Initial Option Appraisal for Health Service Redesign for Children with Complex Needs
(Appraisal of Benefits)

Combined Child Health

Aberdeen City CHP

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(24/03/09)
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On behalf of the Option Appraisal Steering Group
Initial Option Appraisal: Health Service Redesign for Children with Complex Needs

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Executive Summary

In January 2009 a Steering Group was set up, in response to a request from the Board of NHS Grampian, to conduct an Option Appraisal on Health Service Redesign for Children with Complex Needs. A number of reports had been published in the previous years, highlighting inequities in the service provided for this group within Aberdeen City.

Following an initial meeting of this group, three workshops were held, with participants including members of the steering group and other relevant stakeholders. The three workshops were used to identify the benefits which services for children with complex needs should provide, rank these benefits and give each one a percentage weighting, generate options for service redesign and score each of these options against how well they would deliver each benefit. The workshops took place on three separate days in February and March 2009.

Following the three workshops two preferred options were identified. The first was a Hub and Spoke model whereby highly specialised services or access to equipment would be delivered from a central location and normal specialist provision would be made by teams located in community bases. The second was to have a central base for all staff, with community provision to be delivered by staff on an outreach basis either in the child’s home or through access to community sites and locations. A more detailed interpretation of these two options and of the status quo was carried out, and coupled with financial information and more detail on the process of the workshops, was used to inform the recommendations to be made to the Board.
**Introduction**

In 2002 the charity Capability Scotland reviewed provision of long term healthcare for children with complex disabilities. This report recommended a move towards Child Development Teams delivering a family-centred approach and continuity of service.

In light of this report, NHS Grampian and Aberdeen City Council jointly commissioned a review into services provided by health, education and social work for pre-school children with special needs. This review was conducted by Dr Karen Foster, Consultant in Public Health Medicine and Mrs Eleanor Spalding, Educational Consultant. This report supported Capability Scotland’s recommendation for the provision of Child Development Teams. Aberdeen City Council and NHS Grampian jointly conducted a study into the feasibility of implementing these recommendations (‘**Teams To Meet Needs 2006**’). This report undertook consultation with stakeholders including parents and practitioners from health, education and social work as well as those at a strategic level within these sectors. The report included a model for Child Development Teams including potential staffing and location. It also summarised possible options for future service provision, including retaining the current status quo, and several options for implementing Child Development Teams.

In order to build on the work of these reports, and to provide clarity for the progression of health services for children with complex needs, this Option Appraisal was undertaken. It draws on work carried out in three sessions with members of NHS Grampian staff, parents of children who currently access the services and representatives from Aberdeen City Council and VSA Carer’s Centre. This document will outline the strategic context in which the Option Appraisal is based, give information about current health provisions and state why this process has been undertaken. It will then outline how the benefits each option should be scored against were identified, how the options for service delivery were generated and identify the preferred option(s).
Strategic Context.

Government Legislation:- The government remains committed to the principles of universal, integrated educational and health support for all children, set out in ‘For Scotland’s Children’. In the framework for action described in ‘Delivering a Healthy Future’ it is acknowledged that advances in medicine have led to a higher proportion of children with complex needs surviving for longer periods of time. It emphasises that where possible services for these children should be provided at home or within a community setting and that it is vital that these services are delivered in a consistent and co-ordinated manner. This is supported by the government paper ‘Delivering for Health’ which envisages health care being delivered as locally as possible, by a multi-disciplinary team and with patients and their carers seen as partners in the process.

The 2003 Audit Scotland/ HMIE paper ‘Moving to Mainstream’ states that the number of children with special needs being educated in mainstream schools will rise in the future. The paper emphasises that for this to be successful, support from the NHS and greater collaboration between health, social work and education will be vital. The paper recommends that NHS bodies work with councils proactively to plan for provision for pupils with special educational needs. It is also recommended that the NHS, along with schools and councils look at ways to improve key transitions in children’s lives, including continuity of therapy and support services.

Aberdeen Context: - For Aberdeen’s Children (the integrated children’s services plan) sets out specific targets for providing health, education and social services for children in a co-ordinated way, which meet their individual needs and take into account each child’s views and situation.
Current Provision.

- **Raeden Centre**  Opened in 1974. The Centre provides multidisciplinary assessment, development and therapy input for children aged 0 – 5 years. It consists of an Outpatient Department, assessment unit, and developmental day nursery (funded by NHS Grampian) and a nursery school funded by Aberdeen City Council. It has permanent staff of therapists, doctors, nurses and nursery nurses as well as regular input from Clinical and Educational Psychology services and Social Work.

The assessment unit sees children from throughout Grampian, Orkney and Shetland with occasional referrals from other areas. It provides a multidisciplinary assessment of a child who has been referred by a professional usually a doctor.

Multidisciplinary Assessments usually take place over five days with the morning of the last day being used for the case conference between the family and all professionals involved to give diagnosis if appropriate and plan future care needs. The parents are present throughout the assessment week and should they not live within commuting distance of the centre, free accommodation is available in two bungalows on site, provided by the Friends of Raeden.

Following Assessment the Developmental Day Nursery is available to children aged 0-3 who live either within the catchment area which is an approximate 15 miles radius from Raeden including the feeder towns of Stonehaven, Banchory, Inverurie and Ellon. Children attend here two days a week during which they will receive appropriate therapies as well as developmental input from nursery nurses. Transport for children to and from Centre can be provided free of charge by NHS Grampian on needs basis. Nursery Nurses act as escorts for this facility. In conjunction with ‘Open door’ policy for parents the Nursing team has recently been developing an outreach service to further support the child and family through Assessment and their time attending Developmental Nursery.

The Nursery School is run by Aberdeen City Council and provides places for children aged 3-5 with a variety of special needs. This facility is open to children from within Aberdeen City and offers a half week placement to each child. A number of the children at the nursery school have a split placement between Raeden and local educational provision. Raeden provides the children on its roll with various facilities including a hydrotherapy pool and soft play area, both opened following fundraising by Friends of Raeden.

- **Child Development Team (Aberdeen South)** Currently a Child Development Team is being piloted in Aberdeen South. The team has
been operational for two years. They are based at Tullos Primary School on a temporary basis. The team includes a Medical team with Consultant Paediatrician and two career grade paediatricians, Physiotherapist, Occupational Therapist, Speech and Language Therapist, Nursery Nurse, Educational Psychologist, Social Worker and support staff. They see children and young people from 0 to 18 years for assessment and treatment. The assessments take place in the child’s own environment and are ongoing with involvement from parents and community partners. Multi-disciplinary assessments of pre-school children are undertaken by the Team, generally in the child’s nursery however, a number of pre-school children within Aberdeen South continue to be assessed at the Raeden Centre. Treatment will also take place in an appropriate community setting and the team have worked very closely with all the schools in the team catchment area, including Hazelwood School and the SEN bases in mainstream schools. The frequency with which children will be seen by the team and which members this will involve is individual to each child.

- **Royal Aberdeen Children’s Hospital** the new children’s hospital opened in 2004. It provides a full range of outpatient clinics and is the administrative base for the Community Child Health Service. Therapy services for those children not included in the Child Development Team or attending the Raeden Centre are based in RACH, some being delivered here and others in the schools.

- **The Community Child Health Service** delivers community based secondary and tertiary level medical services to children with developmental concerns or disability, from birth to school leaving age. Services are delivered in locality based clinics across Aberdeen, in Health Centres and Schools, at the Raeden Centre and in the Child Development Team. Medical Staff receive referrals from Primary Care Colleagues eg health visitors, school nurse, GP, as well as from hospital e.g. neonatal service, and education and social work services. The child is offered medical assessment, diagnosis, ongoing management and care coordination of their health needs, in the most appropriate setting, according to their need.
The Need For Change:

In recent years, both NHS Grampian and partner organisations within the public and voluntary sector have produced a number of reports including information on services currently provided for children with complex needs and how these services could change. In 2003 NHS Grampian commissioned the charity Capability Scotland to review health services throughout Grampian. The report focused on services for children with five conditions: Down’s Syndrome, Autistic Spectrum Disorders, Cerebral Palsy and major motor disorders, Hearing Impairment and Visual Impairment. The report stated that although the clinical and therapeutic care provided at Raeden and at the children’s hospital was high quality, the lack of community provision left health services within Aberdeen unequal and inconsistent with national policy. The report suggested moving to a community model, either with the provision of three Child Development Teams or through the creation of a single unified child health and social care service involving NHS Grampian, Aberdeen City Council and relevant groups within the private and voluntary sector.

In 2004 NHS Grampian and Aberdeen City Council jointly published ‘Review of pre-school services in Aberdeen City for children with special needs’ the report identified a number of issues with the current health provisions. These included; the need for partnership working between council and health services, a need for a wider range of community services, a need to reduce the inequalities in the service received by children, more active involvement of family in child’s care, better use to be made of the skills of Allied Health Professionals and appropriate surveillance and screening of children. The report recommended a refocusing of services to a community setting which provided a continuum of provision from 0-19 in as local a setting as possible. The report recommended this should be done through three Child Development Teams based within the community providing assessment and treatment in either a home or local setting such as the child’s school. The report outlined a recommended membership for these teams which included staff from health, education and social work. It also stated that none of the current services should be withdrawn until the new model was fully established.

In 2006, NHS Grampian and Aberdeen City Council jointly funded a report into the feasibility of implementing the recommendations made in the above report; ‘Teams to meet needs’ – Integrating services in Aberdeen City for children and young people with significant additional support needs’. The report also examines several options for service delivery. The option of continuing to provide care in the same way is recognised as being popular and providing a high quality of care for children under five. However it is also seen to provide a lower quality of care for those over five and to be inconsistent with new national laws. The option of creating three Child Development Teams and retaining Raeden is also examined and while it is recognised that this would maintain high quality services for all children and young people, the service would continue to be disjointed. The report
identifies a move to full community provision as providing a service which complies with national law as well as being holistic and inclusive. In order to progress this the report recommends the creation of a pilot Child Development Team in the South of the city.

It can clearly be seen that the need to change the service has been identified for a number of years. Many of the issues raised in the above reports have not been addressed and the current service does not provide an equal standard of care for all children and young people. The Child Development Team in the South of the City has now been operational for two years and it is currently being evaluated. However, this team is a pilot and therefore a decision must be made on the development of this service model. It is also recognised, that depending upon the option selected, any change to the current service may constitute major service change. This has lead to the decision to carry out an Option Appraisal on Redesign of Health Services for Children with Complex Needs.
Identifying the Benefits:

The first workshop was held on the 27th of February at Treetops Hotel between 9.00am and 12.30pm. The workshop was attended by 8 parents, 8 members of NHS Grampian staff and representation from Aberdeen City Council, Voluntary Services Aberdeen and the Board of NHS Grampian. There were also two representatives from the Scottish Health Council in attendance (A full list of participants in all the workshops is provided in appendix 1).

The aim of the first workshop was to agree on which benefits any health service for children with complex needs should include. It was stressed that, at this stage, there should be no discussion of actual service models. This workshop would be used to agree what participants felt they would like to see in any form of service delivery.

In order to identify the benefits they wished to see, participants split into three separate groups; Parents, Clinical Staff and Finance & Management. These groups then identified which benefits they would like to see in the service. To ensure a consensus could be reached on the interpretation of each benefit, participants were also asked to provide an explanation of their understanding of each benefit. These initial results were then examined and a list of benefits was created from them. (The full output of the workshop is provided in appendix 2).

On the 6th of March a second workshop was held to agree these benefits and give each one a ranking and percentage weighting. When examining the output from the first workshop, it was recognised that many of the benefits identified were values which should be present in the service provided regardless of which model was chosen. These values were then removed from the list of benefits which the options would be scored against and it was agreed that they would be viewed as factors which should underpin any service provision for children with complex needs. (A list of values and benefits along with their definitions is provided in Appendix 3). After discussion of the list of benefits, several amendments were made and a new benefit included in the list. The participants then split into the three groups again to rank the benefits. These rankings were then displayed to the group as a whole and the benefits were given a total ranking by calculating an average of the three scores and placing the benefits in order from highest to lowest average. This ranking was used to guide participants in giving each benefit a percentage weighting. The ranking was as follows:

1 Child Focused
2= Early Intervention and Key Stage Support
2= Communication
4 Support Around Initial Assessment and Diagnosis
5 Expertise
6 Co-ordination
The participants then returned to their three groups to give each benefit a percentage weighting. Each group had 100 percentage points to distribute between the 12 benefits in order to weight their relative importance. The three groups then reunited to agree on a single percentage weighting for each benefit. Where there was not a significant range of percentages, an average was calculated.

Where the three stakeholder groups had given a benefit significantly different weightings, these were discussed in more detail and a weighting agreed. At this stage it was agreed that the benefit of ‘Communication’ would be more appropriately described as a value and should therefore be removed from the list of benefits and transferred to the list of Values. It was also agreed that the benefit of ‘Co-ordination’ should be changed to ‘Co-ordination and Communication’.

Following a full and frank discussion in the format of comparing each benefit to those above and below to assess if it was more or less important, it was agreed that the weighting of ‘Inclusion’ should be changed from 6.3% to 9.3% and the weighting of ‘Expertise’ should be changed from 9.3% to 11.3%. This resulted in a list of benefits with the following agreed weightings:
<table>
<thead>
<tr>
<th>Benefit</th>
<th>Weighting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early Intervention and Key Stage Support</td>
<td>12.3%</td>
</tr>
<tr>
<td>Child Focused</td>
<td>12.0%</td>
</tr>
<tr>
<td>Support Around Initial Assessment and Diagnosis</td>
<td>11.3%</td>
</tr>
<tr>
<td>Expertise</td>
<td>11.3%</td>
</tr>
<tr>
<td>Co-ordination and Communication</td>
<td>9.3%</td>
</tr>
<tr>
<td>Inclusion</td>
<td>9.3%</td>
</tr>
<tr>
<td>Parent/Family Support</td>
<td>7.0%</td>
</tr>
<tr>
<td>Continuity</td>
<td>6.7%</td>
</tr>
<tr>
<td>Empowering/Enabling</td>
<td>6.7%</td>
</tr>
<tr>
<td>Access</td>
<td>4.3%</td>
</tr>
<tr>
<td>Setting</td>
<td>3.0%</td>
</tr>
</tbody>
</table>

NB Due to the conversion of the benefit ‘Communication’ into a value the weightings in this table do not total 100%.)
Generating the Options:

A third workshop was held on Friday 13\textsuperscript{th} of March in order to generate the options for service redesign and to score these options in order to identify the preferred option(s). To generate the options, the participants split into two ‘mixed’ groups (that is, groups which consisted of a combination of parents, management and clinicians). These groups then generated options and the participants came together to discuss these and to create a single agreed list of options for service change. The options generated are listed below:

**Options generated**

**Option 1**
Status quo i.e. Raeden, with no Child Development Team

**Option 2**
Status quo i.e. Raeden, with one Child Development Team – making the pilot in the south of the City permanent

**Option 3**
Status quo i.e. Raeden, but moved to the new school, with no Child Development Teams

**Option 4**
Centralised service for 0 to 3 years and community based service (Child Development Teams) for 3 to 18 years

**Option 5**
Centralised health services for 0 to 18 out with hospital

**Option 6**
Child Development Teams for 0 to 19 years, in a locality based service enhancing/replicating the Child Development Team service in Aberdeenshire

**Option 7**
Hub and spoke model

Hub – specialist centre providing specialist treatment and support to communities
Spokes – teams based and working in localities
Option 8

Outreach – teams and treatment at central location going out to deliver services

Option 9

Age related options:
Option 9a – centralised service
Option 9b – dispersed service delivered in schools

Option 10

Condition related services - centralised

Option 11

Hospital based services – non specialist

Option 12

Services delivered by primary care i.e. not a specialist service

Option 13

Two separate services for diagnosis and treatment (treatment delivered by Child Development Teams)

Option 14

Separate medical and therapy services – not working in teams

Following the generation of options, participants were each given an individual scoring sheet on which to score each of the agreed options on how well they would deliver on each benefit. Participants gave each option a mark from 0-3 based on the following scale: 0- does not meet expectations at all, 1- partly meets expectations, 2- meets expectation to a satisfactory standard, 3- fully meets expectations. The individual scores where then totalled and, along with the weightings of each benefit, used to calculate the ranking of each option. Once these calculations had been carried out the options were ranked as follows:
<table>
<thead>
<tr>
<th>Option</th>
<th>Final Weighted Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Status Quo</td>
<td>144.6</td>
</tr>
<tr>
<td>Status Quo with 1 CDT</td>
<td>140.2</td>
</tr>
<tr>
<td>Status Quo moved to new school</td>
<td>142.1</td>
</tr>
<tr>
<td>Centralised service for 0-3, community service for 3-18</td>
<td>155.1</td>
</tr>
<tr>
<td>Central service out with hospital</td>
<td>128.6</td>
</tr>
<tr>
<td>Child Development Teams 0-19</td>
<td>194.2</td>
</tr>
<tr>
<td>Hub and Spoke model</td>
<td>247.4</td>
</tr>
<tr>
<td>Central Base with Community Outreach</td>
<td>216.9</td>
</tr>
<tr>
<td>Centralised age-related option</td>
<td>86.9</td>
</tr>
<tr>
<td>Dispersed Service delivered in schools</td>
<td>76.8</td>
</tr>
<tr>
<td>Centralised condition specific services</td>
<td>54.1</td>
</tr>
<tr>
<td>Hospital based non-specialist service</td>
<td>37.6</td>
</tr>
<tr>
<td>Services delivered by primary care</td>
<td>33.8</td>
</tr>
<tr>
<td>Two separate services for diagnosis and treatment</td>
<td>85.1</td>
</tr>
<tr>
<td>Separate medical and therapy services</td>
<td>47.2</td>
</tr>
</tbody>
</table>
This identified the two preferred options as ‘Hub and Spoke’ and ‘Central Base with Community Outreach’. In order to ensure that stake holders from each of the three groups (that is, parents, finance and management and nurses and clinicians) were in agreement as to the preferred option(s), the scoring sheets were colour coded to make it possible to determine how each group had ranked each option. The following spider graph shows the relative ranking of each option by the total group and by each stakeholder group. The options are represented on each ‘spoke of the web’, and the ranking is demonstrated by their position relative to the centre. The centre of the graph represents the favourite option, with least favourite being the outside ring of the web.

Blue Group= Finance and Management
Pink Group= Nurses and Clinicians
Green Group= Parents

By looking at this graph it can clearly be seen that there was a lot of consensus within the groups as to the ranking of options. (a full list of the ranking of options both by the group as a whole and by the three separate groups can be found in appendix four)
The Preferred Options.

This section of the document will look at the two preferred options in more detail. Details of the Status Quo will also be included for the purposes of comparison.

Hub and Spoke:

A central hub - which would offer highly specialised assessment and treatment - that could only be provided in one location for the City and Grampian. This would include access to specialist equipment, or highly specialised/trained staff above the level of skill or expertise of the specialist staff that would be based in the community teams. Children would attend the hub at any time in their care journey when these additional skills or equipment are required, but would return to the community teams or to general health service provision between these times. In addition, the hub would act as a resource centre and support base for the staff in the community teams, providing training, information, resources and other support as necessary.

The Community Teams which would constitute the ‘Spokes’ in this option, would be based within communities (number of teams and locations to be determined). There would be a specific base for these teams and they would network with other community services within their area (GPs, Health Visitors, schools, social care services, voluntary organisations etc). They could reach in to the hub - but would be community based. Their base would include appropriate space for multi-disciplinary working and treatment, as well as supporting home based treatment.

Central Base with Community Outreach:

The provision of a centralised base which would offer highly specialised assessment and treatment in one location for the city and Grampian. This site would, in addition, be the location of all staff within the community teams. These staff would provide services within the community on an outreach basis. These services would be provided either in the child’s home or through access to community sites and locations.

Status Quo:

Children aged 0-5 continue to receive assessment, treatment and care from the Raeden Centre, the pilot Child Development Team in Aberdeen South is disbanded. Older children continue to receive medical and therapeutic care from members of the Community Child Health Team.
Conclusion:

In conclusion, it has been recognised that the current provision of health services for children with complex needs is not providing a high quality of treatment and care for all children and is not equitable. The service provided in Aberdeen City is also inconsistent with local and national policy. Due to this, the work contained within this document was carried out. Following three workshops which included a variety of stakeholders a consensus was reached on the two preferred options for service redesign. These were ‘Hub and Spoke’ and ‘Central Base with Community Outreach’. These two were recognised by a majority of stakeholders as best fulfilling the criteria of benefits the group had previously agreed they would like to see included in the services.
Appendix 1: - List of participants in the three workshops:

Elaine Allan (Lead School Nurse)
Babs Barrie (Nurse Manager Raeden)
Sue Barnard (VSA)
Anne Brockman (Head Paediatric Occupational Therapist)
Dr Jacqueline Crum (Consultant Paediatrician, Combined Child Health)
Susan Dutch (Paediatric Clinical Psychologist) did not attend first or third workshop
Rhona Jarvis (Policy Officer, Education Aberdeen City Council)
Heather Kelman (General Manager Aberdeen City CHP)
Dr David Kindley (Consultant Paediatrician, Raeden) did not attend first workshop
Harry Norton (Group Finance Manager NHS Grampian)
Alan Pilkington (General Manager, Royal Aberdeen Children’s Hospital)
Christine Simmonds (Specialist Health Visitor, NHS Grampian) did not attend second or third workshop
Pam Simpson (Education Aberdeen City Council) did not attend second or third workshop
David Tummelty (Head of service, social care for children and young people Aberdeen City Council) did not attend second workshop
Dr Justin Williams (Consultant Paediatric Psychiatrist) did not attend first workshop
Hilary Young (Health Visitor/ Service Manager Aberdeen City)
Eight Parent/Carer representatives, all of whom attended workshop one, seven of whom attended workshop two and five of whom attended workshop three

Facilitators:
Laura Dodds (Public Involvement Officer NHS Grampian)
Laura Gray (Director of Corporate Communications NHS Grampian)
Catriona Hagan (Management Trainee NHS Grampian)
Lauren Milne (Public Involvement Officer NHS Grampian)
Alan Ross (External Facilitator)

In Attendance
Emma Ashman (Scottish Health Council)
Elizabeth McDade (non-executive Board Member, NHS Grampian) did not participate in ranking or weighting due to potential conflict of interests
Christopher Third (Scottish Health Council)
Appendix 2: - Output of First Workshop

1. PARENTS

Recognition that children are individuals
(even with same condition/ syndrome)

Child focussed
- Setting appropriate to need / age
- 0-3, 3-5, 5-11, 11-19 – needs different at different stages (child and family)
- Ask and listen to children (child/developmentally appropriate)
- Support throughout / not to ‘tail off’ e.g. at puberty

Continuity of service
- Regular reviews
- Consistent
- Between appointments

Co-ordination
- Health can’t act alone
- Between agencies
- Between ages
- Within service

Less Stressed Parent and Child

Early intervention

Listening and involving parents
- Feedback
- Continued / regular
- Acting on
- Evaluate services
- Reduce cynicism

Feedback
- Written
- Consistent
- To parents
- Following appointments
- Better documentation
- Shared with others in health team
- Updated

Communication
• ‘2 way’ - family and service
• Honesty
• Within service, between professionals, multidisciplinary, planned, co-ordinated
• Clinical staff more open
• Share knowledge
• Doctors more holistic / integrated approach (not just medical model)
• Confidentiality ‘complex’
• Non judgemental
• Sensitive GPs
• Professionals to be less precious

Family support
• Support for siblings
• Not seeing child in isolation
• Extended family e.g. grandparents
• Information

Parent support
• Keeping families together
• Respite
• Counselling
• Reassurance
• Support groups
• Training

Confidence in service

Diagnosis
• Upfront info
• Sensitive
• Honesty
• Recognition that beginning of process, not end
• Not patronising
• Reduce isolation
• Follow up for support

Easy “open door” access
• Self referral
• Flexible
• Not discharge but ‘on hold’

Access
• Joint clinics - would mean better communication, joint working,
less appointments
- Range of settings e.g. schools
- Timing - not waiting too long at appointments
- 9am appointments not always good
- Range of times
- Better parking
- Easier to make appointments
- Responsive service

Transitions
- Between ages
- Gradual
- Smooth
- Co-ordinated
- Planned in time
- Supported

Setting
- Accessible e.g. parking
- Child friendly e.g. quiet areas
- Facilities e.g. pool, gym
- Local if appropriate
- Appropriate for exams
- Healthy environment
2. FINANCE AND MANAGEMENT

ASPIRATIONAL:

Aim for the best
• Ambitious
• Dynamic
• Innovative

FAMILY:

Family centred
• Service assisting the family to support the child

Accessible
• Ease of “entry” to services
• Service delivery
• Access to information
• Physical access:- parking, location, disability access etc, transport

Hub
• Communicate
• Information
• Networking

Welcoming
• A service that is friendly and welcoming
• Valuing children and families
• Feeling safe – physical, emotional

VALUES:

Transparent

(Positive) energetic

Equity
• Equal access for every child (with children), every family (with families), staff (with staff)
• No disadvantage
• Non discriminatory (culture, race)

Empowering/ enabling
• Empowering the child to maximise quality of life
• Enabling – Patient enabled to exert parenting authority-not undermining
• Not feeling “subject to the system”

CHILD:

Child centred
• Meet the needs of the child first
• Put the child in the right environment for the child
• The team grouped around the child

STAFF:

Staff feeling valued
• Staff trusted and empowered to do best job possible e.g. environment, equipment, safety, resources

SERVICE DELIVERY:

Clinically effective and professional
• Continuous personal development of staff
• Support continuous improvement
• Appropriately trained and developed staff, enabling teaching
• Team work, inter-agency, within NHS and with voluntary sector
• Meeting holistic needs of child as well as being effective in individual teams

UNIVERSAL:

Needs based
• Service designed in such a way as it can be sustained
• Available as and when required, short and long term
• Measurable - performance of service and outcome for child
• Adequate to meet needs of children e.g. appropriately staffed
• Structure within service that delivers appropriate to need
• Responsive, prompt without delay

Communication
• Service users connected to the service
• Services connecting with each other
• Information flowing around the child to ensure effective communication and service provision

Service that listens
3. Clinical and Nursing

Integration
- Continuity
- Supported transition
- Genuine commitment → PARTNERSHIP working (joint budget)
- Education and other agencies
- Community inclusion
- Local services (e.g. brownies, voluntary groups)
- Connecting strategic and operation policy planning
- Connecting policies (IAF service outcome agreement)

Inclusion
- For all
- Adequate facilities and resource
- Cultural issues
- Appropriate, timely information for all (languages, etc)
- TAILORED to children and families needs
- Service for all children where there are enduring concerns re-development and disability e.g. not diagnosis specific

Expertise
- Signposting to other services
- Input from all agencies inc. voluntary sector
- (Adequate) Training – available from various sources
- Appropriately trained professionals (all groups inc. admin support)
- Joint working
- Synergy
- Team working (inc. patients)
- Development of Transdisciplinary working (sharing and working together)

Informed choice
- Intervention
- Parents/carers
- Child
- Flexibility
- Time, venue, where possible

Adequate resources
- Advocacy
- Integrated single and multi agency training
- Sharing across and within sectors
- Facilities (Accommodation)
- Staff
• BUDGET
• Research training
• Information
• Care co-ordination access services- intra agency

Empowerment
• Supportive network
• All agencies supporting
• Parents feel able to care for their child (all agencies have a part to play)
• Parents feel able to make choices
• Appropriate care in the appropriate place at the appropriate time

Access
• Flexibility
• Co-ordination, co-operation between and within agencies (agreements)
• Culture
• One that people see as a benefit
• Geographical distance
• Physical environment
• Clear referral routes in and out
• Times suitable

Management
• Multi agency service managers
• PFPI .....links....Parent involvement within local service (PFPI)
• Local service
• Joint management
• NHSG and other agencies committed to joint working at both operation and strategic level.

Responsibility
• Child
• Joint working within and out with services
• Service level / provision
• Professional
• Parental
• Empowerment - self-care

Local
• ? Educational developments
• Developmental nurseries
• Family centres (social care)
• School network
• Parental choice (e.g. school, work, home etc)
• What is local? Defined neighbourhood, balance between city wide or in specific areas
Appendix 3: - A List of the Agreed Benefits and Values

Values:

Aim for the best
Whichever service option is selected it should always aim to provide the best possible care, treatment and support

Recognise that children are individuals
Even if two children have the same condition, they are very different people. Any service option should take into account the importance of treating every child as an individual

A Service that listens
Any service should listen to parents and involve them, providing feedback and the opportunity for evaluation. This should be provided continuously and regularly and feedback should be acted upon. The service should endeavour to reduce cynicism.

Staff feel valued
Service should always ensure staff feel trusted and empowered to do the best job possible.

Confidence in service
Any service model can only succeed if staff and parents can have confidence in it.

Welcoming
The service must provide a safe and friendly environment, where children and families are valued.

Transparent
The service must be open and honest.

Positive, Energetic
The service must be delivered in a positive way, with commitment and energy.

Communication:
All communication should take place in an honest, non-judgemental way, whether it is between staff, staff and parents or staff and children. Clinical staff should be open and ready to share knowledge. Doctors should consider than just the ‘medical model’. It is important
for parents to receive feedback after appointments and parents should also be enabled to communicate with each other.

Benefits:

Continuity:
The service should be consistent throughout the time which the child and family accesses it. This not only means that transitions including the transition to adult services, are well planned and supported but also that children receive regular reviews and appropriate support between appointments.

Co-ordination and Communication:
To fully meet the requirements of each child, there must be co-ordination and communication between health professionals and co-ordination and communication with other agencies in the public and voluntary sector. There must be a genuine commitment to partnership working at all levels. The service should link to local schools, family centres, nurseries and appropriate extra curricular activities such as Brownies.

Parent/Family Support:
The service should provide information and support for parents but also for siblings and extended family such as grandparents. The service should aid with access to counselling, training, respite, support groups.

Access:
Flexibility should be provided, with a range of appointment times and locations. The services should have clear referral routes in and out and an ‘Open Door’ policy.

Support Around Initial Assessment and diagnosis:
Information on the child’s diagnosis and the implications should be delivered honestly but sensitively and in a non-patronising way. Efforts should be made to reduce isolation and to support the child and family. There needs to be recognition that diagnosis is the beginning of the process and not the end.

Setting:
Services should be located somewhere which is easy to reach both by car and public transport and has good parking. The setting should be as local as is appropriate. The environment, within which the services are delivered, should be child-friendly, healthy and safe with
consideration of facilities such as baby changing rooms, medical facilities, hydrotherapy pool, gym and sensory rooms.

**Child Focused:**
The service should put the child first and should be needs based, taking into account different ages, key stages and different needs. The service should be structured and staffed in such a way that it can do this. Children should be listened to and supported throughout.

**Empowering/Enabling:**
The child should feel empowered and enabled through provision of appropriate services to maximise their quality of life. Parents and children should be equal partners in making choices about the child’s care.

**Expertise:**
All staff who work in the service should have the appropriate skills and training including admin and management staff. Continuous professional development should be supported and encouraged. All staff should take a holistic approach to the needs of the child. Parents should be encouraged to work with staff and parent’s expertise should be recognised and appreciated. Transdisciplinary† working should be encouraged to broaden the spectrum of knowledge and experience. Staff should also be aware of services provided by other agencies and be able to signpost this to parents.

† transdisciplinary; pertaining to or including more than one discipline; interdisciplinary (Webster’s New Millennium Dictionary of English, Preview Edition (v.0.9.7))

**Inclusion:**
The service should be tailored to the needs of each child and their family. Rather than setting rigid criteria for referral, the service should include all children about whom there are enduring concerns regarding development or disability. The service should also ensure that cultural and linguistic differences are taken into account and do not hinder access to the service. Provision of services should be focused towards allowing children to attain an equality of life with their peers, whoever they may be.

**Early Intervention and Key Stage Support:**
Ease of access to services prior to diagnosis and at key life stages thereafter, with joint working with universal health services
Appendix Four - Table of ranking for each options by group as a whole and by three separate groups

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<thead>
<tr>
<th>Ranked Order of Options</th>
<th>Whole group Ranking</th>
<th>Finance/Management Ranking</th>
<th>Nurses/Clinician Ranking</th>
<th>Parent Ranking</th>
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