Making CAMHS accessible for Young people who have Autism

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Our background – Manchester CAMHS

- Autism Assessment Pathway
- Provide autism specific interventions
- Make existing interventions more bespoke
- Train and consult to others in core teams
IAPT LD ASC Diploma

- IAPT – Increasing Access to Psychological therapies
  - Training which aims to support staff in statutory and voluntary sector services in delivering mental health intervention to children with autism and learning disabilities
- Course covers curriculum set out by national IAPT advisory group and adheres closely to NICE guidelines.
- Includes lectures and supervised practice and involves assessment of autism and delivery of evidence based interventions in mental health for children with autism or children who have other additional needs
- First set of students due to complete their diploma in March 2019
Disclaimer

- Although we will be trying to think about what makes outpatient CAMHS more accessible we are in no way saying we have got this sorted!
- Today is more about sharing our ideas and what we have learnt along our working journey
- Examples of good practice from the audience gratefully received
Aims: What has to happen to make CAMHS accessible?

- Practical
- Cultural
- Political
# Visual Timetable

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Why do we need accessible Child and Adolescent Mental Health Services?

- NAS estimate that 70% of children with Autism have one mental health problem and 40% have two.

- A significant number of children will need to access their local CAMHS but provision is patchy and sometimes non existant.

- Services have often developed without those with additional needs in mind.
Mental health services failed to improve the mental health of two thirds of children with autism.

43% of parents whose children are currently registered with mental health services said their child’s mental health had got worse because they could not get the services they needed.

Parents are twice as likely to say that CAMHS have improved their child's mental health when they told us that an autism specialist was involved in their treatment.
Over half of parents do not think that mental health services know how to communicate with their child.

83% of the children first experienced mental health problems before the age of ten, and half before the age of five.

Nine out of ten parents said that the mental health problems their child faced had had a negative impact on their own mental health and that of the whole family. Over a quarter of family members needed support from mental health services as a result.
NICE Guidelines

- Very clear guidance on what interventions should be offered by CAMHS; including
  - Interventions to support core difficulties e.g. communication
  - Interventions for understanding and supporting behaviour that challenges
  - Interventions for co-existing mental health problems e.g. CBT and anxiety
Practical adaptations

Information

- What information do we send out in advance to let people know what CAMHS is about?
  - Website? – Leeds CAMHS

- What online resources do we use? e.g. Get self help
  - [https://www.getselfhelp.co.uk/docs/AnxietySelfHelp.pdf](https://www.getselfhelp.co.uk/docs/AnxietySelfHelp.pdf)

- Appointments and letters?
Invite to ADHD clinic

The Carol Kendrick Centre

When you come to the Carol Kendrick Centre your mum will let the receptionist know you’ve arrived, then you sit in the waiting area for a bit until it’s time for your appointment.

You will be seeing (Clinician).

He/she will take you and your mum to a room to have a chat.

(clinician name) might need to ask you a few questions but mostly will be talking to your mum. You can play on mums phone when he/she is talking to your mum if you like.

(clinician name) will need to measure and weigh you and might need to take your blood pressure.
Mum - Dad will talk to Jo
Jo + Alison will talk to me and play some games untene

What happens at an Autism assessment?

Alison will come and watch me in class
Alison will work at books with me
Language

- Slow
- Pace
- Give adequate processing time
- Avoid double negatives
- Use concrete anchor points (did you feel low before the Christmas holidays?)
- Reduce complex sentences. (‘The dog bit her’ rather than ‘She was bitten by the dog’)
- Closed questions can be easier to answer – ‘Have you been feeling sad?’ Rather than ‘tell me how you’ve been feeling’
- With written information - use Flesch formula on word to calculate readability
Visuals can reduce language and make session more comfortable e.g. use of yes/no don’t know visuals and choice boards; talking mats

- May capture more of the young person’s voice

- Can explain routine and reduce anxiety - visual timetables

- Involve child’s interests

- Support risk plans and help young person to think about what helps them manage their stress e.g. Positive Behaviour Support Plan
Stay Safe Plan

My Name: ____________________________
My Birthday: ________________________
Completed with: ______________________
Young person? [ ]
Family? [ ]

This is my plan to help me stay safe and well.

What helps me to feel calm and happy?
(activities, sensory, people, pets)

What can other people do to help when I start feeling upset?

What are my triggers?
(Things that can cause me to feel upset/distressed)

What else can I do to stay safe when I am in an upset/meltdown?

What can I do to stay safe when I am in an upset/meltdown?

Completed by: ________________________ Date: ____________
Environment

- Waiting room? Radio on? Alternative?
- Clinic rooms – comfy? Alienating? Sensory toys? Option for time out?
- Does all therapy need to be in a clinic? 9-5?
- Sessions - too long? Too talky? – Opportunity for videos – pacing of session with talking and other non talk activities
- Timing of sessions, breaks
Technology

- You tube – may be more helpful to some visual thinkers
- Apps? These are some that are available – note – we are not recommending one above another just summarizing examples
  - Mood Kit – £4.99
    - Includes a daily journal for monitoring negative thoughts and reflecting on what you did to overcome them
  - Mind shift - free
    - Focus on role of thought in anxiety management
  - Self-help for Anxiety Management SAM – Free
    - Tracks anxiety thoughts – includes a cloud feature so you can link with other users
  - CBT thought Record Diary – Free
    - Thoughts and feelings tracker
  - MoodTools – Free
    - Thoughts and feelings log, suicide safety plan, online videos to watch
NICE Guidelines - Adapting CBT

- Emotion recognition training
- Greater use of written and visual information and structured worksheets
- A more cognitively concrete and structured approach
- Simplified cognitive activities, for example, multiple-choice worksheets
- Involving a parent or carer to support the implementation of the intervention, for example, involving them in therapy sessions
- Maintaining attention by offering regular breaks
- Incorporating the child or young person's special interests into therapy if possible.
Adapting clinical intervention

- Review the evidence base
- Consider your core clinical skills – what you already know!
- Consider the practical adaptations described above
- Be creative
- Consider who else in the child’s wider system you might co-work with and support to implement some strategies and to ensure work generalizes – parents, teaching assistant, short break provider
Case Examples

- Adapting a key mental health intervention – CBT
- Developing a resilience group for managing anxiety
- Riding the Rapids – support for parents to understand and manage their child’s challenging behaviour
Resilience Group

- For young people in years 7 8 and 9 to help introduce anxiety management techniques and build resilience
- Group sessions for parents at the same time as the session for the young people – helps promote generalisation
- Bespoke discussion on what builds resilience in people with autism – e.g. consideration of sensory needs, social overload, environment
- Introduction to mindfulness and CBT using group exercises – e.g. court of law
- Quieter break out rooms available
- After school slot
Riding the Rapids

- Developed in house in response to need. Aims to support parents of children with additional needs who needed to understand their child's behaviour better. Started as a series of single case reports – then part of a waiting list control study (Beresford et al 2010)

- Ten week intervention aimed at helping parents create their own formulation to understand their child’s behaviour and use different behavioural and communication strategies to manage that behaviour

- Interventions also looks at ways of managing stress and improving parental coping
Adaptations compared to generic parenting groups

- Focus on the individual; recognition that each child is different; behaviour that challenges is not just about attention
- Uses lots of visuals, modelling how to do this for parents and supporting those parents who also have autism themselves
- Uses ‘in house videos of parents of children with autism explaining how they have used some of the strategies uses in the group
- Involves lots of live practice and active problem solving
- Shares skills of parents and professionals
Outcomes show significant changes in pre and post Riding the Rapids scores

- In terms of behaviour – as measures by Eyberg and Goal based outcomes
- Parenting stress – as measured by SLODOM and Parenting Coping Index
Outcomes

- CAMHS has to measure success of intervention – no ideal set of measures but goal based outcomes, session rating scales, SLDOM – best to discuss with the young person and their families what they feel comfortable with and check understanding of measure

- CHI

- Parent Journeys
Cultural
Cultural adaptations

- Specialist teams have a clear role to play in delivering mental health intervention for young people with autism

- But – there is a risk that core CAMHS will be deskilled and will see Autism as someone else’s business

- We believe there is strength in having specialist teams embedded in core services; offering consultation and supporting training and development of generic practitioners – in CAMHS and in the voluntary sector
Supporting mental health is not just about delivering intervention; it can encompass advocacy and support to other staff in the team around individual children – this requires a commissioning shift.

Development of services benefits from co-production – another cultural service shift.
I-Thrive – New model for Manchester CAMHS

- No ‘tiers’ – more systemic approach to providing care
Commissioning developments in Manchester to co-incide with i-thrive include:

- A ‘parent post’ to act as a point of contact for parents and young people who may want information about local service or want to talk more about what CAMHS can offer or need signposting to alternative services.
- A ‘training post’ to support health visitors, school nurses and other community staff to adapt their practice to ensure more autism specific early intervention can be employed.
Political adaptations

- **Resources** - We realise that many CAMHS are under huge amounts of pressure in terms of waiting lists and managing emergencies and change can feel difficult in this climate – there needs to be strategic and political support to ensure services are adequately resourced.

- **Cohesive strategy** - Clear and cohesive policy for the UK regarding what is minimum expected standards – alongside best practice – local service mapping.

- **Lobbying for political change** - We need to continue to lobby widely to improve the experiences of young people with Autism who access CAMHS – Cross party parliamentary committee and local CCG’s.
The environment should not have ticking clocks and other things that disturb the senses

The environment should have activities suitable for older children and young people not just toys for young children

CAMHS professionals should give different options – open ended questions can be very difficult to answer

CAMHS should give you choice not say what you have to do

CAMHS should give more information

CAMHS professionals should understand Autism and that everyone is different
- CAMHS should work with education
- CAMHS should give you choice about who you see
- The environment should have a space for you to release stress
- CAMHS should make sure you see someone when you need it – a bad day drop in and that you can contact them by phone or email
- CAMHS should offer home visits alongside visits to services and going somewhere neutral
- CAMHS should take you out to help you through scary situations
Our suggestions for a more Accessible CAMHS

- **Listen** - most powerful way of making CAMHS accessible is to listen to what young people and their families are telling us they want and respect what they say.

- **Be the one** – Don’t think someone else will do it. If there isn’t already an autism champion in your service - be the one.

- **Do things differently** – we don’t have to stick doing what we have always done because we have always done it. Do something different, evaluate it, share it.

- **Find your tribe** – find and make allies across services and with parents – sharing of skills and knowledge will achieve more.

- **Find or – offer** – a voice to the strategic boards in your area.
Know about the Local Offer - what's out there in terms of leisure and social activities – good mental health isn't just about therapy

Consider practical issues – letters, information, websites – are they easy to understand and accessible for all?

Good autism practice is good practice – making CAMHS accessible for children and young people with autism makes it more accessible for all children and young people. 80% children and young people with emotional and behavioural difficulties also have significant unidentified language difficulties (Hollo et al 2014) – so good autism practice will support these children too

Seek out further training – e.g. IAPT; Year long diploma with the aim of training front line staff to make therapies more accessible for young people with autism and those with learning disabilities
References


- Riding the Rapids (primary and secondary) – information available on website for Encompass Psychological Services; www.encompasspsychologicalservices.co.uk


- [https://www.thecommunicationtrust.org.uk](https://www.thecommunicationtrust.org.uk)

- IAPT LD ASC course – for further details contact [nigel.freeman@gmmh.nhs.uk](mailto:nigel.freeman@gmmh.nhs.uk) or Jo Bromley on [jo.bromley@gmmh.nhs.uk](mailto:jo.bromley@gmmh.nhs.uk)

- [I Thrive](http://www.implementingthrive.org)

- NICE guidelines
  [https://www.nice.org.uk/guidance/cg170](https://www.nice.org.uk/guidance/cg170)