

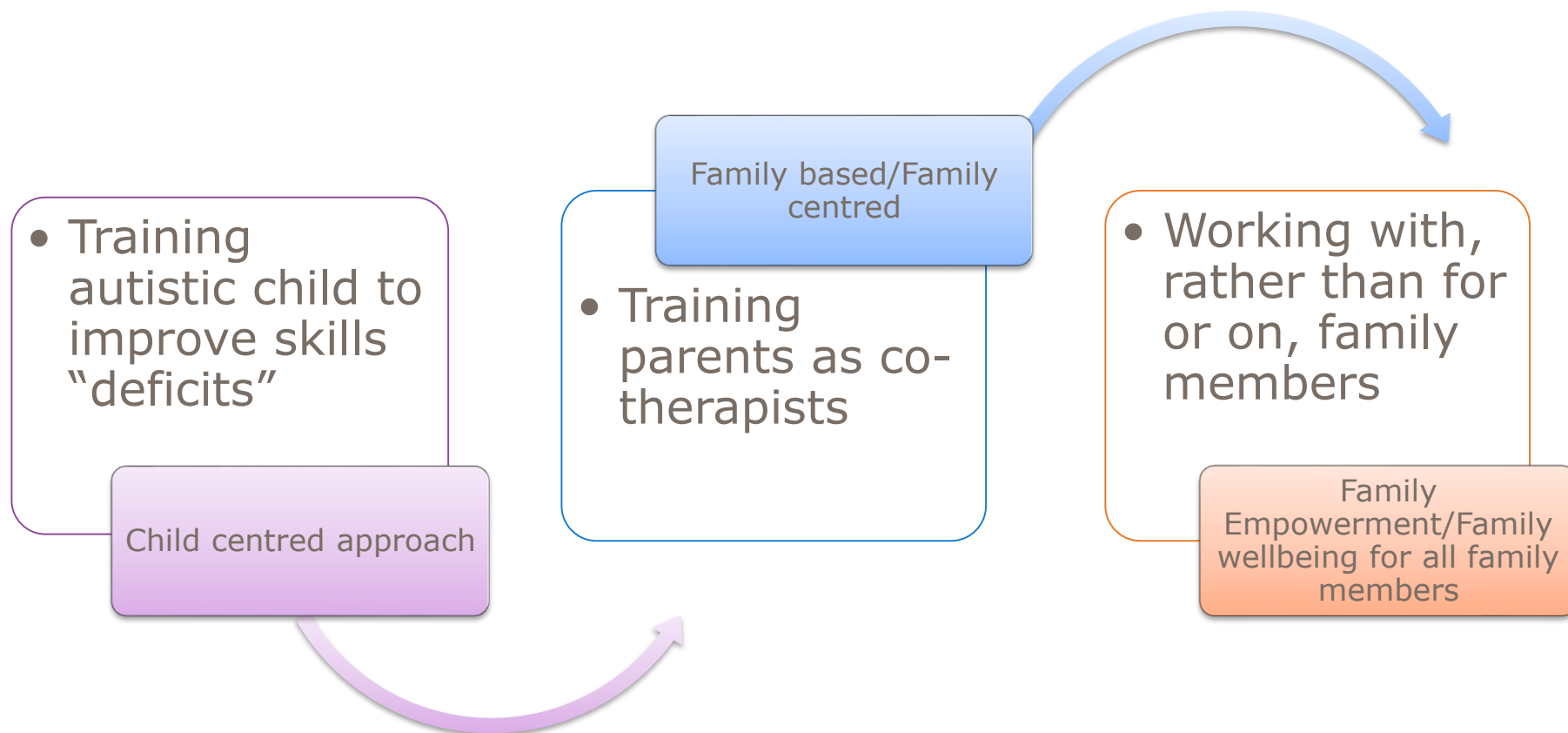
IMPROVING ACCESS TO PSYCHOLOGICAL SERVICES –IAPT FOR AUTISTIC CHILDREN, YOUNG PEOPLE AND THEIR FAMILIES

Dr Georgia Pavlopoulou

**Module Lead CYP IAPT
AUTISM/LEARNING
DISABILITIES**



How do we move from 'fixing' to shared power and co-designed models of positive support?



About today's talk

Moving away from a deficit narrative: Lessons from siblings on family wellbeing

The mental health of autistic needs and their families

Working with, rather than on, autistic CYP in the therapy room: A need to move from modification to mutuality

IAPT Service transformation: Values, Curriculum and Opportunities to get a funded place for training and/or join our National Network

What do we know about families of autistic children?

A large number of previous research in the late 90s /early 2000s suggests that much of the stressfulness of parenting an autistic child emanates from factors directly related to the child's disability (Hastings, 2002; Koegel et al., 1992; Konstantareas & Homatidis, 1991)

The negative impact hypothesis has not been proven (Hastings 2016)

...yet specialists still target the autistic traits and behaviours missing the real struggles; sleep, anxiety, loneliness, unemployment, early preventable deaths, stigma etc that we know affect mental health.

An autism deficit focus?

A number of published metaphors have been used to describe autistic kids, all looking at autistic beings from a deficit perspective according to which they need intensive intervention.

hidden behind walls or within fortresses (Bettelheim [1972](#); Waltz [2003](#); Broderick and Ne'eman [2008](#)); **as aliens** (Hendriks [2012](#), p. 6; Sacks [1995](#); Silverman [2008](#); Hacking [2009](#); Broderick and Ne'eman [2008](#)); **as animals or savages** (Waltz [2003](#); Hendriks [2012](#), pp. 3–6); **as robots or other machines** (Hendriks [2012](#), pp. 7–10; Danforth and Naraian [2007](#); Fein [2011](#)); **as mindblind** (Dinishak and Akhtar [2013](#)); **or as puzzles** (Waltz [2003](#)).

An autism deficit focus?

The reference of autism as an “**epidemic**”; (e.g. Gillberg et al., 2006; Eyal et al., 2010) or “**disease**” (e.g. Jepson, 2007) is also typical, with the apparent association being the outbreak of a contagious disease.

Parents, along with the diagnosis, are introduced into the socially constructed ideology that autism is bad, abnormal and unexpected (Jaarsma, 2014). In order to render the unexpected expected, families engage with a number of therapy hours in intervention programs per week for decades.

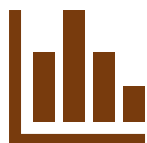
What are they intervening with?

Why siblings?

- “We will become caregivers for our siblings when our parents no longer can. Anyone interested in the welfare of people with disabilities ought to be interested in us.”
- The way we experience and connect with our siblings may be an important and specific predictor of major depression in adulthood (Waldinger et al. 2007)
- Siblings spend a great deal of time together, on average, 40 minutes out of every hour, when at home (Rivers and Stoneman 2003)
- 80% of children with disabilities have at least one brother or sister
- Predefined behavioural categories and maternal and teachers’ reports often different from siblings’ self reported family experiences.



What do we know about siblings?



The exclusion of autistic voice from family research reinforces the de-evaluation of autistic people.

What have we learnt from non-autistic siblings?

‘I don't live with autism; I live with my sister’. Sisters’ accounts on growing up with their preverbal autistic siblings

Georgia Pavlopoulou  , Dagmara Dimitriou



The language used and narratives shared by siblings revealed how they experience concepts of disability in the community and highlighted how they experience disability through their sibling relationship. Recognising the struggles while not stigmatising. Many already challenge concepts of normalcy in their local communities, none is using the word 'disorder', many have unmet needs but don't consider their needs 'complex'



The results showed the feelings, needs and thoughts of the children's experiences as siblings, friends and carers, but also as students and citizens with a passion for advocacy, albeit it with limited support in the community. Lack of acceptance= lack of opportunities to activities that cultivate positive feelings, thoughts and actions= at risk for mental health problems



They describe family experience having an autistic brother or sister as a continuation of their human experience - rather than just negative or positive influences.

I don't live with autism, I live with my sister (Pavlopoulou and Dimitriou, 2019)

The research highlighted opportunities for wellbeing within the family and sibling relationship as well as the positive contribution of autistic family member



Family members collaborate and communicate in reciprocal ways in order to create flexible environments to accommodate siblings' needs at home and support each other by providing information and sharing observations



Strong sense of social justice, high levels of empathy, appreciation of differences, standing up for others at school and in the community



Feeling connected by things they share and enjoy together.

What can we learn from autistic siblings?

(Pavlopoulou and Dimitriou, under review)

Siblings at home:

Sense of belonging
Defined by things siblings can do
Knowing mine and my sibling's 'normality'
Creating flexible environments to accommodate needs
Being creative in communicating and resolving problems

Siblings in the community:

Feeling different, notion of 'othering'
Abilities remain hidden, problems highlighted
Not the 'norm', creating troubles
Trying to fit to others' expectations
Protecting each other



Inspiring and inspired when sharing time with sibs at home and neighbourhood



Free and talented in solitary play, hobbies and special interests



A sense of being different in local community and school
e.g. over-worried about conflicts in the playground



Struggling with routines and safety rules

A humanistic view of wellbeing (Pavlopoulou and Dimitriou, 2019)

Insiderness

understand their
personal and subjective
views

Agency

their ability to make
choices

Uniqueness

autistic kids seen as
individuals not as
categories

Sense making

their interpretations of
school and family life

Sense of place

feeling sensory comfort
and sense of belonging

Implications for mental health practitioners working with autistic CYP and their family members

Inform families that it is possible to lead healthy, happy lives- recognise what already works- identify strengths- don't assume pathology in relationships

Remain curious through the use of mentalising questions- Avoid epidemic/tragedy narratives

Promote acceptance of neurodiversity- no need to fix autism but clear need for many families to improve daily routines, functioning etc

Identify struggles and secure support for everyday routines and bigger life issues (sleep, sexuality, access to leisure activities etc)

Balance the agenda- make sure the autistic person contributes to therapy agenda!

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Autism and mental health: what's the issue

Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people around them.

Autism is **NOT** a mental health problem, but far too many autistic people go on to develop mental health problems. By the age of 11, 71% to 80% of autistic children develop one or more of the following:

Anxiety

Phobia

OCD

ADHD

Oppositional
or conduct
disorder

Depression

Autism and mental health: what's the issue

These comorbid psychiatric conditions are well documented in autistic people across the lifespan. Mental health difficulties may present as behavioural difficulties that compromise life choices



There is no evidence that psychological interventions will ameliorate core symptoms of autism but there is evidence that certain therapies may improve obsessive compulsive disorder, bipolar disorder, depression, anxiety that often underly to the visible behaviours of concern

Power imbalance in every day life

Sleeping sea dragons

(Living the day in a hostile society makes it harder to sleep at night)

Close my eyes
Breathing 2 am
Empty space that tastes
of safety
Waiting for mental
assembly
Repairing the fragments
of the day
That stream either side of
my heart

Close my eyes
Breathing 2 am
Running the day thru
multi-facet filters
Did I make it clear?
Did I make it?
Waiting for the patterns
of nite talk
Click click
Clicking in my mind

Autistic CYP may struggle to notice, recognise and monitor their affective states

Difficulty in recognising and understanding ones' own emotions (known as alexithymia) is affecting 40–65% of individuals and importantly has recently been reported as a key cognitive mechanism in the development on anxiety in autism.

Griffin, Lombardo MV, Auyeung 2015; Maisel M, Stephenson KG, South M, Rodgers J, Freeston MH, Gaigg 2016

I feel good, but do I feel happy? Proud? Serene? I feel bad, but am I feeling shame? stress? sadness? My feelings show up like a stray cat at my door. I don't know where they came from or what their story is. I have to consciously think back to what I experienced that day [@AutistMakingWay](#)

Part of alexithymia & autism is also delayed emotional processing. It's not just missing social cues that someone likes you or doesn't like you. It's getting good or bad news and not having an emotional reaction. It's just not there. You don't have one yet.

[@AutistMakingWay](#)

Autistic people struggle to sleep (N>1000) (Pavlopoulou and Dimitriou, In press. Sleep Medicine) #SleepFocusAutistic

9 in 10 respondents reported poor quality of sleep with frequent and prolonged night-time awakenings

Over 70% said they experience difficulties falling asleep and/or staying asleep,

Sleep issues are associated with sensory issues and high anxiety levels

Around half are unable to stay asleep for long, whilst 4 in 10 experienced nightmares.

“ For me, poor sleep has a day to day impact on my quality of life. A particularly bad night leads to a 'bad autism day'. These are days when my balance is poor, where sensory issues have a more extreme affect than usual and where I can only tolerate other people for a limited time, before my stress levels rocket and I'm desperate to go home.”

(Anonymous, autistic participant)

Parents' views on CAMHS journey from referral to transition- NAS '*You Need to Know*' campaign

- Just one third (32%) of parents believe that CAMHS have improved their child's mental health.
- Less than half (46%) of parents think CAMHS staff know how to communicate with their child.
- Parents are twice as likely to say that CAMHS have improved their child's mental health when they report that an autism specialist has been involved in their treatment.
- 44% of parents find it difficult to get a first referral to CAMHS for their child, with a quarter waiting over four months for a first appointment following referral.

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Sample of common evidence based practices and modifications

Common practices of cognitive behavioural therapy (CBT) for social anxiety includes

- encouraging participants to identify and challenge negative thoughts,
 - encouraging them to enter anxiety-provoking social situations,
- and develop new ways of coping.

Unlike CBT for in non-autistic individuals, treatment also included social skills interventions.

Improvements in social anxiety, depressive symptoms, social skills, and activity levels were noted. Generalisability of results is hampered, however, by the small number of studies and participants and lack of randomised controlled trial conditions employed.

**Spain, D., Sin, J., Harwood, L., et al.
(2017) Cognitive behaviour therapy for social
anxiety in autism
spectrum disorder: a systematic review.**

Useful adaptations in therapy practice may include

- Emotional recognition training
- Integrating special interests, either by integrating them as a tool for use in therapy
- Relaxation strategies
- Visual support and structured worksheets to help autistic CYP to engage with cognitive components of therapy such as multiple choice of rational alternative thoughts to replace socratic-style questions
- Repetition
- Video modelling

**Ozsivadjian, A.; Magiati, I., and Howlin, P. (2011)
Delivering Cognitive Behavioural Intervention For Emotional Disorders
in Children and Young People With Autism Spectrum Disorders: A
Survey of Current Practice Among South London And Maudsley
Psychologists. Clinical Psychology Forum. 220, 20-25**

Note that self-reported measures completed by autistic service users show small, non-significant effect size!

Review

Effectiveness of cognitive behavioural therapy with people who have autistic spectrum disorders: A systematic review and meta-analysis ☆

Lisa Weston ^a, Joanne Hodgkins ^a, Peter E. Langdon ^{b, c}  

.."small to medium effect size overall when CBT was used to treat affective disorders associated with ASD, but this varied depending on the outcome measure used. Analysis of self-report measures was associated with a small non-significant effect size whilst informant-report and clinician-rating measures demonstrated a medium effect size, with CBT being superior to control conditions."

Adapting psychological therapies for autism

Cooper, Loades and Russell, 2018

Almost all therapists reported making adaptations to CBT practice when working with autistic clients.

Therapists were relatively confident about core engagement and assessment skills but reported **less confidence in using their knowledge to help autistic people who ask for their services.**

Therapist confidence was not associated with years of practice or number of adaptations made.

"having to manage parental stresses and anxieties too which put pressure for the therapy to "work" and quickly"

"Inability to concentrate, poor written skills, difficult to adapt models to aid understanding, retention of information."

"Limitation of service I work in to meet needs, e.g. shorter more frequent sessions might have been more helpful"; "learning after client dropped out that I perhaps needed to take things slower"

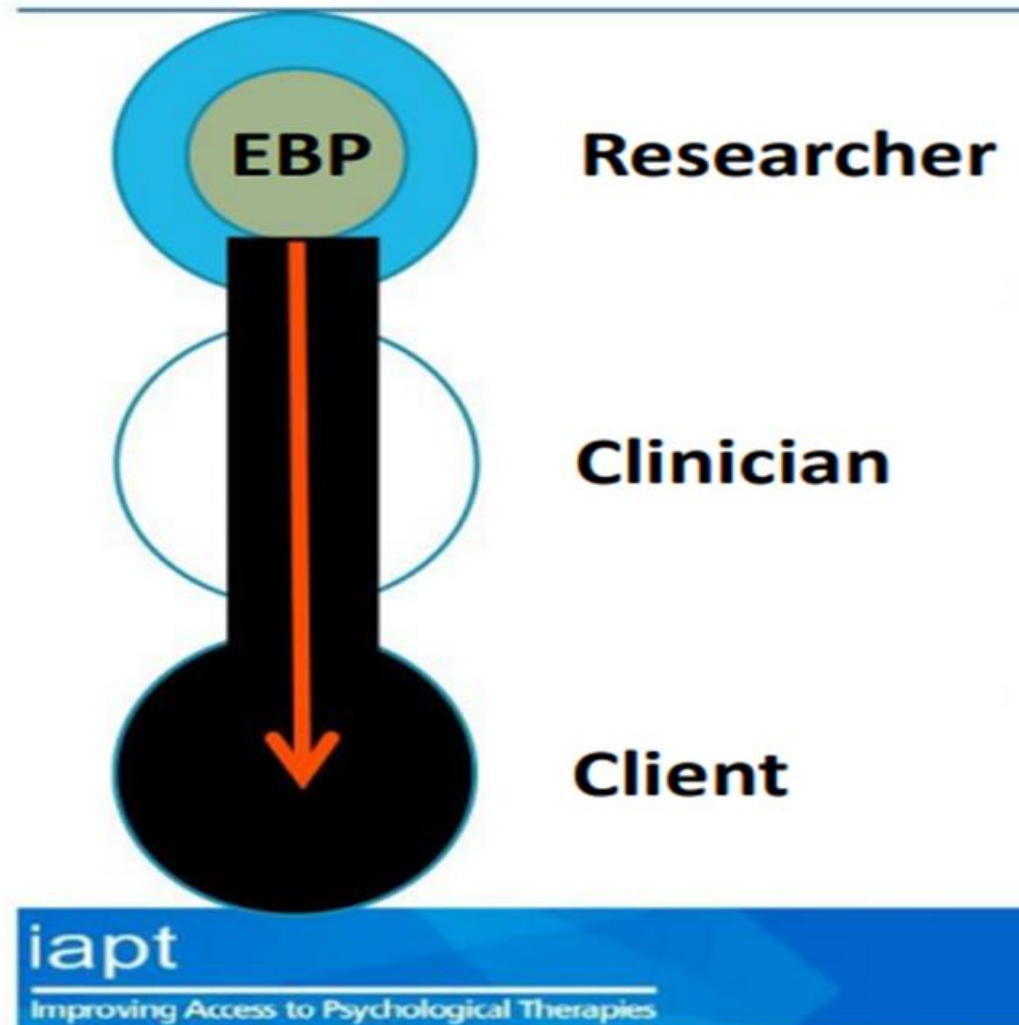
"It can be really hard to shift, cognitive process issues, not being able to move from one topic to another"; "Difficulty with a very fixed world view"

Autistic CYPs' experience of accessing mental health services Crane L, Adams F, Harper G, et al. (2018)

- 57% could differentiate their autism symptoms from their mental health symptoms. The rest either couldn't or were unsure.
- 90% had sought support from clinical services for their mental health, but levels of satisfaction were about 37% (for finding the service extremely/very useful). Fewer people had accessed support from charities/non-profit organisations and overall satisfaction was about 40%: these satisfaction figures are not that dissimilar.
- Only 10% had confidence with regard to accessing formal support for mental health needs. This is interesting considering that 81% of participants had already experienced mental health needs and accessed formal services.
- Lower quality of life (on standardised measures) compared with population norms.



Service users tell us that ITS NOT OK TO DELIVER UNTO AUTISTIC PEOPLE VIA FIELD WORKERS FROM RESEARCHERS' ON HIGH



Important to flip the narrative –Not changing is not an option

**UNIMPORTANT
DISEMPOWERMENT
STIGMA
IGNORED
MISUNDERSTOOD
SCARY
USELESS
DEHUMANISING**

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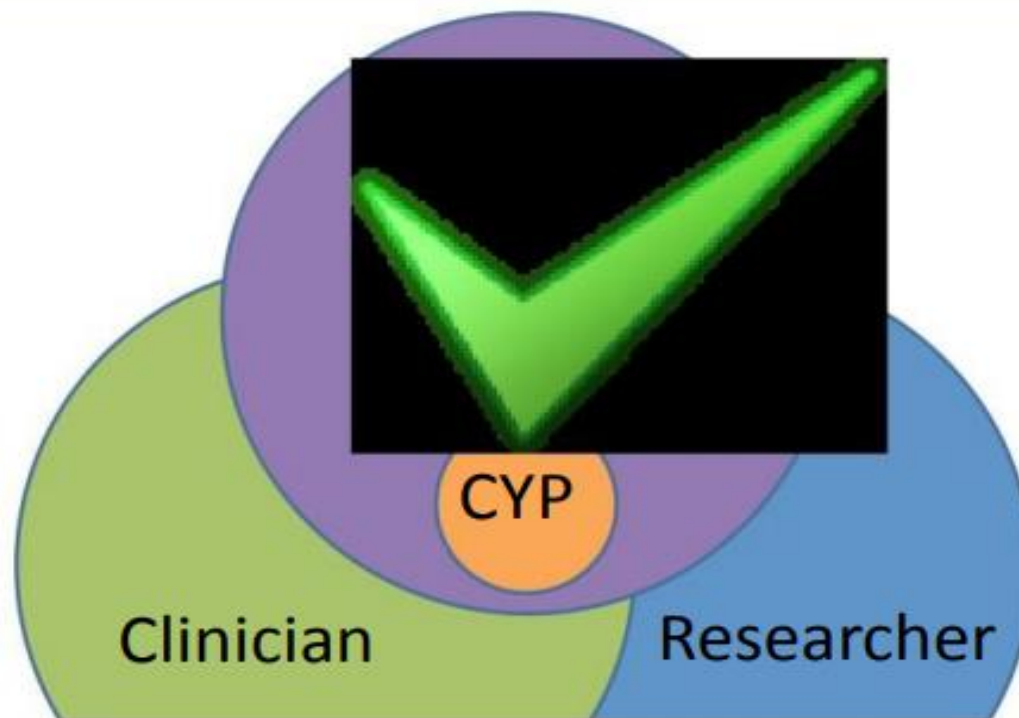
The Children and Young People's Improving Access to Psychological Therapies programme (CYP IAPT)

A service transformation programme that aims to improve existing Child and Adolescent Mental Health Services (CAMHS). Funded by NHS England and Health Education England.

As such, it is different from the adult IAPT model, which is focused on setting up *new* services.

The principles behind CYP-IAPT underpin the development and delivery of the '[Local Transformation Plans](#)' and run throughout '[Future in Mind](#)'.

The autistic young person in the heart of what we do



A fundamentally participatory and co-produced (co-constructed) enterprise in which client, researcher and clinician are all fully engaged

The role of therapist- consider the self you bring in the room

Our society thrives on efficiency, quick answers, role of expert...Where does the your practice stand? How do you deal with pressure from service, families, schools?

Feelings or facts?

People or their problems?

Exploring or advising?

Empathy or sympathy?

Reflecting or leading?

Facing pain and reality or quick fix?

Deficit or Difference? Modification or Mutuality?

“Impairments in the ability to recognise and understand others’ mental states may give rise to problematic interactions.”

Baron-Cohen et al., 2001

“I feel that anxiety and depression I have suffered over the years is the result of my autistic mind having to cope with a neurotypical world.”

Jon Adams, Autistic Adult’s personal account

“Whilst it is true that autistic people can struggle to process and understand the intentions of others within social interactions, when one listens to the accounts of autistic people, one could say such problems are in both directions.

From the earliest written accounts of autistic people one can see numerous mentions of this lack of understanding from others. It is this issue of empathy problems between autistic and non-autistic people being mutual in character that led to the development of the ‘double empathy problem’ as a theory.”

Milton, D. (2012) On the Ontological Status of Autism: the ‘Double Empathy Problem’.

Forms to set goals and measure change; It is about starting a conversation and collaborate- Not scores and numbers!

Agree where you will get and how you when this has happened

Being open to the definitions of wellbeing of autistic CYP

See numbers as an invitation for dialogue and collaboration – remember that many outcomes measures do not cover issues of autistic meltdown, autistic joy, alexythymia, sensory overload etc

Ask autistic people what outcomes they want, rather than asking them to set goals that aim to bend autistic people into a neurotypical ideal of “normal”.

Acknowledging the limitation of templates

The templates do not necessarily include **the personal meaning of the factors and life events**, as opposed to a list of external triggers (abused by stepfather; diagnosed with cancer; bullied at school; etc.).

Psychological theory suggests that the impact of difficult circumstances or events is mediated through the meaning they hold for the individual (Kinderman et al., 2008)

Personal meaning is the integrating factor in a psychological formulation



Good Practice Guidelines on the use of psychological formulation

December 2011

Moving on from modifying to mutual understanding and collaborative practice

Grant me the dignity of meeting me on my own terms.

Recognise that we are equally alien to each other, that my ways of being are not merely damaged versions of yours.

Question your assumptions.

Define your terms.

Work with me to build bridges between us.

Sinclair, 1993

MAKE A DIFFERENCE FROM THE START: Collaborative formulation

The importance of holding multiple conceptualisations of presenting issues, as well as the necessity to employ pragmatic, evidence-based interventions, as matched to collaboratively-agreed goals

MAKE A DIFFERENCE FROM THE START:

Collaborative formulation

Informs the co-construction of individual narratives in a way that puts back what deficit narrative of a mental health diagnosis often takes out:

Restores context

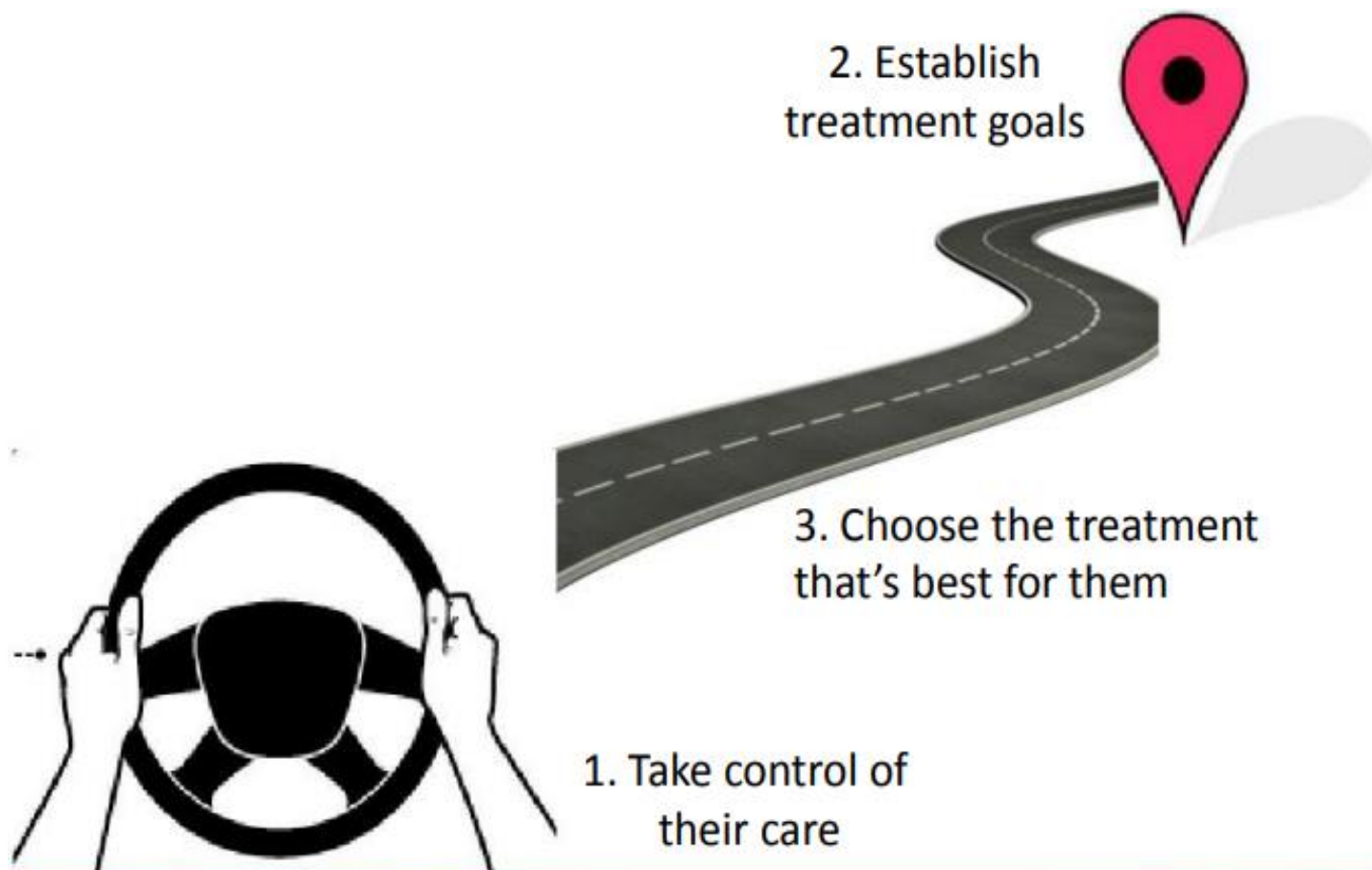
Restores meaning

Restores agency

Restores hope

Ensures the voice of autistic CYP is included

Empowering and working collaboratively with autistic children and young people enables them to



Empowering and working collaboratively with autistic children and young people enables them to

4. Improve their own health



IAPT SERVICE TRANSFORMATION THROUGH IAPT COURSE AT ANNA FREUD CENTRE

PG 2 years Diploma- Email irina.nedelcu@annafreud.org

Involves therapists, supervisors managers and autistic people

Sessions often bring relevant groups together

Actively monitors, supports and facilitates change through ongoing visits to the partnerships

- Provision of further training around outcomes and specific training for professionals not on the course (Short Courses co-designed with autistic experts)

Helping develop conceptual and pragmatic skills to deliver evidence-based practices – Didactic teaching – Practice tutor groups

IAPT AUTISM NETWORK

Monitoring the partnerships' journey of implementation , spread and improvement

Providing ongoing consultation and support to service managers and leads in services

Sharing best practice through implementation meeting groups

Providing bespoke, tailored short courses and ongoing supervision.

Email: georgia.pavlopoulou@annafreud.org

Address the risk of developing mental health difficulties

Psychoeducation on how to differentiate autistic traits/perseverations from comorbidities: sleep problems, OCD, depression. Helping the person know HIS/HER normal and to know where to look for help when feeling different

Provide with emotional support or information about how to access autism specific support groups

Give concrete and personalised meaning to intrinsic motivation: connect with personal ambitions and interests

Practice perspective taking with all family members using mentalising questions to unlock flexibility and strengths for all

Working with people with less typical modes of thinking, experiencing and engagement can challenge and enrich our clinical practice.

Unhelpful- for who?

Challenging-who is challenging who?

Fun, honest

Attention to detail

Rich knowledge on
preferred topics

Experts in their
conditions



We are missing autistic expertise in research and practice- do we value more the voices of non-autistic people about autistic people?

Who is setting the therapy agenda? Who is referring the person? Who is measuring progress?

'Right from the start, from the time someone came up with the word 'autism', the condition has been judged from the outside, by its appearances, and not from the inside according to how it is experienced.'

(Williams, D., 1996, p.14)

CYP IAPT SERVICE TRANSFORMATION PRINCIPLES

a) Full partnership and collaboration with children, young people and parents and carers in all aspects of care and service delivery.

Children and young people's participation is mandated not only in the design of individual treatment packages but also in service design and delivery of care as well as the recruitment, training and appraisal of staff.

b) Regular use of outcome and feedback measurement to guide treatment and service delivery. Participation is further assured using regular feedback through regular outcome monitoring and or outcome monitoring that is adapted. This incorporates a mixture of individualised goal and symptom measures suitable for all those admitted to an inpatient CAMHS service.

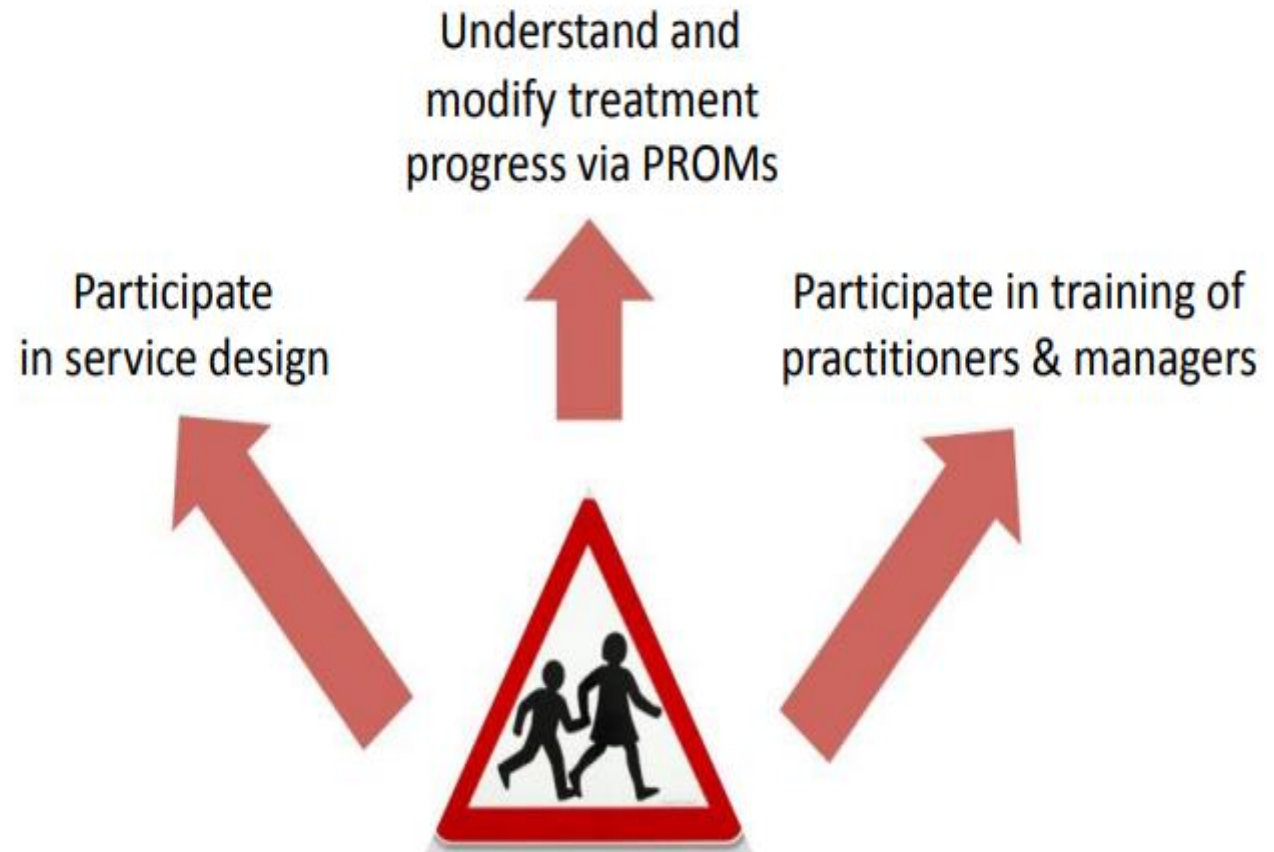
c) Improve access to evidence based treatment and services

Supports the training of staff in standardised curricula of NICE approved and draws on the best evidenced therapies for the treatment of children/young people within an inpatient setting where possible. Whole team training is one of the best ways of incorporating and disseminating evidence based practice and builds on practice based evidence.

d) Consistency and continuity in the delivery of care.

Staff should be trained in the principles that care and interventions should be delivered in consistent way by all team members to reduce the risk of confusion in approach.

How do we aim to empower autistic CYP in IAPT services?



Why is participation important?

Aids the provision of more accessible, appropriate and responsive services

Improves relationships between those using services and those providing them –

Empowers young people and enhances their life opportunities

Helps us develop our skills as therapists, service leaders and services planners

Increases satisfaction with services

Inform planning and service development

Helps service transformation and change

An example of working with values from an IAPT trainee on Improving Participation of Service Users

Children and Young Persons Increasing Access to Psychological Therapy (CYP IAPT) at the heart of the Government's transformation strategy for Child and Adolescent Mental Health Services (CAMHS).

Participation: a Core IAPT Principle

Active role of service users in their treatment and the service

Shared decision making

1st task for IAPT trainees: to learn more about what matters to clients when they receive mental health services and to get an idea of how your service is doing if we use clients' views as a benchmark.



A step into the unknown. Autistic CYPS' experiences visiting for first time a CAMHS service in East London

Uncertainty and lack of information fuelled anxiety before the meeting:

- *"I was like, 'who are these people?' They took me down a corridor with lots of rooms with numbers on and signs. I was thinking 'what is this, are there cameras in the room filming me?'"*

Very positive experiences of staff recounted once appointment started.

- Smiling and straight-forward questions
- *"You're gonna see nice people who will tell you how to make it better for you. It's a happy place....."*

Autistic CYPs suggestions to staff in order to reduce anxiety before CAMHS visit

Expectation setting

What to expect on arrival

Understanding why they are there

What they would have to do

Visual information emphasised

What the appointment room looks like (with photo)

Who they would be meeting (with photo)

Specific details important

Start and finish time of appointment




Interview Plan

- Details about your first appointment
- Information you received before your appointment and how you were feeling before you came.
- Your first impressions when you arrived for your first appointment
- Getting a good understanding of you, your strengths and difficulties at your first few appointments
- Your overall view of CAMHS
- Your feedback on the interview

Samples from East London CAMHS


How Important are each of these in an information leaflet?

Photographs of the waiting area




Really important / Not very important

Photographs of the rooms patients are seen in



Really important / Not very important

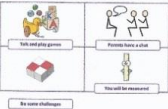
Photographs of the people you might see when you come



Really important / Not very important

Description of what would happen

Today's Plan



Really important / Not very important

Other things: what?

How CAMHS can help people.

Time to start and finish.

Really important / Not very important

Really important / Not very important

Child Session Rating Scale (CSRS)
(Ages 6 to 12)

Name Age (Yrs) 13 Session # Date: 13/03/2019

How was our time together today? Please put a mark on the lines below to let us know how you feel.

Listening

did not always listen to me. / listened to me.

How Important

What we did and talked about was not really that important to me. / What we did and talked about were important to me

What We Did

I did not like what we did today. / I liked what we did today.

Overall

I wish we could do something different / I hope we do the same kind of things next time.

The information on this page is for illustration purposes only. Please go to <http://scottmiller.com> and follow the link for "Performance Metrics" to download the measure

THANK YOU. QUESTIONS?

For information on HEE funded places on PG CYP IAPT AUTISM also visit;

<https://cypiapt.com/recruit-to-train/> or email me

For HEE funded IAPT short courses co-designed and co-delivered with autistic people visit Anna Freud Website;

← → ↺ 🏠 annafreud.org/training/training-and-conferences-overview/training-at-the-anna-freud-national-centre-for-children-and-families/improving-access-to-psychol... ☆ ⓘ

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> [Improving Access to Psychological Services \(IAPT\) for Autistic Children and Young People](#)

Improving Access to Psychological Services (IAPT) for Autistic Children and Young People

21st October 2019 – 22nd October 2019

Details

Location: The Kantor Centre of Excellence, 4 - 8 Rodney Street, London, N1 9JH

[Map](#)

Length: 2 days

Times: 09:30 – 16:30

Tutors

[Dr Georgia Pavlopoulou](#)
[Ann Memmott](#)

[Marriana Murrin](#)

[Dr Damian Milton](#)

[Julia Arora](#)

Price

£00.00

This course is funded by Health England

Education

Events quick search

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