

**Improving Support by CAMHS and Social Care  
for Young People in Hertfordshire:**

**Lessons from a Case Study**

**Sally Russell OBE**

**July 2016**

## Executive Summary

Social Care and Child and Adolescent Mental Health Services (CAMHS) are under greater pressure than ever before with exceptional demand and poor levels of funding. The Government has announced that there will be additional support given to these services and it is to be hoped that this will reach the level of practitioners.

In Hertfordshire, there is already a planned transformation of CAMHS services following a review and planned development of Disabled Children's Services. It is to be expected that these will help improve the experiences of young people who are in need of care.

This report describes the experience of Isaac Russell and his family in accessing care over the past six years and suggests a number of specific ways in which services were provided well and others in which we felt they may be provided differently to better effect.<sup>1</sup>

We are unaware of the detail of the work already underway, so it is likely that some of the suggestions we make are already being considered. We also recognise that significant difficulties stem from the historical development of services. Nevertheless, we hope that these child and parents' views will be helpful for commissioners, managers and practitioners.

There are 28 recommendations made covering diagnosis, communication, support available, outcomes, decision-making and system-difficulties with eligibility criteria, timeliness and professional boundaries. The full list is shown in Appendix 5.

In summary, it is suggested that much could be achieved by minor alterations to ways of working and it was concluded that there were four areas to focus upon:

- Amendments in service structures: eligibility criteria, communication and decision-making;
- Development of ways of working to use a broad, collaborative action-planning approach to ensure support is effective, including the use of new resources (such as apps and workbooks) by clinicians;
- An ethos that allows and expects staff to take responsibility, see things through and ensure a timely responses;
- Automatic reviews of the cases where young people have been in the CAMHS system for 1 or 2 years.

In addition, Isaac's particular problems were exacerbated by a lack understanding of Pathological Demand Avoidance, a form of ASD. It is not surprising given that expertise in this area has been limited to date and it is taking time for research to be published. Nevertheless, more and more children are being identified with the condition in Hertfordshire and some training is already being conducted. This now needs to be provided for CAMHS and Social Care professionals.

---

<sup>1</sup> For further information contact Sally Russell  
sally.c.russell@gmail.com @sallyrssl

## 1.0 Introduction

This report describes the experience of Isaac Russell and his family in accessing care for Isaac over the past six years and suggests a number of specific ways in which services were provided well and others in which they may be provided differently to better effect.

Our experiences have covered Social Care (Disabled Children's Team), Tier 3 and Tier 4 CAMHS, and a number of other primary and secondary health services.

Although Isaac's particular needs are his alone, the experiences we had in working with professionals will not be untypical, and are particularly likely to resonate with young people with complex difficulties who require support over a long period. In addition, through our exposure to many different services we gained a wide range of understanding of what was helpful in terms of ways of working.

Isaac was very keen that our experiences should be explained in a constructive manner and he has been part of the development of this report. We are aware that the cost of his current care is now so significant that others may be denied as much care as they might need. It is highly likely that this course could have been averted with better general understanding of Isaac's particular needs and systems that focus on early intervention.

Just before entering the care system, a friend and health visitor suggested to us that:

*"If Isaac's current state of mental health were a result of parental negligence, social workers would be here and taking him into care.*

*But because it is the result of the ineffectiveness of the social care and CAMHS systems themselves, no one even appears to notice and they consider it acceptable to take months to find solutions."*

We recognise that this is the price we all have to pay for systems that focus primarily on legal requirements at a time when resources are tight. However, at such times, a greater focus on supporting young people earlier and more effectively is even more needed and we hope that this report may be a contribution to that effort.

### 1.1 Isaac's Needs

Isaac has complex and unusual difficulties and it has taken a number of years for them to develop and for us all to understand the source of them. He is now just 17 and has been under the care of CAMHS since the age of 11, and under social care since the age of 15-16. He moved into full-time residential care in February 2016.

Isaac's difficulties stem from his Autism Spectrum Disorder. This was difficult to diagnose, firstly, because of his atypical presentation, being rather articulate, sociable and apparently emotionally attuned to others, and secondly, as his particular difficulties with the form of ASD known as 'pathological demand avoidance' are not widely understood.

As a result the sources of problems were only identified and pinned down between the ages of 13.5 and 16 years.

Please also note, Isaac is transgender, so uses male pronouns and has changed his name to Isaac by Deed Poll. Although he had a different name and gender prior to age 13/14, we still use male pronouns for his younger years in line with his wishes.

A summary of Isaac's difficulties is shown in this Table along with our journey towards understanding them and the involvement of key services. A fuller list of interventions is provided in Appendix 1.

Age	Difficulty	Understanding of cause	Health and Social care involvement
4	<ul style="list-style-type: none"> <li>Sleep and behaviour more generally</li> </ul>	Wilful child Psychologist explained we would need to keep him safe in his teenage years	<ul style="list-style-type: none"> <li>Paediatrics behavioural unit</li> </ul>
6 – 10	<ul style="list-style-type: none"> <li>Friendships</li> <li>Low mood for periods</li> </ul>	Characterful personality	
11-13	<ul style="list-style-type: none"> <li>Friendships</li> <li>Mood swings</li> <li>Not growing out of challenging behaviour</li> </ul>	Characterful personality (plus impact of brother's poor health) Both resulting in poor mental health	<ul style="list-style-type: none"> <li>CAMHS – clinical social worker</li> </ul>
13	<ul style="list-style-type: none"> <li>Came out as transgender</li> <li>Self harm</li> <li>Unable to cope in school (though behaviour problems mainly at home)</li> </ul>	Developmental disorder, possible Asperger's  Gender Identity Dysphoria	<ul style="list-style-type: none"> <li>Psychiatrist (continues to see to present)</li> </ul>
13.5	<ul style="list-style-type: none"> <li>Anxiety prevents all school attendance</li> <li>Increasing difficulty eating</li> </ul>	Autism Spectrum Disorder	<ul style="list-style-type: none"> <li>Tavistock Gender Identity Developm Service</li> <li>Dietician</li> </ul>
14-15	<ul style="list-style-type: none"> <li>Withdraws from activities, finds daily life increasingly hard</li> <li>Anxiety &amp; depression</li> </ul>	Family realise Isaac fits 'Pathological demand avoidance' profile	<ul style="list-style-type: none"> <li>Prescribed anti-depressants</li> <li>CAMHS Crisis team, outreach (now called C-CAT)</li> </ul>
16	<ul style="list-style-type: none"> <li>Increasing fatigue and pain, walking becomes difficult</li> <li>All daily functioning is extremely difficult: dressing, washing, drinking etc No weight gain in 2-3 years.</li> <li>Completely isolated</li> </ul>	Physical problems caused by Hypermobility – suspected Ehlers Danlos Syndrome (Brother also diagnosed with CFS at this time – same physical cause)  Diagnosis of Atypical Autism characterised by Demand Avoidance.	<ul style="list-style-type: none"> <li>Assessment by consultant rheumatologist</li> <li>C-CAT referral (rejected)</li> <li>Assessment by Elizabeth Newson Centre</li> <li>Social Care assessment of needs</li> </ul>
16.5	<ul style="list-style-type: none"> <li>Drinking and eating become particularly</li> </ul>	Recognition that worsening mental health due to uncertainty	<ul style="list-style-type: none"> <li>C-CAT</li> <li>Clinical psychologist</li> </ul>

	<p>difficult, need regular heart check-ups</p> <ul style="list-style-type: none"> <li>Anxiety levels reach crisis level – seek sedation medication</li> </ul>	<p>about future, but PDA creates difficulties in finding short term solutions</p>	<p>intervention</p>
			<ul style="list-style-type: none"> <li>Transition to Residential setting</li> </ul>
17	<ul style="list-style-type: none"> <li>All daily functioning extremely difficult</li> <li>Experiencing extreme emotions</li> <li>Using a wheelchair</li> </ul>	<p>Focus on details of PDA (allows some access education and increasing socialisation)</p>	<ul style="list-style-type: none"> <li>Awaiting NHS rheumatology appointment</li> <li>Ongoing CAMHS support</li> </ul>

## 2.0 Initial Diagnosis and Assessment of Needs

### 2.1 What was done well:

- The CAMHS Psychiatrist immediately recognised that the Isaac's problems were attributable to a developmental disorder (some form of Autism Spectrum Disorder).
- The 'Child in Need' assessment reflected our understanding of Isaac's needs well.

### 2.2 What could have been improved:

Isaac was under CAMHS for 2-3 years before seeing the Psychiatrist. He regularly saw an individual therapist through that time and was party to two runs of family therapy (the first to help his brother's anxiety). He was seen by perhaps 5 or 6 professionals.

Once the Psychiatrist had identified a developmental disorder he asked the Community Paediatrician to do an assessment. They were too busy to see us and so the Psychiatrist kindly went through the diagnostic procedures. He identified ASD but tools didn't bring out the traits of PDA (which is a rare condition) and so a full diagnosis wasn't made for a further 3 years.

- CAMHS staff may benefit from simple reminders showing how to 'spot the signs of ASD' which include the more hidden aspects.
- CAMHS staff would benefit from a greater knowledge of ASD in its more atypical forms and specifically of Pathological Demand Avoidance.
- Any child attending CAMHS for 1 or 2 years should be reviewed to check for unidentified causes.

## 3.0 Communication between CAMHS and family

### 3.1 What was done well:

- Staff were friendly and easy to talk to.
- They considered Isaac's difficulties carefully and they involved the family regularly, with Isaac's agreement.

- The Psychiatrist was thorough and ensured Isaac was getting physical check-ups by the GP to ensure he wasn't in danger from his poor eating and drinking.

### **3.2 What could have been improved:**

In the early years Isaac found it difficult to communicate his thoughts and feelings, and sometimes felt that what he had said hadn't been properly heard.

In the later years, the contact between Isaac and Psychiatrist was an update rather than therapeutic intervention. Where they resulted in follow-up actions we would have been happy to have had a shorter discussion, and for the remaining time to be spent on writing the referral to speed things up.

Making new appointments or ringing with queries was often difficult. CAMHS staff keep their own diaries and yet are usually unavailable to talk to and too busy to respond to messages left. At times, it would take many phone calls to get answers to relatively simple questions creating huge anxiety at home and wasting time of staff.

It wasn't possible to have any contact by email, so even reports had to be photocopied and delivered by hand.

While interventions often provided us with suggestions for things to change behaviourally within the home, we were never provided with any written information on the issues and external sources of support. Successful interventions often rely on changing dynamics within the household so outcomes may be significantly improved by simply having explanatory material for people to take away.

4. Exploration of different modes of communication should be the norm to see what is most effective. For example, use of texting or sitting next to the young person rather than facing them.
5. When appropriate, ask clients whether they would like to cut short discussions for more immediate referral-writing
6. Use online appointment diaries. Allow administrators to access diaries so they can give some feedback to parents and support clinical staff with suggestions.
7. It is incredible helpful for a parent to feel that there is 'someone on their side' helping to get an answer when a query is urgent. Current administrators are very good and I believe now do this but it wasn't always the case. There should be clear guidance on 'customer service' rather than 'gate-keeping' ethos for new staff joining.
8. Simple email contact would be of benefit – even just an 'in-box' to receive reports would be a step forwards.
9. CAMHS should provide general written information about sources of support to ALL parents/carers and more specific information for the family on topics as needed e.g. eating disorders, self-harm.

## **4.0 Support available for ASD young people**

### **4.1 What was done well:**

- CAMHS Crisis team signposted us to HARC and ADD-vance (the worker had seen a poster on their noticeboard)

- The Psychiatrist signposted us to a college course / parenting class /organisation as he came across them.
- ADD-vance provided a half-hour free consultation with an expert who recommended materials to help us.
- Arranged by education, we met with a great 'specialist autism teacher' who was able to further identify Isaac's needs.

#### **4.2 What could have been improved:**

Having had a diagnosis of a developmental disorder, it was suggested that Isaac may need to have a different school environment, but we were left to discover what that meant in practice. Professionals relied on having come across information themselves rather than having access to central source of local expertise.

Soon after the initial ASD identification we were referred to CAMHS Crisis outreach. The CPN said to us 'this is completely beyond my level of expertise'. Nevertheless, Isaac liked her and they met for 6 sessions before being referred back to CAMHS. This was probably a waste of resource, though he needed something.

ADD-vance advised that CBT doesn't work well for those with Autism, so we were then reluctant to ask CAMHS for CBT therapy. CAMHS were unable to identify what other forms of intervention might be useful and who might provide them.

I believe these days CAMHS have staff who are more able to support those with Autism, but nevertheless the Psychologist we met had not heard of PDA, Isaac's form of ASD, which requires a different approach.

10. Where 'developmental considerations' are identified, the effect they have needs to be explored and properly understood with the young person and family.
11. Local CAMHS would benefit from having an individual specialise in ASD and knowledgeable about local services including how to get support in education and through social care. This would need little additional training, but the individual would act as a key resource for other clinicians. Having a resource shared with the single point of access might be helpful. (NB Staff I met at Kids HUB were not equipped to fulfil this role, and it needs to be embedded so clinicians can provide the service and not just signpost)
12. Crisis workers need sufficient understanding of ASD and if there is such complexity to be unable to help, appropriate expertise should be found.
13. Although we cannot comment on current CAMHS practice it would be worth considering whether there is value in investigating autism-friendly therapeutic inventions.

## **5.0 Outcomes from CAMHS**

### **5.1 What was done well:**

Careful consideration of issues led to suggestions of support (eg dietician / medication), and there was then a follow-up discussion as to progress at a later appointment.

## 5.2 What could be improved:

I understand that in recent years it is expected that goals are set more explicitly and young people and parents are invited to complete questionnaires so that there is more detailed feedback on progress. Because we have been under the Psychiatrist since the practice came in we have never had the opportunity to work through this sort of process.

A greater involvement of families as sources of expertise and the use of more innovative methods and resources may help young people to progress more quickly.

It is especially important for young people who are 'stuck in the system' that there is a good understanding of the causes of problems and a clear pathway to help them progress.

14. A more goal-oriented approach with actions and timescales may lead to additional work for staff (eg through chasing up opportunities) but it should be more efficient if good outcomes are reached faster.
15. Professionals should seek to unlock the expertise of parents or other family members.
16. Self-help resources such as worksheets, books and apps should be discussed with the young person and with family or carers. *Guided* self-help resources may be particularly effective and take little additional time for the clinician.

## 6.0 Communication between Social Care service and family

### 6.1 What was done well:

- The Child in Need assessment was done quickly, the report shown to the family and the social worker did well to capture Isaac's needs.
- Social workers were friendly and gave clear impression of wanting to help, while not promising what couldn't be delivered.
- Staff provided email addresses so we could send reports, ask questions and more easily make appointments.
- Use of a brokerage process is good and ought to make placements more secure and cost-effective.

### 6.2 What could be improved:

The current call centre system is ineffective, incredibly frustrating and anxiety provoking.

Although the placement referral form appeared accurate it was apparently difficult to interpret by brokerage and some highly unsuitable settings were suggested. Some weeks and quite possibly months could have been saved if the family were able to talk briefly to brokerage rather than relying on social workers and the poor internal communication systems to be the go-between.

17. Calls should go directly through to the social worker or to their support, and support workers should aim to ensure queries are answered and not left and give an accurate picture of when an answer may be provided. The 'customer service' ethos is already exemplified in the service and this should prove more effective with better access.
18. Social workers shouldn't be the go-between for every conversation between the family and management or family and brokerage. Decisions should be taken case-

by-case as to whether it is valuable to get a better understanding of needs through a direct phone call to a family.

## 7.0 Decision-making in Social Care

### 7.1 What was done well:

- We were generally kept informed about who needed to decide what and when it might happen.

### 7.2 What could be improved:

The multi-agency panel would ask question of social workers, brokerage or the health team to which answers were not known, or guesses were made. As a result, it would require further information to be gathered and a further delay.

It appeared that social workers were unable to take responsibility for getting things done and so we were constantly told they were waiting for replies from emails they had sent to colleagues.

19. Family involvement in Panels: There should be an option in highly complex cases where there is uncertainty about the detail of a child's needs, for a 10 minute conference call with the family to resolve issues. Alternatively, a short call between Panel Chair and parents in the run-up to the meeting would significantly reduce the work needed to be done later on.
20. Social workers should be empowered to help ensure the little decisions by management and brokerage are made quickly. For example, they may set notional deadlines in headings on emails, or call to discuss an issue. This would have a hugely positive impact on the family.

### 7.3 Crisis-triggered decisions

We felt that the situation was moved along most quickly when points of crisis were reached. However, the time taken even at these times was lengthy and we felt that we were at a point where there was some risk to Isaac's life which was both extremely upsetting and unnecessary.

21. Speeding up decision-making has financial consequences, but so does delays, and the overall impact on the child and their family means needs become ever greater. Commissioners should focus on a reducing the crisis management approach.

## 8.0 Communication between services

### 8.1 What was done well:

- A Multi-Agency Panel allows Social care, Health and Education to come together to take decisions on cases.
- Professional meetings were arranged to discuss the case prior to decisions being taken.

## 8.2 What could have been improved:

There was also little or no communication of services offered by others. Isaac's school (up to age 13-14) didn't let us know about special needs support and CAMHS didn't inform us of entitlements to benefits, social care local offer, or relevant support activities. For example, we found out about an eating disorders parent support meeting because we happened to see a leaflet in reception. CAMHS (at that time) would not hand out leaflets from Carers in Herts.

In our experience, referrals were made quickly to other health services, such as dietician or GP, but not to education or social care resources.

In terms of daily communication, we found that a range of services had difficulties communicating with each other which was not helped by CAMHS primarily using the telephone and social care using email.

Once social care became involved, the health service left managing the process to them, which is understandable, but it may be that more help to drive the process forwards might have avoided a further intervention by the Children's Crisis Assessment and Treatment Team.

22. A collaborative approach should focus on the child and helping them in the most effective and timely manner. This should include basic information about where else to go for help.
23. The need for involvement of other services should be considered in the first instance and reviewed at least annually.
24. Basic communication systems between professionals needs improvement, and staff need enough support to be able to keep up to date and progress the cases they have.

## 9.0 Eligibility criteria

There were a number of occasions when we were told that Isaac was not eligible for services.

### ***Child in Need Assessment***

A request for an assessment in November 2014 was rejected on the basis that Isaac was too 'high-functioning', despite our protests that he was not able to 'function' at all.

When CAMHS commissioners and management requested an assessment be done 6 months later it was accepted immediately.

High IQ is not relevant to the overall needs of a child and was an artificial barrier that prevented earlier intervention.

### ***PALMS (Positive behaviour, Autism, Learning Disability and Mental Health Service)***

A locum psychiatrist and clinical psychologist separately tried to involve PALMS, recognising Isaac's complex needs. It appeared that PALMS were, at the time,

- restricted to diagnosing ASD where there was no previous diagnosis

- unable to support young people with a high IQ
- unable to give much detailed advice on Pathological Demand Avoidance

### ***Children’s Crisis Assessment and Treatment Team (C-CATT)***

The re-commissioning of C-CATT meant that they were unable to take on young people with a ‘chronic crisis’, or long-standing but severe deterioration in health, but were only commissioned to support those who were at risk of emergency admission.

### ***Education – Education, Health and Care Plan***

Education were unable to conduct an EHC plan assessment as he had been out of school (or home-schooled) for 3 years. As a result Social Care were initially unable to consider a placement with school attached. We were grateful that the Catch 22 situation was resolved by social care and health agreeing to fund the educational placement.

25. Services should be available on the basis of need and while eligibility criteria are helpful to give an indication of the types of individuals who may access a service, professional judgement should always be part of the process.
26. Despite being under strain, new ways should be found to spread some of the expertise in tertiary services. Commissioning would create fewer constraints and enable more collaborative working if outcomes were truly at the centre.

## **10.0 Timeliness**

***Wait for intervention*** from a clinical psychologist for Isaac’s anxiety: **13 months**

***Referral to C-CATT:*** We never met or spoke to the C-CATT Psychiatrist, and it took about 7 weeks to be transferred back to our CAMHS Psychiatrist. As a result, Isaac was without even an anti-depressant prescription for almost **4 months** despite being in a crisis condition.

***Placement selection:*** Having agreed that Isaac needed to move into residential care (which took around a year), the process of then finding the right place took **5+ months**

***Time between Panels:*** Two weeks is interminable when a family is in crisis, and the need to return cases to Panels creates a rollercoaster of emotions. Panels are necessary but it is essential to see progress between panels and it should be expected that changing to the new 3-week time-scales would have a further significant impact on families.

27. With proper service configuration, provision, and improved communication, the wait times for services should be reduced. Services should monitor cases which are taking longer and ensure managers are alerted to help move them forward.

## **11.0 Over-systemisation and professional boundaries**

### **11.1 What was done well:**

- We always trusted professionals to make judgements in the best interests of Isaac

## 11.2 What could be improved:

Options available were always bound by professionals' expectations of their roles and an acceptance of the inflexibility of systems. So a clinical psychologist offers around 6 weekly meetings, a psychiatrist offers the help of C-CATT, a Psychologist, an external health service and / or medication. When it took months for meetings to come along, that was just the way it was.

28. Professionals should continue to strive for more holistic, solution-finding ways of working and continue to advocate internally for the ability to provide support when it is needed.

## 12.0 Conclusion

There were very many good aspects to the care that Isaac received over the past 6 years, and all the individuals we have met have worked hard and done their utmost to help Isaac to better health. We are very grateful and hope that this report does not undermine that work, but helps the experts to find ways to maintain and enhance it.

In our assessment there are two reasons why Isaac has moved into care:

1. A lack of understanding of Pathological Demand Avoidance amongst many of the professionals we met.

Young people with this condition do not behave as others with ASD, and the solutions are quite different. Without knowledge of this it is very difficult to help. There are others with PDA being supported by CAMHS and social care in Hertfordshire so further training of staff in this area would be very beneficial.

2. The inability of professionals to bring appropriate support to bear in a timely manner because of ways of working and systems. In addition, immense time pressures appear to be hampering the creation of innovative solutions.

Many of the problems identified are a result of the way in which systems and professions have developed over very many years, combined with an environment of extremely tight resourcing. Nevertheless, the recommendations are generally low level and practical.

The recommendation which may have the most significant impact on outcomes is the suggestion that clinicians should have access to new resources which they can integrate into their work, maximise the opportunities for young people to help themselves in a guided way. Examples of such resources are shown in Table 2. This broader approach enhances rather than undermines evidence-based practice and along with a dedication to collaborative 'problem-solving' should increase effectiveness.

An example of a flow diagram allowing profiling of a child with extreme demand avoidance is shown in Appendix 2. The first part of an explanatory sheet is shown in Appendix 3 and an example of helpful general information that might be provided for the wider family is shown in Appendix 4. A generalised summ

- A simple exercise to determine how a young person would feel most comfortable communicating
- Use of emojis to explore situations and feelings
- Use of flow charts to help visual actions and consequences
- Use of apps to help change behaviours eg Habitica, the habit-creating role play game
- Joint development of profiles to improve understanding of needs by others, such as Education providers or family members
- Information on support available to families both generally and on specific topics

**Table 2: Some of the types of resources which may increase effectiveness of work**

The impact of Isaac's range of conditions on his health and well-being cannot be underestimated, and recovery (to the extent it is possible) will take significant time.

We all firmly believe that if we had had better knowledge of the source of difficulties at a much earlier stage, and support to find appropriate solutions, the deterioration would have been much less and Isaac may have been able to thrive in a special school without the need for a residential setting, and with significant cost-savings to tax-payers.

We hope that this report provides something of a legacy for Isaac, such that others are helped more effectively.

## Appendix 1: Services Involved with Isaac Russell

### Education:

Specialist Autism teacher  
Home education review  
EHC Plan request

### Dental:

Guys hospital psychologist  
Guys paediatric dental dept  
Eastman dental hospital

### Eating:

Dietician Watford General Hospital  
Watford General Paediatrician  
(GOSH Eating Disorders Clinic)

### Chronic Fatigue / Muscle Pains:

[Neuro-muscular consultant]  
[Specialist Physiotherapist]  
Rheumatology clinic, Watford General

### Mental Health:

Clinical social worker  
Family therapy team  
Psychiatrist

### Mental Health Cont':

Clinical psychologist  
Outreach CPN  
(C-CATT)  
C-CATT Occupational Therapist

[Integrative Counsellor]

### Autism:

(Community Paediatrician)  
(PALMS)  
Elizabeth Newson Centre

ADD-Vance advice

[ADD-vance Coach]

### Transgender:

Tavistock Gender Identity Development  
Service

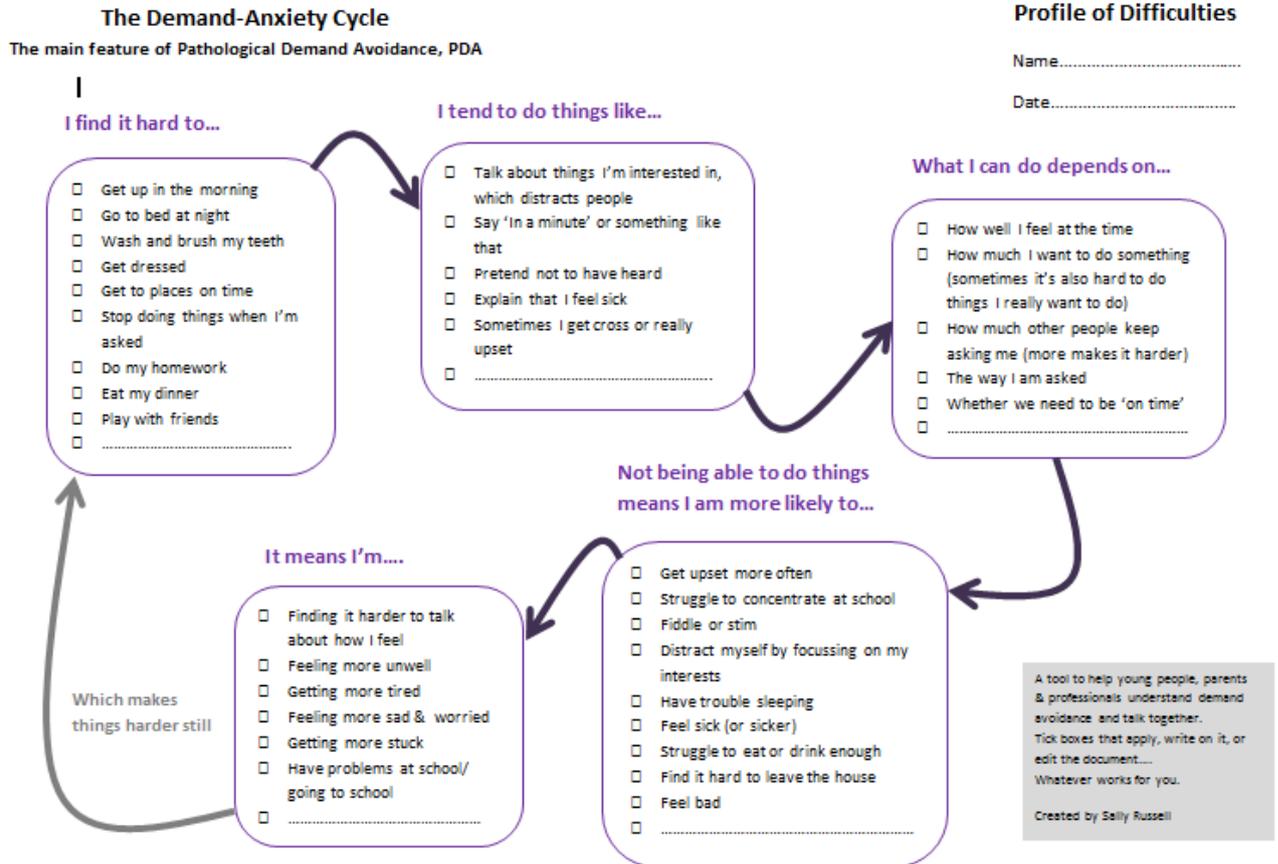
### Social Care:

Disabled children's team  
Kid's Hub  
Buddy

Brackets indicates referral wasn't accepted

Square brackets indicates intervention was self-funded

## Appendix 2: Example of profiling flow-chart



Available for downloading from the PDA Society website

## Appendix 3: Example of more detailed profiling

### What PDA Means for Me

I have Pathological Demand Syndrome. It means my brain is wired differently from most people's. I have some things that I can do better than most people as a result and I find other things very difficult. I get very anxious much of the time and am quite good at covering it up sometimes but it makes life very difficult for me.

I hope this sheet will help you to know what will help me.

PDA Trait	What it means for me	What would help
Demand avoidance: I struggle when I WANT to do something for myself – I often find I can't		
Demand avoidance: If asked to do something directly, I can almost never do it		
Mood lability (extreme mood swings)		
Plans and lack of routines		
Overload and Choices		
Affirmation but not praise		
Impulsivity		
Sensory difficulties		
Difficulty conveying some thoughts		
Easily distracted / tuning out		
Tendency to get absorbed in own 'special interests'		
Difficulty stopping talking		
Unable to understand what people are thinking or feeling		
Have very high levels of anxiety		
<b>I am also good at these things....</b>		

A completed example of this sheet, along with a blank template is available from the PDA Society website

## Appendix 4: Sources of Information and Support

If you have a child who is visiting CAMHS, it may be that you are looking for a bit of advice or to find out more about specific problems, or to see what other support you might be entitled to. For many parents and carers it can help just to talk things through with someone.

Here are some of the national groups that might be useful to you. Some of them are rather stretched, but don't give up if you don't get the help you need first time round – any support for you will also help your young person.

Helplines operate at different times, so you may wish to check online before phoning if you can. Many charities also provide support through email or online chat, available through their websites\*

### **Young Minds**

– young people's mental health, parent helpline  
0808 802 5544  
[www.youngminds.org.uk](http://www.youngminds.org.uk)

### **Mind**

- the mental health charity  
0300 123 3393  
[www.mind.org.uk](http://www.mind.org.uk)

### **Samaritans**

08457 90 90 90  
[www.samaritans.org](http://www.samaritans.org)

### **Citizen's Advice Bureau**

[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

### **Beat**

– national eating disorder charity  
08456 341 414  
[www.b-eat.co.uk](http://www.b-eat.co.uk)

### **Bullying UK**

0808 800 2222  
[www.bullying.co.uk](http://www.bullying.co.uk)

### **Adfam**

– families, drugs and alcohol  
[www.adfam.org.uk](http://www.adfam.org.uk)

### **Relate**

– help with all relationships including parent–child  
0300 100 1234  
[www.relate.org.uk](http://www.relate.org.uk)

### **Family Rights Group**

- confidential advice for families with a child involved with social care services  
0808 801 0366  
[www.frg.org.uk](http://www.frg.org.uk)

### **Coram Children's Legal Centre**

– free legal information and advice  
[www.childrenslegalcentre.com](http://www.childrenslegalcentre.com)

### **Carers in Herts**

- local information and support for parents  
01992 586969  
[www.carersinherts.org.uk](http://www.carersinherts.org.uk)

### **Family Lives**

– listening, supportive and non-judgemental  
0808 800 2222

### **Netmums**

– a supportive community & info on local groups  
[www.netmums.com](http://www.netmums.com)

### **Family Matters Institute**

– advice and support for Dads  
[www.dad.info](http://www.dad.info)

### **Grandparents Plus**

– support for grandparents and the wider family who care for children  
0300 123 7015  
[www.grandparentsplus.org.uk](http://www.grandparentsplus.org.uk)

### **Gingerbread**

– support for lone parents  
0808 208 0925  
[www.gingerbread.org.uk](http://www.gingerbread.org.uk)

### **Contact a Family** –for families with disabled children

0808 808 3555  
[www.cafamily.org.uk](http://www.cafamily.org.uk)

### **The National Autistic Society**

0808 800 1050  
[www.autism.org.uk](http://www.autism.org.uk)

### **24 hr National Domestic Violence helpline:**

0808 2000 247  
[www.nationaldomesticviolencehelpline.org.uk](http://www.nationaldomesticviolencehelpline.org.uk)

### **Aanchal Women's Aid** – support for Asian Women

0845 4512 547  
[www.aanchal.org.uk](http://www.aanchal.org.uk)

## Appendix 5: Generalised Recommendations

### Initial Diagnosis and Assessment of Needs

1. Adopt simple reminders showing how to 'spot the signs of ASD' which include the more hidden aspects.
2. Ensure greater knowledge of ASD in its more atypical forms and specifically of Pathological Demand Avoidance.
3. Review any child attending CAMHS for 1 or 2 years to check for unidentified causes.

### Communication between CAMHS and family

4. Explore different modes of communication to see what is most effective. For example, use of texting or sitting next to the young person rather than facing them.
5. When appropriate, ask clients whether they would like to cut short discussions for more immediate referral-writing
6. Use online appointment diaries which administrators can access.
7. Ensure administrators exhibit a 'customer service' rather than 'gate-keeping' ethos.
8. Allow simple email contact even if just an 'in-box' to receive reports.
9. Provide all parents / carers with general written information about sources of support and more specific information on topics as needed e.g. eating disorders, self-harm.

### Support available for ASD young people

10. Where 'developmental considerations' are identified, the effect they have needs to be explored and properly understood with the young person and family.
11. Local CAMHS needs an in-house specialist, knowledgeable about special needs local services including how to get support in education and through social care.
12. Crisis workers need an understanding of ASD and if there is such complexity to be unable to help, appropriate expertise should be found.
13. Ensure availability of autism-friendly therapeutic interventions.

### Outcomes from CAMHS

14. Use a more goal-oriented approach with actions and timescales to include staff taking a lead on chasing up opportunities for external support (additional work in the short-term, but more effective outcomes).
15. Professionals should seek to unlock the expertise of parents or other family members.
16. Self-help resources such as worksheets, books and apps should be discussed with the young person and with family or carers. *Guided* self-help resources may be particularly effective and take little additional time for the clinician.

### Communication between Social Care service and family

17. Calls should go directly through to the social worker or to their support, and support workers should aim to ensure queries are answered and not left and give an accurate picture of when an answer may be provided.
18. Social workers shouldn't be the go-between for every conversation between the family and management or family and brokerage. Decisions should be taken case-by-case as to whether it is valuable to get a better understanding of needs through a direct phone call to a family.

## **Decision-making in Social Care**

19. Family involvement in Panels: There should be an option in highly complex cases for a 10 minute conference call with the family to resolve queries.
20. Social workers should be empowered to help ensure the little decisions by management and brokerage are made quickly by setting deadlines in emails or discussing directly.
21. Speeding up decision-making has financial consequences, but so does delays, and the overall impact of delay on the child and their family means needs become ever greater. Commissioners should focus on a reducing the crisis management approach.

## **Communication between services**

22. A collaborative approach should focus on the child and helping them in the most effective and timely manner. This should include sharing basic information about where else to go for help.
23. The need for involvement of other services should be considered in the first instance and reviewed at least annually.
24. Basic communication systems between professionals needs improvement, and staff need enough support to be able to keep up to date and progress the cases they have.

## **Eligibility criteria**

25. Services should be available on the basis of need and while eligibility criteria are helpful to give an indication of the types of individuals who may access a service, professional judgement should always be part of the process.
26. Despite being under strain, new ways should be found to spread some of the expertise in tertiary services. Commissioning would create fewer constraints and enable more collaborative working if outcomes were truly at the centre.

## **Timeliness**

27. With proper service configuration, provision, and improved communication, the wait times for services should be reduced. Services should monitor cases which are taking longer and ensure managers are alerted to help move them forward.

## **Over-systemisation and professional boundaries**

28. Professionals should continue to strive for more holistic, solution-finding ways of working and continue to advocate internally for the ability to provide support when it is needed.