Isle of Wight NHS Trust

NHS Isle of Wight Clinical Commissioning Group

14 May 2018

Briefing paper for the Children and Young People's Health and Care Scrutiny Committee

Introduction and background

Since 2012, the Autism Diagnostic and Research Centre, (ADRC), Southampton had been contracted to provide an autistic spectrum disorders (ASD) assessment and diagnostic service for Isle of Wight children and young people under the age of 19 years old. ADRC approached the Isle of Wight Clinical Commissioning Group (CCG) formally in September 2018 to discuss a number of operational concerns and their intention to cease accepting referrals from 31 October 2017 and to focus only on completing diagnostic assessments already underway by end of December 2017.

Since September 2017, the CCG has explored a range of options to address both the backlog of referrals (currently estimated to be in the region of 150 individuals) and a response to new referrals made since the closure of ADRC.

The CCG contacted a range of NHS Trusts that currently provide ASD assessment and diagnosis services including Southern Health Trust, Sussex Partnership Foundation Trust and Solent NHS Trust who were unable to help or commit to seeing any IoW referrals due to capacity and current waiting times within their own areas.

In addition, the CCG explored third sector and private providers including the National Autistic Society and other specialist providers. This needs to be understood in a national context of varying provision and very long waiting times.

The CCG has been working closely with the Isle of Wight NHS Trust, (IoW NHS Trust), to consider whether we can aspire to deliver a co-produced whole life service as unilaterally recommended by all the young people, parents, carers and professionals as identified in the co-produced Whole Integrated Systems Redesign (WISR) workstreams.

The Trust has agreed to deliver this new service for the assessment and diagnosis for children and young people under the age of 19 years old.

Commissioners have held a series of meetings with GP's, Paediatricians, Child and Adolescent Mental Health Services (CAMHS) and Child and Adult Learning Disability Teams to agree implementation of the National Institute for Health and Care Excellence, (NICE) pathway for Autism assessment and Diagnosis for <19's.

Interim Arrangements

The CCG now has an agreed referral pathway in place, ready for implementation when the Trust has recruited the clinical expertise needed to provide a safe, clinically led service for the Island which we expect will be within the next 6 – 8 weeks.

Both the CCG and Trust have worked to establish, as quickly as possible, a clinically robust service in the short term to address the obvious immediate demand as well as for the longer term to respond to the need to invest in a comprehensive and clinically safe, NICE compliant service for Island in the longer term.

These may be found as the documents appended as :-

Appendix A	Clinical Referral Pathway
Appendix B	CAST Screening Questionnaire
Appendix C	ASD Referral letter – ASD
Appendix D	ASD Referral letter – Paediatrics
Appendix E	ASD Referral letter – Family Support

The CCG has also liaised and consulted with social care and education colleagues to work with them to understand the NICE guidance pathway so that this will ensure that only those referrals that require a full diagnostic assessment will progress to the assessment and diagnostic service, through the correct referral channels. This will also ensure that children and young people who require support in schools and who do not yet have a formal diagnosis receive the support necessary to promote wellbeing within the educational environment.

Whilst the CCG has sought to establish a new service as quickly as possible, it has also considered possibilities for an interim arrangement.

Extensive research and assessment of options indicated that there was little or no capacity to commission a mainland provider, either an NHS Trust or private / third sector service. There is a lack of clinical resource both locally and nationally within autism services across all ages and as such, this has contributed to the difficulties faced in securing clinical skills to deliver a service on an interim basis.

In recognising the impact of the withdrawal of ADRC and noting the length of time taken for the Trust to be in a position to confirm service provision, the CCG has ring-fenced additional resources during 2018/19 to address the backlog of referrals and also committed an additional >100% increase on the 2017/18 annual budget to improve significantly, the service for any new referrals going forward.

This is as follows :-

Funding Allocation	Notes	2018/19 Resource
Recurrent Core Funding	Annual baseline funding for service provision	£204,200
Recurrent funding	Additional funding into baseline in anticipation of increased activity	£205,000
Non recurrent funding	Addition funding to address backlog of referrals (2018/19 only	£175,000
		£584,200

Once new staff are recruited the first priority will be to review and triage the back log of referrals and obtain a clearer indication of the amount of work needed.

Each case will be reviewed in line with NICE guidance, and then prioritised for either full diagnostic assessment within the Autism Service or referral to the most appropriate resource for help. Where a full diagnostic assessment for autism is not indicated, parents / carers will be informed on an individual basis at this point.

It should be noted that recruitment of the full team is anticipated to be challenging as there is a national shortage of clinical expertise and many local NHS Trusts are experiencing similarly long waits exacerbated by staffing shortages / recruitment difficulties.

The Trust is in the process of securing the services of Professor Jeremy Turk on a part time basis from 18 June 2018. Professor Turk is a Consultant Child and Adolescent Psychiatrist and a Professor of Developmental Psychiatry at the Institute of Psychiatry and has also held the position of Consultant Psychiatrist with the National Autistic Society's Lorna Wing Centre.

In addition, the Trust is also in the process of engaging the services of Dr Tony Brown, (Consultant Psychologist), formerly of ADRC whose priority will be to commence work on the backlog of referrals. Again, we expect him to commence work within the next 4 weeks.

As soon as the CCG has confirmation of timescales we will promptly share this with families, carers and partners.

The CCG will also continue to update families and carers as well as our partners on progress through individual contact, social media and through the CCG, Trust and Council websites. The CCG has already responded to a large number of individual enquires and will continue to do so on a case by case basis.

Further, we have met collectively with families and carers at two meetings in April facilitated by HealthWatch and attended by approximately 90 individuals and we intend to arrange further meetings over the next 4 – 6 months.

We are working closely with our education colleagues and note that this is a matter of significant concern for families and carers. We will continue to communicate with senior education colleagues, particularly those with responsibility for the provision of Special Educational Needs services and seek assurance that the resources accessible to those without a diagnosis are not disadvantaged by the education system.

We acknowledge that the timings have slipped due to recruitment and we also realise that our general communication has not been as comprehensive as it may have been and as such, we undertake to be more robust to give assurance that all affected by this are kept appraised of developments.

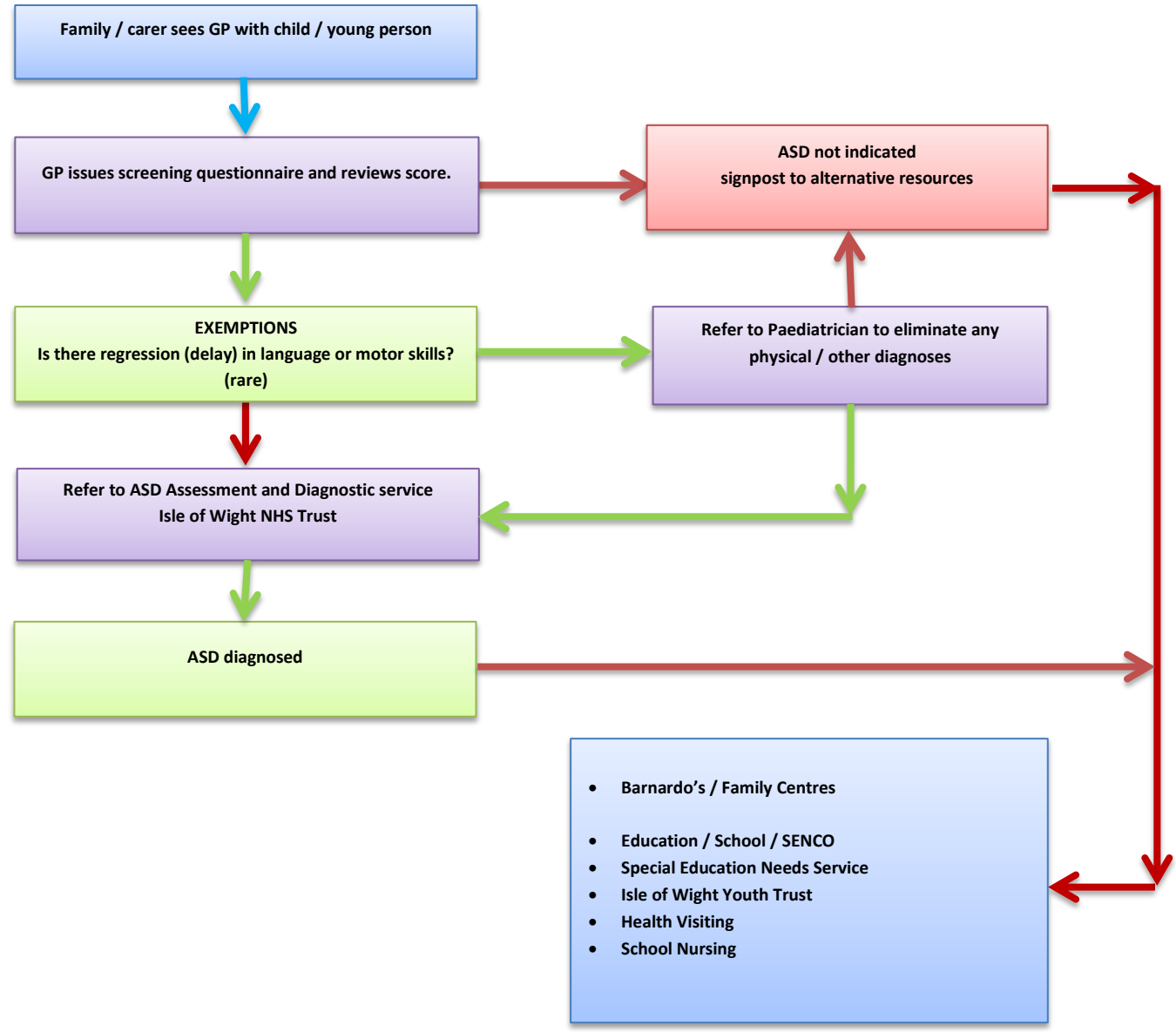
The Clinical Commissioning Group (CCG) and Isle of Wight NHS Trust takes very seriously, any distress or anxiety faced by parents / carers as they continue to wait for news of their child`s referral and /or assessment. We would like to give assurance that our priority is to ensure that the service we set up is as safe and effective as possible.

The steps we are taking at this stage will help us ensure that this is the case however progression has been slow due to lack of clinical resources and we do acknowledge the need to expedite establishing a new service as promptly as is possible.

Gordon J Pownall
Deputy Head of Commissioning
Children and Young People, MH, LD and Dementia

16 May 2018

Appendix A – Agreed Autism Assessment and Diagnostic Pathway for Children and Young People



Isle of Wight NHS Trust

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Appendix B – CAST Screening Questionnaire

Please ensure that this form is fully completed– any gaps in information or responses will result in the form being returned to you for full completion.

Please note that in providing the information on this questionnaire, your consent is assumed to share this confidentially with health and / or social care and / or education colleagues who may be approached for additional information or clarification on the information provided below.

Child / Young Person's Name				**Age**		**Gender**	**M / F**
Single or multiple birth				**If multiple, order number**			
Name of Parent / Guardian				**Birth parents Occupation**			
Age parents left full time education	**Father**		**Mother**				
Address of current residence							
	Post Code			**Telephone Number**			
Address of school							
	Post Code			**Telephone Number**			

Name of GP		**Name of GP Practice**	
Address of GP Practice			
	Post Code	**Telephone Number**	

For GP Practice Use Only

Date of Initial Consultation (GP)			**Date form received back at GP Practice**			
CAST						
Action Taken	**Local / Other**		**Paediatrics**		**ASD Clinic**	
Date Parent / Guardian Informed						

Please read the following questions carefully and circle the appropriate answer for every question. All responses are confidential.

Question No	Question	Response	
1	Does s/he join in playing games with other children easily?	YES	NO
2	Does s/he come up to you spontaneously for a chat?	YES	NO
3	Was s/he speaking by 2 years old?	YES	NO
4	Does s/he enjoy sports?	YES	NO
5	Is it important to him/her to fit in with the peer group?	YES	NO
6	Does s/he appear to notice unusual detail that others miss?	YES	NO
7	Does s/he tend to take things literally?	YES	NO
8	When s/he was 3 years old, did s/he spend a lot of time pretending (e.g., play-acting being a superhero, or holding teddy's tea parties)?	YES	NO
9	Does s/he like to do things over and over again, in the same way all the time?	YES	NO
10	Does s/he find it easy to interact with other children?	YES	NO
11	Can s/he keep a two-way conversation going?	YES	NO
12	Can s/he read appropriately for his/her age?	YES	NO
13	Does s/he mostly have the same interests as his / her peers?	YES	NO
14	Does s/he have an interest which takes up so much time that s/he does little else?	YES	NO
15	Does s/he have friends, rather than just acquaintances?	YES	NO
16	Does s/he often bring you things s/he is interested in to show you?	YES	NO
17	Does s/he enjoy joking around?	YES	NO
18	Does s/he have difficulty understanding the rules for polite behaviour?	YES	NO
19	Does s/he appear to have an unusual memory for details?	YES	NO
20	Is his/her voice unusual (e.g., overly adult, flat, or very monotonous)?	YES	NO
21	Are people important to him/her?	YES	NO
22	Can s/he dress him/herself?	YES	NO
23	Is s/he good at turn-taking in conversation?	YES	NO
24	Does s/he play imaginatively with other children, and engage in role-play?	YES	NO
25	Does s/he often do or say things that are tactless or socially inappropriate?	YES	NO
26	Can s/he count to 50 without leaving out any numbers?	YES	NO
27	Does s/he make normal eye-contact?	YES	NO
28	Does s/he have any unusual and repetitive movements?	YES	NO
29	Is his/her social behaviour very one-sided and always on his/her own terms?	YES	NO
30	Does s/he sometimes say "*you*" or "*s/he*" when s/he means "*I*"?	YES	NO
31	Does s/he prefer imaginative activities such as play-acting or story-telling, rather than numbers or lists of facts?	YES	NO
32	Does s/he sometimes lose the listener because of not explaining what s/he is talking about?	YES	NO
33	Can s/he ride a bicycle (even if with stabilisers)?	YES	NO
34	Does s/he try to impose routines on him / herself, or on others, in such a way that it causes problems?	YES	NO
35	Does s/he care how s/he is perceived by the rest of the group?	YES	NO
36	Does s/he often turn conversations to his/her favourite subject rather than following what the other person wants to talk about?	YES	NO
37	Does s/he have odd or unusual phrases?	YES	NO
38	Have teachers / health visitors ever expressed any concerns about his / her development?	YES	NO
39	Has s/he ever been diagnosed with any of the following :-		
	Language delay	YES	NO
	Hyperactivity/Attention Deficit Disorder (ADHD)	YES	NO
	Hearing or visual difficulties	YES	NO
	Autism Spectrum Condition, incl. Asperger's Syndrome	YES	NO
	A physical disability	YES	NO
	Other (please specify) :-	YES	NO

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Appendix C – ASD Referral – ASD

Dear Doctor,

Re :- Autism Assessment and Diagnostic Service – Patient referral without developmental delay

Child / Young Person's Name		**Age**		**Gender**	**M / F**
Name of Parent / Guardian					
Address of current residence					
	Post Code		**Telephone Number**		

Following a recent Consultation with the above name patient I would appreciate your opinion on this child who possibly has ASD.

I attach a copy of a completed Childhood Autism Screening Tool and an encounter form containing details of past medical history.

Yours sincerely,

Appendix D – ASD Referral – ASD Referral letter – Paediatrics

Dear Doctor,

Re :- Autism Assessment and Diagnostic Service – Patient referral with developmental delay

Child / Young Person's Name		**Age**		**Gender**	**M / F**
Name of Parent / Guardian					
Address of current residence					
	Post Code		**Telephone Number**		

Following a recent Consultation with the above name patient I would appreciate your opinion on this child who may have some developmental delay in either language or motor skills. The patient presented with ? ASD and may need onward referral to the ASD assessment and diagnostic service at your discretion.

I attach a copy of a completed Childhood Autism Screening Tool and an encounter form containing details of past medical history.

Yours sincerely

Appendix E – ASD Referral – ASD Referral letter – Family Support (no ASD Diagnosis)

Dear Barnardo's,

Re :- Patient Referral to Targeted Early Help Team Service

Child / Young Person's Name		**Age**		**Gender**	**M / F**
		DOB			
Name of Parent / Guardian					
Address of current residence					
	Post Code		**Telephone Number**		

Following a recent Consultation with the above name patient with regard to a potential Autism diagnosis which has not been confirmed **and having obtained permission from them to contact you**, I would appreciate your contacting this family as soon as possible to identify to them, the services you may be able to offer in support of the child.

In particular, it may be that your Family Centre Services and / or Parenting Support Services may be able to offer help and guidance.

Yours sincerely,

Child and Young People Scrutiny Committee
Adolescent Mental Health Services
(CAMHS) Benchmarking Report 2017 Summary

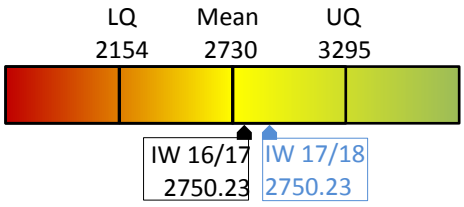
The report provided a national overview of findings for 82 organisations providing community and inpatient CAMHS during 2016/17, including the Isle of Wight NHS Trust. A bespoke report from the Isle of Wight has not been produced for comparisons. However, the below analysis has been undertaken using the data available from the Isle of Wight CAMHS dashboard produced by the Performance Information and Decision Support team.

Referrals

Referrals received (per 100,000 population)

In 2016/17, the Isle of Wight made more referrals than the UK national average and in 2017/18 referral rates increased further above the national average.

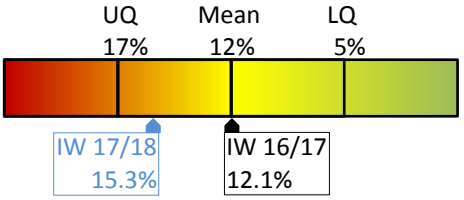
Most referrals on the Island (49.5%) were made by GP's and Hospital Paediatrics making 20% of referrals. The remainder came from other sources.



Percentage of urgent / emergency referrals (%)

Nationally, 12% of LD referrals were urgent / emergency cases and this is the same on the Island. The number of urgent / emergency referrals in 2017 /18 increased to 15.3%.

In 2016/17, the number of people admitted to a bed based service on the mainland was 18 plus 2 to a local Mental Health Ward. In 2017/18, this increased to 39 young people admitted to a bed based unit on the mainland plus 3 referred to a mental health ward.

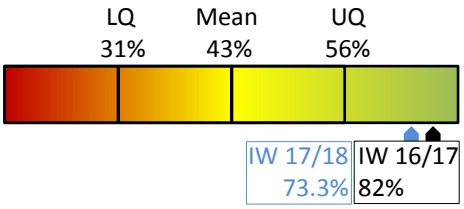


Waiting Times

Percentage of referrals to treatment seen within 6 weeks (RTT %)

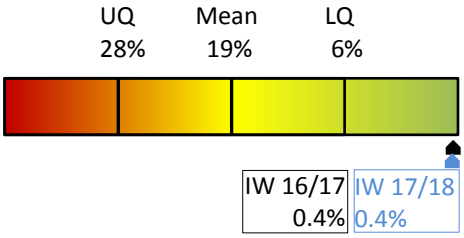
On the Island, 82.2% of people referred were seen within 6 weeks compared with the national average of 43%.

Although the majority of people are still seen within 18 weeks, waiting times have increased with people waiting longer and falling within the 6-18 week category during 2017/18.



Percentage of referrals to treatment seen after 18 weeks (RTT %)

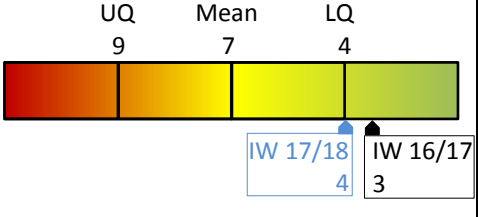
In 2016/17, less than 0.5% of referrals exceeded the 18 week maximum target. This is significantly better than the national average of 19%.

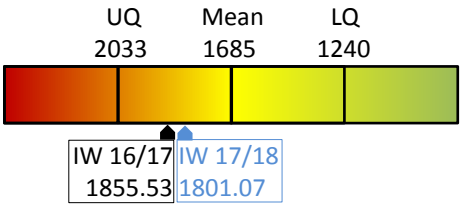
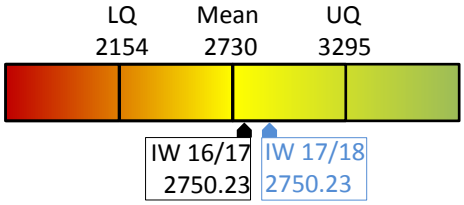
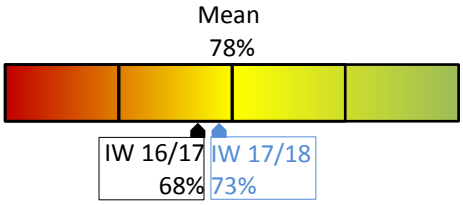
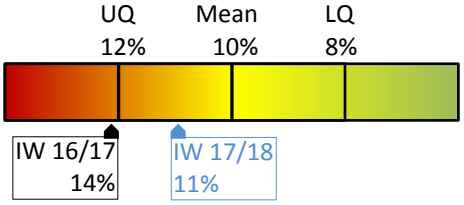
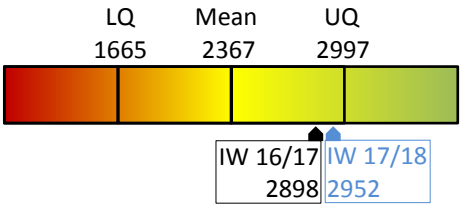


Average waiting time from referral to first appointment (weeks)

Average waiting times on the Island (3 weeks) is better than the national average (7 weeks).

This increased during 2017/18 to an average 4 week average wait due to increased referrals.



Activity	*Caseload (per 100,000 population)* In 2016/17 the Island's caseload was higher than the national average but this decreased in 2017/18. Of those Children and Young People being supported through CAMHS, in 2016/17 12% were on a register (Looked After Children, Children in Need or Child Protection Plan). This increased to 20% in 2017/18.	
	Number of contacts (per 100,000 population) The number of contacts per person shows a significant variation on the Island which may have arisen through a data discrepancy. It is possible that this may reflect being able to dedicate more time to a smaller local caseload, but requires further auditing.	
	Contact type (%) The majority of contacts are on a face to face basis. 68% of people referred were seen individually on a face to face basis and this increased to 73% in 2017/18). This is lower than the national average, but is increasing. Note: The RAG scale has been used for continuity. However, with innovative developments in technology and remote access the percentage split has the potential to shift in either direction and still result in adherence to clinical best practice and improved outcomes.	
	Did Not Attends (DNAs) (%) The Isle of Wight benchmarked significantly higher for DNAs at 12%. Performance has improved during 2017/18 with a decrease to 11%.	
	Discharges from CAMHS (per 100,000 population) The Island benchmarked significantly higher for discharges and also saw an increase in 2017/18. There has been a national decrease in discharge rates from 2015/16 to 2017/18 which the Isle of Wight has not mirrored.	

Finances	*CAMHS spend (per 100,000 population)* The average cost of community CAMHS is an average of £4.9m per 100,000 population. For 2017/18 the Isle of Wight spend equates to £6.4m per 100,000 population. This is amongst the highest but is mostly attributable to the diseconomies of scale regarding the small population of Children and Young People.