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Bwrdd Iechyd Prifysgol Bae Abertawe Swansea Bay University Health Board



Meeting Date	23 rd Novemb		Agenda Item	4.3		
Report Title	Position Update Neurodevelopment Service					
Report Author	Michelle Maso Clinical Lead	Michelle Mason-Gawne, Divisional Manager/Kath Ellis, Clinical Lead				
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Presented by	Michelle Maso Clinical Lead	on-Gawne, Divis	ional Manager/ł	Kath Ellis,		
Freedom of Information	Open					
Purpose of the Report	The purpose of this report is to provide a further update on the performance within the Neurodevelopmental Service, Childrens Services. This report will also include the strategy to get to best practice position					
Key Issues	The key points of this paper are to provide an update on progress of service delivery, including actions required to achieve best practice.					
Specific Action	Information	Discussion	Assurance	Approval		
Required	\boxtimes		\boxtimes			
(please choose one only)						
Recommendations	Members are	asked to:				
	position date, a identifie	the current n, the actions ta and to seek sup ed necessary to waiting times ar	aken to increas oport for the fu build a sustair	e capacity to urther actions nable service,		

Neurodevelopmental Disorders Service Position Statement Childrens & Young People Division

1. INTRODUCTION

The purpose of this paper is to provide an updated position statement of the Neurodevelopmental Disorder service, including strategy to get to best practice position.

2. BACKGROUND

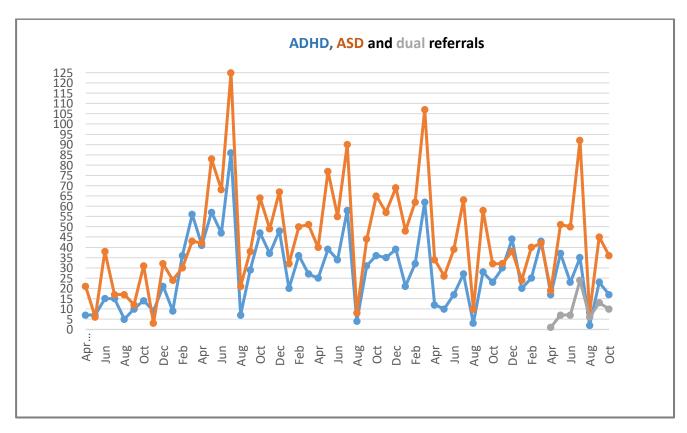
The Neurodevelopmental Disorders (ND) team was established in November 2017, and since then, the team has aimed to provide a robust and equitable service to children and young people requiring an assessment of Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD) or both. Performance has been significantly impacted upon by the large demand on the service, and limited capacity. Subsequently, the ND team received funding, in 2019, to support the expansion of this specialist team with an aim of increasing capacity to meet demand. This funding has now been confirmed as recurrent in support of the service need. Due to the specialist nature of the service, recruiting into these posts has taken considerable time to deliver.

A detailed paper was provided to the Committee in April 2021 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. A further update was presented at the July 2021 Committee meeting.

3. CURRENT POSITION

3.1 Referrals

Referral rates have continued to be steady as predicted, with the expected rise in July 2021 but reduction in August 2021, as schools submitted outstanding referrals before their six-week summer break.



The type of referrals received by the ND team continue to vary, with the primary reason for referral being ASD. The referral variance provided 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 has now been reviewed as part of the planned validation of the waiting list to ensure there are no duplicate entries and to enable a more specific profile of demand which will in turn, inform capacity planning.

3.2 Capacity

The ND team continue to be dedicated to continuously strive to review their capacity, in order to ensure each clinician's time is maximised. They have continued to operate within an altered capacity throughout the pandemic whilst some Health Boards have not been able to deliver their activity.

The team successfully 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). The new staff joined the team throughout February 2021 to April 2021, the period of induction has now been completed and they have now integrated into the team well, contributing to the increased delivery of activity from capacity of 17 assessment appointments at January 2021, to an increase of a minimum of 38 assessment appointments up to October 2021.

Most recently, additional Consultant hours have been secured to replace capacity lost due to retirements. This has resulted in delivery of an additional shared post with 0.5 capacity for ND assessments from baseline funding. The post holder commenced at beginning of this month (November 2021). This will also increase capacity up to 42 per month as soon as Consultant completes induction. This post has been agreed with Cwm Taf Morgannwg Health Board as a joint arrangement with additional benefits of increased medical capacity to assess and treat ADHD cases. This will reduce the delay between diagnosis and medication trial, which will improve patient outcomes and experience. Furthermore, this new post an integrated approach between ND and CAMHS will ensure a timely transfer for these cases to the CAMHS ADHD medication monitoring service, after their titration is complete.

The ND team continue to revise 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 has been a noticeable increase to the team's capacity due to the team's continuous efforts.

Additional Waiting List Initiatives have been utilised where possible but these have been limited and dependent on clinician availability. Training in waiting list management and capacity planning continues to progress, together with refining referral pathways and processes.

It was hoped that the ND service could have secured further additional funding in May through the Welsh Government CAMHS funding stream. Unfortunately, the criteria for applications was specifically restricted to Specialist CAMHS services, e.g. crisis, eating disorders, inpatient services. ND service were not eligible to apply or secure funding.

With further funding, the Clinical lead believes that recruitment to further 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.

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. However, there are some small improvements being achieved.

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	< 11	12 - 17	18 - 25	26 - 35	36 - 51	> 52	Grand
Pathway type	weeks	wks.	wks.	wks.	wks.	weeks	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

Table 1 demonstrates the waiting list position as at 31st March 2021.

Table 2 demonstrates the waiting list position as at July 2021.

	< 11	12 - 17	18 - 25	26 - 35	36 - 51	> 52	Grand
Pathway type	weeks	wks.	wks.	wks.	wks.	weeks	total
ADHD	86	22	13	30	13	92	256
ASD	119	20	36	31	59	272	537
Dual diagnosis	0	3	10	10	8	54	85
Grand Total	205	45	59	71	80	418	878

Table 3 demonstrates the waiting list position as at October 2021.

	< 11	12 - 17	18 - 25	26 - 35	36 - 51	> 52	Grand
Pathway type	weeks	wks.	wks.	wks.	wks.	weeks	total
ADHD	43	15	20	19	38	74	209
ASD	92	31	32	20	59	248	482
Dual diagnosis	25	12	5	8	2	52	122
Grand Total	160	58	57	47	117	374	813

Through increasing capacity and validation of waiting list, October's waiting list position shows 538 patients waiting over 26 weeks compared to 647 in March 2021, a reduction of 109 patients.

4. RISKS

As within any team in the current climate, the impact of Covid on the team has been a significant risk, both to staff members and due to the current restrictions in place. There are also risks associated with a long-term absence/HR issue, which is in the process of being resolved.

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. Currently IAS only accept new referrals from 17;9 years. If young people are already on our ND waiting list, we cannot transfer them because they would join the bottom of the IAS list. Any time served on our ND waiting list is not counted. This means ND must expedite their assessment 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 is scheduled for 18th November 2021, following a previous meeting being cancelled by IAS. A verbal update of actions agreed at this meeting will be given at Performance and Finance Committee on 23rd November 2021.

The service continues to experience the additional clinical risk highlighted in July 2021 briefing, associated with a sharp rise in mental health comorbidity for all ND cases, and face clinical risks with these, now adult patients, within Children's Services workforce. The service aims to expedite these patients in order to complete their six-month assessment process before their 18th birthday. We now have clear, high level principles from WG regarding waiting list transfers from ND to IAS/Adult services. This was sent in April by Dr Williams, Senior Medical Officer for Welsh Government. Operational processes are now under review, in partnership with all stakeholders.

5. HALFWAY SUMMARY FEEDBACK FROM WELSH GOVERNMENT ALL WALES AUDIT OF ND SERVICES

As planned, the Clinical Lead has participated in the first stage of the independent review into demand, capacity and design of Neurodevelopmental services commissioned by Welsh Government. They are currently planning for the second stage of the ND Demand, Capacity and Design Review which will identify priorities for action and identify two options for a national ND service that would improve and maximise the timeliness and quality of services – one of which could be achieved within the existing budget and another which could be achieved with an increased budget. Due to service pressures, further implementation of these processes were delayed until autumn. However, a summary of feedback and key findings was presented at a recent meeting:

There was substantial funding provided historically for ND but still long waiting lists across Wales. To date, 70 interviews have taken place with staff across Wales, plus 50 families, and other agencies, e.g. police, education. The purpose of the review within the terms of reference is ASD and ADHD focused, however, there is recognition that ND is wider than ASD and ADHD but purpose of this review is ASD and ADHD only.

The review to date has identified that the demand across Welsh Health Boards is 50% higher than capacity (includes Aneurin Bevan, Cardiff & Vale, Hywel Dda, Powys, Swansea Bay Health Boards). It has noted that the data is incomplete and based on school reported data around primary need:

- ASD 1.9% reported, higher than 1% expected
- ADHD reported as 0.7%, lower than 5% expected.

The waiting times across Welsh Health Board range between 2 - 3 years for initial assessment appointments.

Drivers for change identified:

- Increased public awareness about neurodiversity
- Change in diagnostic classification with a broader distribution
- Previous services were patchy, so new services are flooded with demand
- CYP and their families want to make sense of difference and their identity, so turn to ND for answers
- Perception you need a diagnosis to access support services

- Protection for CYP managing in primary but parents want to safeguard secondary school and adulthood
- WG policy, e.g. Autism Code, ALNET

The impact is always clear to the service but this is also now clearly being identified as part of the feedback from the families and Children and Young peoples who are taking part in this including:

- Frustration for Children and Young people and their families
- Pressures on services and staff exhaustion and burnout due to demand from every sector
- Some staff leave and there are no appropriately trained specialist staff to replace them.

Options to decrease demand are being scoped, by the review team. To date these options include:

- Gatekeeping for referrals
- Build capacity to meet need differently however, there is no evidence at present that this will reduce demand
- Undertake additional waiting list initiative work to clear backlog initially and maintain capacity in line with demand doing todays work, today.
- Further consideration of outsourcing GP ADHD medication monitoring, ASD teacher support
- Exploration of different roles within ND non medical prescribers, cheaper options, broaden MDT

The review has identified clear unmet needs including:

- ADHD adults IAS now for ASD but no ADHD adult service
- Whole ND approach, not just ASD and ADHD
- Subthreshold cases that don't meet diagnostic criteria
- Minority groups
- Transition points, e.g. ND to IAS.

The capacity assessment shows:

- NICE guideline results in 10-15 hours needed for holistic and quality assessment. (Already highlighted within our previous papers)
- Small highly specialist team for whom any change impacts on everyone
- More experienced staff can do more complex cases and work more quickly
- Lack of admin and clerical support for clinicians, who then have to do non-clinical work
- Non-staffing challenges: accommodation and IT.

Further options to increase capacity

- Digital solutions
- Efficiency solutions

- Have all the information you need at the start of the Assessment to prevent the process stalling
- Clear planning and scheduling for clinics/staff

Options for redesign

- Increased funding could enable new services, e.g. adult ADHD service, all age ND
- Any new services would need to reflect NICE guideline about core team to assure clinical quality and safety of assessment
- Recruitment often means staff move from one HB to another, doesn't solve the problem
- Wary of impact of change on teams already struggling with demand
- Need action elsewhere in the system, e.g. integration with CAMHS
- Increase capacity for formulation without diagnosis, e.g. ALNET graduated response, NEST

There are three themes emerging from the halfway review summary, which include:

- i. No change is not an option
- ii. Service redesign may address unmet need but will also increase demand. A longterm system wide strategy is required.
- iii. Action may need to come first, which will need increased funding, but on its own, that will not be enough.

6. ASSURANCE

Since November 2019, the Clinical Lead and Service Co-ordinator have already implemented efficiency solutions using Prudent Healthcare principles, strict chronological booking into fixed appointment slots two – four weeks in advance. An electronic referral system has been initiated in parallel with routine paper copies. They have also ensured scrutiny of referrals in line with NICE guideline to ensure referrals are robust with only those demonstrating clinical need are listed for assessment and a capacity plan was completed which created weekly work plans to ensure maximum clinical efficiency without waste.

Finally, in April 2020, the SBUHB was a pilot site for Attend Anywhere with full staff usage within a month. The team continue to deliver services through a hybrid model of digital and face to face to minimise footfall on site for staff and families, whilst ensuring a timely and safe assessment.

In the two years since the appointment of the Clinical Lead, diagnostic capacity has increased through a delegated model of service delivery; using band 7 staff to conduct appointments with one contact with the Clinical Lead as diagnostician for the case. This clear and robust governance structure with quality assurance was not present previously. 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 referrers provide evidence of exceptional circumstances 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. This reflects the ALNET Code of Practice

which expects all professionals to meet need in partnership with parents; this is not dependent on a diagnostic 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 continue to benchmark services; the Clinical Lead met recently with their counterpart in Betsi Cadwaladr Health Board to discuss workforce, process and patient experience. The clinical team continue to explore further solutions to improve performance and reduce waiting times for patients.

7. CAPACITY PLAN AND STRATEGY/PROPOSAL TO GET TO BEST PRACTICE

The ND team are committed to 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 were not able to deliver their service.

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 team have made some progress in reducing the number of patients waiting for assessment over recent months; however, the service believes that further funding will be required to increase capacity in order to take cases off the waiting list for ASD assessments, which holds the largest number of patients waiting. They would function in the same way as the existing workforce with work delegated by the Clinical Lead as named diagnostician.

There is a clear requirement to balance the demand and capacity within this service, which is in line with the halfway review of ND services across Wales, together with proposing a strategy to clear the backlog of 538 patient waiting over 26 weeks.

There are a total of 813 children awaiting ND assessment within the service at Swansea bay Health Board. A similar problem is recognised across Wales. Of the 813 patients waiting in Swansea, 374 are waiting over 52 weeks and a further 164 patients are waiting between 26 - 52 weeks (totalling . Whilst we understand there is always a challenge to investing in additional staff, the service feels that they have already followed innovative practice to put the service in the best possible place currently and it is only with additional investment that the service can move forward given the task of clearing a backlog.

To clear the backlog of 538 cases waiting more than 26 weeks, the total number of clinical hours has been calculated. Each case takes different lengths of time depending on the reason for referral. ASD cases take approximately 15 hours, ADHD cases take approximately 20 hours and DUAL cases take approximately 30 hours.

This includes direct and indirect work but does not account for complications such as cases who are referred for ASD or ADHD but need a DUAL assessment; divorced parents who want separate appointments, safeguarding or other complications which must be managed and can

add considerable time to a routine case capacity. All staff have 20% within their work plan for supervision, MDT meeting and referral triage. The table below shows a typical distribution within the total number of 65% ASD referrals, 25% ADHD referrals and 10% DUAL referrals (both ASD and ADHD). Whilst this is not an exact distribution, it provides data to calculate capacity needed to meet demand.

Table 4

538 total	Number	Clinical time	
65% ASD	350	15h	5250
25% ADHD	135	20h	2700
10% DUAL	53	30h	1590
			9540
Workforce capacity needed			
37.5h x 80% x 42w	1260h per year	9540/1260	7.6wte staff needed

This 7.6 wte is the suggested number of additional staff needed to clear the current backlog. This includes additional medical staff and practitioner additional hours with an estimated cost of up to £550,000. Any increase in clinical staff would also require further administrative and clerical staff hours to deliver increased performance. This cost will be detailed within the full business case.

The current workforce is 2.2 wte diagnosticians (4 doctors and 1 Advanced Practitioner), plus 5.4 wte B7 staff, with 1.0 wte B7 not available due to HR issues. An urgent decision to resolve the long term shortfall in B7 capacity is needed.

As well as the waiting list, the team have 300 cases already with open duty of care. These cases have had their first appointment and are in their sequence of assessments or medication trial. These cases are a clinical priority because their assessment is not finished.

Finally we have new referrals which need triage; to date this year we have received 789. These are reviewed by the admin team to remove any with obvious missing or irrelevant information. They are then passed to a clinician for triage according to NICE guidelines. Each referral will take approximately 45 minutes of clinical time.

Demand/capacity planning must consider the ND caseload in its entirety because of the team's professional duty to the population to support identification and referral, their duty to referrers to process the referral in a timely way and their due to assess cases accepted on the list.

To date, that caseload totals 1113 cases for whom the team has different duty:

- 300 open cases
- 813 waiting list, of whom 538 are waiting over 26 weeks.

The local position mirrors the national demand/capacity conflict and given the number of cases, there needs to be increased investment to fulfil the duty to assess whilst maintaining the duty to the population and to referrers. Any increase in workforce capacity would also need a clear commitment to alternative accommodation as current accommodation and clinical space is already inadequate. Block D currently houses 15 staff in three rooms, using very limited clinical space in the Children's Centre or Children's Assessment Unit. Current accommodation and clinical space would not support any additional staff or clinical activity.

Given the significant number of children awaiting assessment, there needs to be a three stepped approached to addressing the patients waiting and the backlog as follows:

- i. Increase baseline capacity to meet demand this will cease the growth of the waiting list by bringing demand and capacity into balance.
- ii. Clear the over 52 week backlog by undertaking WLI clinics and exploring outsourcing options reducing the waiting times to 52 weeks by April 2023,
- iii. Continue this approach, reducing the number of patients waiting 26 52 weeks so the overall waiting time is 26 weeks by April 2024

The above will need to be tested with a healthcare systems engineering modelling process.

8. FINANCIAL IMPLICATIONS

There is a clear requirement to increase capacity further in order to meet demand develop a sustainable and acceptable waiting time for our patients through expansion of the existing team as outlined above as further pathway redesign has been exhausted at this stage.

The current establishment will be able to continue to deliver up to 42 initial assessments and the necessary follow-up appointment to make a diagnosis and prescribe appropriate treatment. The existing backlog of patients require assessment and follow-up appointments to reduce the number of patients waiting over 26 weeks to 80%. The service welcomes final outcome of the National service review.

Table 2 outlines opportunities to increase capacity from July onwards through a stepped approach whilst recruitment is progressed. The additional capacity will cost £331,775 plus administrative support.

The service must be supported to repatriate the 93 referrals waiting for an ASD assessment under the SLA with Cwm Taf Morgannwg. As each assessment takes approximately 15 clinical hours, this would release 1.1 wte clinical capacity to see Swansea Bay patients as well as reducing the waiting list by 11%, reducing overall waiting times for the remaining patients and their families.

Qualitative impact of SLA

Families tell us they do not wish to travel from Bridgend to Neath Port Talbot and ask why they cannot be seen in the Princess of Wales. They have no interest in the political or financial reasons for service design; they want timely, local care. A Swansea parent struggling with her teenage daughter's wait for assessment as her mental health deteriorates, has emailed to explain the impact on the whole family;

"As I've explained previously, the long term stress of living with C's undiagnosed difficulties, coupled with being a full time carer for her younger sister, has had, and is continuing to have, a severe adverse effect on family relations, and I've hit breaking point on many occasions. We have been 'in the system' and battling for answers under very difficult and pressured circumstances. I am now concerned at the impact all of this is having on the mental health and well-being of our family as a whole, as well as what the whole process is doing to a very complex teenager who has spent her whole life feeling different but not knowing why... I understand your hands are tied with regards to the waiting list, and am also fully aware that a diagnosis isn't a magic wand. All we as parents want and need is for our daughter to have the answers and explanation she needs for the difficulties she faces daily, to enable her to remove 'the mask', and to begin to understand and accept herself for who she is. If we as parents are feeling broken by this whole process, then I hate to think how C feels." Whilst we are supporting this family, in partnership with other agencies, the resolution of the SLA would meet the needs of families in Bridgend who want local care and reduce the waiting time for SBUHB families. Whilst neither HB has the capacity required to meet the demand, this is the case for every HB; the needs of these young people and families are paramount. This patient experience is one of many; the team receive several calls every day with waiting list enquiries. Some of these are parents who are angry or tearful, some with spiralling mental health issues for themselves, their child or other family members. As a values led organisation, the admin team listen and support families. Whilst most do not complain formally, this does not reflect the demand or impact on staff.

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 on the Health Board but this could be part of the solution to close the demand and capacity gap. However, this would de-stabilise CTM service as they have confirmed that they are not in a position to treat these patients for a minimum of 12 months. However, the halfway results of the national audit show that all Health Boards have a demand/capacity conflict and whilst a long-term system wide strategy is needed, families are disadvantaged by the current SLA.

The service expansion included as key priority for Children and Young Peoples Division within Recovery and sustainability plan and a full business case will be completed for approval by end of December 2021, in order to commence recruitment process early in 2022.

9. NEXT STEPS

A number of key steps have been highlighted and agreed for the next 6 months, which include:

- Continue to take opportunity to further redesign pathway in line the independent national review with National guidance and standards, demand and capacity modelling;
- Appoint interim nursing cover for workforce issue gap in service
- Opportunity to continue to utilise agency medical hours to increase capacity (GS)
- In line with WG request in April 2021, meet with IAS to agree transfer of rising 18-yearold cases to prevent them being expedited and causing harm to those waiting in turn.
- Confirm arrangements with CTM to repatriate their patients to reduce our waiting list and improve patient experience and access to local services.

There is an option to await the outcome of the All Wales Welsh Government service review and implement findings, however it must be noted that the interim summary received, already highlights a demand and capacity gap across Wales.

10.RECOMMENDATION

The Performance and Finance Committee are asked to note the current Neurodevelopmental Disorders Service position, the actions taken to increase capacity up to November 2021, and to support the strategy to get to best practice position.

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