A Father's Insights into Navigating the System

Presentation to the All-Party Parliamentary Group on FASD
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Introduction

Good afternoon and thank you for the opportunity to present. I am a parent who adopted two children just over 5 years ago. I am here today as a parent of a child with probable FASD awaiting diagnosis. But I also happen to work for a Clinical Commissioning Group. This has given me another perspective on what we are exploring today and as well as awareness of pathways of care and their purpose. Conflicts of Interested have been noted with my employer and I'll offer some of my reflections on the survey and report.

But first I want to present my experience seeking diagnosis and care for my son who has a strong likelihood of FASD and the impact of delay in diagnosis.

Our beginning…

In the final adoption panel before we met our children for the first time I remember spontaneously saying "they are beautiful kids". And they very much still are. Taylor was 8 then and is now 13. He is good looking and when we first saw a photo of him and his sister we are asked about his biological background as immediately to my wife, Rachael, and I there was something a bit different, in an appealing way, about his appearance. The answer back was there was nothing suggesting a non-European ethnic influence and nothing further was made of this.

He and his sister were placed with us in March 2014 and after 20 months the placement was considered successful and we had received the Adoption Order in December 2015 – a period of about 20 months.

The placement period had had its challenges, but about five months after the Adoption Order Taylor's behavior worsened and we sought help with the LA from which they been placed. Most thinking centered on improving 'therapeutic parenting' but this had no real impact. We knew that, as with many children in care, their family background included what are termed the 3Ds – drink, drugs and domestic violence. For this reason, Rachael started to look further afield in terms of understanding what was going on and came across a seminar on FASD.

We attended the FASD seminar and where cautious at first with what we heard as there seemed a high overlap between our understanding of the impact of trauma and FASD. I asked the speaker to help explain the difference – the Community Paediatrician replied that the main difference was seen in how the child responded to parenting though time; with a child with FASD they did not repair or improve in response to parenting the way a non-FASD child would be expected to.

The journey…

This rang true with our experience and we began to investigate further. We knew that to get a diagnosis underway we would have to start with our GP. Our GP was not aware of FASD but understood our issues and was happy to refer to the Community Paediatrician.

There we had a little luck – the clinician had practiced in Canada and so knew about FASD enough to discuss the likelihood and what was known about our son's family background. But he was unaware of any pathway for investigation of FASD in the UK and had to investigate that. With that established he was happy to begin the necessary screening process with blood tests and referral to a community genetics service run by Great Ormond Street Hospital to rule out genetically related development issues such as Fragile X etc.

The GOSH geneticist confirmed there were no genetics issues but as part of her assessment she took a number of photos of Taylor to review with colleagues. From this she confirmed that he has some mild flattening of the face and epicanthic folds, which may point to FASD.

With this result the GOSH consultant was clearly eager to help us with an onward referral – but to where? She offered some options she could refer to but agreed that on balance they were less likely to be conclusive in their assessment compared to the Surrey FASD diagnostic clinic we had told her about but she was unable to directly refer us there. So, armed with her support, we went back to our Community Paediatrican to seek a referral.

There the Paediatrican told us that he could only access the services our CCG allowed for an NHS referral. As someone working in a CCG I understood this perfectly and we contacted our CCG to check matters. We were told no, the Surrey Clinic was not funded and that our best option, rather than go through a Individual Funding Review, was to speak to the children's LA and ask for funding through the Adoption Support Fund (ASF).

This we did, but it led to a lot of discussion about why we thought this assessment was necessary and what the benefit would be. By now we had seen our son significantly struggle in transitioning to secondary school and he was school refusing. We argued that the detailed assessment offered by Surrey – for was is a complex disorder – would help us unpick what was going on for Taylor and inform both home and school of the better strategies to work with.

Despite these practical benefits, we were told that the ASF could only be used for assessments of a multi-disciplinary format if they included assessment for Attachment. So we gathered together the necessary evidence that there was an Attachment element in the Surrey Clinic's review but this is did not meet with immediate agreement; then oh, two more months had past and having reached a three-year milestone from the Adoption Order the children's LA were no longer providing us post-adoption support and we were transfer to our local LA.

Facing this, and with the difficulties evident in the home and worsening, I chose to make a private referral to Surrey and fund the assessment personally. We are currently in the queue – which we joined in January and hope to be seen this coming October. That said, we are in discussion with our new post-adoption support team and may get funding from our local LA.

Meanwhile… (the impact of waiting)

This has been our diagnosis journey. This takes time – but the child doesn't wait.

Taylor's development continues and he has moved into early puberty. His difficult behaviours have continued and their trajectory worsened which has an impact on his sister and parents and is a real risk to his adoption. He has been seen by CAMHS and has been described as 'very complex' and not within their scope of care or assessment. I can see that his issues are multifaceted – stemming for his very early life and the drugs, drink and domestic violence present at home. But with no completed mental health assessment nor FASD diagnosis it can not be surprising that one of the remarks made at his most recent Child In Need (CiN) meeting this February was "what are we dealing with; do we know?"

The answer is we don't. But without that knowledge major decisions still have to be made. For instance, is it right for Taylor to remain at home? – this tough question is necessary because of his withdrawing from others but also his verbal and physical aggression.

And what if we had known more about FASD when he was transitioning to secondary school? That bridge is now past; but of all that has happened in the last five years this is the event by which time I wish we had been able to secure more knowledge about Taylor in order to better influence the school and plan his transition. We did tell his school about likely FASD but 'likely' fell on ears that had not been educated to its significance and possible accommodations were not made. After a difficult first half of a term Taylor started to cocoon himself at home, became irregular in attendance and had all but stopped going to school by the end of the first term. That was 18 months ago.

Reflections… (some thoughts from a health commissioning background)

FASD is a clinical condition. It is invisible but it is clinical and it is life-long.

How do we expect other clinical Long Term Conditions (LTCs) such as diabetes, COPD or cancer to be managed? We expect early diagnosis – because early diagnosis allows for early management and better outcomes clinically and financially within the health economy. We expect prevention actions too – both in terms of primary prevention to avoid the condition and secondary prevention to help someone with a LTC not deteriorate or experience exacerbations.

The needs for those with FASD are the same. Actions are needed to prevent FASD in the first case, education and advice to women planning conception, and to properly handle and support those who have been affected by alcohol while in the womb. A child's development is strewn with high-stress events – all opportunities for exacerbation of FASD unless understood and managed by those around them. Failure to manage a FASD child well will be costly in whole-system terms of education, social care and health. For example, if as currently planned my son is moved to residential care, and assuming he is in that setting until 16 – although more likely it will be longer – the cost using Sir Martin Narey's analysis of residential care would be in the order of £390,000[1]. This is over 100 times the cost of a FASD assessment, knowledge from which might avert or mitigate the need for residential care. While this is anecdotal, looking at the opportunity the other way around, if proper FASD diagnosis and care plans for 100 children it would need only one child to avoid 2.5 years of residential care for the intervention to be cost neutral. With 100 children I think it is reasonable to expect the economic and social payback to be more covering the gamut of better efficacy of mental health interventions, better use of education, prevention of social harm and use of criminal justice system. A proper costs analysis could be very revealing.

Currently, in my commissioning role if I identify the potential for saving £50,000 in LTC management, my Director wants to know about it. The economic opportunity here looks significant and, along with Martin's survey, deserves asking what is should be done about it? Or, why it is little happening?

To answer that, I trust we all know that NHS and their CCGs are challenged. Working against demographic pressures, innovation pressures and budgetary pressures there is already more than enough to do transform and sustain heath care for the future. In this environment it is perhaps reasonable that CCG's behaviours will be focused on managing to the priorities they are given from either from national bodies (DoH, PHE, NHSE, NICE) or Local Authorities as statutorily required.

With this reality, what commissioning steps would move FASD care forward in a systematic way rather than the patchwork of locally agreed care built around local experts and champions that NOFAS-UK's survey identified?

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[1] Residential Care in England; Report of Sir Martin Narey's independent review of children's residential care, July 2016. This report notes the average cost of residential care as £3,000 per week (page 10); the review's data source is the Children's Homes data pack from the Department of Education, December 2014.

A good model would be that of the national Tuberculosis strategy[2] where a five-year programme began with the population analysis skills of Public Health England to develop the strategy and the commissioning response to be then implemented by NHS England through the CCGs. Similarly, a national review of FASD needs could begin the alignment of resources, current and additional, to develop a national FASD network for care.

The TB approach required national leadership of a governing TB Board; this then allowed the CCGs to follow their cue and pick up the implementation strategy. The current development of Sustainable Transformation Partnerships (STPs) and integrated systems of care should fit well with this approach for two reasons. The first is that it is likely that the regional level is the right one of a sustainable service. The second is that moving from health-only to whole-care-system thinking and planning will be important to understand the impact of FASD care across social care, education and health.

Final remarks…

I recognise that my son's needs are complex and that there are other factors to consider such as Attachment. But understanding if he has FASD, and if so what the key factors are, is crucial.

FASD is recognised clinically in US, Canada, Australia, Scotland… and in the UK. But in all of the former there is maturity about their pathways and systems of care that is lacking in the UK.

This can only lead to delay; a delay in diagnosis, a delay in appropriate care and thereby to exacerbations of the developmental problems the child carries. I have estimated that from a point where Taylor was clinically assessed in December 2009[3], a system of FASD risk assessment and active management could reasonably have led to his being assessed early in his primary care schooling. This assessment could also have informed how he and his parents were supported through adoption as well as his transition to secondary school. By my estimate timeline difference is 7 years and 4 months. Or a perhaps a better way to say this is a FASD assessment would have been is achieved by the time Taylor was 8 rather than his being still unassessed today at 13 ½.

Delays work against carers and teachers trying to understand the needs of the child and a low understanding of FASD will lead to inappropriate or wrong interventions. Proper diagnosis helps shape the response, the care, offered by others. That is why barriers and delays need to be removed.

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[2] Tuberculosis strategy for England, 2015-20; https://www.england.nhs.uk/tb-strategy/

[3] Taylor was assessed by a clinical psychologist Dec 2009. Behaviour profiles included; emotionally reactive, anxious/depressed, somatic complaints, withdrawn, sleep problems, attention problems and aggressive behaviour. Five of these seven were scored as being in clinical range.

I would ask that to remove delays, a national needs-lead commissioning board and programme is set-up by Public Health England that will remove current ambiguities over pathways and commissioning. This should aim to deliver benefits to the children and adults that need assessment as well as the potential for significant economic benefits within our systems of care.

Richard Clements
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Outline timeline comparing actual FASD risk management and pathway progresses with potential alternative scenario with active management.

The table below offers a description of actual timeline experienced by Taylor's family against a hypothetical alternative where the risk of FASD is noted and managed resulting in earlier action to diagnose.

In the actual events description the elapsed time from the detailed psychological report noting significant behaviours (Dec 2009) to FASD assessment completed is 9 years 10 months (assuming completion in Oct 2019). The elapsed time from request of FASD assessment to completion is 2 years.

In the alternative hypothetical scenario, active management achieves earlier diagnosis in a 2.5 year timeframe from the same detailed psychological assessment (Dec 2009) highlighting concerns. The diagnosis pathway, referral to complete, is assumed at 6-9 months based on regional service provision. This then informs and supports primary schooling, adoption management and transition to secondary school.

Date	**Actual events**	**Events with suggested 'active' management**
Oct 2005	*Birth of Taylor* No contemporaneous record of family circumstances.	Risk factors recorded to assist monitoring of development.
Aug 2007	*Family support programme* Taylor, sister and mother received in care programme to help mother parent. Family observations made.	Inclusion of observations in FASD risk rating
Dec 2009	*Psychological assessment of family and children* Prior to Court Order, clinical psychologists	

	reviews family history, including pre-birth, to determine impact on family – especially children. Evidence of impact of alcohol, drugs and domestic violence noted. Child assessment note 5 out of 7 developmental behaviours are in 'clinical range'. Review is used for Court but not added to medical records or to inform care.	Findings noted for FASD risk rating and used to inform care and management plan for Taylor.
Aug 2011	*Taylor and sister placed in for Foster Care.* Reports from foster carers of difficulties experienced.	Inclusion in care plan; decision to initiate assessment for FASD. FASD assessment completed in 6-9 months informing foster care, schooling and adoption matching.
Mar 2014	*Taylor and sister placed with adoptive family.* Start new school in May 2014	Training in FASD management for prospective adoptive parents. Schools informed on management and EHC Plan initiated.
Dec 2015	*Adoption Order granted* 5-6 months later behaviours at home deteriorate. Support sought from LA.	
Oct 2017	*FASD seminar attended by parents* Parents request FASD assessment from GP. Taylor now at secondary school but starts school refusing.	
Jan 2019	*EHC Plan initiated for Taylor; final pre-assessment*	

	work for FASD assessment (genetic results) completed. CAMHS report enables start of EHC plan to start FASD assessment referral completed	
Oct 2019	*Estimated date for FASD assessment*	