Meeting Date	**25th May 2021**	**Agenda Item**	**4.7**
Report Title	**Position Update Neurodevelopment Service**		
Report Author	Michelle Mason-Gawne/Meghann Reynolds/Kathryn Ellis		
Report Sponsor	Jan Worthing		
Presented by	Meghann Reynolds		
Freedom of Information	Open		
Purpose of the Report	The purpose of this report is to provide a further update on the performance position of the Neurodevelopmental Service, Childrens Services. Previous reports submitted have provided an in-depth overview of the service and its structures.		
Key Issues	The key points of this paper are to provide an update on progress of service delivery including demand and capacity issues related to performance.		

Specific Action Required ***(please choose one only)***	**Information**	**Discussion**	**Assurance**	**Approval**
	☐	☐	☒	☒

Recommendations	Members are asked to: • **NOTE** the current Neurodevelopment Service position, the actions taken to increase capacity to date, and to seek support for the further actions identified necessary to build a sustainable service, reduce waiting times and improve performance.

Neurodevelopmental Service Update
Childrens & Young People Services

1. INTRODUCTION

The purpose of this paper is to provide a further update on the position of the Neurodevelopmental team, in order to deliver the Welsh Government target of 80% of children and young people assessed within 26 weeks.

2. BACKGROUND

The Neurodevelopmental Disorders team was established in November 2017, and since then, the team aims to provide a robust and equitable service to children and young people requiring an assessment of Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD) or both.

A paper was provided to the Executive Team in November 2018 outlining the background to the Neurodevelopmental Service, and the ongoing increase in demand causing insufficient capacity to meet the unreported Referral to Treatment waiting times. Further update papers have been produced since this time. This paper was presented to the Performance and Finance committee in April 2021.

The following recommendations were included within the 2018 paper, and have been partially progressed as outlined:

(i) Secure additional funding to close capacity gap – suggested options WG CAMHS funding and ICF funding

The Health Board provided recurrent funding for the expansion of the ND team.

(ii) ***Secure centralised accommodation***.

The team have secured appropriate office accommodation within the newly refurbishment Block D building on the Neath Port Talbot site. Two clinic rooms have been made available to the ND team within the Neath Port Talbot Children Centre. A further clinic room has been provided within the Childrens Assessment Unit on the Neath Port Talbot main hospital site. As the team expands further, there will be a requirement for further space.

(iii) Produce capacity plan to support request for additional funding to close capacity gap and removal of backlog.

See page 8, section 4.

(iv) Source private providers to remove backlog

This service is highly specialised with limited providers across Wales. When exploring the opportunity to outsource to independent providers, it was identified that there was too great a risk to the Health Board to replicate the standards of care put in place within the core ND team. Independent providers were unable to provide appropriate clinical governance along with Quality and Safety assurances to meet the needs of these young people and their families. This significantly affects the services ability to reduce the backlog in a timely manner.

(v) The key investment required is in three areas, assessment, clinical lead, and an administrative co-ordinator role.

The team have appointed a Clinical Lead and Administrative Co-ordinator, who have been in post since November 2019. As an Advanced Speech and Language Therapist, the Clinical Lead functions as a diagnostician for ASD. This has increased the assessment capacity and enables the Consultant staff to assess cases requiring medication, i.e. ADHD or dual cases.

3. GOVERNANCE AND RISK ISSUES

3.1 Current Position

Following successful appointment of the Clinical Lead and Administrative Co-ordinator posts in late 2019; recruitment to further clinical posts identified in the original plan was delayed. This was due to the need to prioritise agreement of job plans/timetables for existing team members, together with securing associated resource requirements such as office accommodation and clinic rooms. The previous Consultant Psychiatry capacity has been reduced over past 12 months due to their retire and return arrangements, resulting in reduced sessions. This has occurred since the agreement of the additional funding in 2018 to increase capacity to meet increased demand on the service.

The team have recently appointed an additional Clinical Nurse Specialist (0.8WTE) and two Specialist Speech and Language Therapists (1.6wte, of which 0.6 wte is a replacement post of a leaver). The new staff joined the team throughout February 2021 to April 2021, with plan to complete a period of induction training during their initial first few weeks.

The team have now been asked to review plans to recruit to the remaining posts outlined in the original proposal, including the vacant Consultant psychiatrist's capacity. The long term absence of another clinical member of staff needs to be backfilled in order to increase capacity opportunities and options of how to do this in the best way are being explored

In addition, training in waiting list management and capacity planning continues to progress, together with refining referral pathways and processes. This remains a newly formed team, and what would be considered standardised processes in other established services continues to be a challenge culturally.

Covid-19 has inevitably had an impact on the ability to undertake assessments routinely. The ND team were one of the first teams within the Division to lead the digital appointment initiative in early April 2020 and since the introduction of Attend Anywhere have conducted 359 new and 1244 follow-up appointments virtually. This function has enabled the team to continue to appoint patients throughout the pandemic albeit not at the same level due to social distancing guidance. Unfortunately, it was not appropriate to utilise virtual appointments for patients with ADHD because they require a physical examination. This has led to an imbalance in the waiting list, with patients appointed out of chronological order.

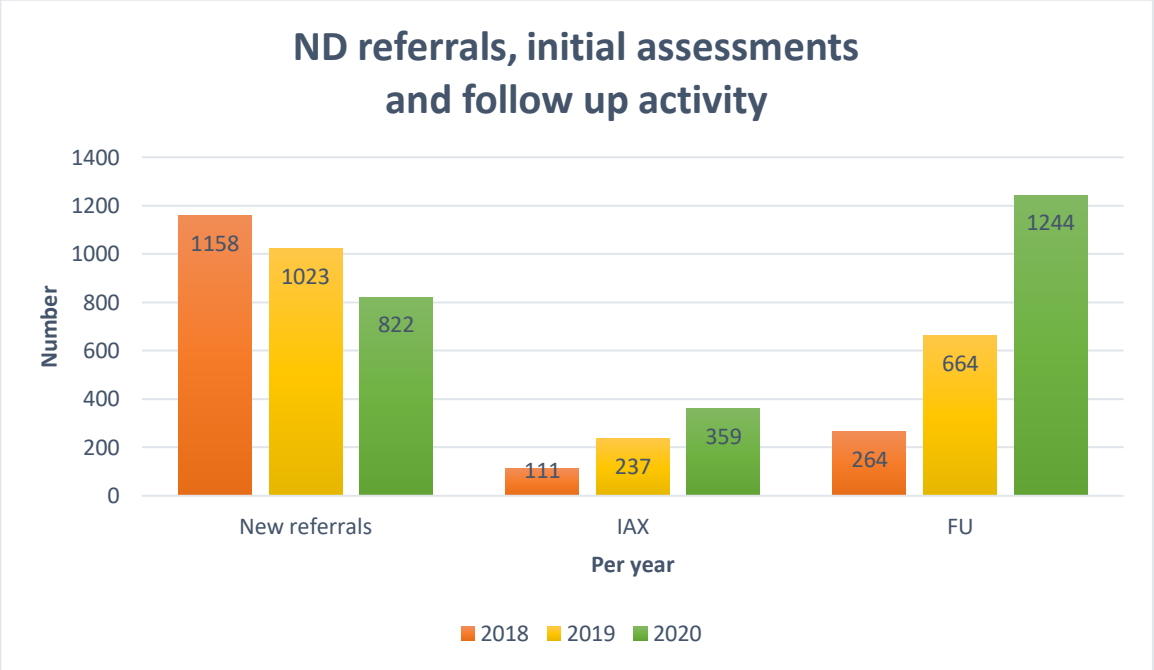
Additional Waiting List Initiatives have been utilised where possible (reinstated very recently) but has been limited and dependent on clinician availability.

3.2 Referrals

There has continued to be a steady increase in referrals since the inception of the service, which peaked during the summer of 2018/2019 at around 100 per month. Since 2019/2020, this has settled at an average of 67 per month currently. Surprisingly, there has been little reduction since school closures due to the pandemic. The current referral rate remains much higher than the current planned capacity, which contribute to the long waiting times experienced by our patients and families.

The graph below illustrates referrals received, together with the initial assessments and follow up activity delivered over the three-year period 2018 – 2020. It is pleasing to see activity has increased for initial assessments and follow up appointments in order to make diagnosis and provide treatment.

Table 1:



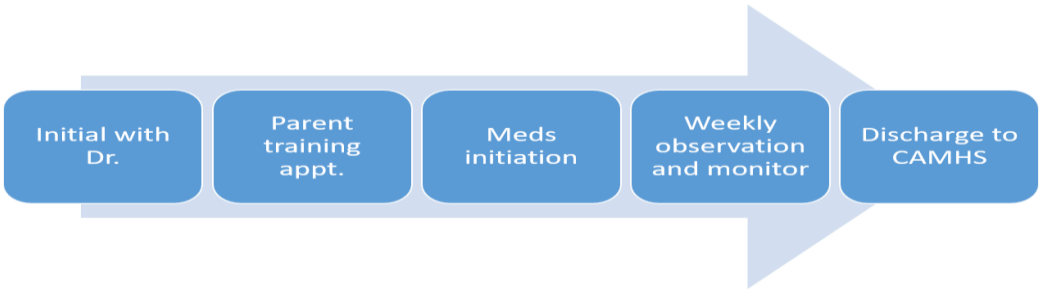
The type of referrals received by the ND team will vary, with the primary reason for referral being ASD. The referral variance provides gives evidence as to the importance of recruiting the appropriate skill mix within the team, as each diagnosis (ASD, ADHD or Dual) will require a different skill mix and a variable appointment pathway. Dual are those children who will be assessed for both ASD and ADHD simultaneously - the coding of these patients on the waiting list will be reviewed as part of the planned validation of the waiting list to ensure there are no duplicate entries.

The terms *initial assessment* and *follow up* refer to specific appointments in the assessment process. Every case has an *initial assessment* (IAX) with the family, which takes 1.5 for ASD, 2h for ADHD and 2.5hrs for dual cases. At this point, they are removed from the waiting list, which makes up the RTT performance data. For each initial appointment, the clinician also needs 4-5 hours of documentation review and report writing.

All cases then have *follow up* (FU) appointments in order to reach a diagnosis. These are not reviews; they are the rest of the assessment for ASD, or the rest of the assessment and treatment for ADHD or dual cases. Overall the total clinician hours required for each case to reach diagnosis are:

- ASD assessment – 15 hours
- ADHD assessment and treatment – 20 hours
- ASD *and* ADHD (dual) assessment and treatment – 30 hours.

ASD and ADHD Diagnosis process;



Dual Diagnosis process;

This process is the combination of each appointment involved in the ASD and ADHD diagnosis process.

It is important to note that every case needs a named diagnostician responsible for the diagnosis. There are also restrictions on which diagnostician is able to undertake which diagnosis pathway. For ASD cases, the Advanced SLT Clinical Lead is named diagnostician. For ADHD or dual cases requiring possible medication, the diagnostician must be a Doctor or Consultant. This affects waiting list management because every case must be correctly allocated to one of the four diagnosticians depending on patient need.

The recent appointment of the Clinical Lead has shown clear cost benefits because the post has increased assessment capacity using an Advanced AHP role. It also allows a cost effective delegated care model with most appointments undertaken by a Band 7 colleague with only one contact with the Advanced SLT and the family. This workforce model provides value based care; less cost and safe outcomes.

The team have continued to offer education and support to schools and parents throughout the Covid period regarding referral submission guidance. As a result, there has been a significant decrease in the number of inappropriate referrals received. In order to further support appropriate referrals being received, the team have recently implemented an electronic referral system. This has been welcomed by referrers and increased efficiency within the administration team.

3.3 Waiting times

The increased demand on service, together with impact from Covid pandemic, has resulted in continued long waiting times for this service. The end of March 2021 waiting list/times position is detailed below:

Table 2

Pathway type	< 11 weeks	12 - 17 wks	18 - 25 wks	26 - 35 wks	36 - 51 wks	> 52 weeks	Grand total
ADHD	68	16	43	15	26	152	320
ASD	87	24	44	49	64	341	609
Grand Total	**155**	**40**	**87**	**64**	**90**	**493**	**929**

It is important to note that 10% of the overall waiting list accounts for the Cwm Taf Morgannwg Health Board cohort of patients, which the ND team continue to provide support as part of the ongoing Service Level Agreement. If the team were to serve notice, this would release much needed capacity within the service but this would create a cost pressure as no posts could be released with this disaggregation. The service would like to repatriate the Cwm Taf Morgannwg referrals which equates to 105 patients but Cwm Taf Morgannwg Health Board (CTMHB) have confirmed that they would not be in a position to action this for at least 12 months.

3.4 Benchmarking and best practice

The development of service models across Wales, and progress against the target, is monitored by the All Wales Neurodevelopmental National Steering Group (NSG), under the umbrella of the "Together for Children and Young People" Programme.

The programme has recently been relaunched in 2020, (T4CYP 2), and the Clinical Lead attends. The ND service forms an integral part of the development of a whole system framework that supports children, young people and their families, and delivers proposals for best practice and service development. It also considers the development of an All Wales Neurodiversity approach. The work will be underpinned by evidence-informed, needs-led, values driven, co-produced services that are digitally supported.

Work stream specific areas include:

- Supporting the further development of pathways and standards

- Engaging, consulting and embedding the standards and ways of working across all Health Boards and Local Authorities.

Identifying, developing and implementing technology based solutions that increase capacity within the system. At the NSG Clinical Leadership Group meeting in November 2020, all Health Boards shared their current waiting time position and activity during COVID.

Swansea Bay Health Board Clinical Lead shared the most current information at that time:

- End of month waiting list, October 2020: 921 waiting, 714 patients waiting over 26 weeks (with only 23% receiving initial assessment 26 weeks)
- Immediate implementation of Attend Anywhere in April 2020
- Confirmed that service has remained open throughout the pandemic albeit at a reduced level between April – October 2020 digitally enabled activity saw delivery of:
    - 207 initial assessments
    - 517 follow up appointments

Other Health Boards shared their most current position at that time:

- Clinics had been closed but reopening in November 2020 with 1100 on the waiting list
- Service currently closed, Attend Anywhere due to start, increasing waiting list as a result
- 1900 on the waiting list, 1500 waiting over 26 weeks, poor digital access
- 500 on the waiting list with 100 waiting over 26 weeks and 100 on an internal waiting list for ongoing assessment. 60 initial assessments completed since March 2020.

- 700 on the waiting list, 600 waiting over 26 weeks, plus an internal waiting list for ongoing assessment for diagnosis.

3.5 Risks

The lack of service sustainability has been included on the risk register since October 2018, with a risk score of 16 for demand on the service and the limited capacity available. The size of the team is small, highly specialist, and is therefore sensitive to normal periods of leave, which have a direct impact on performance.

More recently, a risk has been identified with transition for children and young people to the Integrated Autism Services (IAS) as they approach their 18th birthday. There is no nationally agreed protocol to enable young people to move across to the adult ASD assessment team (IAS) if they approach their 18th birthday whilst waiting for their ND assessment. This means ND must expedite them before they turn 18 years because ND is a Children's Service whose staff are not qualified to assess adults. This leads to waiting list management risks with patients appointed out of chronological order. A meeting has been held but no simple solutions were found. Further work and discussions need to take place to resolve this issue.

The following further accepted risks include:

- As within any team in the current climate, the impact of Covid on the team is a significant risk, both to staff members and with regards to the current restrictions in place seeing patients
- There are also risks associated with long-term sickness absences and HR issues, which are in the process of being resolved.
- Due to the specialist nature of the team, there are risks associated with not being able to recruit the required staff who have the appropriate skill mix for the team.
- As noted above - the impact of having to expedite >17 year olds based on age due to the Integrated Autism Service (IAS) not having capacity to transition patients early.
- Variance in referral rate each month, particular risk in referral surge because of the pandemic and schools not being open.

4. CAPACITY PLAN AND PERFORMANCE

The ND team are committed to continuously reviewing their capacity, in order to ensure each clinician's time is maximised, and as mentioned earlier, they have continued to operate in an altered capacity throughout the pandemic whilst some Health Boards have not been able to deliver.

Capacity has been lost for initial assessments because of both CAMHS consultants retiring and returning to the service, which reduced capacity by loss of their sessions from 1.2 to 0.8. However, the following actions are being taken to increase this capacity within existing allocated resources as follows:

- The Clinical Lead is in discussions with CAMHS regarding additional Consultant hours to replace capacity lost due to retirements. This could be operationalised quickly as current governance arrangements already in place for the two existing Consultant Child and Adolescent Psychiatrists in ND service. If this 0.5 post were confirmed, it would increase capacity to appoint cases waiting for ADHD or dual assessments.

- With further funding, recruitment to Band 7 posts would increase capacity to take cases off the waiting list for ASD assessments. They would function in the same way as the existing workforce with all work delegated by the Clinical Lead as named diagnostician.

Since the appointment of the Clinical lead, there has been, a detailed process mapping exercise completed which has redesigned the patient pathway. Prior to this, there was no specified outline of what appointments were required and when, and there was also no detailed job plans for any member of the team, all capacity took place on an ad hoc basis.

The ND team have recently revised their capacity plan adopting a Prudent Healthcare approach, whereby the workforce have been organised around the specific skills of each member of the team i.e. “only do what you can do” principle. Following initial review, together with these recent new appointments, there is now a noticeable increase to the teams’ capacity due to the team’s continuous efforts.

Table 3, shows the current revised capacity based on 42 weeks per annum (including newly appointed staff included from April 2021) and further proposed resources required to meet the demand (not including clearing backlog). This shows a stepped increase in capacity from March 2021 through to July 2021. Whilst this plan will start to have an impact on delivery of activity, there is still a clear gap. A trajectory of the ND teams’ performance, number of patients waiting, along with the available and proposed capacity is detailed within Table 3 below:

Table 3

2021/22	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar
Added Referrals	42	45	80	45	67	67	107	14	54	65	59	73	42	45	80
Total Waiting	919	934	952	929	954	979	1041	1010	1019	1039	1053	1053	1022	994	1001
Waiting > 26 weeks	694	668	662	647	640	647	635	633	663	653	670	659	614	575	536
Breaches in Month			40	27	28	38	33	39	36	35	34	28	34	34	34
Capacity	21	24	28	35	42	42	45	45	45	45	45	73	73	73	73
Breach - Capacity			12	-8	-14	-4	-12	-6	-9	-10	-11	-45	-39	-39	-39
Difference			290	282	352	375	449	420	399	429	426	437	451	462	508
Performance	24%	28%	31%	32%	35%	37%	41%	39%	37%	39%	39%	41%	42%	44%	49%

Table updated to April 2021 position. *indicates impact of additional staff resource, trajectory will need to be reviewed on quarterly basis to ensure any changes to demand management, number of breach patients converting, waiting list validation and further pathway redesign can be captured and updated within the capacity plan

In addition to the capacity outlined, there will be a requirement to undertake one slot per month for specialist learning disability patients, which can be organised on a case-by-case basis and provided by specialist Consultant from CTMHB.

5. FINANCIAL IMPLICATIONS

The team were allocated £309,000 funding in 2018 to increase capacity. This funding has now been secured on recurrent basis. In order to continue to build a sustainable service, this funding will need to be secured recurrently. The increased establishment will be able to continue to deliver 42 initial assessments per month and the necessary follow-up review appointments to make a diagnosis and prescribe appropriate treatment. Of this funding, £79,652, is being used for additional Consultant hours on a temporary basis but the service

has a potential plan to utilise the funding on a more permanent basis and this capacity is included within the capacity plan of 42 IA's per month seen in table 3.

There are opportunities to further increase capacity from 42 to 73 from July through to December 2021 through a stepped approach whilst recruitment is progressed but this heavily relies on further investment. The cost of the further investment to deliver additional capacity (the increase of 31 assessments monthly from December 2021 onwards) has been estimated at £331,775.

There is a clear requirement to increase capacity further in order to meet demand and develop a sustainable service and acceptable waiting times for our patients through further pathway redesign and expansion of the existing team as outlined above. The backlog of over 400 patients requiring assessment and follow-up appointments to reduce the number of patients waiting will also need to be addressed. The service welcomes the opportunity to submit a bid for any funding that is made available from Welsh Government for Paediatric and Adult Mental Health Services in the imminent future.

The service could also consider disaggregating from the Cwm Taff Morgannwg SLA to diagnose and treat 11 – 16 year olds, which would release capacity to see Swansea Bay patients, however, there are financial risks associated with this action as this SLA is worth £149,805. If we gave notice on the SLA, this would free up clinical time to invest into our service but would be at a cost pressure to the Health Board but this could be part of the solution to closing the demand and capacity gap. However, this would de-stabilise CTMHB service as they have confirmed that they are not in a position to treat these patients for a minimum of 12 months.

6. ASSURANCE

The appointment of the Clinical Lead has increased diagnostic capacity and implemented a clear governance structure with quality assurance. Every case receives standardised clinical care at every stage. Assessments are evidence based using DSM-5, the international diagnostic criteria. The service meets all six of the All Wales Neurodevelopmental Disorders standards, and clinical practice reflects NICE guidelines for ASD (NICE CG 128) and ADHD (NICE NG 87).

The waiting times and lack of sustainable capacity remain a concern for the clinical staff, however, where they are concerned that a specific patient requires expediting, this is discussed and agreed as a multi-disciplinary team and actions taken to ensure all patients remain as safe as possible whilst waiting for their initial assessment.

The service applies Prudent Healthcare principles with a robust model of delegated care from senior practitioners, with a named Doctor or Advanced Practitioner as the diagnostician. Every case is discussed in full detail, in order to reach diagnostic consensus. This model ensures an efficient, safe flow through each assessment stage, within the All Wales Delegation Framework. Family and Friends feedback confirms that parents/carers feel they have been listened to and are satisfied with their care.

The team's efficiency has improved with a routine capacity plan and advance booking system (previously absent). The Clinical Lead and Service Co-ordinator meet weekly with the rest of the clerical team to identify risks to performance based on demand/capacity data. The team continue to embed one system that is values driven, evidence-informed and digitally enabled.

The clinical team are committed to exploring further solutions, including further benchmarking of services, together with working and striving to improve the current position in order to reduce the waiting times for the patients. The service welcomes the opportunity to work with Welsh Government in order to participate in the review of how services are organised, by reviewing demand, capacity and design of our services and others across Wales to develop recommendations and evidence informed options for improving service delivery. This work has been commissioned by Welsh Government and is about to begin imminently.

7. NEXT STEPS

- Continue to take opportunity to further redesign pathway in line with National guidance and standards and explore alternate options to manage demand

- Validation of waiting lists including 'dual assessment' patients

- Undertake further work to understand the true release of clinical time should notice be given on SLA with CTM HB, including analysis of impact on both services.

- Appoint substantively to the remaining Consultant hours in order to step increase capacity again by July 2021 and

- Secure further additional funding to close capacity gap, including exploring options of securing WG CAMHS funding.

- Participate in WG demand, capacity and design of neurodevelopmental service review during 2021

8. RECOMMENDATION

The Quality and Safety Committee are asked to:

- **NOTE** the current Neurodevelopment Service position, the actions taken to increase capacity to date and support further actions necessary to build a sustainable service.

Governance and Assurance		
Link to Enabling Objectives ***(please choose)***	**Supporting better health and wellbeing by actively promoting and empowering people to live well in resilient communities**	
	Partnerships for Improving Health and Wellbeing	☒
	Co-Production and Health Literacy	☐
	Digitally Enabled Health and Wellbeing	☐
	Deliver better care through excellent health and care services achieving the outcomes that matter most to people	
	Best Value Outcomes and High Quality Care	☐
	Partnerships for Care	☐
	Excellent Staff	☒
	Digitally Enabled Care	☐
	Outstanding Research, Innovation, Education and Learning	☐
Health and Care Standards		
(please choose)	Staying Healthy	☐
	Safe Care	☒
	Effective Care	☒
	Dignified Care	☒
	Timely Care	☒
	Individual Care	☒
	Staff and Resources	☒

Quality, Safety and Patient Experience
This paper provides a summary of the key issues and challenges that have a direct impact on service delivery. The service meets all six of the All Wales Neurodevelopmental Disorders standards, and clinical practice reflects NICE guidelines for ASD (NICE CG 128) and ADHD (NICE NG 87).
Financial Implications
The paper provides a demand and capacity plan demonstrating the use of current resources and includes opportunities to increase capacity further from July 2021 and then December 2021 onwards through a stepped approach whilst recruitment is progressed. The additional capacity cost from December 2021 is estimated as £331,775.
Legal Implications (including equality and diversity assessment)
Nil
Staffing Implications
The staff skill base is extremely specialist but the service is confident they will be able to recruit to the proposed additional posts in the near future and also develop staff within service.
Long Term Implications (including the impact of the Well-being of Future Generations (Wales) Act 2015)
N/A

Report History	Briefing to Executive team November 2018
Appendices	Nil