive at ASD diagnosis
Demographic details of Newcastle

Population 0-4 year olds:
Office for National Statistics 17,400
GP Registered 16,404 (2014)

Stable population

Population based ASD assessment service

Preschool Age

Defined population
• During diagnostic interview secondary behavioural difficulties are sought through specific questioning

• Screening for comorbidities

• Enabled data collection for project

The Project

• Assessed 84 children in 2015

• 64 diagnosed at initial assessment
Aims...

Prevalence of Secondary behavioural difficulties:
- Sensory difficulties
- Restricted eating
- Poor sleep
- Aggressive behaviour

Methods...
- Retrospective case notes analysis of 64 pre-school children
- Diagnosed with ASD between 1st January and 31st December 2015
- Aged: 18 months - 4 ½ Years (Median age: 2 years 11 months)

Data gathered...
Sensory sensitivities

• Not a full sensory profile
e.g:
• Tactile or auditory aversion
  • Food/ messy play/ clothing/ labels
  • Household items: hoover
  • Hand dryers

Restricted eating

‘Do they eat the same as the rest of the family?’

If not:
• Record specific list of what they do eat, usually very limited

Poor sleep

‘Do they have any problems with sleep?’
e.g:
• Difficulty settling
• Night waking
Aggressive behaviour

‘Do they have any aggressive or challenging behaviour?’

e.g.:  
• Kick/bite/punch others  
• Self injurious

At Diagnostic Interview, Caregiver’s specifically asked about Secondary Behavioural Difficulties

If:
• Affected daily functioning  
• Required professional intervention  
• Viewed as problematic by the parents

Data gathered for this study

Methods...

The Results
Results…

- 55 (85%) Children had at least one difficult secondary behavior at diagnosis
- 18 (30%) children presented with difficulties in all four areas
Reported prevalence
Typically Developing children
Reported prevalence ASD children

<table>
<thead>
<tr>
<th>Sensory difficulties</th>
<th>33%</th>
<th>Up to 94%</th>
</tr>
</thead>
</table>

- Significantly more and concurrent
- Now a specific diagnostic criteria: DSM-5

Sensory difficulties

**73%**

(47)

Restricted eating
Reported prevalence for Typically Developing children:

- Sensory difficulties: 33%
- Restricted eating: 18.9%

Reported prevalence for ASD children:

- Sensory difficulties: up to 94%
- Restricted eating: 41.7%-66.2%

Significant:
- Limited diet ~ 5 foods
- Food texture affects choice in 70% ASD children


### Poor Sleep

<table>
<thead>
<tr>
<th>Difficulty</th>
<th>Typically Developing</th>
<th>ASD Prevalence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensory difficulties</td>
<td>33%</td>
<td>Up to 94%</td>
</tr>
<tr>
<td>Restricted eating</td>
<td>18.9%</td>
<td>41.7%</td>
</tr>
<tr>
<td>Poor Sleep</td>
<td>30%</td>
<td>44-83%</td>
</tr>
</tbody>
</table>


## Reported Prevalence for ASD Children

<table>
<thead>
<tr>
<th>Difficulty</th>
<th>Typically Developing Children</th>
<th>Reported prevaience</th>
<th>Our ASD Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensory difficulties</td>
<td>33%</td>
<td>Up to 93%</td>
<td>75%</td>
</tr>
<tr>
<td>Restricted eating</td>
<td>18.9%</td>
<td>41.7%</td>
<td>63%</td>
</tr>
<tr>
<td>Poor sleep</td>
<td>30%</td>
<td>44-83%</td>
<td>56% (36)</td>
</tr>
</tbody>
</table>

### Aggressive Behaviour

### Sensory difficulties

<table>
<thead>
<tr>
<th></th>
<th>Reported prevalence for Typically Developing children</th>
<th>Reported prevalence in ASD children</th>
<th>Prevalence in Our ASD population</th>
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<td>73%</td>
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</tbody>
</table>

### Restricted/Repeating

<table>
<thead>
<tr>
<th></th>
<th>18.9%</th>
<th>41.7%</th>
<th>63%</th>
</tr>
</thead>
</table>

### Poor Sleep

<table>
<thead>
<tr>
<th></th>
<th>30%</th>
<th>44-83%</th>
<th>56%</th>
</tr>
</thead>
</table>

### Aggressive behaviour

<table>
<thead>
<tr>
<th></th>
<th>16.6%</th>
<th>30%</th>
<th>59% (38)</th>
</tr>
</thead>
</table>

- Aggression and self-injury begin after the second or third birthday
- Aggressive behaviour is linked to low IQ and poor language ability


#### Known associations...

- More than literature

---

Sensory Sensitivities and Aggressive behaviour

- The distress caused by particular sensory inputs can cause severely disturbed and aggressive behaviour in those with ASD who cannot explain their distress


Sensory Sensitivities and Aggressive behaviour in Our Population

- Yes 33 (70%)
- No 14

Prevalence of aggression and sleep difficulties

- In children with developmental delay, sleep problems are more common in younger children and are often associated with self injury, aggression and other behavioural problems

Those with Aggressive behaviour who have Sleep difficulties in Our Population

- Yes 24 (63%)
- No 14

Associations...

- Crucially sleep abnormalities in ASD children increase the lifetime risk for major depression

Discussion...
What makes this data relevant?

- Population based, not self selecting
- The way the question is asked…

Why high prevalence…

- Youngest
- Often more severely affected
- Undiagnosed language and IQ deficits

Limitations

- Point Prevalence: Some difficulties may be fleeting, follow up data shows some haven’t developed yet
- Haven’t looked at IQ or level of language
- Not a full assessment of difficulties e.g. sensory profile, useful yield but could even under estimate problem
- We didn’t look at anxiety found by Davis 2010 to be very prevalent in ASD pre-schoolers.
What this means for service planning…

Pre-school, Population based services
• Demonstrate need
• Compete for limited resources

• Services need adequate input from allied health professionals: psychology, OT

• Families need access to support post diagnosis

• Wider Service Evaluation project incorporated Parent Feedback
The future…

• Service Evaluation Project
• Improving post diagnostic support
• Expanding the service

The early onset, severity, persistent course and frequent occurrence of atypical behaviours brings into clearer focus what a difficult and stressful period very early childhood is for children with ASD and their parents.

Dominick et al. 2007

The case for providing tailored support and early intervention for these difficult behaviours is strengthened in a bid to help families cope with their future.
Questions…

With Thanks…

To my Supervising Consultant
Dr Helen Leonard

To the Families for sharing their experiences
Clinicians’ knowledge of our Trust’s safeguarding proformas and body maps – but do we know where to find them?

Dr Jennifer Ho
ST1 Paediatric Trainee at North Middlesex Hospital
Dr Susie Gabbie
Paediatric Consultant at The Royal Free Hospital

Problem

Incomplete documentation in safeguarding cases
Incomplete knowledge of the accessibility of the safeguarding proformas and body maps
Frequently rotating junior doctors
Unsafe management of children with safeguarding concerns

Recommendation – The RCPCH Child Protection Companion 2013
The documentation of a clinician’s findings should be clearly and contemporaneously documented on a proforma

Aim:

• To increase paediatric clinicians’ knowledge of the accessibility of the safeguarding proformas and body maps on the hospital’s intranet
Method

- 4 question audit proforma
- Data
  - Paediatric clinicians
- Time period
  - November 2015 - March 2016
  - 1st cycle (pre-interventions) - 23 cases
  - 2nd cycle (post-interventions) - 16 cases

Results - Demographics

1. What level of doctor are you?
2. Do you know how to access the safeguarding proforma on the Royal Free’s Freenet?

**Results**

- **Yes** (48%): 11
- **No** (52%): 12

**Distribution by Role:**
- Consultant: 0 YES, 1 NO
- Paediatric trainee: 1 YES, 9 NO
- GP trainee: 4 YES, 2 NO
- FY doctor: 6 YES, 1 NO
Results

3. Do you know how to access the MASH forms?
- Yes (13%)
- No (87%)

4. Have you ever in the last three years made a referral to social care either using CAF or MASH forms?
- Yes (35%)
- No (65%)

Interventions
- ‘How to’ quick guidesheet
  - Email
  - Person
  - Induction pack
  - Doctors office
- Consultants’ meeting
- Departmental induction for junior doctors
- Pop up workshop
Re-audit results - Demographics

What level of doctor are you?

<table>
<thead>
<tr>
<th>Level</th>
<th>Consultant</th>
<th>Pediatric trainee</th>
<th>GP trainee</th>
<th>FY doctor</th>
<th>Physician assistants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Count</td>
<td>2</td>
<td>1</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

Re-audit results - Do you know how to access the safeguarding proforma?

BEFORE INTERVENTION

48% (11) Yes
52% (12) No

AFTER INTERVENTION

100% (16) Yes
0% (0) No

Re-audit results

Graph showing the increase in clinician’s knowledge of where to access the safeguarding proformas

<table>
<thead>
<tr>
<th>Level of clinician</th>
<th>Before</th>
<th>After</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consultant</td>
<td>30%</td>
<td>70%</td>
</tr>
<tr>
<td>Pediatric trainee</td>
<td>40%</td>
<td>60%</td>
</tr>
<tr>
<td>GP trainee</td>
<td>50%</td>
<td>75%</td>
</tr>
<tr>
<td>FY doctor</td>
<td>60%</td>
<td>80%</td>
</tr>
<tr>
<td>Physician assistants</td>
<td>70%</td>
<td>90%</td>
</tr>
</tbody>
</table>
Recommendations
1. The absolute importance of completing the mandatory safeguarding paperwork
2. The need for regular updates especially with a high turnover of clinicians
3. Quick guides are an effective method of disseminating knowledge
4. Face-to-face workshops consolidate knowledge
Thank you!

• Any questions?
Health needs of unaccompanied asylum seeking CHILDREN: A descriptive analysis

Dr. Georgie Siggers, Designated Dr LAC Kent
Dr. Rachel Coyle, Specialist Registrar in Public Health
Nancy Sayer, Designated Nurse for LAC, Kent & Medway
Dr. Ana Draper, CAMHS

The Kent experience

- May-Oct 2016, large surge in numbers; 213 children in May 15, 1000 by Oct 16
- End of Dec 2015, 600 who had not received IHA
- Historic arrangement with GP practice for 4 per week
- Range of health and safeguarding concerns

National transfer

- Effective from 1st July
- Voluntary system at present
- YP arriving in Kent – request new region
- Aim to move them in 5 days
- Fitness to travel screening to deal with immediate health issues
Where do they go?
- Foster care
- in and out of county
- Reception centres
- Independent living

Health
- Massive vulnerabilities and risks
- Experiences in country of origin
- Traumatic journeys
- Exposure to diseases not common in UK
- Effect of malnutrition
- Unmet screening and immunisation needs

The study
- 154 IHAs analysed
- Completed by GPwSI & Comm Paeds
- Dr. Rachel Coyle, Specialist Registrar in Public Health
- Need for TB screening, prevalence of Hep B & parasitic infection modelled
Health Needs

- Psychological signs/symptoms (41%)
- Physical complaints common
- Dental (43%)
- Vision (35%)
- High risks for TB & Hep B

The Detail

- Range of chronic health conditions – asthma, diabetes, epilepsy
- Acute Hep B, TB
- Burns, fractures, infected wounds

Gastro-intestinal Issues

- Almost universal complaint
- Pain, bloating, reflux
- Refeeding?
- Nutrition training & advice
Mental health issues
- 16% PTSD
- Acute distress, aggression
- Self harm
- Action research project
- Hope work

Sleep
- Body clock reversal
- Sleep training – staff & YP
- Sleep packs
- Sleep prescription

www.uaschealth.org
Thank you for listening

UASCs are children first, asylum seekers second
The context of the child:
Recognising social risk factors in a paediatric population.

- McKenna C.1, Singh G.2, Lakhanpaul M.1

1. Population, Policy, Practice. UCL Great Ormond Street Institute of Child Health
2. NHS Whittington

Introduction

- Social determinants of health (SDH)
- Upstream factors which influence physical and mental health
- Context
- The ‘causes of the causes’
- Especially relevant in paediatrics

Unemployment

Childhood obesity
Aims

1. To explore paediatricians’ experience of the SDH in their clinical practice
2. To identify which social risk factors paediatricians encountered.
3. To determine which services paediatricians feel would be valuable in tackling social risk factors.

Methods

- 72 doctors working across 2 District General Paediatric departments
- Online survey
- Their experience of SDH in clinical practice over the preceding 3 months
The survey

1. Do you think that the social determinants of health are relevant to your practice as a paediatrician?
2. In the past 3 months, have you encountered patients whose presentation or medical condition you felt was affected by any of the following factors?
3. As a paediatrician do you think it is your responsibility to address the social determinants of health?
4. Do you feel confident in addressing the social determinants of health?
5. In the past 3 months have you encountered any families who you feel would have benefited from one or more of the following services?
6. What would help you to better address the social determinants of health?

Results

- 60% response (n=43)
- 100% said SDH relevant
Table 1: Social risk factors in paediatrics (n=43) felt had impacted upon the presentation or medical condition of children they had encountered over the preceding 3 months.

<table>
<thead>
<tr>
<th>SOCIAL RISK FACTOR</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Language barriers</td>
<td>40</td>
<td>93.0%</td>
</tr>
<tr>
<td>Difficult family relationships (e.g. fighting in the home, domestic violence)</td>
<td>38</td>
<td>88.4%</td>
</tr>
<tr>
<td>Parental mental illness</td>
<td>37</td>
<td>86.0%</td>
</tr>
<tr>
<td>Poor quality housing</td>
<td>36</td>
<td>83.7%</td>
</tr>
<tr>
<td>Poverty</td>
<td>32</td>
<td>74.4%</td>
</tr>
<tr>
<td>Addiction to alcohol or other substances (parents or young person)</td>
<td>28</td>
<td>65.1%</td>
</tr>
<tr>
<td>Difficulty accessing healthcare facilities</td>
<td>27</td>
<td>62.8%</td>
</tr>
<tr>
<td>Living in an unsafe area</td>
<td>20</td>
<td>46.5%</td>
</tr>
<tr>
<td>Difficulty accessing healthy food</td>
<td>18</td>
<td>41.9%</td>
</tr>
<tr>
<td>Limited resources of food</td>
<td>16</td>
<td>37.2%</td>
</tr>
<tr>
<td>Lack of community facilities</td>
<td>13</td>
<td>30.2%</td>
</tr>
<tr>
<td>High levels of air pollution</td>
<td>9</td>
<td>20.9%</td>
</tr>
<tr>
<td>Food insecurity</td>
<td>8</td>
<td>18.6%</td>
</tr>
</tbody>
</table>

Results

• 74% (n=32) felt it was their responsibility to address the SDH
• Only a 21% (n=9) felt confident doing so.

• Recurring themes:
  • Lack of training
  • Lack of influence
  • Limited resources
  • Time constraints

“Absolutely! But feel frustrated by lack of apparent actions that I can take as a doctor on a busy ward. I feel to bring it up on the ward round even raises eyebrows and I don’t want to slow things down. So many of our patients have complicated backgrounds and what we do in hospital only touches the surface of dealing with that. I know that for many of my patients I will see them again in a few weeks or months because it is their social situation that actually led to their admissions…”
Paediatric trainee (ST4-5)

“Feel responsible to advocate for children’s health in wider society however on a day to day basis I feel unable to address these issues fully due to time pressures. I would like to take a more active approach to helping patients with these problems.”
Paediatric trainee (ST1-3)

“Depends on what’s meant by ‘addressing these’. I’m not confident that I can alter poor income or housing for instance… Many of these factors are determined by local and central government.”
Consultant paediatrician
Table 2: Services which paediatricians (n=43) felt would have been beneficial for families they had encountered over the preceding 3 months.

<table>
<thead>
<tr>
<th>PROPOSED SERVICE N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>total sample</td>
<td>100.0%</td>
</tr>
<tr>
<td>Housing advice</td>
<td>88.4%</td>
</tr>
<tr>
<td>Parenting support</td>
<td>86.0%</td>
</tr>
<tr>
<td>Support organisation which provides English language classes</td>
<td>84.4%</td>
</tr>
<tr>
<td>Mental education</td>
<td>73.5%</td>
</tr>
<tr>
<td>Assistance with childcare</td>
<td>73.5%</td>
</tr>
<tr>
<td>Social environment (e.g. children's centre)</td>
<td>69.8%</td>
</tr>
<tr>
<td>Welfare/Benefits advice</td>
<td>65.1%</td>
</tr>
<tr>
<td>Support organisation for family conflict or domestic violence</td>
<td>62.8%</td>
</tr>
<tr>
<td>Additional education for children (pre-school/outside school)</td>
<td>58.1%</td>
</tr>
<tr>
<td>Legal advice</td>
<td>39.5%</td>
</tr>
<tr>
<td>Child Rights advice</td>
<td>34.9%</td>
</tr>
<tr>
<td>Assisted food supply</td>
<td>34.9%</td>
</tr>
<tr>
<td>Debt advice</td>
<td>27.9%</td>
</tr>
<tr>
<td>Assisted clothing supply</td>
<td>20.9%</td>
</tr>
<tr>
<td>The patient's local constituency office</td>
<td>11.6%</td>
</tr>
</tbody>
</table>

Results

- What would help respondents better address the SDH?
  - Increased training
  - Awareness of local services
  - Political engagement
  - Increased social care resources

"It would be good if doctors could prescribe things like "better housing", "healthy food" etc. There's no reason why we couldn't prescribe coupons or vouchers... to make sure they could get at least healthy food for their children?"
  
Paediatric trainee (ST4-5)

"Perhaps some more education on the community systems in place locally and what we can do to help: as we move hospitals so often, I don't know what local services are available and who would be eligible."
  
Paediatric trainee (ST4-5)

"Closer links between health and MPs (and those involved being engaged with the concept that social and health care bills can negatively or positively impact on families on a major scale in this country)."
  
Paediatric trainee (ST4-5)
Conclusions

- Paediatricians recognise the importance of SDH
- Can identify multiple social risk factors
- Lack of confidence in addressing the SDH
- Possible shortfalls in training

“"I am not a social worker.""

How can we address SDH?

- Local
  - Ask routinely about social risk factors
  - Raise the profile of SDH in training
  - Reinforce importance / duties
  - Access to local services
How can we address SDH?

• National
  • Political advocacy
  • Research
  • Raise awareness

"It is not enough to work at the individual bedside in the hospital... (but also to influence) the school boards, health department, legislature, be an advisor to judge and jury and to sit in council."

(1838-1919) Abraham Jacobi
'Father of social paediatrics'

Caoimhe.mckenna@nhs.net
A new landscape in SEN & disability – two years in what has changed; what challenges remain?
Amanda Allard, Assistant Director, CDC

Childhood deaths: Trends in Western Europe, 0-14 year old

5 excess child deaths daily compared to Sweden
The new SEN system – Key elements

1. Involvement of children, young people and parents
2. All duties apply to all state-funded schools, including Academies
3. A clear, transparent local offer of services for all CYP with SEND
4. LA, health and care services to commission services jointly
5. Coordinated assessment: 0-25 Education, Health and Care Plan
6. Statutory protections for 16-25s; focus on preparing for adulthood

The Act: a cultural programme

- The importance of taking into account the views, wishes and feelings of young people, parents and carers
- A focus on outcomes and a personalised approach to support
- Local offer – local support
- Information, advice and support for young people and families
- Co-ordination – joint commissioning

What has been achieved!

- The high profile of SEND Policy ..with new money to support implementation
- The spirit and direction of the SEND reforms, the final recognition that families are equal partners and that children and young people have aspirations and a part to play in their own lives
- The coming together of the very different worlds of SEN and Social Care and the nurturing of health as a partner
• 50%: Joint commissioning arrangements well developed.
• 14% fully in line with requirements of Code of Practice.

Implementation of Children and Families Act initially focussed on operational aspects (e.g. EHC Plans and maintaining a Local Offer) without Joint Commissioning Arrangements fully established in all areas.

BUT...

Joint Commissioning Arrangements are required for strategic changes required to support this delivery.

Without JCA there will be increasing pressure on operational delivery and frontline professionals - potentially undeliverable.

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Delivering integrated services without joint commissioning

---

... And with
Positive Practice from Inspections

Early Identification:

- A single, streamlined pathway for identifying needs and making referrals to well understood across education, health and care agencies
- Clear pathway for referral by health visitors
- Using standardised developmental checklist supports consistent identification across health visitors 2 (2.5) year development check and 5 year old check
- Universal health teams have good access to the support provided by the schools and families specialist support service

Positive Practice from Inspections

Commissioning - Agreements in place to pool budgets between LA and CCG leading to improved capacity to jointly commission services to meet the needs of children and young people.

EHC Planning - Vision of education, health and care plans is understood by all staff and consistently implemented

The use of a single agency health report template for assessment in relation to education, health and care plans has brought about more cohesive working between the health teams, rather than each health team submitting an individual report

Working Together - Education, health and care hub meetings and joint funding panel for "exceptional needs" provides tripartite funding for complex needs

Demonstrating improving destination outcomes

Areas identified as needing further development

- Lack of shared vision across system partners
- Joint commissioning arrangements not established
- No DMO or DCO- limiting CCG's ability to strengthen and improve the health provision
- No or inadequate training for staff across partner organisations
- Lack of measuring or monitoring of clear outcomes at system or individual level means services and system leaders unable to demonstrate impact
- Lack of health and social care input into plans
- Problems with provision of therapy services due to poor integration
- Poor Local Offer- consistent theme across most inspections
Key challenges for implementation – learning from health

- Clear support at senior level within CCG’s for children and young people with SEN and disability.
- Development of a Participation Strategy with children and young people and families.
- Development of shared strategic outcomes for children and young people with SEN and disability, based on engagement with children, young people and families and analysis of strategic data.

Key challenges for implementation – learning from health

- A clear, jointly owned Education, Health and Care Assessment and Planning Process, developed with input with health, social care, including effective information sharing and oversight arrangements
- Clear protocols with provider organisations for delivery of key aspects of EHC Plans
- Ensuring health services reflected in the development review of the Local Offer and this contributes to strategic commissioning decisions
- Process for including adult health services for 18-25 year olds
- Consideration of delivering reforms to children and young people in the Youth Justice System

Key challenge or overlapping strategies for improvement?

Importance of aligning with other priorities that are/will affect the same group of CYP
- Personalisation including personal budgets, IPC
- Transforming Care programme
- Future in Mind – CAMHS transformation
- Lenihan Review
The good news is that whilst there may have been a lack of strategy behind the various initiatives that impact on this group actually there is a lot of activity with very overlapping goals.

So there is an opportunity to help the programmes join the dots together and make the whole more than the sum of the parts.

**Joining up the dots**

How the programmes elements fit together

<table>
<thead>
<tr>
<th>IPC Programme</th>
<th>Children and Families Act requirements</th>
<th>Transforming Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Proactive coordination of care, focus on early intervention and prevention</td>
<td>Local offer</td>
<td>Early intervention and prevention</td>
</tr>
<tr>
<td>Community capacity and peer support</td>
<td>Local offer</td>
<td>Enhanced community and support services</td>
</tr>
<tr>
<td>Personalised care and support planning</td>
<td>Local offer</td>
<td>Early intervention and prevention</td>
</tr>
<tr>
<td>Personalised commissioning and payment (integrated commissioning)</td>
<td>Local offer</td>
<td>Enhanced community and support services</td>
</tr>
</tbody>
</table>

- CHUMS - 3 year research project funded by National Institute of Health Research
- Led by academics at Peninsular Cerebra Research Unit: University of Leeds, University of Leeds, University of York
- Overall aims of CHUMS: What outcomes of NHS care should be measured for children and young people with neurodisability using Patient Reported Outcome Measures (PROMS)?

It's not only commissioning that needs to be joined up
CHUMS research

CDC carried out qualitative research with neurodisabled children and young people (54) and their parents (53):

In this research we addressed the following questions:

1. What health outcomes matter most to neurodisabled children, young people and their parents - based on WHO ICF
2. If existing PROMs are suitable for use with children with neurodisability and address the priorities and concerns of children/parents
3. To consider pragmatic approaches which might motivate children to want, and be able, to complete PROM questionnaires, such as novel technology.

Our findings about outcomes

For both parents and CYP our analysis found:

• Relationship between outcomes: how different outcomes areas inter relate to form broader concepts and life outcome areas
• Hierarchy of outcomes: "high level life outcomes" at top, dependent combinations of lower level outcomes.
• Meaning of outcomes: Individual outcomes have complex set of meaning for parents and children
• There are similarities and differences between the parents and children

Outcome hierarchy parents

- Community
- Emotional wellbeing
- Gaining independence, future aspirations
- Making decisions and choices
- Interpersonal interactions and relationships
- Communication, other mental functions
- Temperament, mobility, self care
- Functions of digestive and endocrine, Genitourinary
- Pain, sensory functions, functions of cardio
- Body structures, neuromusculoskeletal, sleep
Vital health commissioners and providers understand their contribution to young people’s life outcomes

- Individual processes really starting to bed down
- We have a long way to go on structural/system issues
- Need to think about SEN support
Resources

DMO/DCO forum
https://councilfordisabledchildren.onlinegroups.net/

Expert Parent Modules:
http://councilfordisabledchildren.org.uk/learning/sections/parents

The children and Families Act online modules: