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Paediatric Neuropsychology

Service Specification: SS296

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Description	NHS Wales will routinely commission this specialised service in accordance with the criteria described in this policy

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Abbreviations

ADHD	Attention Deficit Hyperactivity Disorder
BPS	British Psychological Society
DoN	Division of Neuropsychology
EIA	Equality Impact Assessment
GP	General Practitioner
HCPC	Health and Care Professions Council
IPFR	Individual Patient Funding Request
MDT	Multi-Disciplinary Team
NICE	National Institute for Health and Care Excellence
NHS	National Health Service
NWJCC	NHS Wales Joint Commissioning Committee
SMC	Scottish Medicines Consortium
QicN	Qualification in Clinical Neuropsychology

Statement

NHS Wales Joint Commissioning Committee (NWJCC) will commission the service of paediatric neuropsychology for children aged up to 16 years in accordance with the criteria outlined in this specification.

In creating this document NWJCC has reviewed the requirements and standards of care that are expected to deliver this service.

Welsh Language

NWJCC is committed to treating the English and Welsh languages on the basis of equality, and endeavour to ensure commissioned services meet the requirements of the legislative framework for Welsh Language, including the [Welsh Language Act \(1993\)](#), the [Welsh Language \(Wales\) Measure 2011](#) and the [Welsh Language Standards \(No.7\) Regulations 2018](#).

Where a service is provided in a private facility or in a hospital outside of Wales, the provisions of the Welsh language standards do not directly apply but in recognition of its importance to the patient experience, the referring health board should ensure that wherever possible patients have access to their preferred language.

In order to facilitate this, NWJCC is committed to working closely with providers to ensure that in the absence of a Welsh speaker, written information will be offered and people have access to either a translator or 'Language-line' if requested. Where possible, links to local teams should be maintained during the period of care.

Decarbonisation

NWJCC is committed to taking assertive action to reducing the carbon footprint through mindful commissioning activities. Where possible and taking into account each individual patient's needs, services are provided closer to home, including via digital and virtual access, with a delivery chain for service provision and associated capital that reflects the NWJCC commitment.

Disclaimer

NWJCC assumes that healthcare professionals will use their clinical judgment, knowledge and expertise when deciding whether it is appropriate to apply this document.

This document may not be clinically appropriate for use in all situations and does not override the responsibility of healthcare professionals to make decisions appropriate to

the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian, or Local Authority.

NWJCC disclaims any responsibility for damages arising out of the use or non-use of this policy.

1. Introduction

This document has been developed as the Service Specification for the planning and delivery of paediatric neuropsychology for children aged up to 16 years for people resident in Wales. This service will only be commissioned by the NHS Wales Joint Commissioning Committee (NWJCC) and applies to residents of all seven Health Boards in Wales.

1.1 Background

1.1.1 Plain Language Summary

Many children and young people can struggle with cognition (thinking), emotions (feelings), behaviour and social skills because of the effects of a chronic or acute neurological condition and/or treatments. A neurological condition can be something a child is born with or develops through childhood, like epilepsy, or can occur following a traumatic event such as a traumatic head injury or following an acute infection like meningitis. These children and young people might benefit from a neuropsychological assessment. This helps to chart any difficulties with cognitive, emotional, and social skills and behaviour. As assessment often includes things like interviews with children/young people and their family members, completing questionnaires, and then the child/young person completing tasks that measure intellect, processing speed, memory and attention skills and executive functioning.

Assessment is useful because it gives information about strengths, difficulties and areas of need, to the child/young person and their family and all the networks around them. It may help to decide if certain medical treatments should be used. Assessment helps to decide if certain psychological or neuropsychological interventions will be useful. Assessment can also inform other agencies about the support the child/young person will need to support them with their difficulties now and in the future.

1.1.2 Epidemiology

The target population is comprised of children presenting with a range of neurological conditions congenital and acquired. Calculation of epidemiology is complex as children and young people presenting with neurological conditions can present with a wide-ranging spectrum of needs.

The UK prevalence rate for children (0–14 years) admitted to intensive care in England and Wales with Traumatic Brain Injury between February 2001 and August 2003 was 5.6 per 100 000 population per year¹. Epilepsy is the most common significant long-term

¹ [Parslow RC, Morris KP, Tasker RC on behalf of the UK Paediatric Traumatic Brain Injury Study Steering Group and the Paediatric Intensive Care Society Study Group, et al Epidemiology of traumatic brain injury in children receiving intensive care in the UK Archives of Disease in Childhood 2005;90:1182-1187.](#)

neurological condition of childhood and affects an estimated 112,000 children and young people in the UK². The overall annual incidence of acute bacterial meningitis in the UK is 1 per 100,000 population³.

1.1.3 Current Service

There are no specialist assessment or treatment options available for children/young people with significant neuropsychological deficits in Wales currently. The commissioning of this service will bring clinical practice and treatment in line with the rest of the UK where children/young people can access to a Paediatric Neuropsychology service.

1.2 Aims and Objectives

The aim of this service specification is to define the requirements and standard of care essential for delivering paediatric neuropsychology for children aged up to 16 years.

The objectives of this service specification are to:

- detail the specifications required to deliver paediatric neuropsychology for children aged up to 16 years for people who are residents in Wales
- ensure minimum standards of care are set for the use of paediatric neuropsychology
- ensure equitable access to paediatric neuropsychology
- identify centres that are able to provide paediatric neuropsychology for Welsh patients
- improve outcomes for people accessing paediatric neuropsychology services.

1.3 Relationship with other documents

This document should be read in conjunction with the following documents:

- **NHS Wales**
 - All Wales Policy: [Making Decisions in Individual Patient Funding requests \(IPFR\)](#).
- **NHS Wales Joint Commissioning Committee policies and service specifications**
 - [Atidarsagene autotemcel for treating metachromatic leukodystrophy in children](#), PP257, April 2023

² [National Clinical Audit of Seizures and Epilepsies for Children and Young People, RCPCH Audits, Report for England and Wales Round 3 Cohort 1 \(2018-19\)](#).

³ [NICE Guidelines for Meningitis - bacterial meningitis and meningococcal disease, March 2024](#)

- [Ataluren for treating Duchenne muscular dystrophy with a nonsense mutation in the dystrophin gene](#), PP118, July 2023
- [Specialised Paediatric Neurological Rehabilitation](#), CP160, April 2018
- [Nusinersen for treating spinal muscular atrophy](#), PP191, January 2022
- [Children's Epilepsy Surgery Services](#), CP174, September 2022
- [Risdiplam for Spinal Muscular Atrophy for people aged under 16 years](#), PP240, May 2022
- **National Institute of Health and Care Excellence (NICE) guidance**
 - [Epilepsies in children, young people and adults](#), NG217, April 2022
 - [Epilepsies in children, young people and adults QS211 December 2023](#)
 - [Suspected Neurological conditions: recognition and referral](#), NG127, October 2023
 - [Spasticity in under 19s: management](#), CG145, July 2012
 - [Epilepsy in children and young people](#), QS27, February 2013
 - [Major Trauma: assessment and initial management February 2016](#)
 - [Cerebral palsy in children and young people](#), QS162, October 2017
 - [Cerebral palsy in under 25s: assessment and management](#), NG62, January 2017
 - [Suspected neurological conditions: recognition and referral](#), QS198, January 2021
 - [Nusinersen for treating spinal muscular atrophy](#), TA588, July 2019
- **Relevant NHS England policies**
 - [Children's Neurosurgical Specification Standards May 2011](#)
 - [Paediatric Neurosciences – Neurology](#), E09/S/b, 2023/24
- **Other published documents**
 - [Neuropsychological Assessment: Past and Future](#), Casaletto K & Heaton R, December 2017, Journal of the international Neuropsychological Society, Vol 23, Issue 9-10
 - [The Efficacy of Cognitive Behavioral Therapy: A Review of Meta-analyses](#), Hofmann S et al, October 2012, Cognitive Therapy and Research, Vol 36, pages 427-440
 - [Outcomes of pediatric neuropsychological services: A Systematic review](#), Fisher L et al, August 2022, The Clinical Neuropsychologist, Vol 36, Issue 6, pages 1265-1289
 - [Changes in child functioning pre-to post-neuropsychological evaluation](#), Combs et al 2020, Child Neuropsychology, Vol 26, Issue 5, Pages 711-720
 - [Royal College of Paediatrics and Child Health \(RCPCH\) Epilepsy12 audit](#)

2. Service Delivery

The NHS Wales Joint Commissioning Committee will commission the service of paediatric neuropsychology for children aged up to 16 years, in line with the criteria identified in this specification.

2.1 Proposed Service

- Diagnostic evaluation for children and adolescents with a neurological condition.
- Assessment of cognitive, emotional, social skills and behaviour using neuropsychological and psychological tests.
- Psychological assessment and interventions for children and adolescents with a neurological condition.
- Neuropsychological interventions to support the deficits identified.
- The provision of consultation for health, social services, education and professionals regarding enabling the sharing of expertise with professionals working with a child/young person in their local area.
- Liaising with MDT, schools, social services, community and other key stakeholders.
- Consultation with adult services.
- Teaching, training in psychoeducation.
- Joint work with multi-professionals.
- Team formulation.
- Reflective practice.
- Teaching / training.
- Facilitation of Special Interest Group for Clinical Psychologists working with paediatric neurology cases.
- Clinical Supervision of allied psychologists and juniors in the team.
- Research.

2.1.1 Workforce

The Paediatric Neuropsychology services provides specialist assessment and intervention services. Which includes:

- Assessment (interviews, neuro psychological assessment, standard questionnaires, clinical observation), feedback sessions and psychological education (on neuropsychological deficits and its impact), written feedback, training and consultation to local health and education teams (this will enhance local teams in their ability to manage the needs of the case).
- Interventions would either be individual or group. Interventions would range in therapy mode e.g. art, music, play, and / or psychology.

To ensure the service is supported adequately there needs to be:

- Consultant Paediatric Neuropsychologist (QiCN qualified)
- Clinical Psychologist/Neuropsychologist
- Educational Psychologist
- Clinical Psychologist
- Family therapist
- Music, Art or Play Therapist
- Assistant Psychologist
- Medical Secretary

A Chartered Clinical Psychologist/Educational Psychologist must complete an additional qualification, the Qualification in Clinical Neuropsychology (QiCN), over several years of clinical practice to be recognised as a Clinical Neuropsychologist. Clinicians working in a Paediatric Neuropsychology service must be able to access the Clinical Supervision and Clinical Governance provided by a more senior clinician who has attained the QiCN. Without a senior person who has this qualification this service cannot operate. All staff are required to have the necessary equipment and training to fulfil their roles e.g. computers/laptops.

Clinical Psychologist/Neuropsychologist

Must have completed accredited doctoral training and be registered with the Health and Care Professions Council (HCPC). A clinical psychologist's aim is to reduce psychological distress and promote psychological well-being. Neuropsychologists focus on neurobehavioral disorders, cognitive processes, and brain disorders.

Educational Psychologist

Must be registered with the Health and Care Professions Council (HCPC). Educational psychologists are concerned with children's learning and development. They use their specialist skills in psychological and educational assessment techniques to help those having difficulties in learning, behaviour or social adjustment.

Children and young people with a brain injury may not always respond to talking therapies due to their brain injury therefore other creative therapies would need to be offered as part of an intervention

Music Therapist

Must be registered with the Health and Care Professions Council (HCPC). Music therapists are highly trained, board-certified practitioners who work with a wide variety of individuals to help manage pain, reduce stress, express emotion, enhance memory, improve communication, and promote physical rehabilitation. Their patients include those with developmental disorders, mental health disorders, neurological conditions, trauma, and other medical needs.

Art Therapist

Must be registered with the Health and Care Professions Council (HCPC). Art therapy employs the creative process of making art to improve a person's physical, emotional, and mental well-being. It is a form of psychotherapy that encourages individuals to express themselves through art-making activities such as drawing, painting, sculpting, and collage making.

Art therapy benefits children struggling with anxiety, depression, trauma, and other emotional and mental health issues. It helps children develop coping skills, improve self-esteem, and healthily express themselves.

Play Therapist

Play therapy is another form of therapy that uses play to help children communicate and express themselves. It is a child-centred approach that provides children with a safe and supportive environment to play and explore their emotions.

Play therapy benefits children struggling with emotional and behavioural issues such as anxiety, depression, ADHD, and trauma. It helps children develop social skills, improve self-esteem, and learn coping skills.

Family Therapist

A family therapist works with families and those in close relationships who experience problems. The therapist explores their views and relationships to understand the problems they are having. It helps family members communicate better with each other. It can help families to change, develop and resolve conflict.

Assistant Psychologist

Duties would involve gathering information for and from assessment, prepare teaching materials and help run individual and group interventions.

Medical Secretary

To provide administrative support, organise clinics, keep databases, prepare assessment results, reports and letters.

Ideally, there should be a permanent office space allocated to accommodate the required workforce, which includes the provision of equipment to facilitate all the working requirements for the service.

All HCPC professionals have a duty to maintain standards of Continuing Professional Development (CPD).

Clinical Supervision needs to be provided by the most senior clinician. If there is not a senior art/music/play therapist there may be a requirement to seek supervision outside of the hosting health board to ensure professional standards are adhered to.

2.1.2 Assessment Environment

Service users may present with motor, emotional, behavioural and cognitive difficulties, which make attending busy or inaccessible clinical settings challenging.

The service would require the following as a minimum:

- dedicated access to appropriate waiting room space (spacious, quiet environments with access to toilets)
- private clinic rooms to complete family interviews and table top assessment activities
- private clinic rooms need to be spacious to accommodate a family (up to four people as a minimum), allow wheel chair access and the provision of any other aids the service user might require
- private clinic rooms would require seating and tables that are accessible for all ages and service users that may have challenges with mobility
- private clinic rooms require camera-enabled computers to facilitate on-line appointments and meetings to improve service user and consultation access to remote and distant locations across Wales
- identification of appropriate clinic rooms across health boards so that satellite clinics can be offered closer to the service users home.

2.2 Exclusion Criteria

- The child/ young person is not, or has not been under the lead care of a Consultant Paediatric Neurologist, Consultant Paediatric Neurosurgeon or Clinical Psychologist
- The child/young person's primary diagnosis is not neurological or doesn't have a health condition that is associated with neuropsychological indicators
- The child/young person has a functional neurological disorder
- The child/young person cognitive, behavioural or emotional needs are not related to their neurological diagnosis or injury
- The child/young person has needs that can be met through other services
- Consent to the referral has not been given

2.3 Acceptance Criteria

The service outlined in this specification is for patients ordinarily resident in Wales, or otherwise the commissioning responsibility of the NHS in Wales. This excludes patients who whilst resident in Wales, are registered with a GP practice in England, but includes patients resident in England who are registered with a GP Practice in Wales.

2.4 Transition Arrangements

All children and young people under the care of the Paediatric Neuropsychology service will need a coordinated transitional care programme leading to transfer of care to an adult neuropsychologist services at an appropriate age.

Transition arrangements should be in line with [Transition from children's to adults' services for young people using health or social care services NICE guidance NG43 and the Welsh Government Transition and Handover Guidance.](#)

Transition involves a process of preparation for young people and their families for their transition to adulthood and their transition to adult services. This preparation should start from early adolescence 12-13 year olds. The exact timing of this will ideally be dependent on the wishes of the young person but will need to comply with local resources and arrangements.

The transition process should be a flexible and collaborative process involving the young person and their family as appropriate and the service.

The manner in which this process is managed will vary on an individual case basis with multidisciplinary input often required and patient and family choice taken into account together with individual health board and environmental circumstances factored in.

2.5 Patient Pathway (Annex i)

Please see Annex i.

2.6 Service provider/Designated Centre

Children resident in Powys will access specialised paediatric neuropsychology services from Alder Hey Children's Hospital, Birmingham Children's Hospital and the Children's Hospital for Wales dependent on their geographical location.

Specialist providers

North Wales

Alder Hey Children's Hospital
East Prescott Road
Liverpool
L14 5AB

South Wales

Noah Ark Children's Hospital
University Hospital of Wales

Heath Park Way
Cardiff
CF14 4XW

Powys

Birmingham Children's Hospital
Steelhouse Lane
Birmingham
B4 6NH

2.7 Exceptions

If the patient does not meet the criteria for treatment as outlined in this policy, an Individual Patient Funding Request (IPFR) can be submitted for consideration in line with the All Wales Policy: Making Decisions on Individual Patient Funding Requests. The request will then be considered by the All Wales IPFR Panel.

If the patient wishes to be referred to a provider outside of the agreed pathway, an IPFR should be submitted.

Further information on making IPFR requests can be found at: [Individual Patient Funding Requests](#)

3. Quality and Patient Safety

The provider must work to written quality standards and provide monitoring information to the lead commissioner. To ensure the delivery of appropriate clinical outcomes, Guidance from leading professional bodies, namely the British Psychological Society (BPS) and its Division of Neuropsychology (DoN), will be adhered to. Psychological and neuropsychological interventions will utilise evidence based therapeutic models. Adherence to appropriate training and clinical supervision standards will ensure highly effective service delivery and use of clinically relevant measures e.g. Strengths of Difficulties Questionnaire. Appropriate referral and intervention data will be collated to assist in service monitoring and evaluation.

The centre must enable the patients, carers and advocates informed participation and to be able to demonstrate this. Provision should be made for patients with communication difficulties and for children, teenagers and young adults.

3.1 Quality Indicators (Standards)

Provider outcomes

The provider must report to the NWJCC:

- All National Reportable Incidents (NRI'S)
- Complaints
- Themes and trends from NRI's and complaints
- Workforce challenges
- Refusals
- Quality Improvement initiatives
- PREMS/PROMS
- Staff well-being and support.

3.2 National Standards

- NICE Quality Standards

3.3 Other quality requirements

- The provider will have a recognised system to demonstrate service quality and standards.
- The service will have detailed clinical protocols setting out nationally (and local where appropriate) recognised good practice for each treatment site.

- The quality system and its treatment protocols will be subject to regular clinical and management audit.
- The provider is required to undertake regular patient surveys and develop and implement an action plan based on findings.

4. Performance Monitoring and Information Requirement

4.1 Performance Monitoring

NWJCC will be responsible for commissioning services in line with this policy. This will include agreeing appropriate information and procedures to monitor the performance of organisations.

For the services defined in this policy the following approach will be adopted:

- Service providers to evidence quality and performance controls
- Service providers to evidence compliance with standards of care

NWJCC will conduct performance and quality reviews on an annual basis.

4.2 Key Performance Indicators

The providers will be expected to monitor against the full list of Quality Indicators derived from the service description components described in Section 2.2.

The provider should also monitor the appropriateness of referrals into the service and provide regular feedback to referrers on inappropriate referrals, identifying any trends or potential educational needs.

4.3 Date of Review

This document is scheduled for review every three years, unless information is received which indicates that the policy requires revision.

If an update is carried out, this version of the policy will remain extant until the revised policy is published.

5. Equality Impact and Assessment

The Equality Impact Assessment (EIA) process has been developed to help promote fair and equal treatment in the delivery of health services. It aims to enable NHS Wales Joint Commissioning Committee to identify and eliminate detrimental treatment caused by the adverse impact of health service policies upon groups and individuals for reasons of race, gender re-assignment, disability, sex, sexual orientation, age, religion and belief, marriage and civil partnership, pregnancy and maternity and language (Welsh).

This policy has been subjected to an Equality Impact Assessment.

The Assessment demonstrates the policy is robust and there is no potential for discrimination or adverse impact. All opportunities to promote equality have been taken.

6. Putting Things Right

6.1 Raising a Concern

Whilst every effort has been made to ensure that decisions made under this policy are robust and appropriate for the patient group, it is acknowledged that there may be occasions when the patient or their representative are not happy with decisions made or the treatment provided.

The patient or their representative should be guided by the clinician, or the member of NHS staff with whom the concern is raised, to the appropriate arrangements for management of their concern.

If a patient or their representative is unhappy with the care provided during the treatment or the clinical decision to withdraw treatment provided under this policy, the patient and/or their representative should be guided to the LHB for [NHS Putting Things Right](#). For services provided outside NHS Wales the patient or their representative should be guided to the [NHS Trust Concerns Procedure](#), with a copy of the concern being sent to NWJCC.

6.2 Individual Patient Funding Request (IPFR)

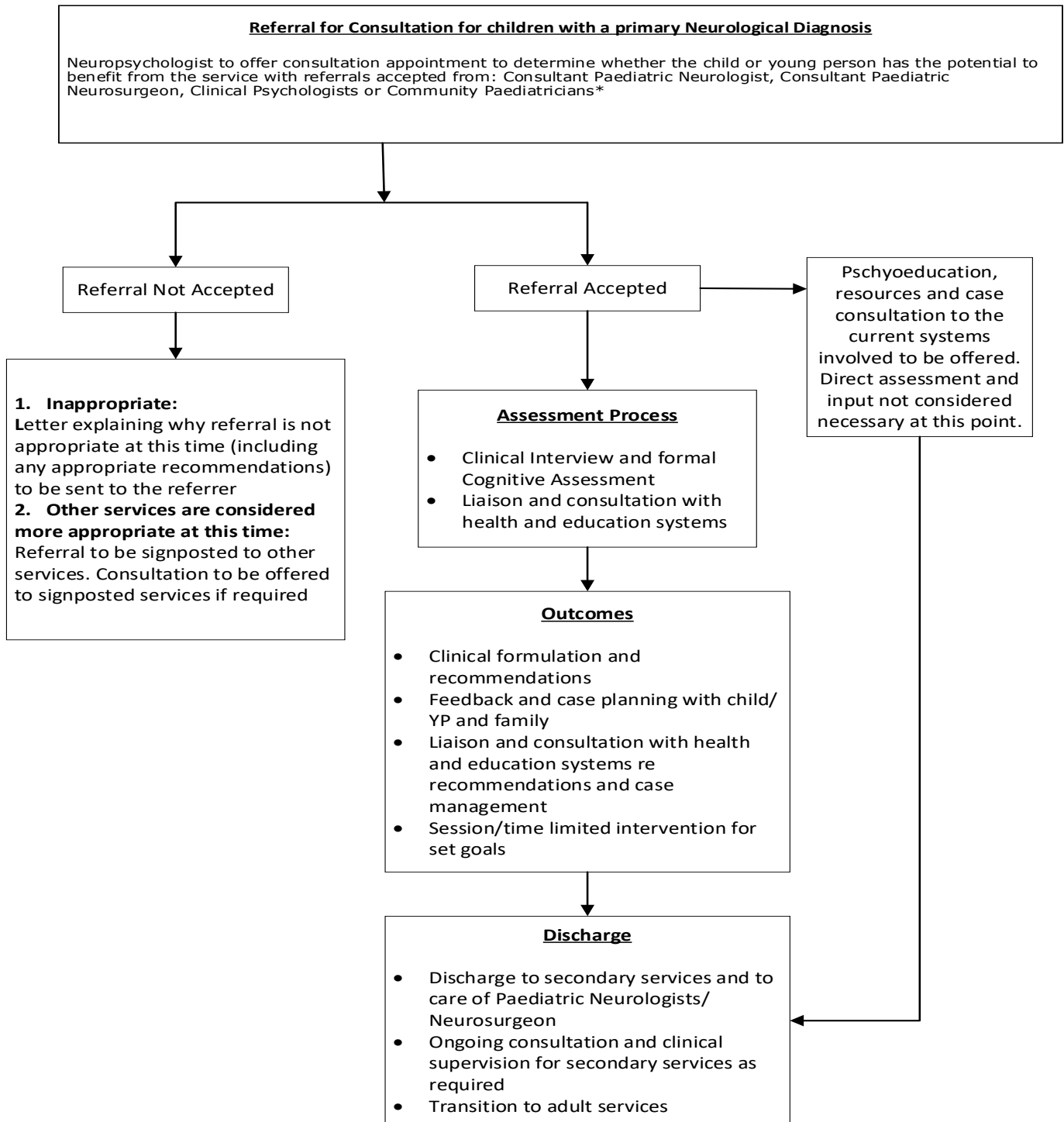
If the patient does not meet the criteria for treatment as outlined in this policy, an Individual Patient Funding Request (IPFR) can be submitted for consideration in line with the All Wales Policy: Making Decisions on Individual Patient Funding Requests. The request will then be considered by the All Wales IPFR Panel.

If an IPFR is declined by the Panel, a patient and/or their NHS clinician has the right to request information about how the decision was reached. If the patient and their NHS clinician feel the process has not been followed in accordance with this policy, arrangements can be made for an independent review of the process to be undertaken by the patient's Local Health Board. The ground for the review, which are detailed in the All Wales Policy: Making Decisions on Individual Patient Funding Requests (IPFR), must be clearly stated.

If the patient wishes to be referred to a provider outside of the agreed pathway, and IPFR should be submitted.

Further information on making IPFR requests can be found at: [Individual Patient Funding Requests](#)

Annex i Patient Pathway



* Referrals will be accepted from Community Paediatricians for patients who have been discharged from tertiary care and they can access the service if they have previously been under the care of a Paediatric Neurosurgeon or Paediatric Neurologist.

Annex ii Glossary

Individual Patient Funding Request (IPFR)

An IPFR is a request to NHS Wales Joint Commissioning Committee (NWJCC) to fund an intervention, device or treatment for patients that fall outside the range of services and treatments routinely provided across Wales.

NHS Wales Joint Commissioning Committee (NWJCC)

NWJCC is a joint committee of the seven local health boards in Wales. The purpose of NWJCC is to ensure that the population of Wales has fair and equitable access to the full range of Tertiary Services. NWJCC ensures that services within our portfolio are commissioned from providers that have the appropriate experience and expertise. They ensure that these providers are able to provide a robust, high quality and sustainable services, which are safe for patients and are cost effective for NHS Wales.

Contact Us

If you have a question related to this document you can contact us using one of the methods outlined below.

If you would like this document in an alternative format and/or language, please contact us for assistance.

Email:

NWJCC consultation mailbox – nwjccconsultation@wales.nhs.uk

Telephone:

General Enquiries – 01443 433112

Website:

[Contact us - NHS Wales Joint Commissioning Committee](#)

Writing:

If you wish to contact the NHS Wales Joint Commissioning Committee, you can write to us at one of our locations below, we welcome correspondence in Welsh or English:

South Wales Offices

Unit 1, Charnwood Court, Heol Billingsley, Nantgarw, CF15 7QZ

Unit G1 The Willowford, Main Avenue, Treforest Industrial Estate, Pontypridd, CF37 5YL

North Wales Offices

Unit 3, Media Point - Unit 3, Mold Business Park, Mold, CH7 1XY

Preswylfa, Hendy Road, Mold, CH7 1PZ