

Scrutinising Child and Adolescent Mental Health Services for Children with Autism





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The National Autistic Society

The National Autistic Society is the UK's leading charity for people affected by autism. We were founded in 1962, by a group of parents who were passionate about ensuring a better future for their children. Today we have over 20,000 members, 100 branches and provide a wide range of advice, information, support and specialist services to 100,000 people each year. A local charity with a national presence, we campaign and lobby for lasting positive change for people affected by autism. For more information, please visit www.autism.org.uk

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Why should overview and scrutiny committees review child and adolescent mental health services for children with autism?

What is autism?

Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people and the world around them. Autism affects 1 in 100 people. It is a spectrum condition, which means that, although people with autism share certain difficulties, their condition affects them in different ways.

Some people with autism are able to live relatively independent lives but others may need a lifetime of specialist support. The main areas of difficulty are in recognising and understanding other people's feelings and managing their own, using and understanding verbal and nonverbal language, understanding and predicting other people's intentions and behaviour and imagining situations outside of their own routine.


People with autism may also experience over- or under-sensitivity to sounds, touch, tastes, smells, light or colours.

Autism¹ is not a mental health problem. It is perfectly possible to have autism and very good mental health. But research has demonstrated that 71% of children with autism develop mental health problems, such as depression, anxiety disorders, and obsessive compulsive disorders (OCD).²

Government research has also found that a quarter of children with autism had self-harmed or had suicidal thoughts.³ Child health mapping shows that 1 in every 10 children who use Child and Adolescent Mental Health Services (CAMHS) have autism – over 10,000 children each year.⁴

Children with autism are particularly susceptible to developing mental health problems, for a range of reasons. They may experience social isolation: one study found that 42% of children with autism had no friends, compared to 1% of other children.⁵ Children and young people with autism can also find it challenging or impossible to express how they are feeling, particularly at times of stress, unhappiness or fear. This struggle to communicate causes frustration and anger, and will often lead to mental health problems.

With the right support at the right time, many of these problems can be prevented. But where mental health problems do develop, because autism is a complex disability, these problems are harder to recognise, harder to evaluate and harder to treat.




In 2010 Sir Ian Kennedy's review "Getting it right for children and young people" called for urgent action to respond to the mental health needs of children and young people, including making services accessible and improving joint-working with other services, especially schools.⁶

The National Institute for Health and Clinical Excellence (NICE)⁷ has also identified a need for further guidance on support for children and young people with autism and is developing two sets of guidelines: one on recognition, referral and diagnosis (expected to be published by September 2011) and a second on management of the condition in children and young people (expected in 2013/14).

In 2010, research by the National Autistic Society (NAS)⁸ found that nationwide CAMHS were failing to improve the mental health of as many as two thirds of children with autism. NAS identified three key improvements to delivering effective CAMHS for children with autism:


- ◇ training CAMHS staff to identify signs of autism in children and make reasonable adjustments
- ◇ specialist staff and services to successfully diagnose and treat mental health problems in children with autism
- ◇ using accurate data about the needs of children with autism and how current services are performing for this group to inform commissioning, supported by children, families and professionals.



A lack of support for their mental health problems not only leads to children's needs escalating, it can also have an impact on the mental health of other family members: the National Autistic Society found that 29% of parents said that they and other members of the family (apart from the child with autism) have needed support from mental health services. Mental health problems can also have a financial impact, with over half (56%) of parents having to reduce their working hours as a result of their child's mental health problems.

Given the high proportion of children with autism who experience mental health problems and access support from CAMHS, this is an area where overview and scrutiny committees could add value, ensuring that local services are delivering good outcomes for this group.

In a time when public finances are increasingly stretched, this is also an opportunity for OSCs to ensure that funding is being used effectively to avoid more costly interventions in the longer term, in some cases into adulthood.



10 Questions to ask

1. How does an understanding of needs influence commissioning?

Joint Strategic Needs Assessments (JSNAs) should reflect the needs of the whole population, yet although 2,500 people in the average local authority area will have autism, just 20% of JSNAs currently mention autism.⁹ OSCs could ask questions about whether mental health support for children with autism is included in strategic planning tools – for example:

Who has responsibility and accountability for commissioning CAMHS locally?

How do the JSNA and other strategies address the needs, including additional mental health needs, of children with autism?

Is there a specific CAMHS strategy and how does this include diagnosis and support for children with autism, including their additional mental health needs?

How do local strategies support integrated working across services? For instance, how do those supporting children with statements of special educational needs work with CAMHS? Can local data be broken down by type of disability?


Does the local service specification for CAMHS include the diagnosis and management of children with autism?

Do commissioners work with schools to identify need?

2. How can services support better outcomes for children with autism?

NAS research suggests that waiting times for children with autism in some areas are longer than for other children. In order to understand how services can successfully support children with autism, OSCs could compare outcomes between children with and without autism, for example:

How is waiting time data for children with autism compared with waiting time data for other children to identify improvements supporting better outcomes?



How is data about 'rates of return' for children with autism and mental health problems compared with 'rates of return' for other children (how many are discharged from CAMHS and subsequently re-referred)?

How could greater flexibility in the duration, frequency and number of appointments lead to more effective interventions for children with autism?

How are outcomes from CAMHS for children with autism and mental health problems compared with outcomes for other children? What action is taken or planned to improve poor outcomes?

3. Are CAMHS professionals skilled in autistic spectrum disorders?

Mental health problems in children with autism are harder to recognise, evaluate and treat. To work successfully with children with autism, CAMHS staff need to be able to identify potential signs of autism in children and adapt behaviour (particularly communication) accordingly. For example, make reasonable adjustments such as flexibility in the duration, frequency or location of sessions. As well as reflecting good practice, this is in line with the Equality Act 2010.

Have the skills of CAMHS staff been reviewed to ensure compliance with standards advised by the Quality Network for Community CAMHS?¹⁰


What actions are planned to address any shortfall in skills for working successfully with children with autism?

What specifications do commissioners make about workforce development in their contracts with providers?

Do CAMHS staff receive any training in autism? If yes, what does this training involve?

4. Is there specialist autism support in the area?

Providing mental health support to a child with autism is a specialist skill. Many therapies and interventions rely on thought processes and communication techniques that do not make sense to children with autism, and only skilful adaptation can make them relevant and useful.



The National Autistic Society's research suggests that when an autism specialist has been involved in the support of a child, the outcomes and service satisfaction both improve dramatically.

An autism specialist can:

- ◇ recognise and diagnose autism in children (or be involved in a multi-disciplinary autism diagnosis)
- ◇ communicate effectively with children from across the whole autism spectrum
- ◇ adapt the way they deliver mental health interventions to meet the needs of children with autism
- ◇ support fellow professionals to provide an appropriate service to children with autism through training and advice

How many CAMHS staff are autism specialists (according to the definition above)?

What disciplines do 'autism specialists' have? For example, psychiatrist, psychologist, occupational therapist?

Is there a specialist multi-disciplinary autism team or service in the area? Are autism specialists accessible to all children across the area, or only to those living in certain catchment areas?

What opportunities are there for other staff to have support from autism specialists to build capacity within CAMHS?

5. What support is there to help families in a crisis situation?

Some parents of disabled children with concurrent mental health problems regularly find themselves needing urgent, immediate support. In recent years there have been national targets aimed at improving crisis support from CAMHS.

Is there 24 hour cover to meet urgent mental health needs of children and young people, in line with a comprehensive CAMHS service?¹¹ Is cover provided by CAMHS staff who are trained to deal with the emergency health needs of children who also have other additional needs, such as autism?

Can a specialist mental health assessment be undertaken within 24 hours or the next working day, in line with a comprehensive CAMHS

service?

Are CAMHS able to provide any of the following – emergency on-call home visits; emergency appointments – as part of their crisis services?

What measures have been taken to ensure that professionals who may come into contact with children needing crisis services know what is available and how to make a referral? How do families know about the services available in a crisis?

6. Are care pathways for mental health support clear?

Many different agencies are involved in delivering mental health services: from NHS organisations, education and social care to voluntary and community organisations and private providers. Clear pathways are needed so that professionals and families alike know how to refer children and young people with autism for mental health support from services which are able to meet their needs.

Is there a specific pathway for mental health support for children with autism in the area?

What training do Tier 1 professionals (for example, GPs, teachers, social workers) get to help them recognise the signs of autism as well as co-occurring mental health conditions and make appropriate referrals?

Are families of children with autism given information about how they can get a referral to mental health services if needed? Is there any support available for families while they are waiting for a decision to be made about their referral, or while they are waiting for an initial appointment following referral?

Is the process for referrals clear, including the criteria for making decisions about eligibility for services? If someone is not eligible for a service from CAMHS, are they given information about other services that are available locally to promote good mental health?

When children with autism have their initial appointment at CAMHS, what steps are taken to ensure that the person carrying out the assessment has training in autism and that the assessment takes place in a location and in a manner that is likely to lead to an effective assessment being carried out?

Following assessment, what processes are in place to ensure that children referred for ongoing intervention receive support from professionals who specialise in autism?

Is a clear protocol in place for the transition of clinical mental health care for children with autism in receipt of CAMHS in line with the “Implementing fulfilling and rewarding lives - statutory guidance?”¹²

7. Are children, young people and families involved with service planning and delivery?

The involvement of parents and children affected by these issues, as well as frontline professionals, can give commissioners a better understanding of what is needed locally and enable them to get feedback about services that are already available. The Coalition Government has set out a vision for the NHS which says that shared decision-making should become the norm – “no decision about me without me.”¹³

How are children and young people with autism and their families involved in the planning and delivery of CAMHS services? Is there a system for children and young people and their families to give feedback about their experiences of CAMHS? Are children and young people and their families aware of this?

How are clinicians, especially GPs, involved in the planning and delivery of CAMHS services? Are providers able to share their views and expertise to inform the planning and delivery of CAMHS services?

Is there a multi-agency CAMHS Partnership (or other multi-agency planning group) or a sub-group of the Children’s Trust Board or Health and Wellbeing Board which looks specifically at services promoting good mental health and emotional well-being in children and young people?

How do other relevant planning and strategy groups, either autism-specific or pan-disability (such as the local parent/carer forum), influence the planning and delivery of CAMHS services?

8. What support is available for children with autism who are inpatients ?

A higher proportion of the children with autism in the CAMHS system are currently in Tier 4 (inpatient) services than any other children (6.5% compared with 4.5%). Children in Tier 4 are those with the most complex and urgent support needs and are usually extremely vulnerable, particularly as they are no longer in the care of parents or carers who can advocate for them. Generic inpatient units are often difficult environments for children with autism who may become stressed by the high stimulus, unfamiliar environment, and loud and busy nature of these facilities. Because children with autism often struggle to form relationships with others, some may mimic the behaviours of other patients in an attempt to fit in. This makes it all the more important that children with autism are placed in settings appropriate for them and in the care of staff who are aware of such risks and how to communicate with children with autism effectively.

The NHS National Specialised Commissioning Group (NSCG) outlines activities within the NHS that should be regarded as specialised and should therefore be commissioned at a regional level. The NSCG has identified “*neuropsychiatric / neurodevelopmental services for children and adolescents including those with a dual diagnosis*” as a tier 4 specialised service.¹⁴ This definition would include services for children with autism and mental health problems, and further demonstrates that specific services are seen as important for this group.

Are children with autism requiring Tier 4 support able to access autism-appropriate support in their region (i.e. a setting where all staff are trained in autism, the environment is suitable for their needs, and autism specialist staff are always available)?

How many children with autism are in Tier 4 units which would not be considered autism-appropriate according to the definition above?

How many children with autism requiring Tier 4 support are placed outside the region? What are the costs of these placements in comparison to placements in units within the region?

9. Do CAMHS services work effectively with parents and schools?

The Government has noted that Child and Adolescent Mental Health should be everyone's business.¹⁵ For some children with autism, the right support in school can prevent mental health problems from developing in the first place. Where problems do develop, CAMHS need to work with the child's school to ensure consistency of approach and prevent problems from escalating further.

Mental health interventions are most likely to succeed where parents understand how professionals are working with their child, and are given advice or support about what they could do to support their child at home. Mental health problems in one or more children can also have an impact on the rest of the family, and so CAMHS role is to provide support for the whole family, not just the child. Yet The National Autistic Society's research found that a fifth (21%) of parents do not know what treatments their child is receiving. Some parents even reported being blamed for their child's autism or accused of a lack of attachment with the child and poor parenting skills, or of 'molly-coddling' their children.

When a child with autism is under the care of CAMHS, is there regular communication and multi-agency meetings between all the different professionals involved in their care, including the child's school?

Are there any other mechanisms in place to build links between CAMHS and education staff more broadly, for example having a mental health nurse based in schools?

Do children with autism and their families have access to a key worker responsible for coordinating all aspects of their care, including support from CAMHS?

Are parents informed about their child's treatment and given strategies to help them to support their child at home?

What arrangements exist to prevent inappropriate child protection referrals being made in respect of children with autism and their families?



10. Recommendations

Recommendations should always be SMART. This will increase the chances that they will be implemented. SMART stands for;

Stretching—be ambitious and challenging


Measureable—be specific and quantify the recommendations where appropriate

Agreed—try to get ‘buy-in’ in advance and some ownership from those who will have to implement them

Realistic—while being ambitious, there is no point in making generic recommendations that no one can implement

Time-bound—set a date for implementation and review their success at this point

What recommendations can be made in respect of the areas identified above?



Further information—Key references

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- ◇ Standard 9: The Mental Health and Psychological Well-being of Children and Young People

- ◇ Autism Exemplar

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Further information—foot notes

¹The term autism is used throughout this document to refer to all conditions on the autism spectrum including Asperger syndrome

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³Green, H et al (2005), *Mental Health of Children and Young People in Great Britain 2004*, Office of National Statistics: Hampshire: pp. 195 - 209

⁴Wistow, R and Barnes, D (2009), *A profile of child and adolescent mental health services in England 2007/8: findings from children's services mapping*, Durham University; Department of Health, Department of Children Schools and Families

⁵Green, H et al (2005). Op cit

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⁷Soon to be renamed The National Institute for Health and Care Excellence (NICE) following the passage of the Health and Social Care Bill

⁸From You Need To Know, The National Autistic Society 2010

⁹National Audit Office (2009) Supporting people with autism through adulthood. Report by Comptroller and Auditor-General HC 556 Session 2008–09

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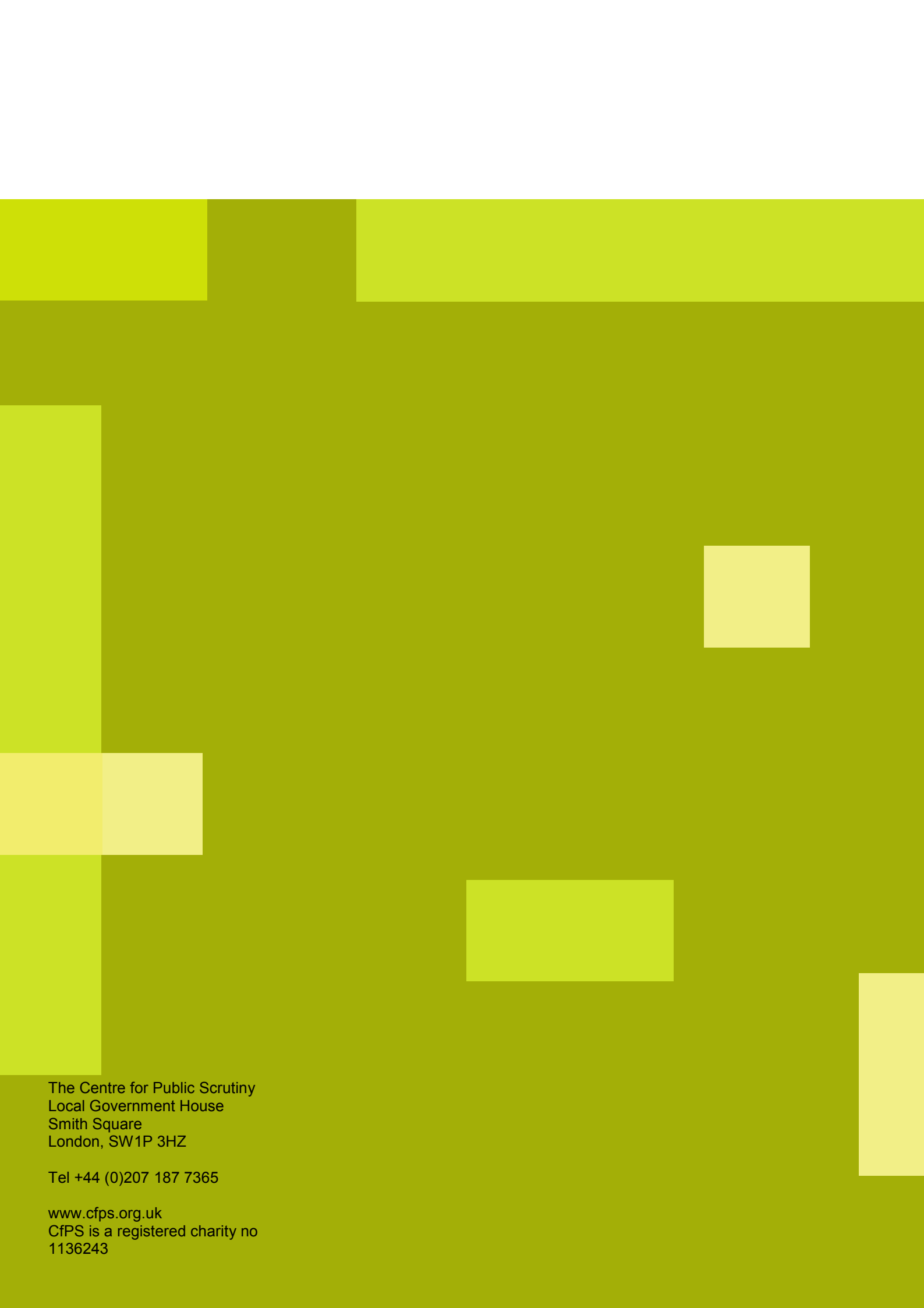
¹¹ National Service Framework for Children, Young People and Maternity Services: The Mental health and Psychological Wellbeing of Children and Young People: Standard 9, Appendix 2 – A Comprehensive CAMHS: *“Arrangements should be in place to ensure that 24 hour cover is provided to meet urgent needs and a specialist mental health assessment should be undertaken within 24 hours or during the next working day.”*

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