Funding pro-forma for Mental Health Service Improvement Fund

Name of health board	Aneurin Bevan University Health Board
Allocation amount for full year (please see covering letter).	Full Year's recurrent funding: **£44,600**
Project Title	ABUHB ARFID Service Avoidant Food Intake Disorder /ED

Please provide a general description of the project. This needs to include a clear case for proposed changes / service development, evidencing how this will provide additionality and added value to current service provision. This section should also include any relevant engagement activity undertaken which enabled prioritisation of proposals. (Max. 400 words).

Avoidant Restrictive Feeding Intake Disorder (ARFID) is now included as an Eating Disorder in ICD-11.

Children and Young People with ARFID present with complicated and varied histories and risk factors that include medical and psychological factors affecting nutritional intake. As they have no body image concerns and often a 'normal' BMI they fall outside of ABUHB existing ED-CAMHS service criteria.

When these children and young people's needs are not met they experience a significant impact on their psychological and physiological development, for example;

- Nutritional deficiencies and poor diet
  - increased risk of developing long term health conditions (including; loss of sight, bone conditions and obesity)
  - increased risk of developing adult health issues; such as cancer.
- Management involves invasive procedures and surgery (NG tubes / Pegs)
- Enteral feeding requirements impacting on QoL and associated costs.
- Bullying from peers due to feeding behaviour / appearance (NG tubes)
- Co-morbid anxiety and depression
- Impact on ability to attend school
- Significant impact on family life
- Impact continues over the child and young person's lifetime.
- Significant intergenerational transmission of eating behaviours impacting on the Well-being of Future Generations.

ABUHB (including ED-CAMHS) does not have a dedicated clinical pathway or service for this group of children and young people which places us at risk of meeting the All Wales Service Guidelines.

Current situation:

- The ARFID children 'appear' in multiple services but as they do not fit 'criteria' and/or are able to access clinical expertise they are falling between the gaps.
- As children's needs escalate they are often simultaneously referred into Paediatrics / CAMHS / ND / ISCAN.
- The clinical expertise is not present within anyone service to meet the complex needs of this group of children.
- The clinicians within services feel deskilled and experience increased stress due to not being able to meet the children and young people's needs.
- The unpredictable referral and treatment patterns for this group increases the likelihood that they will be left with a vague diagnosis and disjointed care plan that lacks the kind of specialist and co-ordinated care that is required to optimise successful outcomes.
- Unfortunately, this has led to parents complaining to the Health board demanding the appropriate care for their children and out of area referrals to specialist teams in England (GOSH and Birmingham).
- The out of area teams provide assessments, formulation and a treatment plan but no input or support to deliver the plan. This leaves parents even more frustrated with our local services.
- Most recently, there have been high profile cases; for example, where young people have lost their sight from a restrictive diet which has escalated complaints and anxiety within clinical teams about providing a service for AFRID.

Proposed change / service development

There are three key groups of ARFID children;

- Children who have had early disruption to establishing feeding. They often remain on enteral feeding in the community; with NG tubes and Pegs and / or are not seen by services as they have a 'normal BMI' but are nutritionally deprived.
- Children who have feeding difficulties due to a co-morbid diagnosis of ASD / ADHD.
- Children who have feeding difficulties due to overwhelming anxiety about eating due to a specific incident such as choking/ fear of vomiting.

It has been found that given the heterogeneity of the clinical presentation of this population it is critical for AFRID service providers to have an understanding of the varied presentations of these children and young people so that they can best diagnose and develop appropriate treatment recommendations. Therefore, the clinical expertise of the 'diagnostic team' should ideally have representation from ED-CAMHS, Paediatrics and ND services.

As stated previously, the complexity of ARFID is predominantly in the assessment and formulation and development of an intervention plan which maximises clinical

outcomes. The majority of children will need 'straightforward' interventions that can be delivered by existing clinical teams; such as Therapies, PCCMHS, ND, PCANS, School Nurses, and Health Visitors within the community.

A small pilot clinic undertaken in a joint – unfunded – venture between Dr A Johnson Paediatric Psychology and Sian Taylor SCAMHS Dietetics has begun to scope the patient population and clinical demand.

The proposed ABUHB ARFID service would develop, deliver and support an end to end proactive, preventative clinical pathway; providing specialist assessments and bespoke intervention plans; training, supervision and direct collaborative support for clinicians within community services to deliver the interventions; and for a small group of the most complex; deliver 1:1 clinics.

ABUHB are not only in a positon to develop the first 'Gold Standard' ARFID service and clinical pathway in Wales (with a potential for funding incoming from other health boards); we are also able to be the first in the UK.

Additional resource required:

0.4 wte Paediatric Psychologist Band 8b to undertake:

- Provide clinical leadership to the team and link with paediatrics
- Specialist psychological assessment
- Specialist psychological formulation
- Plan and deliver bespoke intervention
- Provide training and supervision to the most proximal clinician

0.4 wte Specialist SCAMHS Dietitian Band 7

- Specialist dietetic assessment
- Specialist dietetic / psychological formulation
- Plan and deliver bespoke dietary intervention.
- Provide training and supervision to the most proximal clinician working closely with paediatric dietetic colleagues.
- Provide link with SCAMHS and ED services
- Provide training and supervision to the most proximal clinician working closely with paediatric colleagues, parents and school staff
- Provide link with ND / Paediatric services

Please provide detail on the key milestones that will need to be achieved following approval of funding. (Max. 150 words)

When funding is achieved;

- Recruitment into posts

- Induction of team
- Establish clinical supervision model within the team
- Development of Key Stakeholders Steering Group for the Pathway within ABUHB; including, Education, Health, Mental Health.
- Develop and ratify clinical pathway with key stakeholders
- Establish specialist clinics within ABUHB
- Develop and Deliver training on ARFID to key clinical groups within the pathway
- Roll out ARFID screening tool and consultation model
- Monthly reporting of data and monitoring within Senior Management Team performance sessions and ED steering group
- Liaison with Therapies and Paediatrics with a preventative practise focus.
- 6 monthly and annual activity and performance reports
- Annual Benchmarking submissions
- Offer Out of Area business model for Assessment, Formulation and Bespoke Intervention plans (income generation).

Please provide detail here if your proposal includes any non recurrent funding in 2020/21 to support future planning or service delivery. **(Max. 150 words)**

Non-recurrent funding would include provision of lap-tops, mobile phones, required to increase the flexibility of the service and to improve the response time. This may also include travelling expenses.

Ongoing CPD - Training would need to include ARFID updates and links with Dr Rachel Bryan Waugh – Maudsley Hospital London.

Please provide detail on how you expect the proposal to achieve the expectations laid out in annex b of the covering letter?. Please include how you will ensure that these are measured and monitored. (Max. 200 words)

If this bid proved successful and revenue funding awarded for the additional resources the following benefits could be delivered:

- Children and Young People with ARFID symptoms would have a dedicated proactive, preventative and responsive clinical pathway.
- Young people with the greatest need of specialist help will be able to receive it in a timely manner working across traditional sector and professional boundaries.
- Children and Young People with ARFID would be able to minimise the impact of their condition on their physical and psychological wellbeing (see above)
- An uplift in the numbers of skilled staff in Community (incl. HV, School Nurses), Mental Health and Paediatric Services who are skilled in delivering feeding interventions that prevent the development of ARFID and are able to intervene at an early state in presentation.

- Reduction in the number of services engaged with the ARFID children and a reduction in the number of appointments offered to families.
- Staff resource currently supporting these young people will be more efficiently used, this will have a significant positive impact on routine waiting lists in Core CAMHS paediatrics and ND.
- Reduction in the number of children and young people requiring Enteral feeding with a subsequent reduction in the number referred to the Gastrostomy clinic for surgery.
- Reduction in the number of children seen within inappropriate services as families seek support for their child (including S-CAMHS, PCMHSS).
- Additional resource to the team will ensure that a young person's needs are addressed in a holistic manner in an appropriate environment
- A reduction in the need for out of area assessments and the associated cost implications.
- The provision of collaboration and consultation and advice to staff, and other agencies, linked to direct intervention with children and families in school and at home that should reduce the need for multiple hospital appointments.
- A co-ordinated, evidenced based and timely package of intervention will maximise the young person's resilience and will galvanize local and family support networks.
- Improved access to timely ARFID/ ED assessments - may reduce need for ND assessments in some cases.
- Robust data collection that includes paediatric / dietetic psychology and also monitors the numbers of young people where admission / out of area referral has been prevented.
- The team will use recognised Outcome Measures – ARFID specific and link to the national pilot study being run at the Maudsley.
- All figures and data will be monitored closely by the Senior Management Team and reported at the monthly performance sessions.
- As the service is established; income generation from providing an assessment service for other healthcare providers within Wales and the UK.

Please provide a broad breakdown of costs for this proposal. Please provide the detail for both 2020/21 and 2021/22 (where appropriate) To note costs for 2020/21 are expected to be for the six months currently being issued.

2020/21 6 months (October 20 – March 21)	2021/22

0.4 wte Band 8b Psychologist- Paediatric £12,400 0.4 wte Band 7 SCAMHS Dietitian £8,900 Clinical practice resource, materials, training, equipment and travel costs is around £2,000 x 2 = £4,000 **Grand total: £21,304**	0.4 wte Band 8b Psychologist-paediatric £24,800 0.4 wte Band 7 SCAMHS Dietitian £17,800 Clinical practice resource, materials, training, equipment and travel costs is around £1,000 x 2 = £2,000 **Grand total: £44,600**

Please use this space to provide a high level overview of how the initial six months funding was utilised within the health board to respond to the pressures associated with the current pandemic situation in mental health. (Max. 300 words)

This clinical group is particularly vulnerable to the impact of lockdown as 'family mealtimes become more stressful' confounding the existing difficulties and it can be hard to access the child or young person's accepted food which increases their risk.

Additional funding not available to support this model during the initial outbreak of the COVID19 pandemic, resources to support the model were provided from staff from other areas of the service.

If this bid is successful we can recruit to the additional staff and bolster the services to support the recovery service model and any future pandemic spikes.

Clinicians would be able to deliver training, consultation and collaborative working utilising Attend Anywhere and telephones.

Clinicians would be able to assess and develop formulations and intervention plans with families utilising Attend Anywhere. However; it is important to state that this would not be the optimal service delivery model due to the need to deliver interventions in situ and often with very young children.

An electronic version of this form should be submitted to mentalhealthandvulnerablegroups@gov.wales for consideration once completed.