Liquidlogic

A System for Children with Disabilities

"As Is" Analysis for Newcastle CWD Project	
Date	January 2004
Version	1.2
Author	Anne Parker

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Document References

This section contains references to any other documents that are relevant or referred to by this document including the document name and version number.

Document	Version	Author

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Name	Organisation
Joan Debnam	Manager for Multi Agency Integration, Newcastle Social Services
Ed Jones	Care First Project Manager, Newcastle Social Services
All the practitioners and administrators involved with the pilot system.	

Table of Contents

1 Overview

The ODPM FAME programme consists of a number of product strands designed to deliver multi-agency systems in several key areas. One of those strands is the Newcastle Children with Disabilities Project which aims to deliver an information system to support a range of agencies in the provision of integrated services to children with disabilities.

A major part of the development of this system is the analysis of existing business processes to gain an in depth understanding of current activities and the problems associated with these activities. This analysis will then contribute to the development of the system requirements which, in turn, will form the basis for software development for the system. This document contains a detailed description of current or "as is" business processes and is a key deliverable within the project.

2 Abbreviations used in this document

CAMHS	Child and Adolescent Mental Health Services
CRAMS	Case Record and Management System
CTLD	Community Team for Learning Disability
CWD	Children with Disabilities
EMS	Education Management System
EWP	Education Welfare Officers
FAME Project	Framework for Multi-agency Environments Project
GP	General Practitioner
HONOSCA	Health of the Nation Outcome Scales
IT	Information technology
LEA	Local Education Authority
ODPM	Office of the Deputy Prime Minister
OT	Occupational Therapy
PCT	Primary Care Trust
PCT	Personal Computer
PIMS	Patient Information Management System
SEN	Special Educational Need
SENCO	Special Educational Needs Coordinator
SENTASS	Special Educational Needs Teaching and Support Service
SW	Social Work

3 Methodology

Information on current referral pathways and processes for assessment and review were gained by direct contact with practitioners in each of the services listed below either by on site visit or at practitioner workshops.

The aims of this information gathering exercise were:

- To put into context how services were organised and provided
- To collect information about the referral, assessment and review processes
- To identify IT systems currently in use and the information recorded on them
- To gain an overview of current IT skill levels
- To promote the awareness of the FAME project

Firstly, the reasons why a child would enter the system were examined and from this the possible routes for first referral through different services were identified.

The processes within each service for dealing with incoming referrals were then examined. Following on from that the processes for assessment, planning and review were considered. Finally, the processes for communicating the results of assessments and referring on to further services were discussed. In addition to the process analysis the use of existing IT systems was examined.

4 Current Processes

4.1 Entry into System

Concerns leading to first referrals can be generated at various stages in a child's life. Children may enter the system at birth if they are born prematurely, if they suffer birth injury or if they have a congenital condition. The entry route for these cases is usually through secondary care. Older children may enter the system following injury or as the result of a developmental or degenerative problem. These children may enter the system through a variety of routes including secondary care, primary care, social services or the education system.

4.2 Community Paediatrics

Community paediatricians provide secondary paediatric care and are organised on a locality basis.

4.2.1 Incoming referrals

Referrals are received from:

- Neonatology
- General Practitioners
- Health Visitors
- Specialist School Health Nursing Service
- Physiotherapy
- Occupational Therapy
- Speech and Language Therapy
- CTLD
- SENTASS
- SENCOs
- On call system
- CWD Social Work Team

4.2.2 Outgoing Referrals

Community paediatricians refer on to:

- Tertiary paediatric services
- Physiotherapy
- Occupational Therapy
- Speech & Language Therapy
- SENTASS
- CTLD
- Children's Community Nursing
- Specialist School Health Nursing Service
- Audiology
- Ophthalmology
- Genetics
- Dietetics
- Educational Psychology
- Psychiatry
- Orthopaedics
- CWD Social Work Team

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4.2.3 Flow diagram

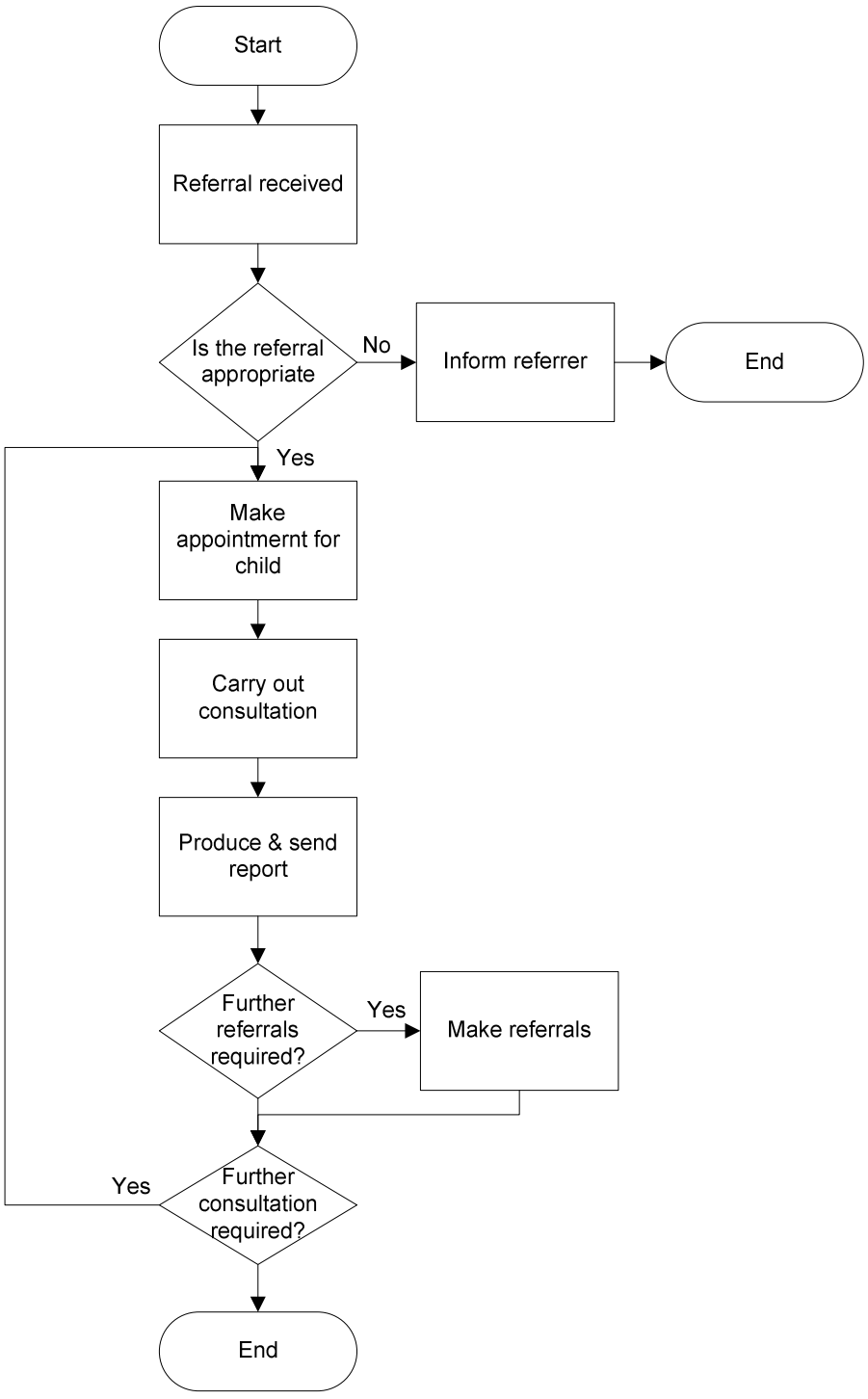

Figure 1 Flow diagram for Community Paediatrics

4.3 Children with Disabilities Social Work Team

This team assesses the needs of disabled children and their families. Following assessment the social worker may offer advice or develop a care plan to support the child or carer.

4.3.1 Incoming referrals

Referrals are received from:

- Parents
- Community Paediatricians
- Children's Community Nursing
- Specialist School Health Nursing Service
- CTLD
- SENCOs
- Child and Family Social Work Teams
- Child Protection
- Hospital Social Work Teams

4.3.2 Outgoing Referrals

The team refers on to:

- Occupational Therapy
- Physiotherapy
- Speech & Language Therapy
- Specialist School Health Nursing Service
- Educational Psychology
- Psychiatry
- Children's Community Nursing
- Housing
- Welfare Rights
- Child and Family Social Work teams
- CAMHS
- SENTASS
- Short Break Services
- Community Resources
- Voluntary & Charitable Organisations

4.3.3 Flow Diagram

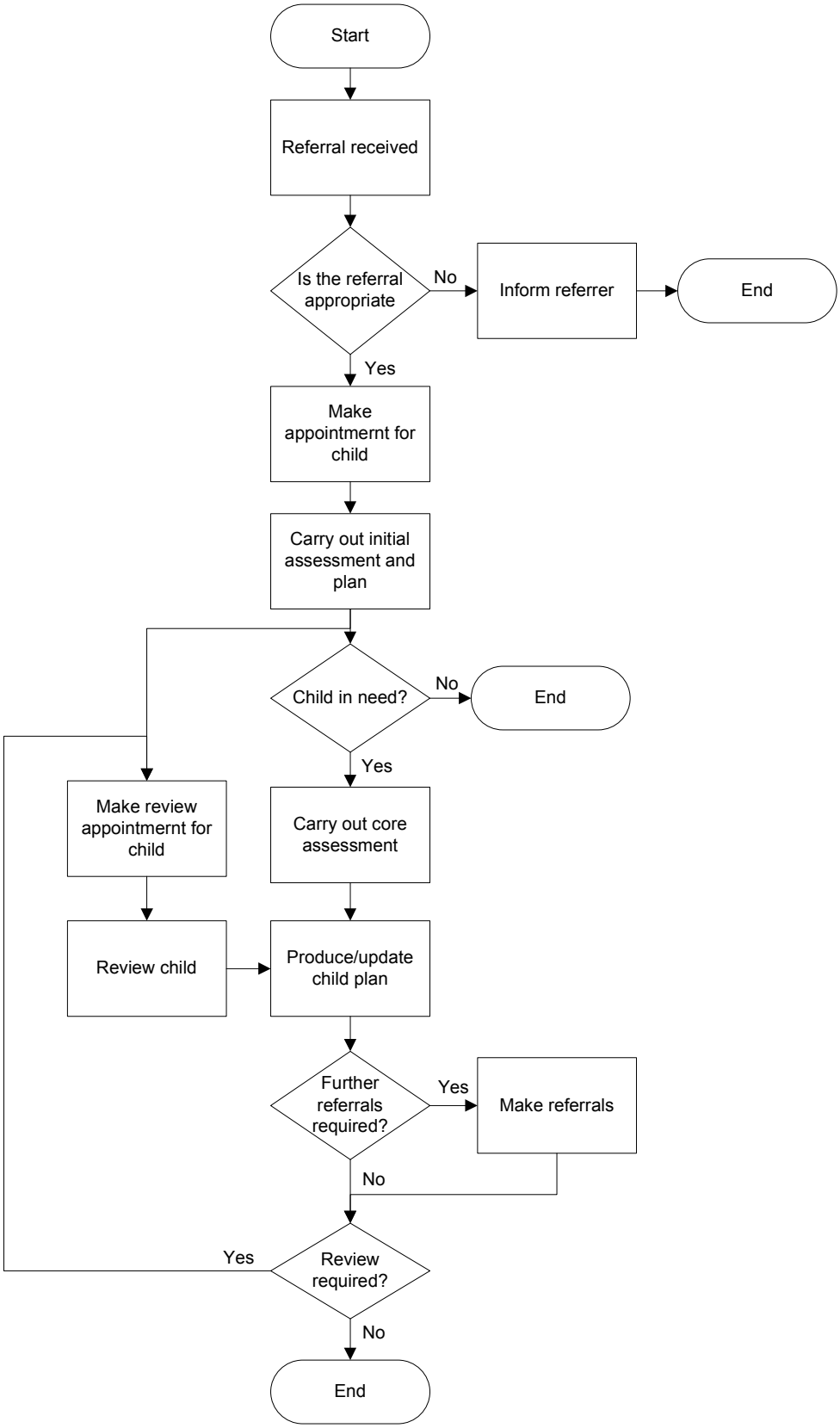

Figure 2 Flow Diagram for Children with Disabilities Social Work Team

4.4 Short Break Services

4.4.1 Acceptance criteria

Referrals are only received from the Children with Disabilities Social Work Team following a core assessment.

4.4.2 Outgoing Referrals

This service does not make referrals to other services.

4.4.3 Flow Diagram

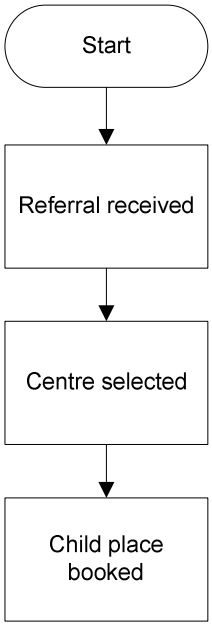

Figure 3 Flow Diagram for Short Break Services

4.5 Children's Community Nursing

The Children's Community Nursing team provide nursing care and support to children with disabilities or complex health needs in their own environment.

4.5.1 Incoming referrals

Referrals are received from:

- Parents (rarely)
- Hospital Paediatricians
- Neonatologists
- Ward Nurses
- Specialist Nurses (Cystic fibrosis, oncology, continence etc)
- Community Paediatricians
- General Practitioners
- Health Visitors
- Community nurses
- Hospital Social Work Team
- CWD Social Work Team
- Children & Families Social Work Team
- CTLD
- School Health Advisors
- Physiotherapy
- Speech and Language Therapy
- CAMHS
- SENTASS
- Voluntary agencies

4.5.2 Acceptance criteria

- Aged 0-19
- Complex health needs; one or more medical or physical conditions with any combination of:
  - Technical dependency
  - Behavioural difficulties
  - Learning/developmental difficulties
  - Speech and language difficulties
  - Mental and emotional difficulties
  - Socio-economic difficulties
  - Multiple professional involvement

4.5.3 Outgoing Referrals

The team refers on to:

- GP
- Health Visitor
- Physiotherapy
- Speech & Language Therapy
- Hospital Social Work Teams
- Children with Disabilities Social Work Team
- Dietetics
- Hospices
- Voluntary Services
- Community Paediatricians
- Housing
- Child and Family Social Work teams
- Voluntary & Charitable Organisations
- Specialist Nurses (Cystic fibrosis, oncology, continence etc)
- CAMHS
- Loan equipment service
- School health advisor
- Hospital Paediatricians
- SENTASS

4.5.4 Flow Diagram

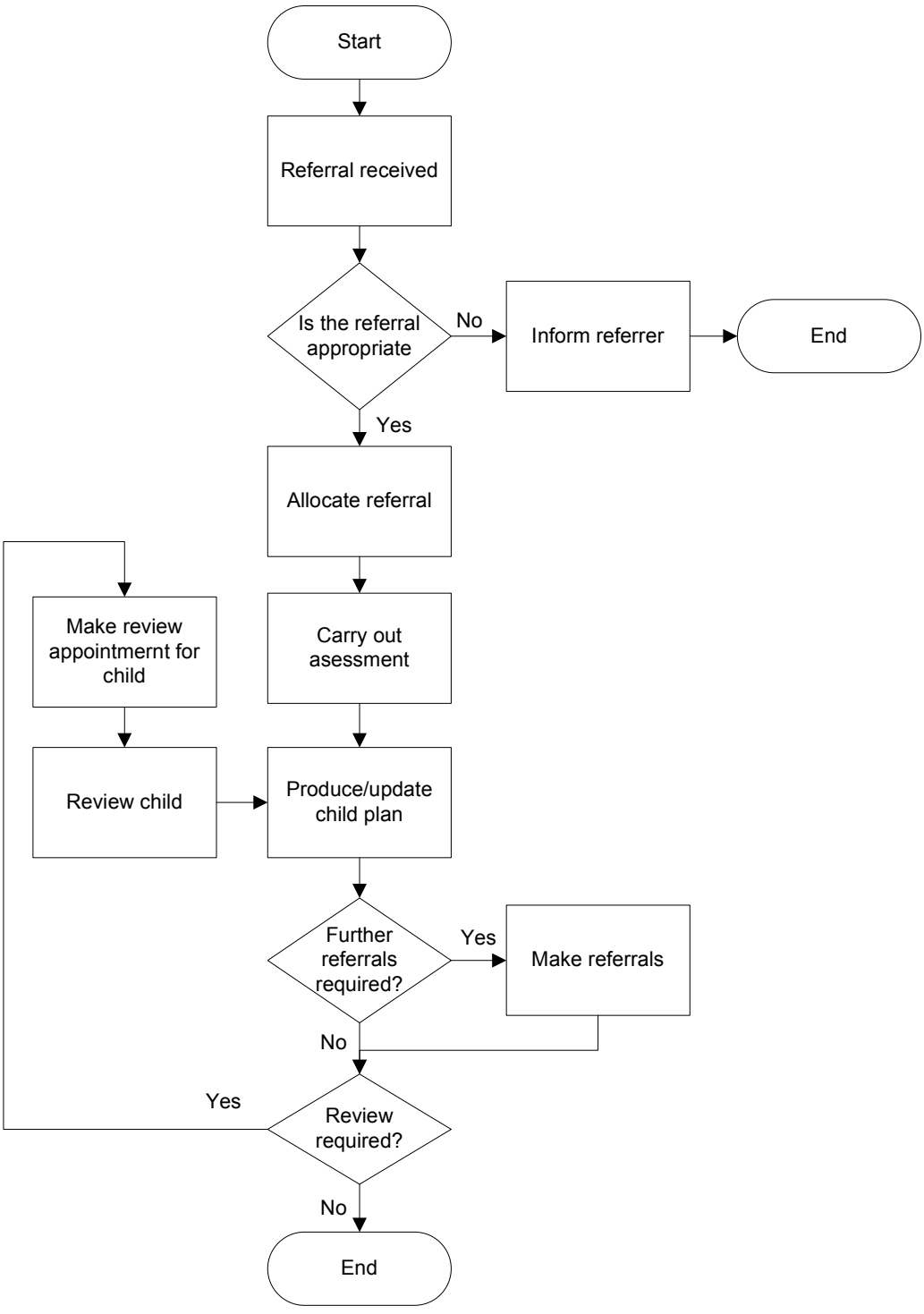

Figure 4 Flow Diagram for Children's Community Nurses

4.6 Specialist School Health Nursing Service

4.6.1 Incoming referrals

Referrals received from:

- Health Visitors
- School health advisors
- General Practitioners
- Community paediatricians
- Hospital consultants
- Ward nurses
- Physiotherapists
- Occupational therapists
- Speech & Language therapists
- Parents
- Teachers
- SENTASS
- Specialist Nurses (Cystic fibrosis, oncology, continence etc)
- CTLD
- CAMHS
- CWD Social Work Team

4.6.2 Acceptance criteria

Children of school age and those in the term prior to entry into the reception class that have a disability and/or complex health need which has a profound affect on their health, development and social functioning.

4.6.3 Outgoing Referrals

- Physiotherapy
- Occupational Therapy
- Speech & Language Therapy
- Hospital Social Work Teams
- Children with Disabilities Social Work Team
- Dietetics
- Hospices
- Voluntary Services
- Community Paediatricians
- Housing
- Child and Family Social Work teams
- Education Welfare
- Voluntary & Charitable Organisations
- Specialist Nurses (Cystic fibrosis, oncology, continence etc)
- CAMHS
- Community Resources
- SENTASS
- CTLD
- School Health Advisors

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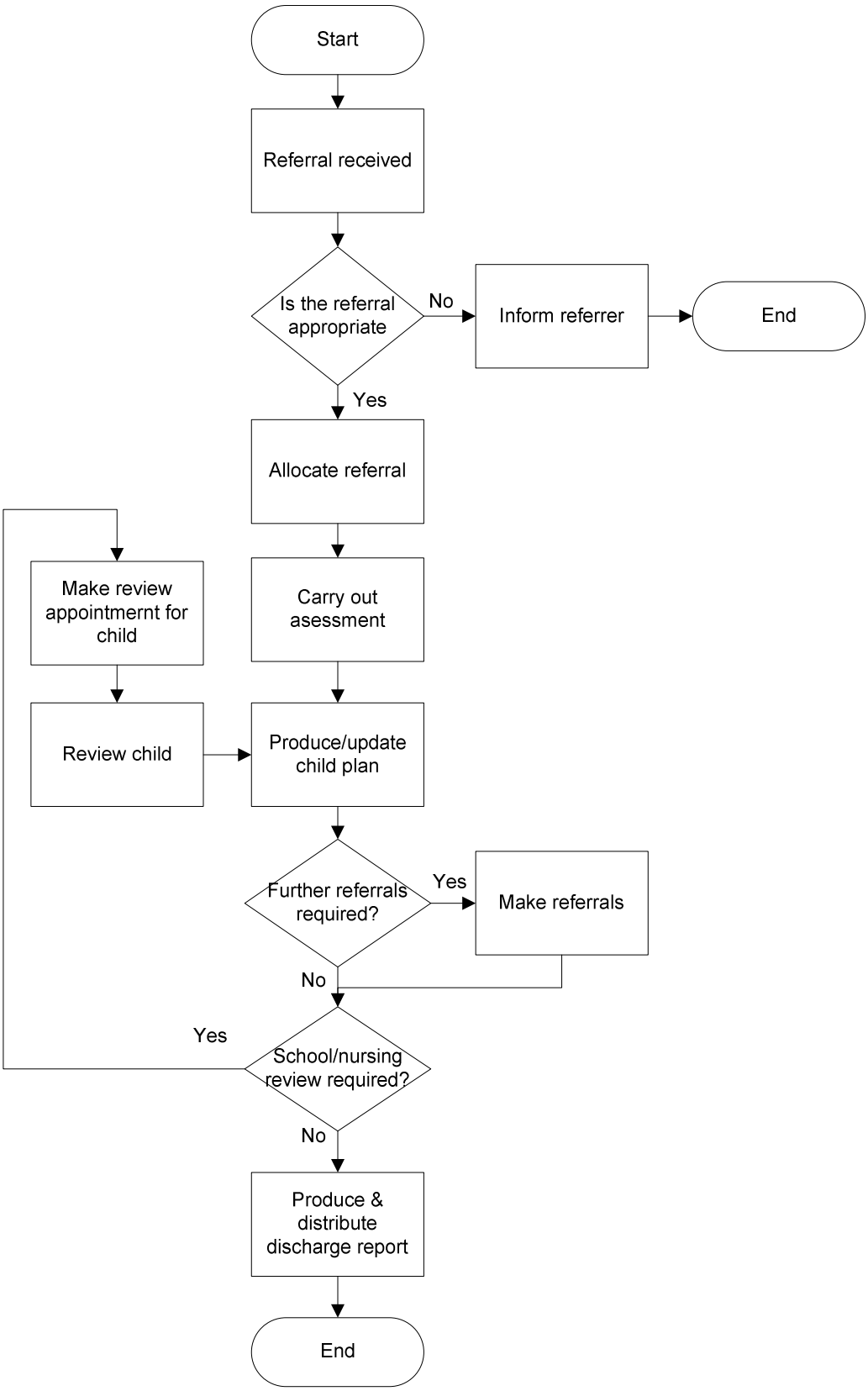
4.6.4 Flow Diagram



- **Figure 5 Flow Diagram for Children's Specialist School Health Nursing Service**

4.7 Educational Psychology

4.7.1 Incoming referrals

No referrals received in the accepted sense. Instead they have an allotted amount of time with each school when they work with the school or with individuals. The LEA also requests help for children moving into the area or those needing statutory assessment. Referrals made by parents or other professionals are generally handled within the school review system.

4.7.2 Outgoing Referrals

No direct referrals made from this service, they are made via the SENCOs.

4.8 Physiotherapy

4.8.1 Incoming referrals

- General practitioners
- Health visitors
- Hospital paediatricians
- Community paediatricians
- Hospital physiotherapists
- School Doctors/School Health Advisors
- Child Development Centre
- SENTASS
- Neonatologists
- Other hospital specialists
- Children's Community Nursing
- Specialist School Health Nursing Service
- CWD Social Work Team
- Occupational Therapy
- Speech & Language Therapy

4.8.2 Acceptance criteria

Children aged 0-19 years that have a condition where community physiotherapy is indicated.

4.8.3 Outgoing Referrals

- CTLD
- Occupational therapy
- Speech & language therapy
- Specialist School Health Nursing Service
- Children's Community Nursing
- Community paediatricians
- Child development centre
- Hospital Specialists
- Podiatry
- Loan Equipment Service

4.8.4 Flow Diagram

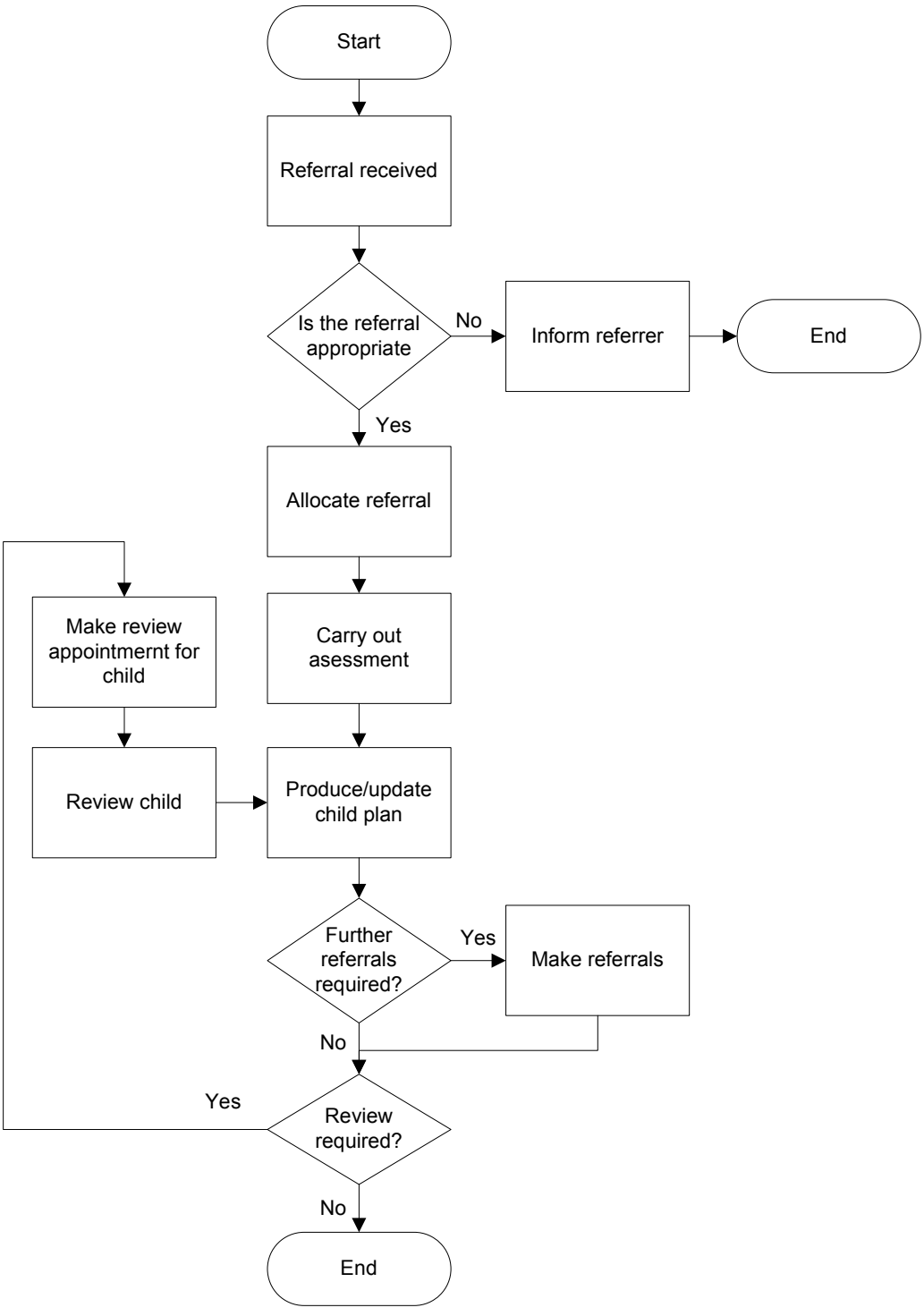


Figure 6 Flow Diagram for Physiotherapy

4.9 Occupational Therapy

4.9.1 Incoming referrals

- Community paediatricians
- Specialist School Health Nursing
- Physiotherapy
- Children with Disabilities Social Work Team

4.9.2 Outgoing Referrals

- Community Paediatrics
- Physiotherapy
- Speech & language therapy
- Housing
- Loan Equipment Service

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4.9.3 Flow Diagram

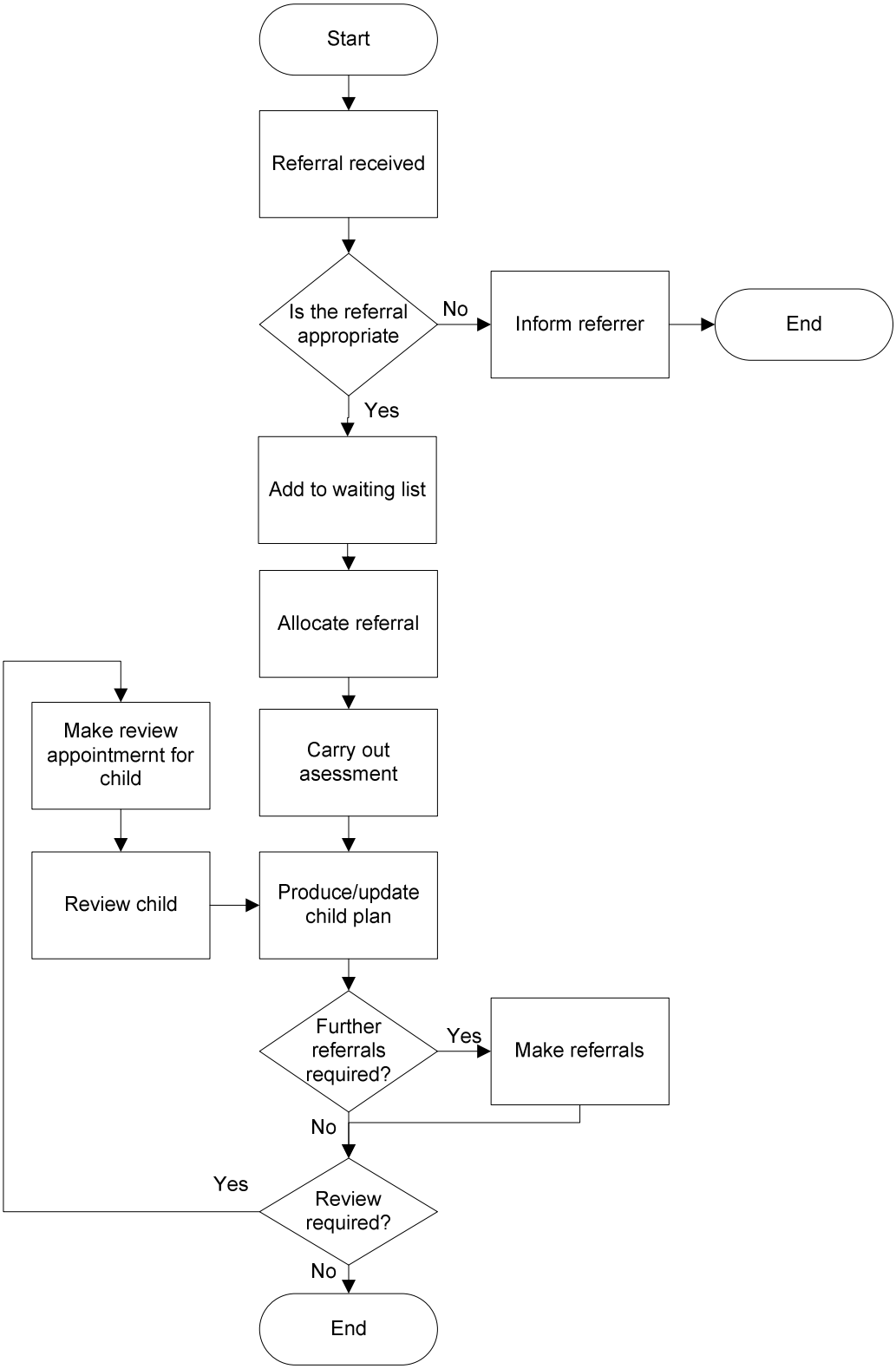


Figure 7 Flow Diagram for Occupational Therapy

4.10 Welfare Rights

4.10.1 Incoming referrals

Referrals received from:

- Social services teams
- Finance officers
- Sensory support team
- Customer service points
- Parents/carers

Plus many other referral routes into the service.

4.10.2 Outgoing Referrals

No actual referrals made but clients may be advised to contact general practitioner, health visitor, occupational therapy or Equipment direct.

4.11 Speech and Language Therapy

4.11.1 Incoming referrals

- Health Visitors
- General practitioners
- School Health Advisers
- Community Paediatricians
- Hospital Paediatricians
- ENT
- Plastics (cleft palate)
- Neurology
- Children's Community Nurses
- Specialist School Health Nursing Service
- CAMHS
- Physiotherapy
- Occupational Therapy
- Clinical Psychology
- Schools, Nurseries and Playgroups – includes independent + Northern Counties School but not Local Authority Special Schools (these are CTLD)
- SENTASS: Young Children's Team, Physical, Visually Impaired, Hearing Impaired
- Behavioural Support
- Dietetics
- Growth & Nutrition Service
- Parents
- CWD Social Work team

4.11.2 Outgoing Referrals

- Physiotherapy
- SENTASS
- Teachers of the deaf
- Educational Psychology
- ENT via GP
- Audiometrician (hearing test)
- Community Paediatrician
- Child Development Centre
- CTLD
- General practitioner
- Health Visitor
- Dietetics

- Growth & Nutrition Service
- Children's Community Nursing
- Specialist School Health Nursing Service
- CAMHS

4.11.3 Flow Diagram

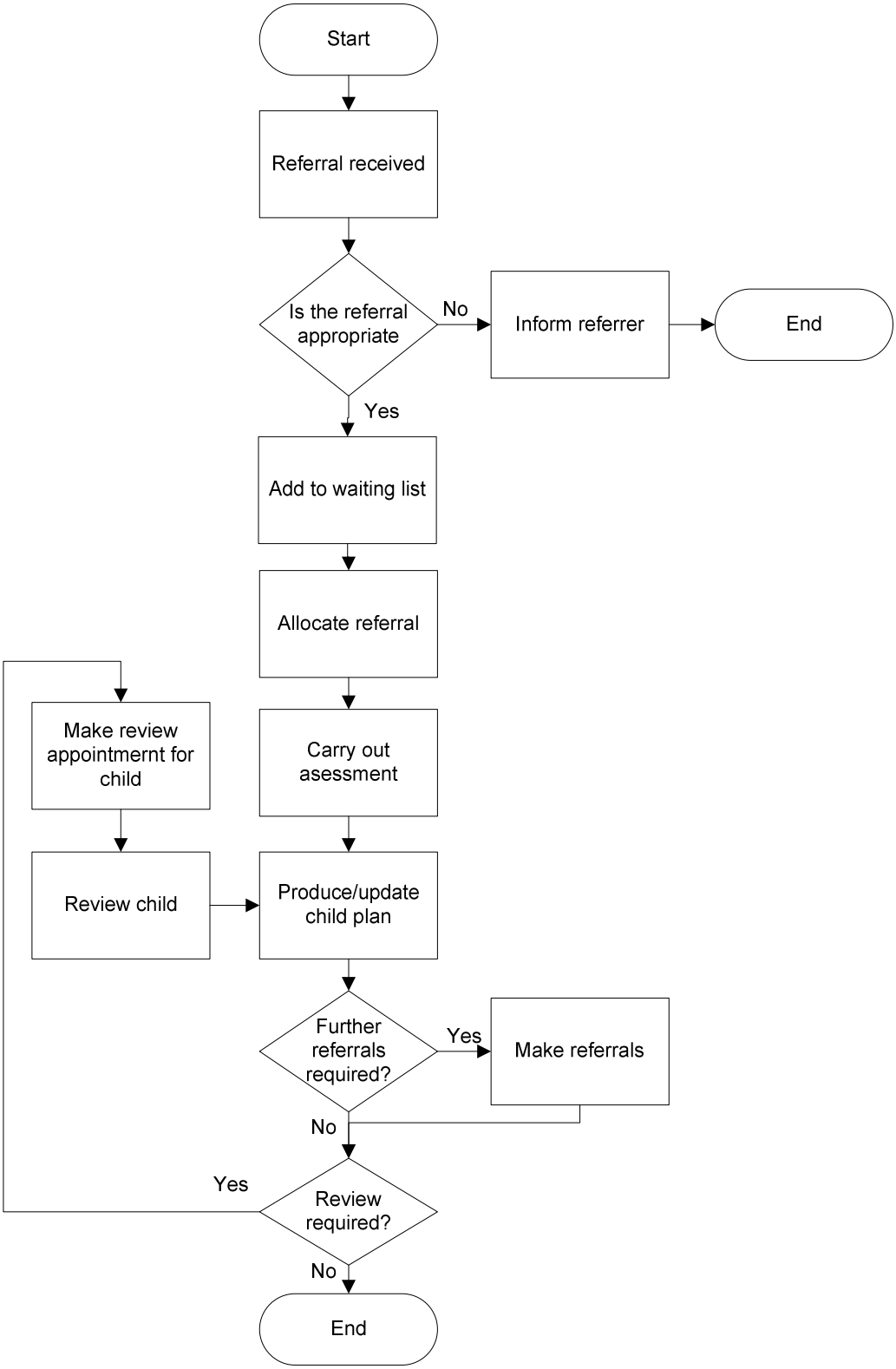


Figure 8 Flow Diagram for Speech & language Therapy

4.12 Community Team for Learning Disability

The Community Team for Learning Disability (CTLD) includes of a number of different disciplines: psychology, speech therapy, physiotherapy and community nursing. Both speech therapy and physiotherapy have a paediatric sub-group. There is also a psychiatrist linked to the team.

4.12.1 Incoming referrals for psychiatry

Incoming psychiatric referrals are handled separately from those to the rest of the team and are only accepted from clinicians:

- General Practitioner
- School Doctor
- Community Paediatrician
- Child Psychiatrist
- Neurologist
- Other CTLD Teams

4.12.2 Outgoing Referrals from psychiatry

Referrals sent to:

- Paediatric Neurology
- Psychiatry
- Community Paediatrics
- Obstetrics & Gynaecology

4.12.3 Incoming referrals for CTLD

Referrals received from:

- Parents/Grandparents/Carers
- General Practitioner
- Continence Advisor
- Speech & Language Therapy (community team/ CDC)
- Community Paediatricians
- Other CTLD Teams
- Health Visitors
- CAMHS (Flemming Nuffield)
- Specialist School Health Nursing Service
- Teachers
- Paediatric Neurology
- Physiotherapy
- Psychiatry
- Social Workers (Learning Disability Team)
- Children's Community Nursing

4.12.4 Outgoing Referrals

Referrals sent to:

- Social Services – Children with Disabilities Team, Child & Family Team, OT
- Botox Clinic
- Child Development Centre
- Community paediatrics
- Orthopaedics
- Dental Service
- School Nursing – mainstream & special school
- Children's Community Nursing
- Schools, for problems in school, route to Ed. Psychology
- Educational Welfare
- GP
- Primary Mental Health Nurses
- CAMHS
- CTLD psychiatry
- Dietician

- Communicate
- Continence adviser
- Art & Music Therapist
- Other disciplines within team
- Same discipline within team at transition to adult (physio)
- Loan Equipment Service
- Regional medical physics
- Connexions
- Welfare rights

4.12.5 Flow Diagram

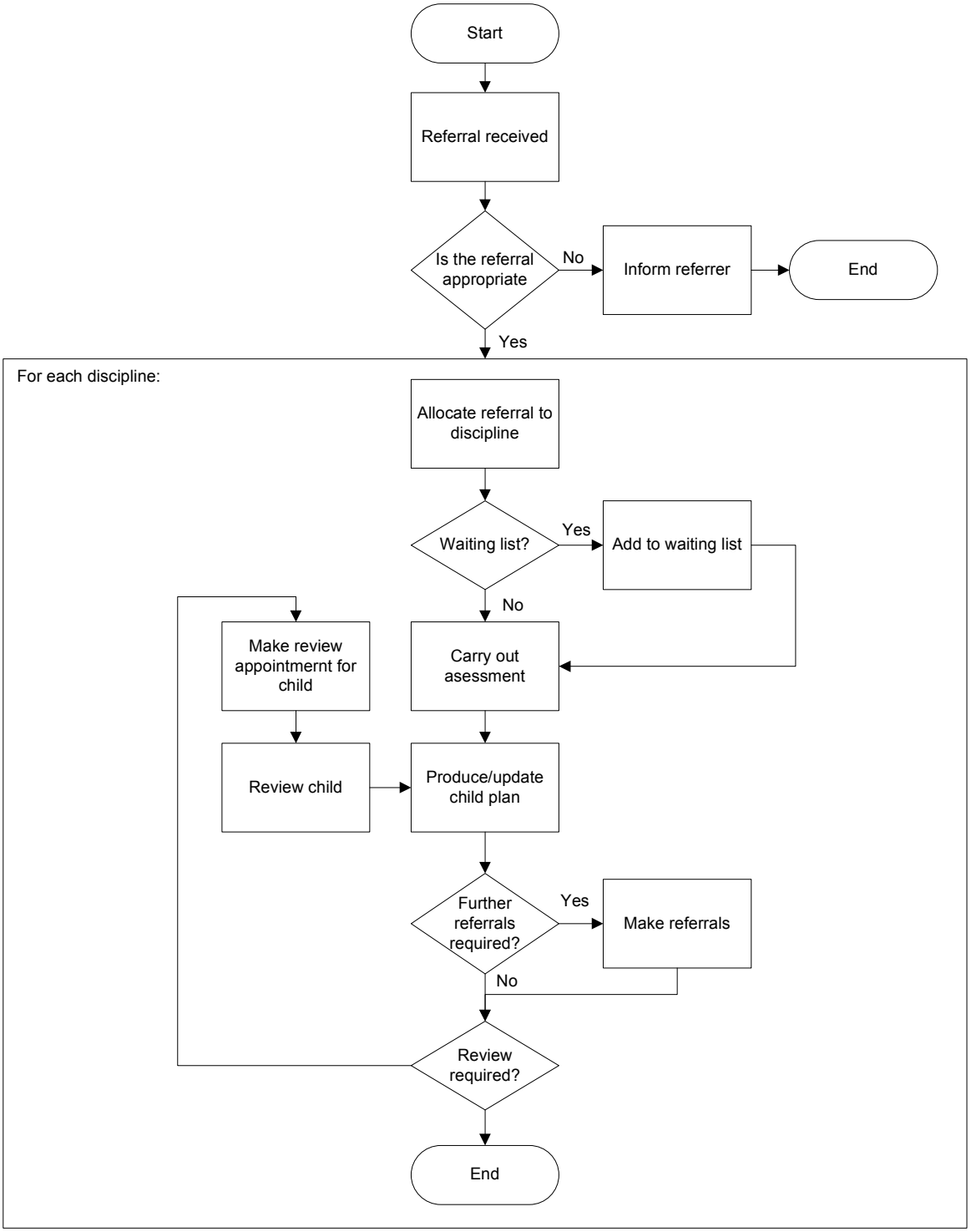


Figure 9 Flow Diagram for CTLD

4.13 SENTASS/SENCO

SENTASS offer support to children with a range of special educational needs. The service incorporates the Young Children's team and the Sensory Team. SENCOs are responsible for coordinating help for children with special educational needs.

4.13.1 Incoming referrals

Sources of referrals depend on the age of the child. There is an open referral system for the SENTASS Young Children's team. For school age children referrals are usually from the SENCO to SENTASS. Overall referrals are received from:

- Community paediatricians
- Health Visitors
- Children's Community Nursing
- Specialist School Health Nursing Service
- Children with Disabilities Social Work Team
- Speech and language therapists
- CAMHS
- SENCOs.

4.13.2 Outgoing Referrals

Outgoing referrals follow much the same pattern:

- Community paediatricians
- Health Visitors
- Children's Community Nurses
- Specialist School Health Nursing Service
- Children with Disabilities Social Work Team
- Physiotherapy
- Speech and language therapists
- CAMHS
- SENCOs.

4.13.3 Flow Diagram

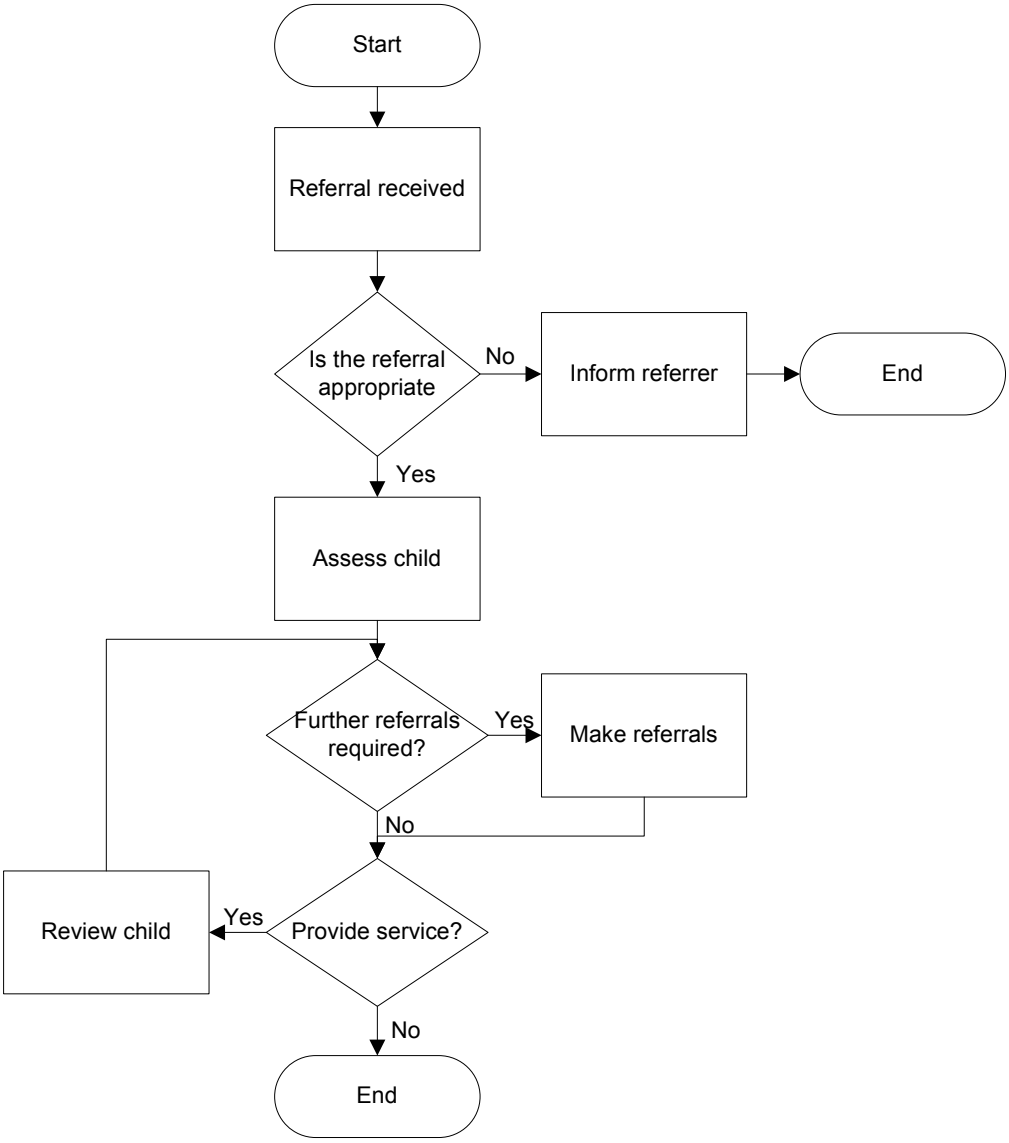


Figure 10 Flow Diagram for SENTASS

The process for statutory assessment is documented in the SEN code of practice.

4.14 Loan Equipment Service

Loan equipment services receive and process requisitions for the loan and purchase of nursing equipment and aids to support daily living. The requests are usually received from community or school nurses, physiotherapists, occupational therapists or CTLD. Requests for the purchase of specialist's equipment are accepted for non stock items. These are prioritised and compete for funding.

The service does not make referrals to other services.

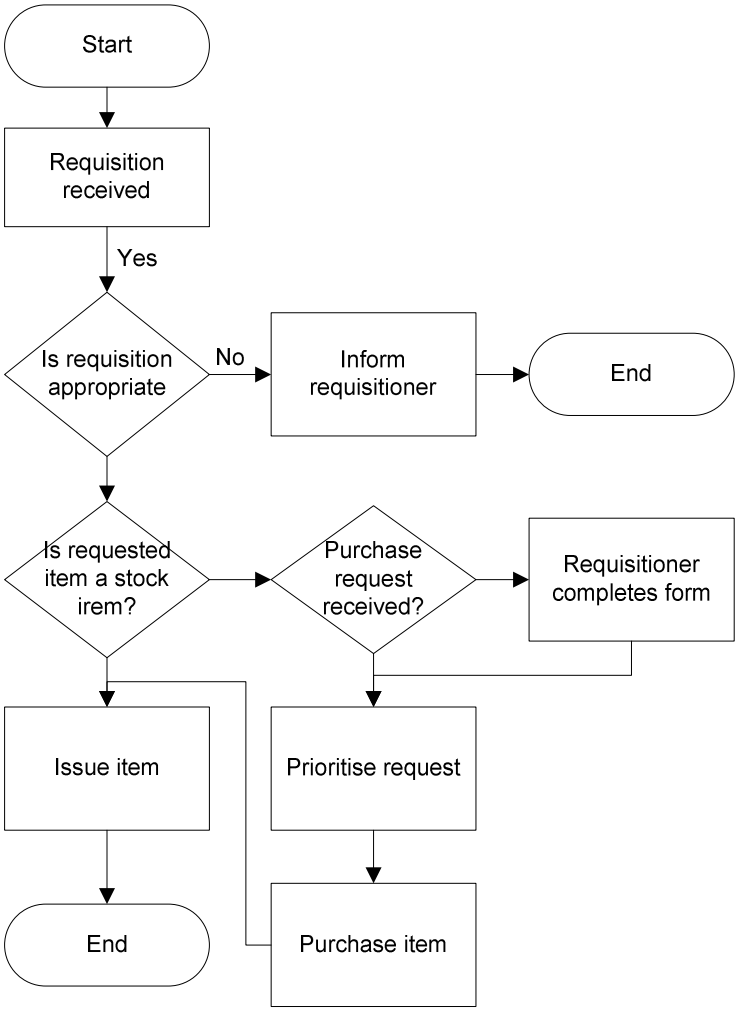


Figure 11 Flow Diagram for Loan Equipment Service

4.15 Child & Adolescent Mental Health Services

CAMH is a specialist service for children and young people providing assessment and treatment of emotional and behavioural problems.

4.15.1 Incoming referrals

Referrals are received from:

- Education (SENCO, SENTASS)
- Educational psychology
- Speech and language therapy
- CTLD
- Community paediatrics
- Children's Community Nursing
- Specialist School Health Nursing Service
- CWD social work team

4.15.2 Outgoing referrals

Referrals are sent to:

- SENCO/SENTASS
- Educational psychology
- Speech and language therapy
- CTLD
- Children's Community Nursing
- Specialist School Health Nursing Service

4.15.3 Flow Diagram

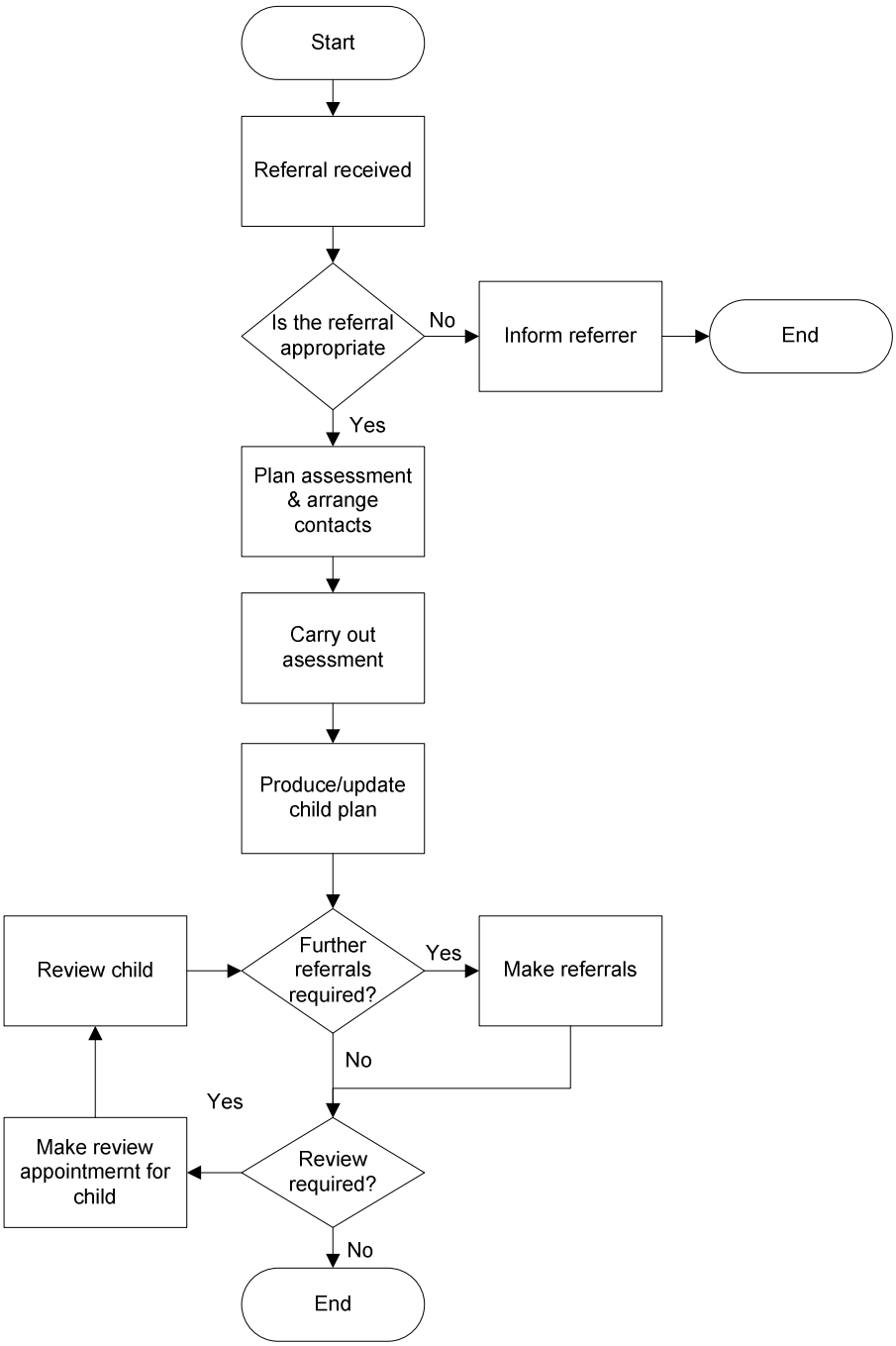
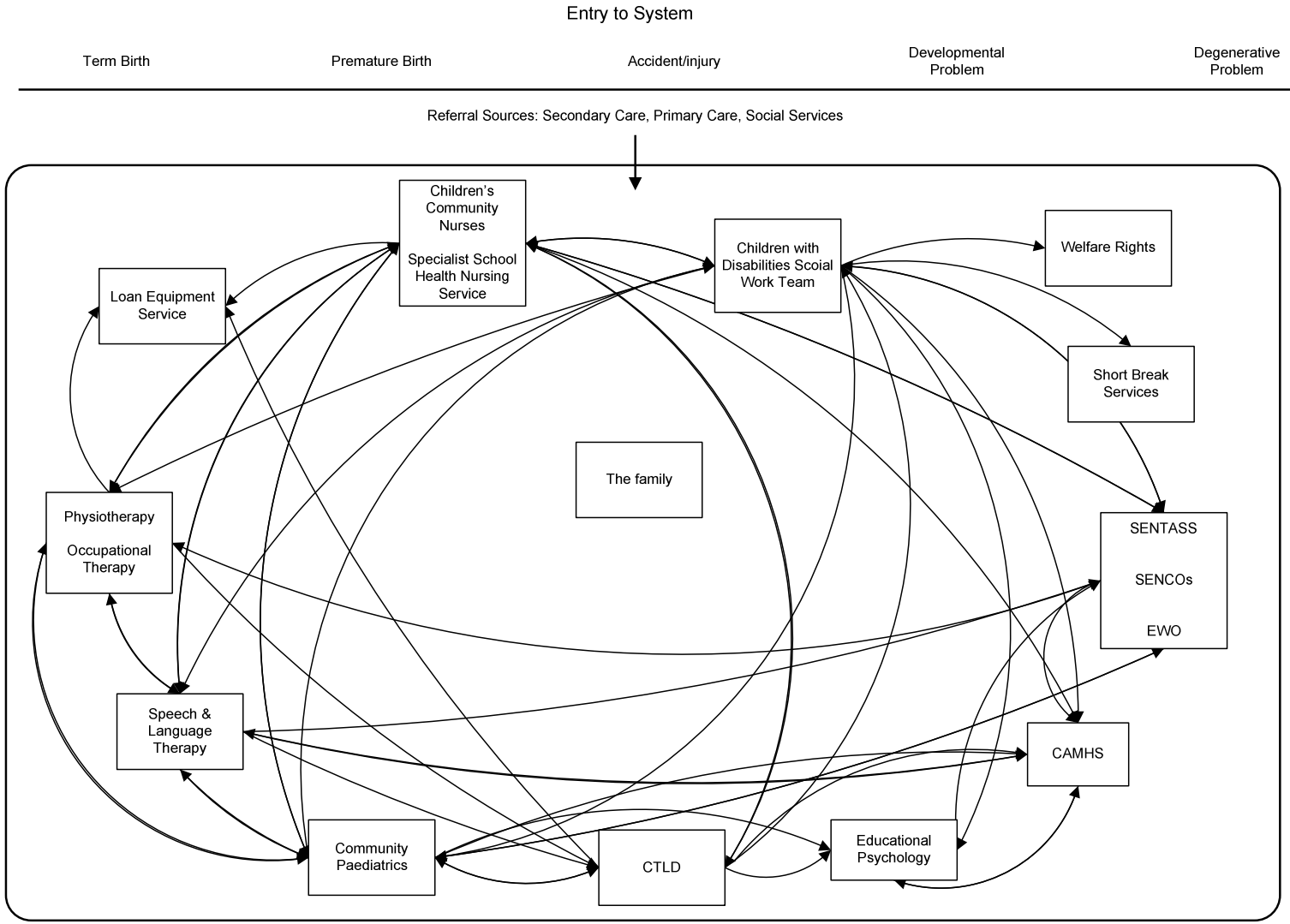


Figure 12 Flow Diagram for CAMH Services

4.16 Referral Pattern Summary



5 Use of Technology

5.1 IT Systems in current use

Organisation	System
Community Paediatrics	Cupid (stand alone Access database)
Children with Disabilities Social Work Team	OLM Care first Stand alone Access database for CWD register
Short break Services	OLM Care First
Children's Community Nurses	Cupid (stand alone Access database)
Specialist School Health Nursing Service	Cupid (stand alone Access database)
Educational Psychology	EMS
CAMHS	CRAMS
Physiotherapy	Cupid (stand alone Access database)
Occupational therapy	Cupid (stand alone Access database)
Speech & Language therapy	Stand alone Access database
Welfare rights	OLM Care First Easy Care
CTLD	PIMS
Education	EMS
Loan equipment service	In need of updating

5.2 Children's Community Nursing, Specialist School Health Nursing Service & Community Paediatrics

These services use a version of the CUPID database. The system is used to record the child's basic details (name, date of birth, gender, address, ethnic group, GP details and carer details) and the details of referrals (date of referral, service referred to, referrer details, referral source, diagnosis), however, some of the non-mandatory fields are used for data other than that originally intended such as diagnosis, expectation and other involved workers.

Activity is recorded against an open episode, details include date of activity, service, attendance, contact time, location and travel time. When the treatment is complete the child is discharged and the episode closed.

The system is used to generate activity reports for contracting purposes. For ad hoc reporting, data is downloaded to Excel and the report generated from within Excel. Ad hoc reports cover all aspects of activities and episodes. Excel downloads are also used to generate caseload reports for individual clinicians.

5.3 Physiotherapy and Occupational Therapy

These services also use a version of the CUPID database. The system is used to record the child's basic details and the details of referrals. The child's basic details (name, date of birth, gender, address, ethnic group, GP details and carer details) are added to the system. It is also used to record referral details (date of referral, service referred to, referrer details, referral source, diagnosis). Activity is recorded against an open episode; details include date of activity, service, attendance and location. When the treatment is complete the child is discharged and the episode closed.

The system is used to generate activity reports for contracting purposes. For ad hoc reporting, data is downloaded to Excel and the report generated from within Excel. Ad hoc reports cover all aspects of activities and episodes.

5.4 Speech and Language Therapy

This department uses its own stand alone Access database. This is used to record basic child details and referral details. Following assessment, the system is used to record the child's diagnosis and to allocate the child to a waiting list. Several waiting lists are held on the system according to the child's age and the type of intervention required. When therapy begins, the details of the intervention are recorded, the outcome of the intervention, date of discharge and the service the child was discharged to. The information is used to generate Korner returns at year end and numerous ad hoc reports for contracting purposes that break down the activity by school, diagnosis or age. It is also used to monitor children through the service pathways and to provide information for clinical audit.

5.5 CWD Social Work Team

This team uses two databases: OLM Care First and a stand alone access database which is effectively the CWD register. The OLM system holds basic child details, contact details and referral details which are recorded by administration staff. Social workers complete the activity log with details of telephone calls and visits but the approach to this is not consistent across the whole team. The details of assessments and care plans are entered using Word templates. For legal reasons these are printed, signed and stored as paper records.

The access database holds information on 330 children and this includes basic child details, diagnosis or health need and details of agencies currently involved with the child, including voluntary agencies. Much of this information is a duplicate of that held on Care First. The database is difficult to keep accurate as the information about the children and their services is passed manually to the database administrator. The database is used mainly for reports on the number of children receiving help from a particular agency.

5.6 CTLD

CTLD have access to the PiMS system from iSoft. This system serves the whole of Northgate and Prudhoe Trust. The system holds basic child details (name, address, ethnic group, GP details, school details and details of relationships), referral details (date of referral, referrer details, referral allocation details), care pack details (care objective, comments, health needs group, responsible clinician), contact details (date, therapist, venue, duration, travel time, contact type and reason, clinical activity and discharge code, if appropriate). The activity details are entered from coded lists which are speciality specific. Each activity is linked to the original referral through the episode of care. Group activities are also recorded where the therapist works with a number of children at once or with a group of parents.

5.7 CAMHS

This department uses its own stand alone CRAMS database. The system is used to record basic demographic information, referral source and GP details. Following assessment, clinicians complete a clinical rating scale, Health of the Nation Outcome Scales (HONOSCA), and the ratings are entered onto the CRAMS system by administration staff. The rating is repeated post intervention and these scores are also added to the system.

5.8 Education

There are two components to the education system, one at the school end and one at the LEA end. Both are EMS supplied by Capita. The LEA system is based on Oracle and the school end is SQL server. The two systems are not linked, instead, each school provides a data extract from their systems on a monthly basis.

The systems hold basic child details (name, date of birth, age, student id, pupil number; email address, address, telephone number, legal status, SEN status, details of guardians, school history and a great deal of information relevant to the school and the LEA. For this analysis, the details relating to the child's special educational needs (SEN) are of particular importance. The SEN details include SEN status, details of statement, assessment details (start date, end date, assessor), involved support services and review details. Information relating to Educational Psychology assessments is not recorded.

The information relating to the statementing process and SEN is not available outside the school and LEA.

5.9 Access to PCs

Organisation	PC access
Community Paediatrics	Consultants and staff all have their own PC
Children with Disabilities Social Work Team	All have their own PC
Short break Services	2 PCs shared between staff on duty (usually three people)
Children's Community Nurses	1 PC between 2 or 3 staff
Specialist School Health Nursing Service	1 PC between 2 or 3 staff
Educational Psychology	All have their own PC
Physiotherapy	1 PC between 3 staff
Occupational therapy	1 PC between 3 staff
Speech & Language therapy	1 PC shared between 3 to 8 therapists
Welfare rights	All have their own PC
CTLD	1 PC for three clinical staff
CAMHS	None for clinicians
SENTASS	All have their own PC
SENCO	Varies from school to school
Loan Equipment service	All have access

5.10 Internet access

Organisation	Internet access
Community Paediatrics	Y
Children with Disabilities Social Work Team	Y
Short break Services	Y
Children's Community Nurses	Y
Specialist School Health Nursing Service	Y
Educational Psychology	Y
Physiotherapy	Y
Occupational therapy	Y
Speech & Language therapy	Y
Welfare rights	Y
CTLD	Y
CAMHS	Not for all clinicians
SENTASS/SENCO	Y
Loan equipment service	Y

5.11 Networks

The following networks are in use across the patch:

- LEA network
- Newcastle Hospitals Network
- Newcastle Local Authority Network
- Northgate & Prudhoe Trust Network
- PCT/MH network

6 Findings

This chapter sets out the results of the analysis. It shows where there is scope for change and where an integrated system for children with disabilities would be of assistance.

6.1 Current Information Systems

There is currently no system that holds the details of all the children with disabilities in Newcastle. Some of the children are known to social services and their details are recorded on the core social services system (Care First) but, equally, many are not and never will be known to social services.

Almost all of the children become known to the education system and have details recorded on the education system (EMS). However, the age at which the children become known to the education system depends upon their needs and children are not necessarily registered at a particular age.

The systems in use in health generally hold only demographic details and activity related information, but not necessarily the clinical details associated with assessment, diagnosis and review. As each discipline has its own stand alone database, only children known to that discipline have details recorded in that database. Furthermore, many of these stand alone databases are old and unsupported following organisational change. The data that is held is, therefore, very vulnerable. The professional's reliance on some of this data is of immediate concern.

Because of this arrangement with IT systems there is no single system that would be usable as a core system providing a basis for the Children with Disabilities System. Protocol could act as a central repository for children's records including referrals, assessments and planning.

Because there is no integration between the different IT systems, professionals in the different agencies have no access to information held on a system other than their own. This makes it impossible for the different disciplines to easily coordinate their activities and provide a truly joined up service for the child.

In addition, neither the child nor their carer is usually able to access the information that has been recorded. Although many would argue that this is not important in the assessment process, it becomes more so when one remembers that the process is supposed to be "Person-Centred". Supplying Service Users with all relevant information helps them to make more informed decisions about their care.

The proposed CWD System will address these issues by integrating with back-end systems, allowing professionals to see information held on these systems according to their access profile. Assessment information, reports and referrals will be held centrally and will be accessible to all involved professionals according to their access privileges.

The system will also be extended to grant access to either the child or their carer, as appropriate.

6.2 Access to Appropriate Technology

All professionals have some access to IT systems but in some cases access is restricted because the equipment is shared with other members of staff. It is acceptable to share PCs between members of staff that do not require concurrent login but where concurrency is needed this will cause problems, for example, when a work tray must be monitored by a member of staff.

The PCs that are in place have internet access via their respective networks.

6.1 Awareness and Competence

A wide range of knowledge and skills was found across the different services. Members of staff within some services were found to be computer literate and felt that they would cope well with any system introduced with training. Others were lacking in either skill or confidence to such an extent that the use of any IT system would be restricted. It is not uncommon for clinical staff to use paper systems and clerical staff to then transfer the information to the computer systems.

The differing levels of computer literacy will need to be addressed by adequate training in both basic PC skills and in the use of the application.

6.2 Making and Receiving Referrals

Mapping of current referral patterns shows that a "referral web" exists at present with multiple entry points for children and frequent referral on to other services within the web. Current communication pathways can be thought of as looping around several services and running bi-directionally. Concerns leading to referral can be generated at various stages in a child's life: at birth, following accident/injury, as a result of an emerging developmental or degenerative problem. There are a large number of referrals between the services within the "web" and within a wider group of services.

Each discipline has its own referral form that must be completed before the referral is accepted. Any professional who makes referrals has to keep a large stock of different referral forms and must know when each is appropriate. Multiple referrals are not uncommon and the current paper-based system requires that the same core information is duplicated on each referral form. A common referral process and form would simplify this situation but must allow the input of discipline-specific information for some referrals.

Using the current system it is not possible for different disciplines to know if the referral they have received is the only referral for the child or one of a battery of referrals to different disciplines. Because of this it is not possible for a receiving agency to know when a multidisciplinary discussion will be initiated or whether it is necessary for them to involve other agencies. There was a general consensus between the different disciplines that knowing which other services are involved with child is important and that this could enable professionals to gain more information about the child prior to contact. The CWD system could easily provide information about involved professionals/services.

Problems frequently occur when the referral form is incomplete. The paper system cannot enforce the completion of mandatory fields so receiving agencies may not receive all of the information they require. To rectify this the receiving professional often needs to make additional phone calls to complete the information about the child. An electronic referral system can easily enforce rules regarding mandatory information and therefore save time by reducing the amount of chasing around that needs to be done.

A last issue identified with regard to referrals (and to the passing of information in general) is that many of the transmission methods are not very secure. The most notable example is that of the fax where, unless the fax machine is in a secure location, any passing person can view information that has been left uncollected.

6.3 Assessments, Care Plans and Reviews

Major problems with the current system are duplication and repetition. For each assessment form, the professional must record the child's personal details; in the absence of an information system this must be elicited from the child and/or their carer or parent. This is a major complaint in that many carers and children feel that they need to give this information over and over again to people who should already have the information.

Duplication within assessments arises because many professionals either do not have access to the information gathered by other professionals or, if they do have access, they do not take the information on trust. As a result the children and their carers may find themselves answering the same questions many times over.

Access to information about the assessments that have been carried out is also an issue, whether the assessment is one carried out by practitioners from a different discipline or is a previous assessment carried out by the practitioner's "own" agency. Nearly all assessment information is held on paper and is not always readily available. Many of the services are bogged down in paper. Professionals have to keep a paper file because there is no provision on existing systems to record the information these forms hold. Assessments are invariably presented on paper; the forms are not generated from electronic files and therefore assessors rely on photocopied forms that can, in many cases, be of very poor quality. Furthermore, if a practitioner wants to copy information from a previous assessment, or share it with another professional, this must be done manually. The distribution of reports based upon an assessment is generally by post.

There is also a danger that any single agency assessment will not give a rounded picture of the child's needs. Many of the assessments are "service led" rather than "needs led". This means that they have been designed to suit the discipline that is carrying out the assessment rather than to elicit information that would give an indication regarding a child's needs in other areas.

There are issues with using the core assessments from the Integrated Children's System because some disciplines are not familiar with them but parts of the assessments could form the basis of core data sets for the CWD system.

Currently there is also limited scope for the children and their carers to contribute to the assessments.

The issue of sharing assessment information involves more than just the mechanics of providing an IT fit to all relevant parties; a culture of trust must be engendered within and amongst the various agencies responsible for service provision. Professionals must be confident that the information recorded by colleagues in other specialities is "fit for purpose". The proposed system will facilitate the standardisation and sharing of "core" information.

Because it is not easy for professionals to find out which services a child is receiving, each professional draws up their plans in isolation and the plan is not shared. This means that if child has complex needs, many different care plans are put in place for a single child. A more child centred approach, as offered by the CWD system, would lead to an appropriate single care plan. For this to work well some work would have to be done around the use of terminology to ensure that meaning as well as information is shared.

The inability to share information means that it is almost impossible to co-ordinate reviews of the provision of services and develop a coherent approach. This is also a common reason for complaint from children and their carers. It would be enormously helpful if the various agencies involved could agree the frequency and purpose of reviews as well as who is going to be responsible for co-ordinating the services provided.

The current situation is that the different agencies carry out service reviews at their own time intervals (in some cases to conform to their legal obligations) and without having access to information about other services currently received. This causes problems for the child and their family as they cannot control the number, date or time of the reviews.

The system will help to organise and plan meetings with a centralised scheduling system which will warn about overlap meetings about the same child. A child calendar facility will allow professionals view a child's appointments, including any that relate to statutory requirements, and enable them to plan around them and combine progress meetings or reviews.

6.4 Management Information

Other than the activity-related information recorded on stand alone data bases, most agencies do not collect detailed information about the services they provide for children with disabilities. The current reporting is solely used for contracting purposes or central returns and is frequently driven by the commissioning process. This lack of information means that it is very difficult to determine referral rates, measure performance and monitor waiting times for different therapies. It is also difficult to gain an holistic picture of all activities relating to an individual child. One exception to this is the Speech and Language Therapy department where some information relating to service provision is collated and used but this is limited.

The CWD system will improve this situation enormously by providing data about the children's needs, their assessments and the type and duration services provided. It will enable better strategic planning of services. Information from referrals that do not result in the provision of a service will provide important information on unmet need.

6.5 Recurring themes

Whichever aspect of providing services to children with complex needs is examined, the same recurring themes emerge. These relate to:

- Lack of shared information
- Too much duplication
- Lack of co-ordination of services

- Use of standalone databases that are not adequately supported
- Information recording is not child centred

The system for children with disabilities will tackle these problems by providing a central repository for children's records and allowing information within those records to be shared according to consent, information sharing protocols and user profiles. The increased sharing of information will reduce duplication of information and activity. It will also allow better co-ordination and an improved level of service delivery for the children and their carers.