

**Consultation on the future
of Children's Autism
Spectrum Disorder (ASD)
Diagnostic Service**

**Report detailing feedback received
during consultation:
19 April 2010 to 14 June 2010**

June 2010

Contents

Introduction	3
Consultation	4
Responses received.....	4-7
Appendices	8

1. Introduction

The Trust's service provision for children with suspected autism is currently provided in clinics held in four different locations across the Trust area. Whilst all the clinics work to the same clinical guidelines, the different processes within the clinics make it difficult for the Trust to operate efficient booking processes, access and discharge arrangements.

The Minister for Health, Social Services and Public Safety has set a target that children will wait no longer than 13 weeks for assessment following referral and a further 13 weeks for commencement of specialised treatment (intervention). At the end of March 2010, it was estimated that approximately 57 children were waiting longer than the recommended number of weeks for assessment.

The Northern Health and Social Care Trust proposes to establish a centralised specialist service for the diagnosis of Autism Spectrum Disorder (ASD) in children. The Autism Spectrum Disorder (ASD) Diagnostic Service Consultation Document sets out the proposal and outlines current service provision and the reasons for, and benefits of, centralising the service.

The Trust consulted on this proposal for an eight week period from 19 April to 14 June 2010. The purpose of the consultation process was to seek views on the proposal from a range of stakeholders including those directly affected by the future of ASD services. This document summarises the feedback received.

2. Consultation

The Trust wrote to all parents and carers of children diagnosed with ASD and those awaiting assessment. The consultation period commenced on 19 April 2010 for an 8 week period and ended on 14 June 2010.

Consultees were advised that a document detailing the proposed changes would be available on the Trust's website (available to the public), or from the Trust intranet (a computer network available within the Trust to Trust staff). Consultees could also request a copy of the document from the Trust.

The Director of Children's Services/Executive Director of Social Work informed all staff in the Children's Directorate that the consultation period had commenced and encouraged feedback.

The Trust received a total of three written responses. In addition, as a result of the consultation process, we received 11 telephone calls from parents who were concerned about the length of time it was taking to commence the assessment process. The Trust responded individually to all those parents who requested or required further information.

3. Consultation Feedback

The key themes raised in the feedback were as follows.

- The proposed centralisation of the ASD Diagnostic Service was welcomed.
- Centralisation is more effective use of resources and a one-stop-shop will minimise stresses experience attending appointments.
- Centralised service will provide equity of service provision across the Trust area.
- Concern was raised that the 'benefits' of centralisation, as detailed in the consultation document, are currently delivered through 2 slightly different models
- Concern was also raised that a centralised model will not be compatible with the Trust's core values.
- A view was expressed that diagnostic process can be emotional for parents and carers and they have a wide variety of needs at the time of diagnosis.
- Respondent queried if a 'variety of assessment approaches' will be used in the centralised service and if the specialist team will include a Music Therapist.
- Welcome the Trust's intention to provide professional staff with appropriate training and access to regular continuing professional development (CPD) opportunities.
- View that the proposed model suggests that a single assessment (one single appointment) will complete the process of diagnosis which is contrary to the recommendation that 'diagnosis is a process and not a single event'.
- Concern was raised that because of the large geographical area the Trust covers, those who live some distance from the centralised location will be disadvantages and non attendance may increase because of child care difficulties.
- Concern that a centralised model risks 'clinicalising' a pervasive disorder of predominantly social and emotional development.
- No evidence in consultation document that other options having been considered – propose the centralisation of administrative procedures with the delivery of services at a local level.

Trust Response

The Trust welcomes the comments received in relation the centralisation of the ASD diagnostic service in Antrim and would like to thank all those who responded for their valuable feedback.

The Trust has taken its direction in developing this proposal from the Health and Social Care Board and the Regional ASD Network.

The Trust recognises the concerns raised by professional staff and is committed to engage with all relevant professionals to develop appropriate services for children and young people with ASD.

The Trust intends to maintain the variety of assessment approaches which include individual and/or multi disciplinary assessments through the development of the centralised diagnostic model.

The Trust feels that the concerns raised regarding the value of local knowledge will be addressed within a centralised model, as is evidenced in many other specialist services.

The Trust is required to offer appointments to all Trust clients in a chronological basis and feels the most fair and equitable method of ensuring consistency is through a centralised model.

The Trust is aware of the benefits of Music Therapy and its contribution to services to children .The Trust will engage in determining the specific role for Music Therapy in relation to Autism as the Regional Pathway for autism services emerge.

The Trust will establish robust engagement arrangements and continue to work closely with staff, families and carers to monitor the implementation of this proposal.

4. Conclusion

The Trust continues to focus on providing safe, sustainable, modern services and understands that, in moving ahead with modernising services, it must acknowledge the concerns, and indeed the ambitions, of all those who have a stake in the future of service delivery. The Trust would wish to thank everyone for their valuable contributions.

Appendix 1

List of Consultees

Parent/Guardian of all children currently diagnosed
Parent/Guardian of all children awaiting assessment
Trust Staff (Children's Directorate)
NI Music Therapy Trust

Appendix 2

List of respondents

NIMT – Northern Ireland Music Therapy Trust

Trust Staff

Dr Clare Bailey, Associate Specialist - paediatrics
Dr Yvonne Doherty, Associate Specialist - paediatrics
Dr Pauline Kennedy, Associate Specialist - paediatrics
Dr Linda Nevin, Associate Specialist - paediatrics
Dr Heather Jack, Associate Specialist - paediatrics
Ms Lisa Vallely – Specialist Speech and Language Therapist – Clinical Lead for ASD services
Ms Ciara McCrory – Specialist Speech and Language Therapist
Mrs Rosemary Miller – Speech and Language Therapist
Mrs Lorraine Ringland – Specialist Occupational Therapist
Mrs Gillian Gamble – Senior Educational Psychologist – specialist ASD

Parents – who wish to remain anonymous for the purposes of this report