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Smoothing the Transition
from child to adult health services
for young people with a learning disability in Forth Valley

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Forth Valley Primary Care NHS Trust

NHS Forth Valley

Smoothing the Transition

guidelines

Smoothing the transition from child to adult health services
for people with a learning disability in Forth Valley.

Funded by the Innovation Fund for Children's Services, Scottish Executive

Issue Date: 23rd Sept 2002. Review by date: End 2004. Author: Janet Smith, Transition Project Co-ordinator

Contents

1. Introduction

1.1 The purpose of this document is as follows:

- To make recommendations for good practice in the transition from child to adult healthcare services for young people with a learning disability (aged 14-19)
- To assist healthcare staff deliver consistent, efficient and evidence based support
- To ensure the transfer is person (family) centred
- To ensure professionals work across agencies in an integrated fashion

1.2 Who are the guidelines for?

The intended target audience is primarily health care staff.
The guidelines will also be useful for our colleagues in education, social services, careers and anyone else involved in the transition process. They will also increase awareness of health transitions, improve communication and assist joint working.

1.3 Definitions of learning disability

The National Review, The same as you? (2000) describes learning disability as:

A significant, lifelong condition that started before adulthood, that affected their development and which means they need help to:

- Understand information
- Learn skills
- Cope independently

Parts of this document will refer to people with 'complex needs'. This means that the young person may have needs arising from both learning disability and from other difficulties such as physical and sensory impairment, mental health problems or behaviour difficulties (The same as you? 2000).

For the purpose of the guidelines, these are the definition we will use.

1.4 Transition

Transition means "passing from one to another".

Transition from adolescence to adulthood happens at different ages for all young people, including those with disabilities.

For the purpose of this document, we are concerned with young people aged 14-19, with a record of need and learning disability, who are moving on from child to adult health care services.

Research suggests that if you get services and support networks in place at this stage, the young person has a greater chance of receiving appropriate services throughout his or her adult life.

The transfer may happen abruptly, or over a long period of time, depending on the needs and circumstances of the individual.

- **Transition planning in health should ideally start at least one year before the young person is due to move to adult services. It should be on a multi-agency basis, well planned, needs led and person centred.**

Demand for many services exceeds resources available, and for some young people a smooth transition may be hampered by a lack of resources.

1.5 Current Research

Research suggests that transition is effective when:

- **The young person assumes the central role on the transition team**
- **A care co-ordinator or key worker is identified and active**
- **Transition plan goals, objectives and time frames are agreed upon**
- **A comprehensive transition plan is developed (in an accessible format) involving:**
  - **Young person**
  - **Family**
  - **School**
  - **Present and future health care providers**
  - **Community based support**
  - **Careers services**
- **Progress towards goals and objectives are regularly evaluated**
- **Transition plans are revised as needed**

(Shultz & Liptak 1998)

1.6 Legislation

Common themes in current legislation include:

- Young person consulted 'on their terms'
- Involvement of parents
- Key worker/co-ordinator role
- Better joint working
- Single assessment process

1.7 What young people and parents in Forth Valley want:

In 2001/2002 a variety of methods were used to identify issues in transition for young people and parents when moving from child to adult healthcare services in Forth Valley.

Young people and parents have said they would like us to:

- **Ensure hand-over happens before leaving paediatric services, so that the young person and parent know the contact name and number, including the doctor, before discharge**
- **Allocate a key worker/co-ordinator throughout transition, across agencies**
- **Identify someone to provide emotional support to the young person, using appropriate language to reach full spectrum of disabilities**
- **Employ more child and adult specialist services within Forth Valley**
- **Invite young people in transition to a peer support group so they can learn from and support each other re: adulthood**
- **Ensure consistencies in service provision, particularly respite**
- **Give honest explanation/information to young person and parent re: how services may change/differ in the adult world**
- **Allocate a health care worker to concentrate on health promotion**
- **Ensure professionals have a summary sheet at the beginning of the young persons notes so they don't have to repeat themselves**
- **Support integration into further education**
- **Ensure 'open door' policy in adult services, (may not require input at time of transition, but may in future need advice/services)**
- **Ask the parents for assistance when communicating with the young person**
- **Paediatric wards should accept young people up to the age of 18 years**
- **In hospital wards, 1:1 ratio should always be available, when dealing with 'complex health needs'**
- **A warm/friendly environment should be available to welcome young people and parents - clinics, hospitals, services in general**
- **Information on benefits, incorporating changes, should be provided to parents and young people**
- **Friendly, understanding doctors should be available in children and adult services (with the availability of female doctors if requested)**
- **Key worker available from the time of diagnosis of a learning disability**
- **Ensure regular reviews take place with all services involved**

2. Principles of a good services

At a health workshop held in April 2002, professionals from child and adult health services concluded that a good service should be:

- **Flexible, accessible and responsive to needs of clients**
- **Person (family) centred**
- **Equitable in access and standards**
- **Consistent with clear aims, objectives and purpose**
- **Transparent, seamless and multidisciplinary**
- **Proactive rather than reactive**
- **Sharing information on a need to know basis only**

2.1 Children First

The Children (Scotland) Act 1995, advocates that services for children with disabilities should be designed to minimise the adverse effects of their disability and enable them to lead lives which are as normal as possible.

Services should be designed to enable disabled children to maximise their independence. People are disabled by society's attitudes and ignorance of their special needs. It is important that young people and their carer's have easy access to mainstream as well as specialist services and support, and to staff who are appropriately trained and informed about disability issues.

2.2 Level of Involvement

There are many health care professionals who could potentially be involved in the lives of people with learning disabilities.

- **Our ultimate aim should be to encourage the young person and their family to be as self sufficient and independent as possible, while recognising where appropriate services and support are genuinely required**

- **Emphasis should be on mainstream as opposed to specialist services wherever possible, however young people should not be denied access to staff who are appropriately trained and informed on disability issues**

3 Confidentiality

3.1 Information Exchange

- **The young person and/or carer should have ultimate say in what information is documented in their transition plan**
- **The young persons transition plan and/or summary sheet should be kept at the beginning of the medical notes, so that the young person and carer do not have to continually repeat themselves when seeing various members of staff**

3.2 Consent

- **Where the young person is deemed capable, every effort should be made to obtain consent from the young person and/or carer prior to passing on any information to other disciplines or agencies**
- **This should be clearly recorded in the young persons medical notes**
- **Any information being shared with other agencies should be subject to an 'Information Sharing Protocol' being in place**
- **A copy of the NHS Forth Valley leaflet "Protecting Information about You" should either be sent out with the letter inviting the parent/carer to the future needs assessment medical, or handed to the young person and carer at the medical**

Where the young person is deemed incapable of giving consent, please refer to the Adults with Incapacity (Scotland) Act 2000.

The trust is currently developing a 'consent policy'.

4 Future Needs Assessment/Transition Planning

Our National Health (2000) states:

> "We expect the NHS to work with partner agencies to ensure that this transition is managed sensitively and with attention to young peoples needs"

"The same as you? (2000), recommends that:

> "GP's, paediatric, learning disability and physical disability services should agree arrangements for people moving from child to adult services to make sure people have appropriate continuity in the healthcare they receive".

The Record of Need process is currently under review and in the future it is likely that fewer children will be recorded. It is hoped that the philosophy and practice of person centred joint working, which is reflected in these guidelines will continue following changes in legislation.

4.1 School Doctors

It is usual practice for school doctors to review the health of children with special needs annually.

Children with a physical, sensory or learning disability, or an emotional or behavioural difficulty who have a record of need will undergo a Future Needs Assessment (FNA) within the 2 years before their statutory school leaving date.

The school doctor may be requested to submit a Future Needs Assessment Medical Report for children with a record of Special Educational Needs at this time.

(There may be various differences in practice between the three local authorities within Forth Valley.)

A Future Needs Assessment Medical Report pro forma has been produced and installed on all doctors and administrators computers. The form can be used flexibly, dependent on the needs of the young person (See appendix 1). **It should be stressed that only school doctors can complete this report.**

- **Ideally the form should be completed at the future needs medical review appointment**
- **In order for the assessment to be child and family centred, it is good practice for both the young person and parent/carer to be present at this particular medical**
- **To increase the likelihood of this happening, a standard letter has been produced and should be sent out to parents at least two weeks in advance of the medical appointment (See appendix 2)**
- **Where there is also involvement from a consultant paediatrician, a written report should be forwarded to the school doctor and attached to the Future Needs Assessment Medical Report**

The school doctor may be invited to attend the Future Needs Assessment meeting for each young person with a record of need.

Due to limited resources, it is impossible for the school doctor to attend every future needs meeting, nor is it always appropriate.

- **Every effort should be made by the school doctor to attend the future needs meetings of young people who have complex health needs**
- **To assist with this, it would be appreciated if the education department could give at least eight weeks notice of the meeting**

For School doctors transition map see appendix 3.
For Consultant Paediatricians transition map see appendix 4

4.2 Nursing and Allied Health Professionals (AHP) services

Part of the Future Needs Assessment Medical form, which the school doctors have to complete requests information on which healthcare professionals are currently involved.

School doctors, parents and young people are not always aware/able to recall who has current involvement in their care.

- **It is therefore essential that all Allied Health Professional's, nurses and other health professionals advise the GP, school doctor and where appropriate the consultant paediatrician when they commence an episode of care with a young person**
- **To begin this process it would be helpful if each discipline writes to the school doctor/paediatrician with a list of current young people in their care**
- **Each discipline, e.g. speech & language therapist, will review their input and decide with the young person and parents/carer's if continued input will be required into adulthood**
- **It may not be appropriate for the continuation of some services into adulthood. Professionals should inform young people and parents/carers of how services may differ in the adult world and work sensitively to manage their expectations**
- **A full review of aids, adaptations and other equipment, in collaboration with education and social services, should be conducted prior to the transfer of care and financial arrangements dealt with**
- **Where there are complex health issues, the key worker should arrange for health professionals to meet prior to the future needs meeting to ensure all health needs have been reviewed and to formulate an overall health plan**
- **Health professionals in consultation with the young person and parent/carer should identify which adult health service will be required and who will be responsible for making the referral/referrals**
- **At least one professional from health should attend the Future Needs Meeting and feed back on the individuals health transition plan (again at least 8 weeks notice is requested)**

Formal referral forms for adult health services, for example community learning disability service, will be held in the Child Health Department, SRI, or available from the adult service direct.

For transition maps of each professional group see the following appendixes:

Community Learning Disability Nursing	**appendix 5**
***Additional Support Team (AST)**	**appendix 6**
Speech & Language Therapy	**appendix 7**
Physiotherapy	**appendix 8**
Occupational Therapy	**appendix 9**
Dietetics	**appendix 10**
Psychology	**appendix 11**

***AST are learning disability nurses who specialise in supporting people with challenging behaviour, dual diagnosis or forensic issues**

These maps are based on current practice and may change as a result of the guidelines.

4.3 Primary Care Teams

General Practitioners and health visitors are two of the few health care professionals who are consistently involved in the lives of people from cradle to grave.

The health visitor has a remit for continual health assessment and is in an ideal position to provide support to the whole family. The support needs of siblings should not be forgotten at this or any other time.

Most young people with a learning disability will not require input from specialist services, but will continue to be supported by their GP and other primary care staff alone.

The family GP is known as the 'gatekeeper' to other services and as such should be included in any discussions regarding the transfer of care. Even if he is unable to attend review meetings, he/she should be aware that they are taking place and receive information on the outcome. General Practitioners in Forth Valley have told us that they are not currently included in the transition process. They would appreciate having a detailed summary of the transition plans and to be advised when paediatric services cease.

- **The GP should be advised by the school doctor or consultant paediatrician in the form of a detailed summary when the young person is no longer under the child health department for review**

- **The education authority should inform the GP/health visitor of the Future Needs Meetings of young people with complex needs so that he/she may attend as appropriate and be involved as much as possible in decisions regarding the transfer of care. (There may be variations in council areas and the numbers of young people with complex needs will be very few)**

- **The consultant paediatrician should inform the GP/health visitor of health review meetings and/or transition clinics for young people with complex needs so that he/she may attend as appropriate.**

- **A summary of the decisions made at the meetings should be sent to all care professionals involved, including the GP**

4.4 Complex Health Needs

Where a young person has complex needs, multi-disciplinary planning well in advance is particularly important. The numbers of people with complex needs leaving school each year is small in number, roughly 11 or 12 per year across Forth Valley.

Health staff should ensure that:

- **Greater effort is made to ensure the young person and family are at the centre of all planning activities, paying particular attention to their communication needs**
- **Health professionals from child health services, primary care (GP/health visitor) and the young person and parents/carers meet to review the young persons health requirements now and into adulthood**
- **A co-ordinator/key worker from health is identified and active**
- **Equipment, aids and adaptations, in collaboration with social services and education, are reviewed by the most appropriate therapist and updated if required**
- **A specific 'health plan' is incorporated into the overall transition plan**
- **The young persons health needs are regularly monitored and reviewed annually until transition is complete**
- **At least one member from the health family attends the Future Needs Meeting and subsequent reviews to ensure joint working**

4.5 Children educated out-with the area

Parents of young people who were at school out-with Forth Valley have told us that their transition to adulthood was particularly difficult.

- **It is therefore crucial that multi-agency, long term planning is well co-ordinated and regularly reviewed when working with young people who are educated out-with the Forth Valley area**

5 Key Worker/Co-ordinator

Recommendation 24 of 'The same as you?' (2000), states that "The Scottish Executive should consider introducing a new duty on local authorities to identify a responsible person to advise and help the person with learning disabilities and their family put the future needs assessment process into practice".

Beattie (1999) recommends that the area strategy group should work with the relevant agencies to set up key worker support arrangements in their area which best meet local needs, and arrangements should include clearly defined roles and responsibilities for the relevant agencies; protocols and guidelines for referral and monitoring arrangements.

"A worker, or key worker, should be identified from whichever service has most direct involvement to whom the young person and his/her family can turn for information/advice" (The Children (Scotland) Act 1995)

- **Further joint working is recommended to establish a local model/models that are appropriate for Forth Valley**

- **The key worker could be from health, education, careers or social services, depending upon the needs of the young person (this will also depend on the capacity of individual practitioners)**

- **In the meantime, health, education and social services staff should ensure that a key worker is identified and active, either before or during the first future needs meeting, so that the young person and family have one point of contact during the time of transition**

- **If the young person has complex needs, then a key worker from health should be allocated before the future needs meeting. If he/she is likely to require input from the adult community learning disability service, then it may be appropriate to introduce a member of the team, for example a community learning disability nurse at this time, to act as key worker (Falkirk locality will be piloting this model in the coming year)**

- **It is particularly important that a key worker is allocated to young people who are educated out-with the Forth Valley area**

5.1 Suggested Interim role of Key Worker

The key worker should:

- **Provide a single point of contact for the young person, parents/carers and professionals throughout the transition process**

- **Identify who is currently involved in the young person's life**

- **Identify the young person's wishes/aspirations for adulthood and which services they need/want in order to achieve their goals (the young person should be interviewed at least once on his/her own)**
- **Support the young person to make a 'transition plan' in an accessible format, using tools if necessary, like maps, paths, talking mats, essential lifestyle planning and passports, (see appendix 5 for examples.)**
- **Act (if required/wanted) as advocate for the young person throughout the transition process (where there are issues of conflict, it may be appropriate to refer to an independent advocacy service)**
- **Manage the expectations of young people and carers by providing up to date/accurate/honest information about which services are available, e.g. length of waiting lists and by encouraging independence and use of mainstream services**
- **Facilitate opportunities for health promotion, to increase independence and knowledge of health issues**
- **Offer consistency throughout the process of transition**
- **Prepare the young person/carer for meetings and make every effort to attend with them**
- **Provide emotional support to young person using appropriate language to reach full spectrum of disabilities**
- **Support the parents throughout the process**

6. Person Centred Planning

"Person centred planning creates a compelling image of a desirable future and invites people to join with the person to make it happen" (O'Brian and Lovett 1992) .

"Person centred planning is a way of helping people who want to make some changes in their lives. It is an empowering approach to helping people plan their future and organise the supports and services they need. It seeks to mirror the ways in which 'ordinary people' make plans" (Sanderson et al 1999).

Person centred planning is:

- **A powerful way to support change**
- **A different way of working together**
- **A better way to listen and respond**
- **Different for different people**
- **An invitation to personal commitment**
- **Working towards inclusive communities for anyone who wants it**

- **Every effort should be made to ensure that the young person and their families are at the centre of health care transition planning**

The family fund trust suggests that the young person should be encouraged to:

- **Start planning early**
- **Get information about choices available**
- **Get help to prepare for meetings**
- **Make a life plan**
- **Use pictures, photographs to help them**
- **Keep their own information**
- **Be involved, invite who they want to their meetings**
- **Get people to talk their language**
- **Get an advocate if required**
- **Build circles of support**

- **The young person's key worker should ensure that he/she is aware of these recommendations by giving him/her a copy of the 'Planning for life after school – what can I do?' sheet, (see appendix 12) and support him/her to utilise tools available to carry them out**

6.1 Tools to assist in Person Centred Planning

The above information sheet 'Planning for life after school - what can I do' is a tool to assist young people to be more involved and actively prepare for their transfer to adult services. Other planning tools are available to assist young people and professionals to work together towards person centred/needs led adult service.

For further information on planning styles, e.g. MAP's, PATHs, Talking Mats, Essential Lifestyle Plans, see appendix 13, which is taken from People, Plans and Possibilities.

- **A 'transition plan', should be drawn up by the young person, carer and professionals from all appropriate agencies involved (child & adult)**

- **The 'transition plan' should be in an accessible format depending on the needs of the young person (i.e. drawings, photographs, symbols, audio/video tape)**

6.2 Making Choices/Communication needs

80% of people with a learning disability have problems with communication (The same as you? 2000).

A useful tool to assist the young person in decision making is talking mats (Cameron & Murphy 2000)

Talking mats could be used:

- **To encourage interaction and conversation**
- **To express views in a non-threatening situation**
- **To plan activities**
- **To allow involvement in life planning**
- **To be used in person centred planning**
- **To facilitate the young person to give their views at future needs meetings**
- **To explore differences of opinions**
- **To explore sensitive issues**

A copy of the report "Making Choices at the Time of Transition for People with a Learning Disability" (Cameron & Murphy 2000) and video "Talking Mats and Learning Disability" are available in the Child Health Department, Stirling Royal Infirmary.

Advice and formal training in using talking mats are available from:

Lois Cameron
Speech and Language Therapy Department
Clinical Services
Forth Valley Primary Care Trust Headquarters
Old Denny Road
LARBERT
FK5 4SD.
Telephone (01324) 404040

7 Information

In order for the young person to feel involved and to make informed choices, they require information on the adult services available in Forth Valley.

Young people and parents in Forth Valley have stated that this is an important element of transition, which has been sadly neglected in the past.

7.1 Directory of Services

A health service directory called "Help for Health" was produced and given to every 15, 16 and 17 year old, with a record of need and identified learning disability across Forth Valley in September 2002.

A copy of the directory has also been given to staff involved in the transition process.

- **It will be the responsibility of the child health department to ensure that every 15 year old, using the same criteria as above, will receive a copy of the directory in September 2003 and 2004**
- **It is particularly important that a directory is given to young people who attend school outwith the Forth Valley area**
- **In 2005 the directory will be reviewed by Forth Valley Primary Care Trust**

Spare copies will be held in the Child Health Department, Stirling Royal Infirmary, but will be in limited supply.

7.2 Other information documents

Other free publications include:

- **"After 16 - What's New? Choices and Challenges for Young Disabled People" The Family Fund Trust**
- **"Having your say at School" an Enquire video for secondary students who need extra support**

Both of these documents are located within the Child Health Department, Stirling Royal Infirmary for reference purposes only.

- **The families should be informed of and encouraged to send for free copies themselves. The key worker or school doctor could point out the contact addresses in the Help for Health directory**
- **The school doctor or key worker should also remind parents to find out about changes in benefits prior to them reaching the age of 16**

7.3 School Eye Clinic

Parent's told us they were not aware that the school eye clinic at SRI stopped seeing people after they left school. They were therefore still waiting for appointments coming through years after their child had left.

- **A standard letter has been produced and should be sent out to all young people who attended the school eye clinic, advising them to register with a high street optician for routine sight tests once they leave school**

- **The hospital ophthalmologist will make a clinical decision and inform the young person if ongoing care is required at his or her clinic**

8 Transfer to Adult Health Services

The young person should not be discharged from paediatric services until:

- **The care has been fully transferred either to primary care alone, or to primary care plus the most appropriate adult specialist service**
- **Feedback has been given by the receiving services to the referrer following initial visit, confirming acceptance if appropriate**
- **A key worker from that service is allocated and active**
- **Information both formal and informal has been passed over**

As previously stated, emphasis should be on using mainstream adult services wherever possible.

8.1 North Transition Clinic

The above clinic is currently run, as part of a pilot project, by a Consultant Paediatrician from the Acute Trust and a Staff Grade Psychiatrist and two community nurses from the Community Learning Disability Service (CLDS).

This friendly, informal, local service gives young people with complex health needs and their carers the opportunity to meet some of the staff from a service which they may require support from in the future.

The clinic provides clear clinical care pathways for those who are likely to require continued specialist input.

It is recognised, however that the clinic requires to be reviewed and made more inclusive of other disciplines and agencies.

The Consultant Paediatrician has agreed to:

- **Facilitate an audit of the current transition clinic**
- **Consult with other medical, nursing and allied health professionals re expanding the clinic to be more multi-disciplinary, inclusive and person centred**
- **Identifying someone to co-ordinate twice yearly multi-disciplinary clinics**
- **Be involved in the development of accessible transition health plans**

See appendix 14 for the North Transition Clinic Map.

8.2 Community Learning Disability Service (CLDS)

The CLDS is currently under considerable review and are moving towards integrated services with the three local authorities. The following information is based on current practice, but please be aware that this will change.

The Community Learning Disability Service (CLDS)

- Provide a service to adults 16 years of age and over, who have a learning disability and complex health needs
- Work in partnership with primary healthcare teams and other agencies to meet identified health care objectives
- Operate within a multi-disciplinary framework
- Operate an open referral system
- Can be accessed Monday to Friday, 9am – 5pm
- Is organised into two sectors:
  - North sector (Stirling district, Clackmannanshire and surrounding area)
  - South sector (Falkirk district and surrounding area)

If there are 'complex health issues', it may be appropriate to refer to the CLDS.

- **The CLDS have a standard referral form, which should be completed in all cases**

- This should not prevent informal discussions with individuals within the service where information or advice is required
- It would be appreciated if the CLDS was notified well in advance of young people with complex needs coming up to 16 years
- For more information on the CLDS, ask for a copy of their leaflet or to see the Community Learning Disability Service Operational Policy Document
- Referral forms, leaflets and a copy of the CLDS Operational Policy Document are held within the Child Health Department or available from the CLDS Administrator on (01324) 404035

See appendix 15 for CLDS Transition map

8.3 Area Rehabilitation Team

The Area Rehabilitation Team has a community focus. The service will provide assessment and rehabilitation for people in the 16-64 age group who are physically disabled and brain injured through trauma or progressive disease and provide support and training for relatives and carer's.

They do not offer a maintenance service therefore transfer of young people at this time may not always be appropriate.

Area rehab also offers an Environmental Control Service for children and adults. Environmental controls is a technical system which can overcome the difficulties people with complex physical disabilities face everyday, when trying to use ordinary remote control handsets. It can also help operate a wider range of tasks which people have great difficulty with e.g. opening windows and doors, switching lights on and off etc. All these tasks work through one central controller, which is operated by an individual switch.

- **Referral to Area Rehab is via a standardised referral form, copies of which along with their leaflet are held within the Child Health Department or available from the Area Rehabilitation Department in Stirling Royal Infirmary**

Informal enquiries are welcome on (01786) 434000 ext. 4366.

See appendix 16 for Area Rehab Transition Process Map.

8.4 Community Mental Health Teams

Aims of the service are:

- To provide a high quality and clinically effective multi-disciplinary mental health service in Forth Valley, prioritising people who have severe and/or other enduring mental health problems in accordance with national guidelines
- To integrate with existing and planned mental health services in Forth Valley and to liaise with social work and voluntary sector services where appropriate
- To support and develop the treatment of less severe psychiatric morbidity by consultation and advice to primary care services
- To promote cohesive and supportive team functioning for the benefit of patients and professionals within the service

CMHT inclusion criteria:

- Patient is registered with a Forth Valley GP
- Patient age 19 – 65 inclusive
- Symptoms of significant psychiatric illness requiring further assessment or treatment in a specialist psychiatric service
- Priority is given to patients with severe and/or enduring mental illness with a serious degree of psychiatric or social morbidity

- **Referrals are accepted from GP's and consultants only, and must be in written format**

- **In exceptional circumstances, telephone requests to a team member, followed by a letter is acceptable**
- **Please refer to the Mental Health Services Interface Agreement (final draft) for guidance on moving people with mental health problems and a learning disability around Forth Valley**

8.5 Adult Neurology/Epilepsy Services

Many young people with Epilepsy are under the care of their GP only.

Some however may have more challenging seizures which are difficult to control and require ongoing assessment and monitoring from a specialist.

As all young people are individuals, who they are referred onto will depend on their individual circumstances and needs.

- **If the young person has difficult seizures but is coping well in all other areas of life, then mainstream adult neurology may be the most appropriate contact for future service provision**
- **If the young person has epilepsy <u>and</u> complex need, it may be appropriate for the young person to also be supported by the psychiatrist/associate specialist and community nurses within the CLDS**
- **The above should be discussed at the Transition Health Planning Meetings or Transition Clinic, in consultation with the young person and parents/carers**
- **Adult facilities, for example day service providers, respite carer's etc should be given information on epilepsy and trained in the management of seizures and administration of rectal diazepam where required**

9 Health improvement /Personal health care

Public health, school nurses, health visitors and health promotion staff are in an ideal position to influence personal health care initiatives/health improvement activities within and out with mainstream and special needs schools. The New Community Schools agenda provides an ideal forum for discussion.

- **Health and education staff should meet to discuss how they could work with young people to improve their understanding of health and wellbeing in its most holistic sense**
- **Educational resources should be utilised on how to access health services in order to increase independence**
- **Discussion forums should be offered on a group or one to one basis on 'the impact of disability'**

10 Respite

The National Care Standards guidance highlights that respite/short breaks should be a positive experience for the individual and for the carer and should not be provided within residential settings, which offer long-stay care. Therefor RSNH is providing only an interim service for a few users until alternative appropriate community resources are available.

From next year, the respite facility at RSNH, Larbert, will be reduced to one bed, which will be housed within the new 26 bedded unit.

- **Negotiations should continue regarding future provision of respite care for people with complex needs**
- **Health and social services should work together to support carer's and identify a range of short break services which will promote choice and flexibility within a community setting**

11. Summary of Action Points

Transition

- **Transition planning in health should ideally start at least one year before the young person is due to move to adult services. It should be on a multi-agency basis, well planned, needs led and person centred**

Level of Involvement

- **Our ultimate aim should be to encourage the young person and their family to be as self sufficient and independent as possible, while recognising where appropriate services and support are genuinely required**
- **Emphasis should be on mainstream as opposed to specialist services wherever possible, however young people should not be denied access to staff who are appropriately trained and informed on disability issues**

Confidentiality

- **The young person and/or carer should have ultimate say in what information is documented in their transition plan**
- **The young persons transition plan and/or summary sheet should be kept at the beginning of the medical notes, so that the young person and carer do not have to continually repeat themselves when seeing various members of staff**

Consent

- **Where the young person is deemed capable, every effort should be made to obtain consent from the young person and/or carer prior to passing on any information to other disciplines or agencies**

School Doctors

- **Ideally the Future Needs Assessment Medical Report should be completed at the future needs medical review appointment**
- **In order for the assessment to be child and family centred, it would be good practice to have both the young person and a parent/carer present at this particular review**
- **To increase the likelihood of this happening, a standard letter has been produced and should be sent out to parents at least two weeks in advance of the medical appointment**
- **Every effort should be made by the school doctor to attend the future needs meetings of young people who have complex health needs**
- **To assist with this, it would be appreciated if the education department could give at least eight weeks notice of the meeting**

- **Where there is also involvement from a consultant paediatrician, a written report should be forwarded to the school doctor and attached to the Future Needs Medical Report**

Nursing and Allied Health Professionals Services

- **It is essential that all Allied Health Professionals, nurses and other health professionals advise the GP, school doctor and where appropriate the consultant paediatrician when they commence an episode of care with a young person**
- **Each discipline, e.g. speech & language therapist, will review their input and decide with the young person and parents/carer's if continued input will be required into adulthood**
- **Professionals should inform young people and parents/carers of how services may differ in the adult word and work sensitively to manage their expectations**
- **A full review of aids, adaptations and other equipment should also be conducted prior to transfer of care, and financial arrangements dealt with**
- **Child health services in consultation with the young person, their parent/carer and family GP should agree which adult health service will be required and who will be responsible for making the referral/referrals**
- **At least one member from the health family should attend the future needs meeting and feed back on the individuals health transition plan**

Primary Care Teams

- **The GP should be advised by the paediatrician or school doctor when the young person leaves school and is no longer under the child health department for review**
- **The GP should be advised of the health planning or future needs meeting of young people with complex needs so that he/she can attend as appropriate and be involved as much as possible in decisions regarding the transfer of care**
- **If the GP is unable to attend the meeting, minutes and a copy of the transition health plan should be sent to him/her**

Complex Health Needs

- **Multi-agency planning should commence at least one year ahead of the transfer**
- **Health professionals from child services, the young person, parent/carer and the family GP should meet to review the health requirements now and into adulthood**
- **Equipment, aids and adaptations are reviewed and updated if required**
- **A specific 'health plan' is incorporated into the overall transition plan**

- **The young persons health needs are regularly monitored and reviewed annually until transition is complete**
- **Greater effort is made to ensure the young person and family are at the centre of all planning activities**

Children being educated out-with the Forth Valley area

- **It is crucial that multi-agency, long term planning is well co-ordinated and regularly reviewed when working with young people who are educated out-with the Forth Valley area**

Key Worker/Co-ordinator

- **Health, education and social services staff should ensure that a key worker is identified and active, either before or during the first future needs meeting, so that the young person and family have one point of contact during the time of transition**
- **Where there are complex health needs, a key worker from health should be allocated to co-ordinate a health planning meeting prior to multi-agency review**
- **The overall key worker could be from health, education, careers or social services, depending upon the needs of the young person.**

Person Centred Planning

- **Every effort should be made to ensure that the young person and their families are at the centre of health care transition planning**
- **The key worker should ensure that the young person has a copy of the 'Planning for Life After School – what can I do? Information sheet and support him/her to utilise the tools available to carry them out**

Tools to assist in Person Centred Planning

- **A 'transition plan', should be drawn up by the young person, carer and professionals from all appropriate agencies involved (child & adult)**
- **The 'transition plan' should be in an accessible format depending on the needs of the young person (i.e. drawings, photographs, symbols, audio/video tape)**
- **A useful tool to assist the young person in decision making is talking mats (Cameron & Murphy 2000)**

Directory of Services

- **It will be the responsibility of the child health department to ensure that every 15 year old with an identified learning disability receives a copy of the 'Help for Health' directory in September 2003 and 2004**
- **It is particularly important that a directory is given to young people who attend school outwith the Forth Valley area**

School Eye Clinic

- **A standard letter has been produced and should be sent out to all young people who attended the school eye clinic, advising them to register with a high street optician once they leave school**

Transfer to Specialist Adult Health Services

The young person should not be discharged from paediatric services until:

- **The care has been fully transferred either to primary care alone, or to primary care plus the most appropriate adult specialist service**
- **Feedback has been given to the referrer following initial visit**
- **A key worker from that service is allocated and active**
- **Information both formal and informal has been passed over**

North Transition Clinic

- **The transition clinic will be audited and reviewed by medical, nursing and allied health professional staff**

Community Learning Disability Service (CLDS)

- **The CLDS have an open referral system**
- **Referral forms are available from the CLDS administrator**

Area Rehabilitation Team

- **Referral to Area Rehab is via a standardised referral form, available from their department**

Community Mental Health Teams

- **Referrals are accepted from GP's and consultants only, and must be in written format**
- **Where the primary diagnosis is a learning disability, please refer to the draft Mental Health Interface Agreement (see appendix 9)**

Adult Neurology/Epilepsy Services

- **If the young person has difficult seizures but is coping well in all other areas of life, then mainstream adult neurology may be the most appropriate contact for future service provision**
- **If the young person has epilepsy and complex need, it may be appropriate for the young person to also be supported by the psychiatrist/ associate specialist and community nurses within the CLDS**
- **Adult facilities, for example day service providers, respite carer's etc should be given information on epilepsy and trained in the management of seizures and administration of rectal diazepam where required**

Health Improvement/Personal Health Care

- **Health and education staff should meet to discuss how they could work with young people to improve their understanding of health and wellbeing in its most holistic sense**
- **Educational resources should be utilised on how to access health services in order to increase independence**
- **Discussion forums should be offered on a group or one to one basis on 'the impact of disability'**

Respite

- **Negotiations should continue regarding future provision of respite care for people with complex needs**
- **Health and social services should work together to support carer's and identify a range of short break services which will promote choice and flexibility within a community setting**

Forth Valley Primary Care NHS Trust

Area Community Child Health Department

Future Needs Assessment - Medical Report

Name: …… D.O.B: ……

School: …….. Responsible Council: Falkirk
Stirling
Clackmannan

CHI No ……

Past history/present medical condition:

Current medication: (including information on allergies to certain drugs)

Implications for future i.e. Special health needs which require planning and support from health and social services now or in the future (e.g. epilepsy, mental health, physical disability):

Health professionals currently involved (e.g. speech and language therapy, occupational therapists, Physiotherapist etc):

New professionals who need to be involved in planning for transition (e.g. health visitor, GP, CLDS, Area Rehabilitation Team etc):

New care needs/practical help required for carers (e.g. aids, adaptations, respite or general support):

Any other comments:

Compiled by ……. Date: ……

Designation: …….

Recommendations discussed with young person/carer: Yes □ No □
Young person requires continued annual health check when leaves school: Yes □ No □

Appendix 2

(Recipients name & address)

Dear Parent/carer

Re:……dob……

In the coming year the Local Authority will review ……’s educational provision and assess his/her need for support in the future. As school doctor I am asked to write a medical report.

I have arranged an appointment for name……..
on…….…….date……at (time)…….
at (place)…….

It would be helpful if you could come along too, so that together we can give accurate, up to date information about your child’s health.

This will also give us the opportunity, where appropriate, to discuss how future health services can be provided, when your child becomes an adult at the age of 16 years.

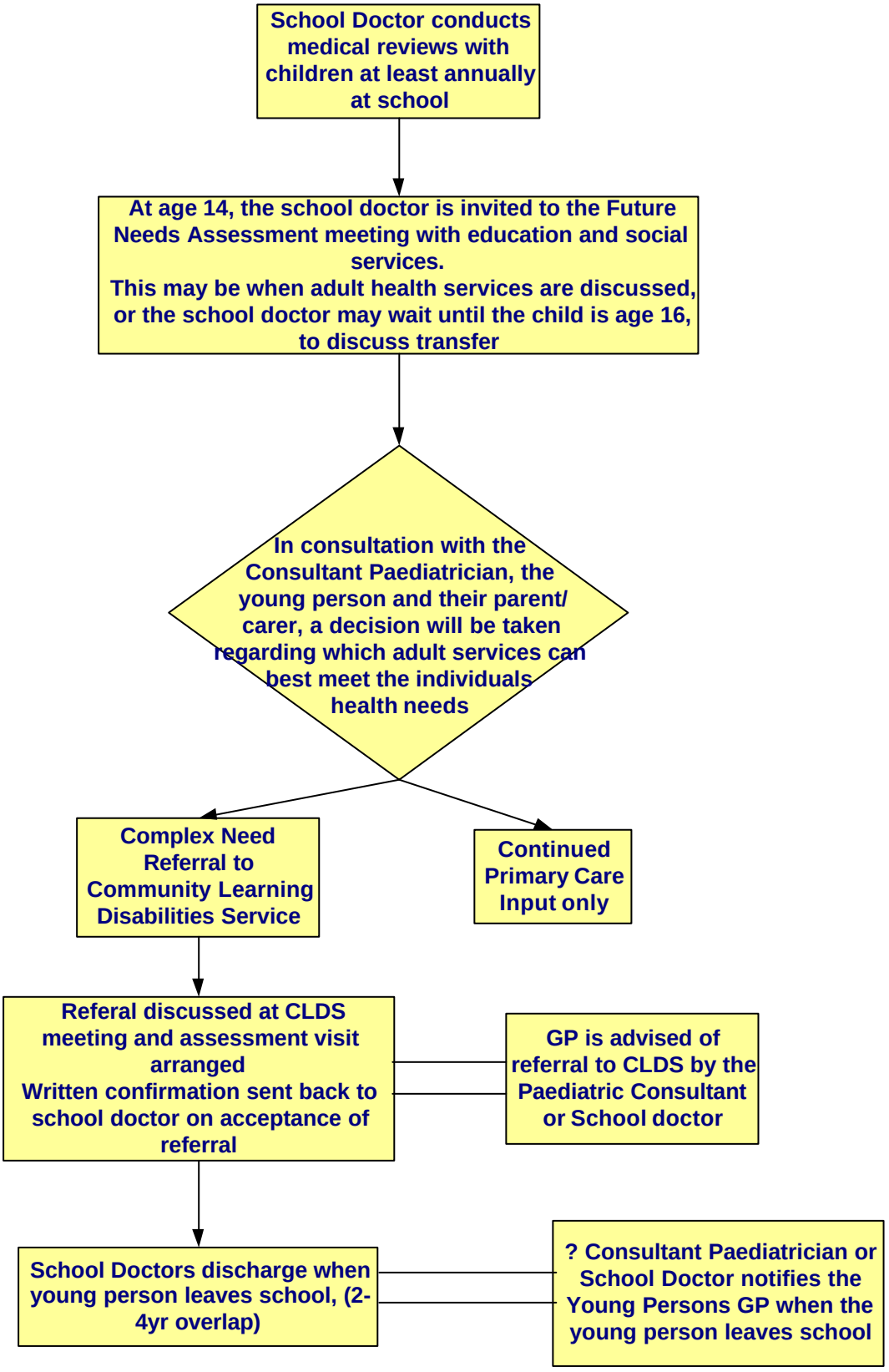
If you are unable to attend please telephone me at the above number to give me the necessary medical information.

Yours sincerely

…….
Staff Grade Community Paediatrician

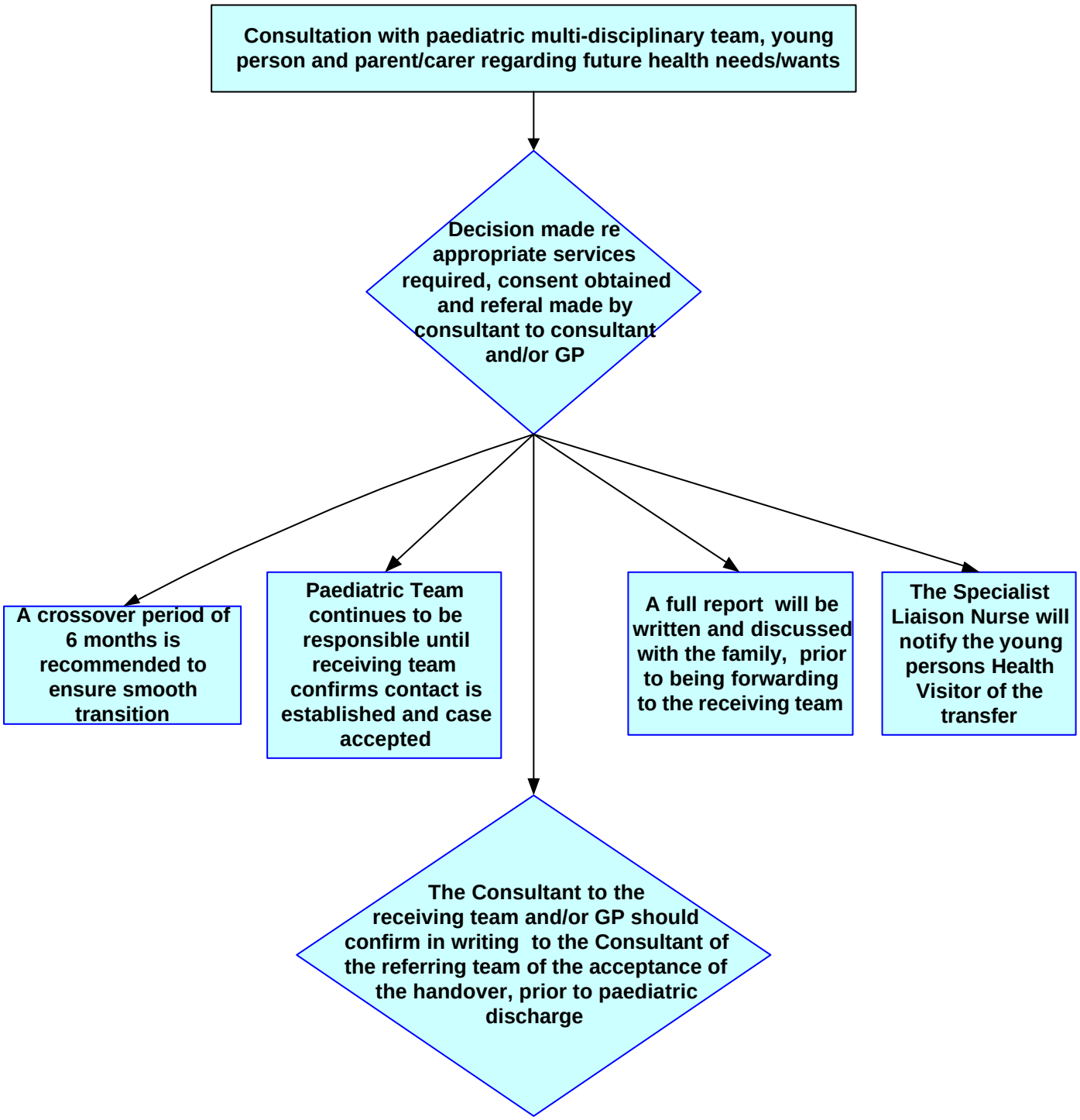
School Doctors

Appendix 3



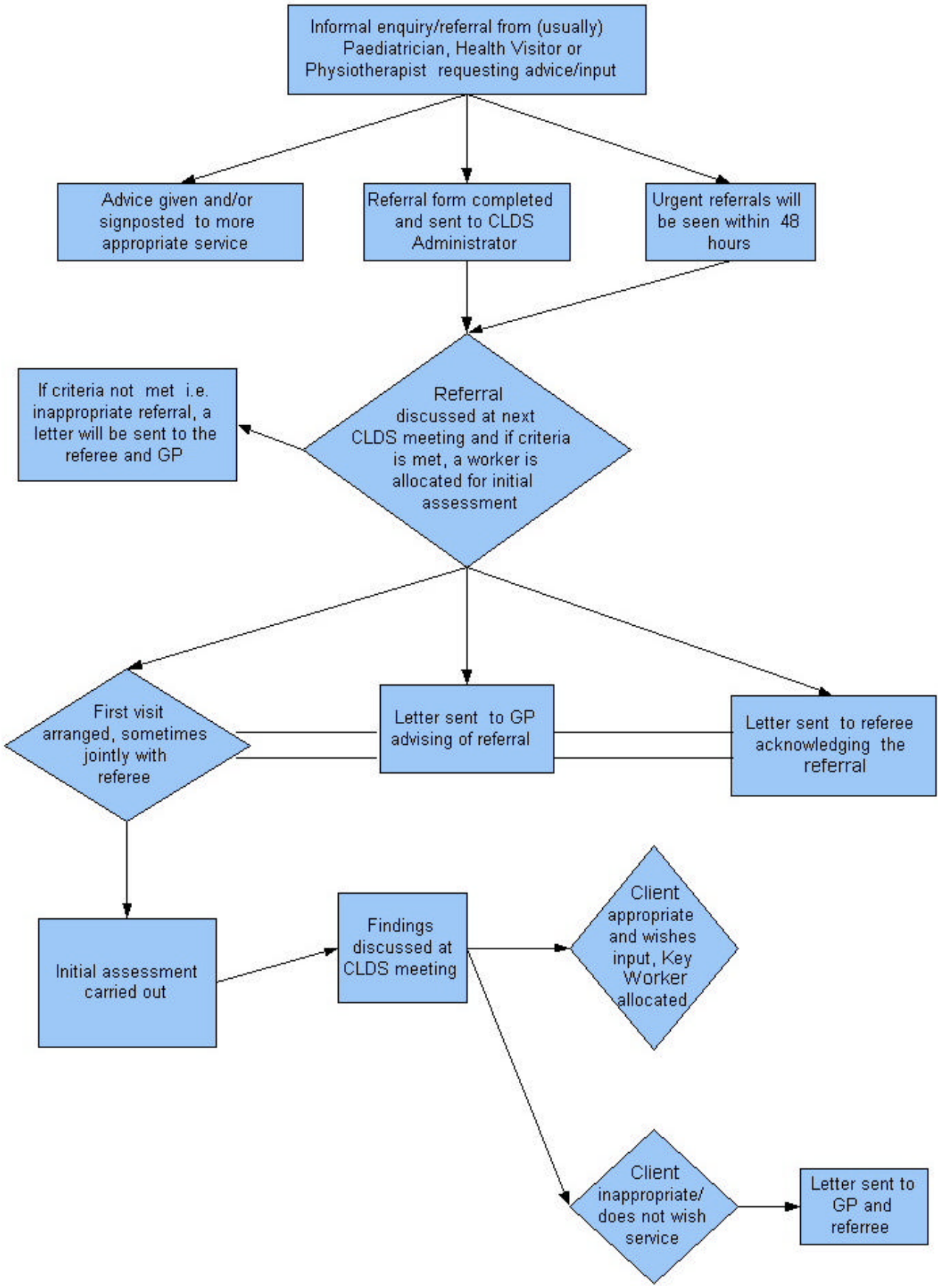
Consultant Paediatricians

Appendix 4

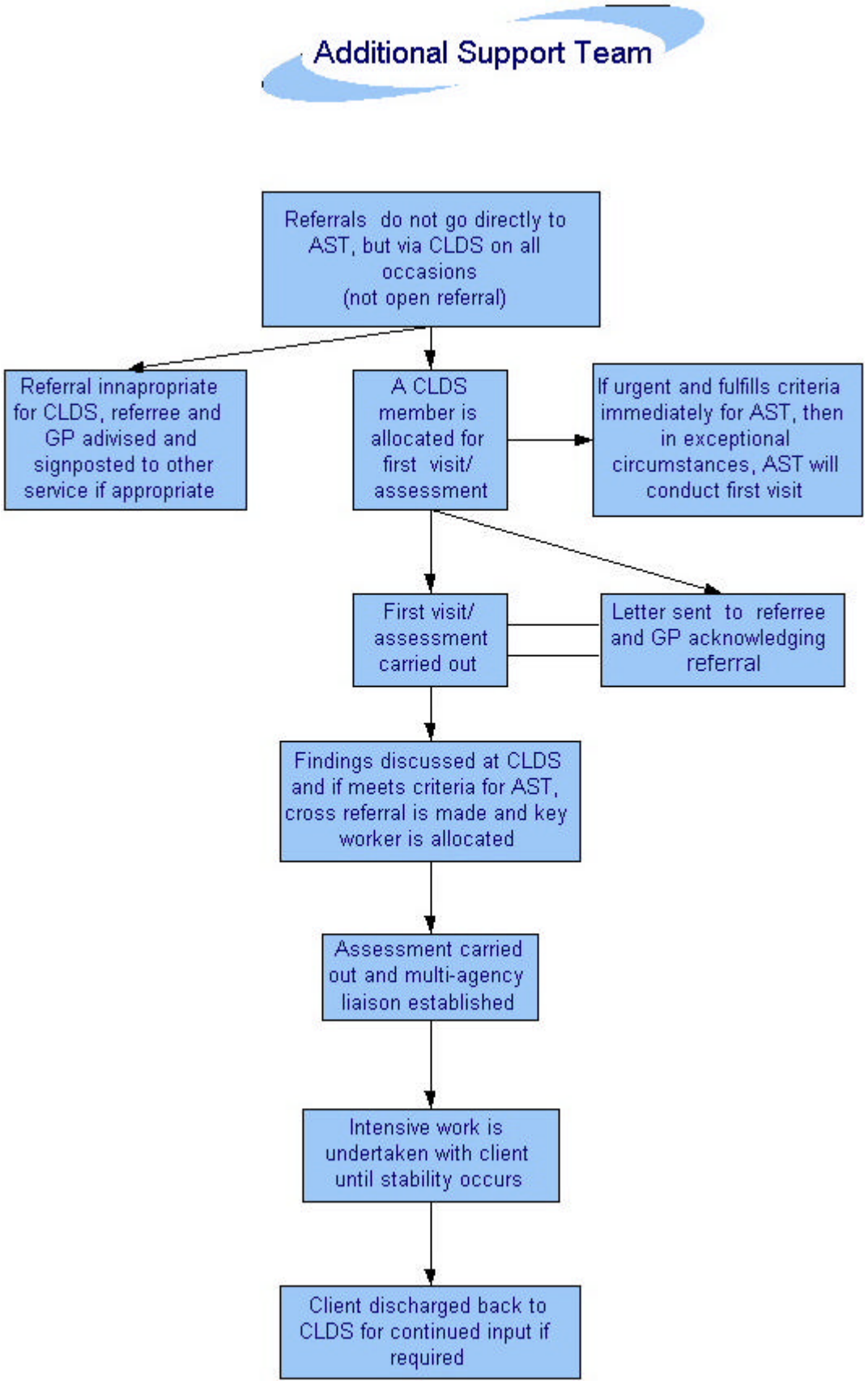


APPENDIX 5

Community Learning Disability Nursing

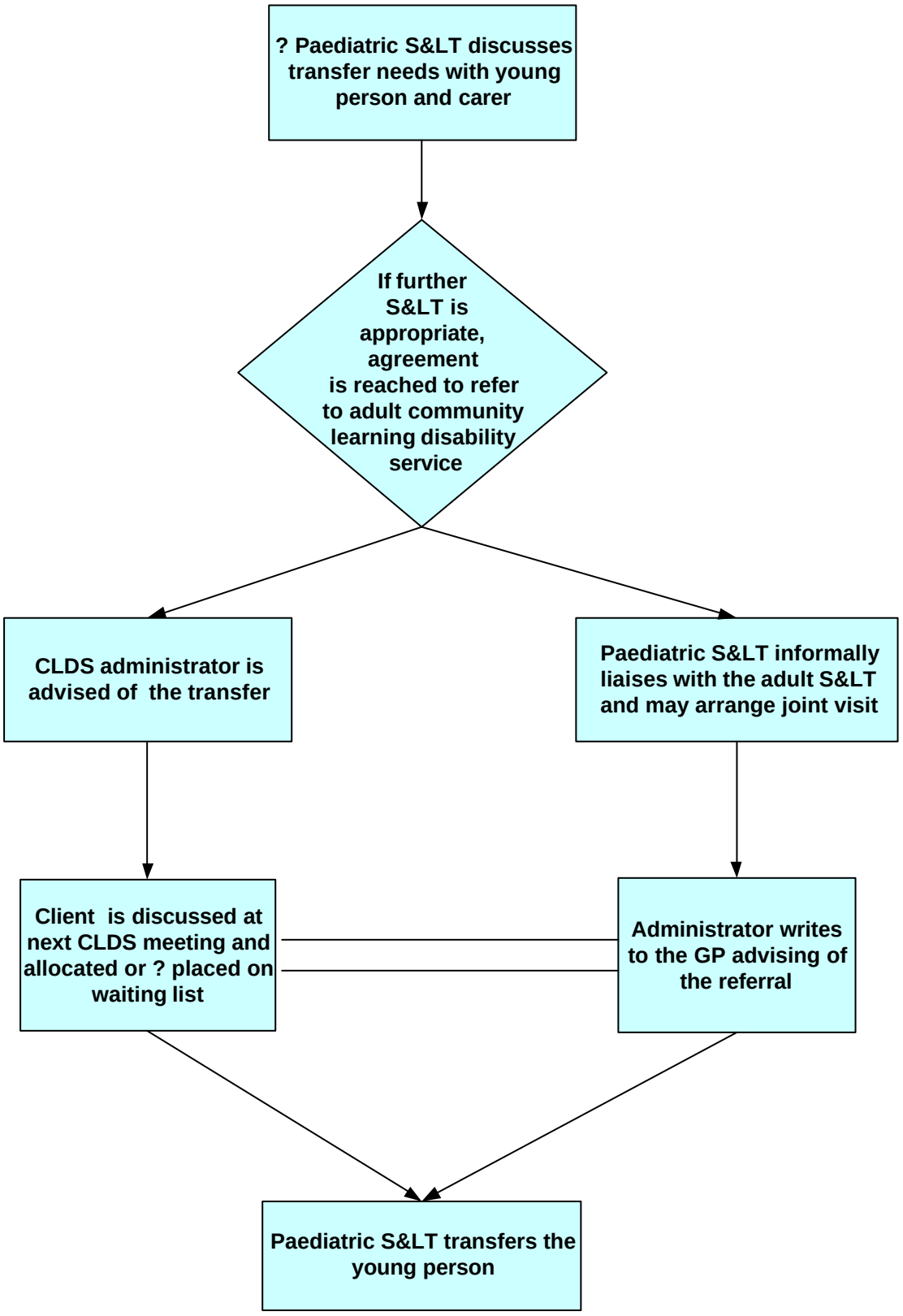


APPENDIX 6


Additional Support Team
Referrals do not go directly to AST, but via CLDS on all occasions (not open referral)
Referral innapropriate for CLDS, referree and GP adivised and signposted to other service if appropriate
A CLDS member is allocated for first visit/ assessment
If urgent and fulfills criteria immediately for AST, then in exceptional circumstances, AST will conduct first visit
First visit/ assessment carried out
Letter sent to referree and GP acknowledging referral
Findings discussed at CLDS and if meets criteria for AST, cross referral is made and key worker is allocated
Assessment carried out and multi-agency liaison established
Intensive work is undertaken with client until stability occurs
Client discharged back to CLDS for continued input if required

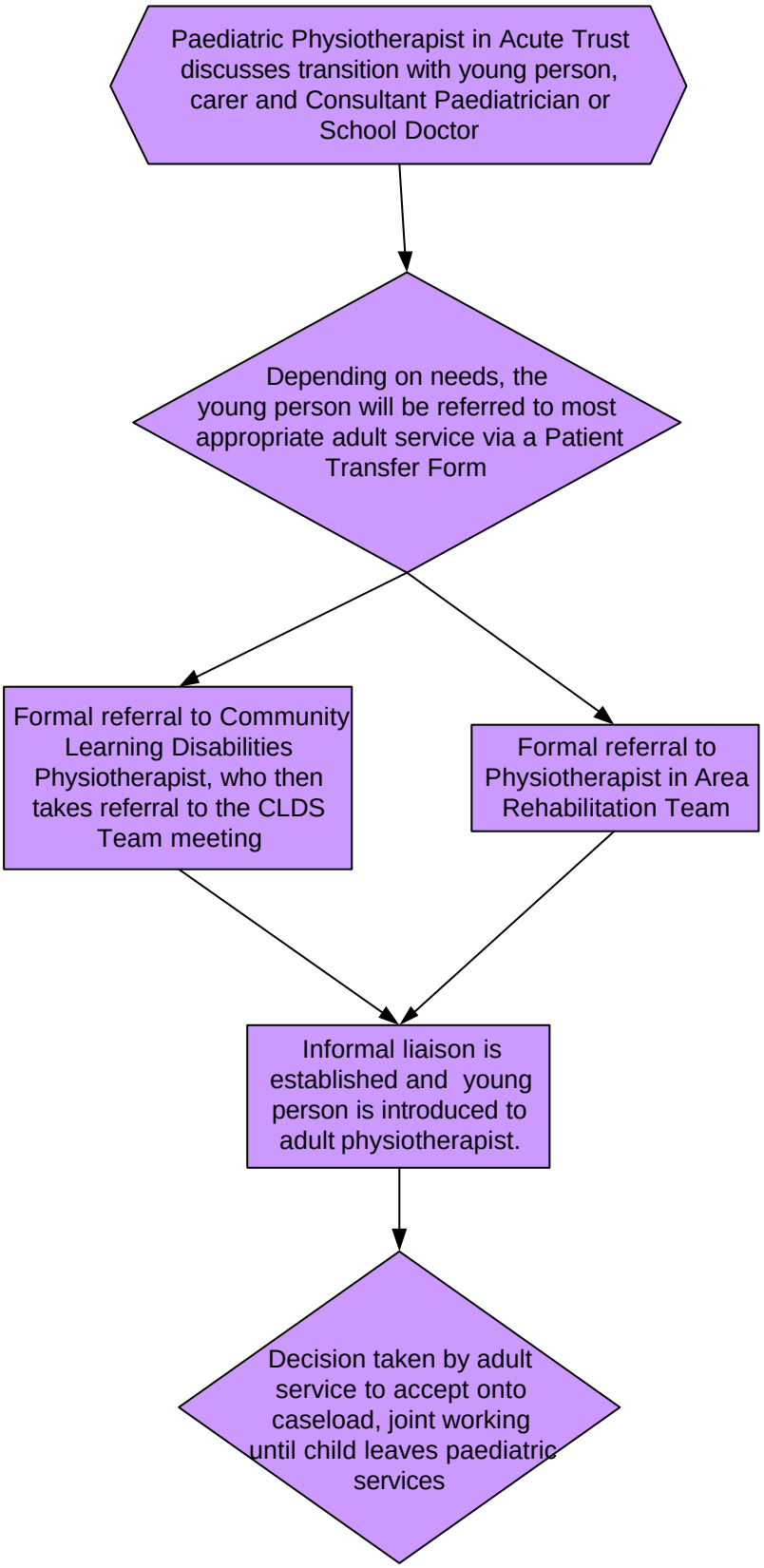
Speech & Language Therapy

Appendix 7



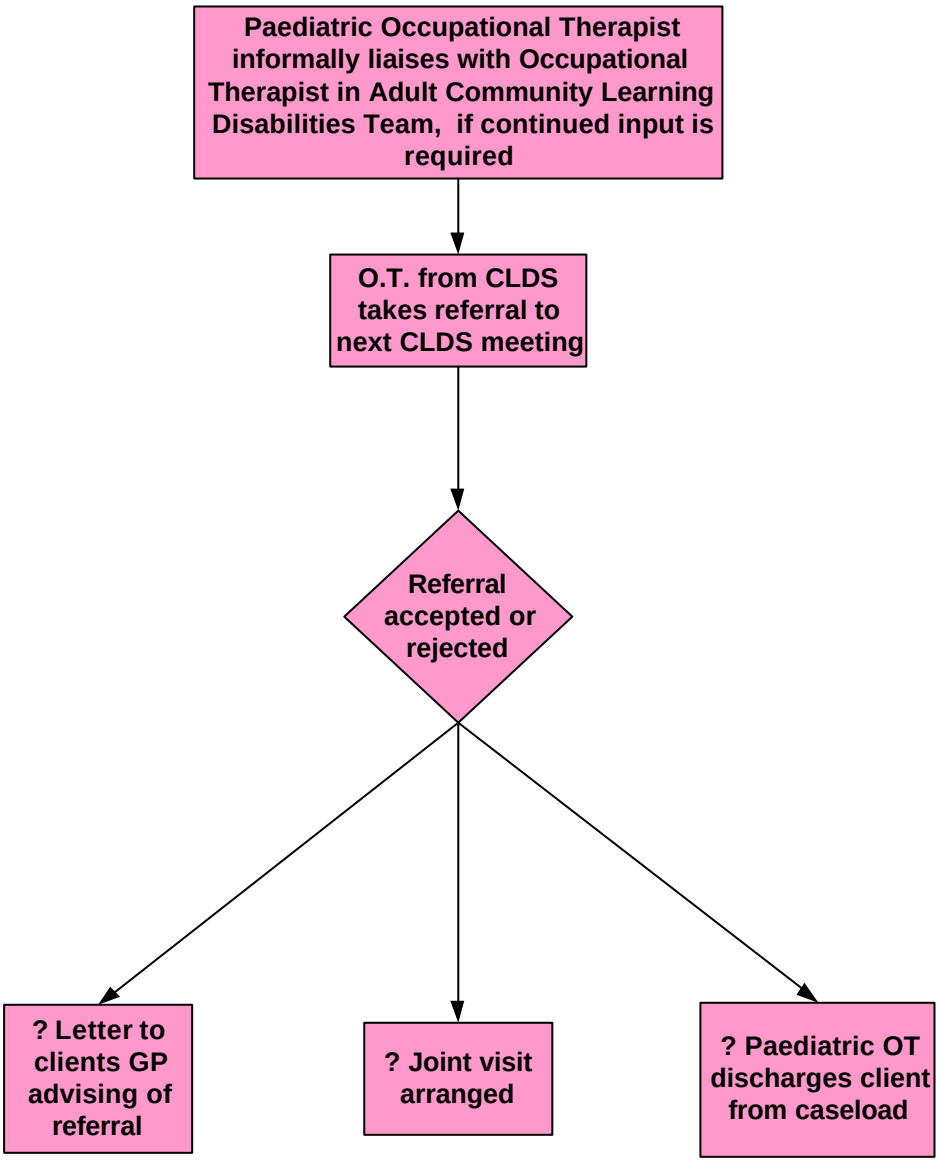
Physiotherapy

Appendix 8



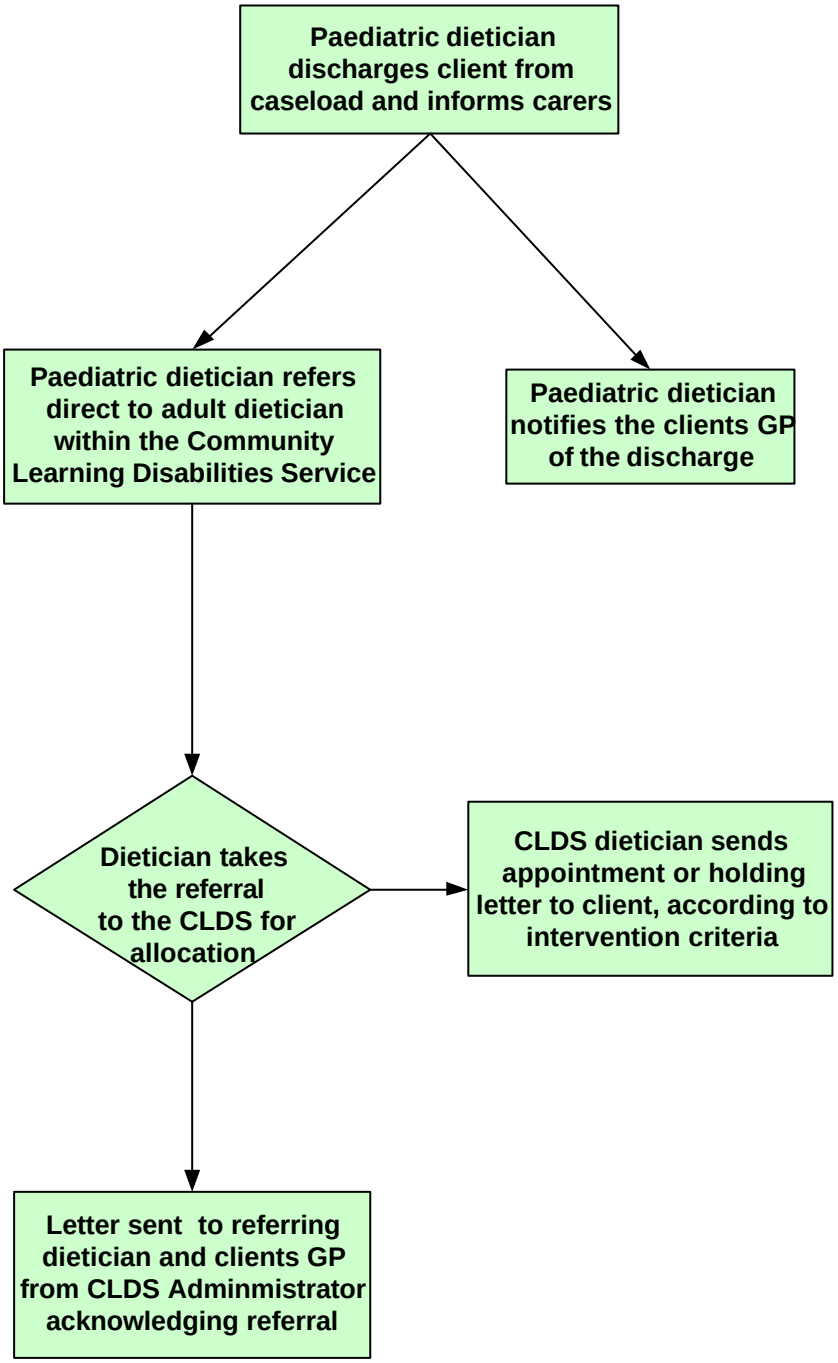
Occupational Therapist

Appendix 9



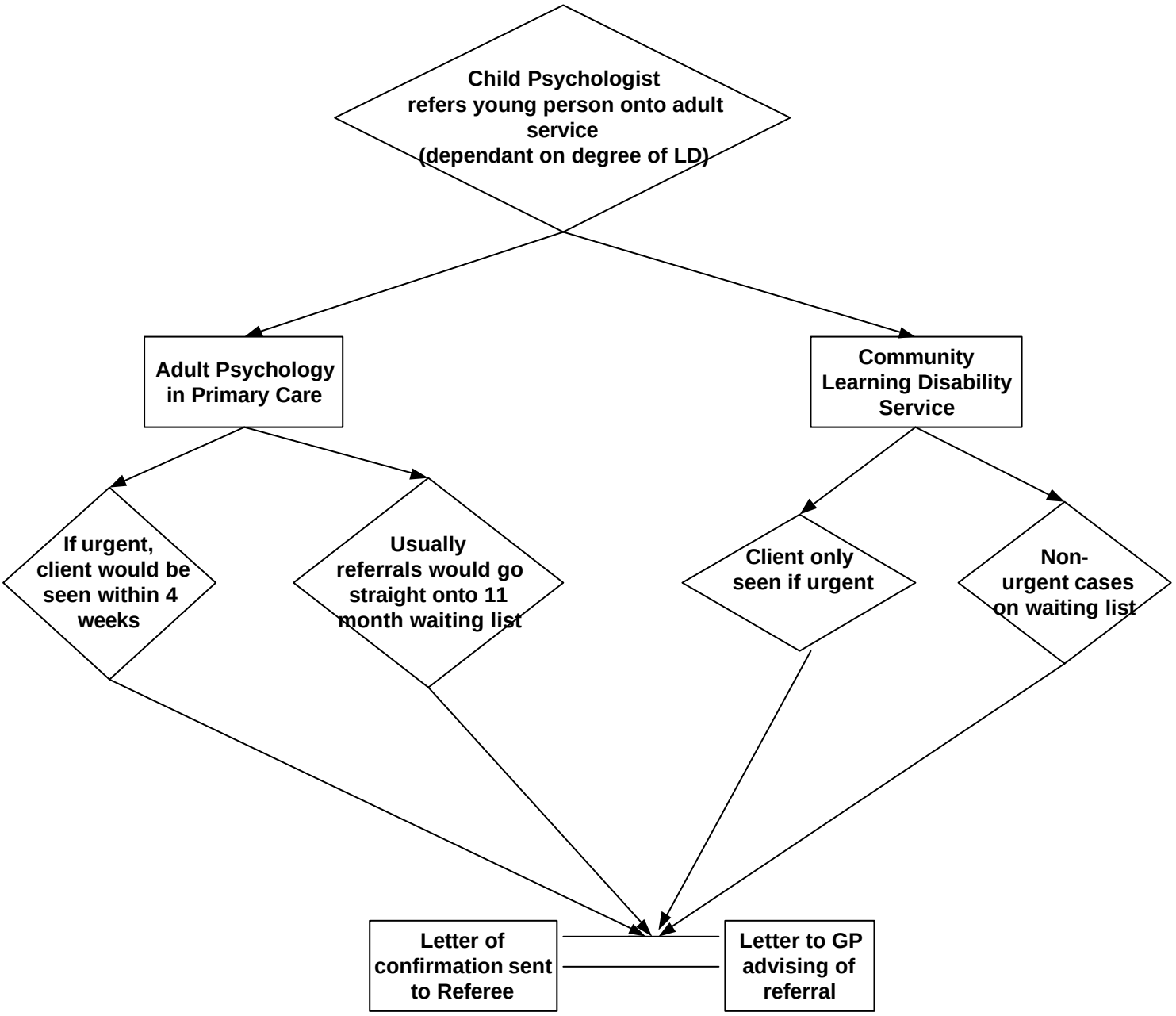
Dietetics

Appendix 10



Appendix 11

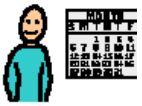
Psychology



Planning for Life after School



What can I do?



Start planning early

Get information about choices available

Get help to prepare for meetings

Make a life plan

Use pictures, photographs to help you

Keep your own information


Be involved, invite who you want to your meetings


Get people to talk your language

Advocates can help

Build your circles of support

Produced as part of the *Smoothing the Transition* Project (NHS Forth Valley)
Based on information from the Family Fund Trust

People, Plans and Possibilities

Planning Styles

Introduction

The previous chapter discussed the distinctive elements in the practice of person centred planning. Each planning style combines these elements in a particular way. This chapter describes five of the planning styles in use in the UK and provides an example of how each style was used with a particular person. The final short section illustrates how a person centred approach can be used to help think about one aspect of a person's life: work.

Finding a planning style does not in itself make a good plan. The quality of work depends on the skill of the facilitator. As facilitators become more experienced in using various styles they adapt them to suit their own style and the situation.

We have made some comments on what has worked well for us in using these styles in particular situations to date rather than any definitive statement about where and how these styles work best.

Each style is based on the same principles of person centre planning: all start with who the person is and end with specific actions to be taken. They differ in the way in which information is gathered and whether emphasis is on the detail of day to day life, or on dreaming and longer term plans for the future. Some styles learn about the person by gathering people together at a meeting, others gather this information before a meeting. It is possible to use any of the styles, except PATH, without having a meeting.

The following sections provide an overview of different styles. They describe a basic way to use the planning style, but each should be used by trained facilitators able to make planning responsive to the individual and her particular circumstances. The descriptions are intended to say enough about each style to help people decide which to learn about in depth.

Different styles of planning

Each planning style combines a number of elements: a series of question for getting to understand the person and her situation; a particular process for engaging people, bringing their contributions together and making decisions; and a distinctive role for the facilitator(s).

PATH and MAPS focus strongly on a desirable future or dream and what it would take to move closer to that. Individual Service Design focuses on the past to help deepen the shared understanding and commitment to the person. Essential Lifestyle Planning and Personal Futures Planning gather information under more specific headings. This format suits a process of regular reviewing and updating. Particular sections – such as the section in Essential Lifestyle Planning on how the person communicates and the section in Personal Futures Planning on local community resources – ensure that someone gathers together what is known and records this information so that everyone can use it.

A skilled and experienced facilitator can adapt any style to cover all the areas in a person's life. People may need to focus on different levels at different times, and therefore use one planning style at one time and another at another time.

In considering what style to use facilitators need to consider the knowledge they already have and the training available to them, as well as how they can access support and feedback. Whether the person has a team to support her, or lots of friends and neighbours who want to get involved or a circle of support can influence the decision about which planning style to use. If the person has a team who do not know her very well, then starting with a planning style which invests a lot of time in really getting to know the person, for example Essential Lifestyle Planning or Personal Futures Planning, could be a useful place to begin. If the person has family and friends or a circle who know and love her, then starting with dreams through PATH or Maps is useful.

When is Essential Lifestyle Planning useful?

Essential Lifestyle Planning is a very detailed planning style which focuses on the individual's life now and how that can be improved. It can help people find out who and what is important to the person and what support the person needs to have a good quality of life. It can help the person to get a life that makes more sense to her, now and tomorrow, and will certainly identify what is not working for her at present. It does not address the individual's desirable future or dream, although this can be built in as an extra section.

Essential Lifestyle Planning specifies the way that support is to be provided on a day to day basis, and this is helpful when different members of staff need to work consistently or when the person herself or the family is not able to give such detailed direction.

Very little is known about some people who use services, particularly those who are moving out of an institution or who do not use words to communicate.

Essential Lifestyle Planning is an excellent style to use as a start to getting to know someone and beginning to build a team around her. It can also provide a valuable safeguard when someone is moving from one setting to another, as it specifies the things which must happen for life to be at least tolerable. These can provide the basis for an individual service agreement between a purchaser and a provider agency.

When if PATH useful?

PATH is a very strongly focused planning style. It pays the most attention to the process of change. It helps a group of people with a basic commitment to the person to sharpen their sense of a desirable future and to plan how to make progress.

It assumes that the people present know and care about the individual and they are committed enough to support the person towards her desirable future over the next year. PATH is not a way of gathering information about a person, but a way of planning direct and immediate action.

PATH focuses first on the dream and works back from a positive and possible future, mapping out the actions required along the way. It is very good for refocusing an existing team who are encountering problems of feeling stuck, and mapping out a change in direction.

It requires either that the person can clearly describe their dream or, if she does not use words to speak, that the others present know her well enough to describe it for her. PATH needs a skilled facilitator to ensure that the dreams are those of the individual rather than those of the team. A PATH can only take place in a meeting. It depends on the momentum generated by a group of committed people. With a skilled facilitator, the meetings are powerful and often emotional, and people may make some profound changes in the way they see and understand the person. This then clears the way for specific actions to help the person make significant changes in her life.

When is Maps useful?

Maps is more of a picture building style than PATH. It can be used in a meeting or it is possible to use the individual components separately.

For some people there are more important lessons to be learnt from looking at their past. Maps have a specific section at the beginning of the process for going over the history of an individual. It goes on to ask the question 'who is the person?' and 'what are their gifts?'. Focusing on the gifts often provides the key to unlocking the community so Maps is a useful process when looking for ways of helping an individual to make connections.

The Maps process allows people to express both their hopes for the future, in the dreaming section, and their fears about the future, in the nightmares section. The action plan is about working towards the dream and away from the nightmare.

It treads a middle way between PATH and Essential Lifestyle Planning, allowing people to dream and including some 'getting to know you' in the process. It is neither as focused as PATH nor as detailed as Essential Lifestyle Planning. It can be used as a starting point with and individual who feels comfortable with dreaming and who already has a few people around her to support her to work towards her dreams.

When is Personal Futures Planning useful?

Personal Futures Planning provides a way of helping to describe the person's life now and look at what they would like in the future. It helps people to build on areas of their life that are working well now and to move towards their desirable future. It is therefore useful when people need to learn more about the person's life (unlike Essential Lifestyle Planning which focuses on getting a lifestyle which works for the person now). It will not provide the detail about what the person requires on a day to day basis in the way that Essential Lifestyle Planning does, but provides an excellent overview from which areas of concern can be considered.

When is Individual Service Design useful?

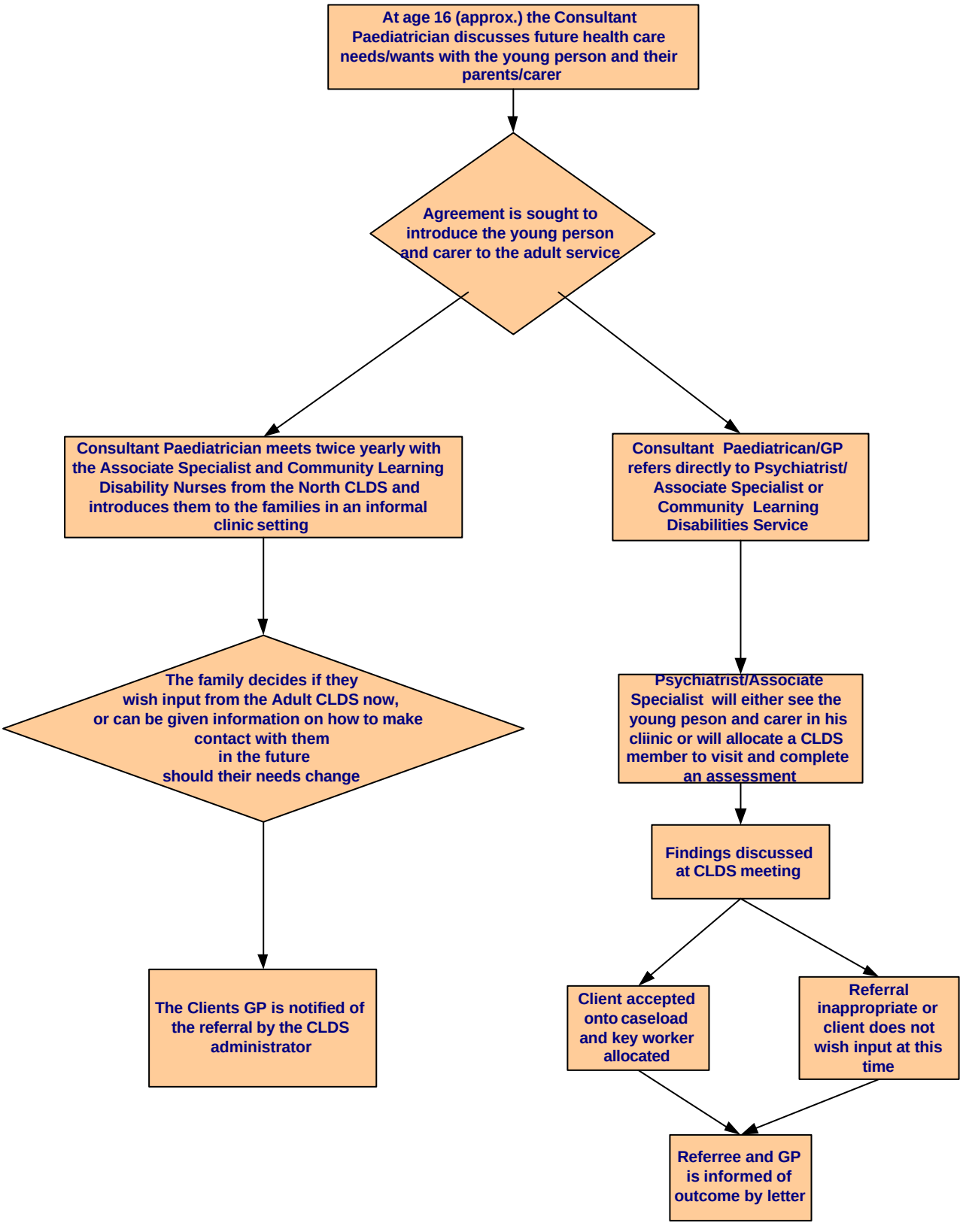
Individual Service Design is rooted in gaining a greater understanding about someone through trying to revisit the past through their eyes. It is an excellent style to use when a staff team are struggling to understand someone, particularly in terms of her behaviour. It requires that there is some information about the person's history available. The deeper understanding that Individual Service Design can produce is then used to identify how a service needs to be designed or changed.

If there is no-one in the person's life who knows her well and likes her, the person is at great risk, and urgent action is needed. This is likely to mean getting her out of the place she is in and into a safer and more welcoming place, and helping her meet some new people who do like her and are prepared to stand up for her. These actions must take priority over the process.

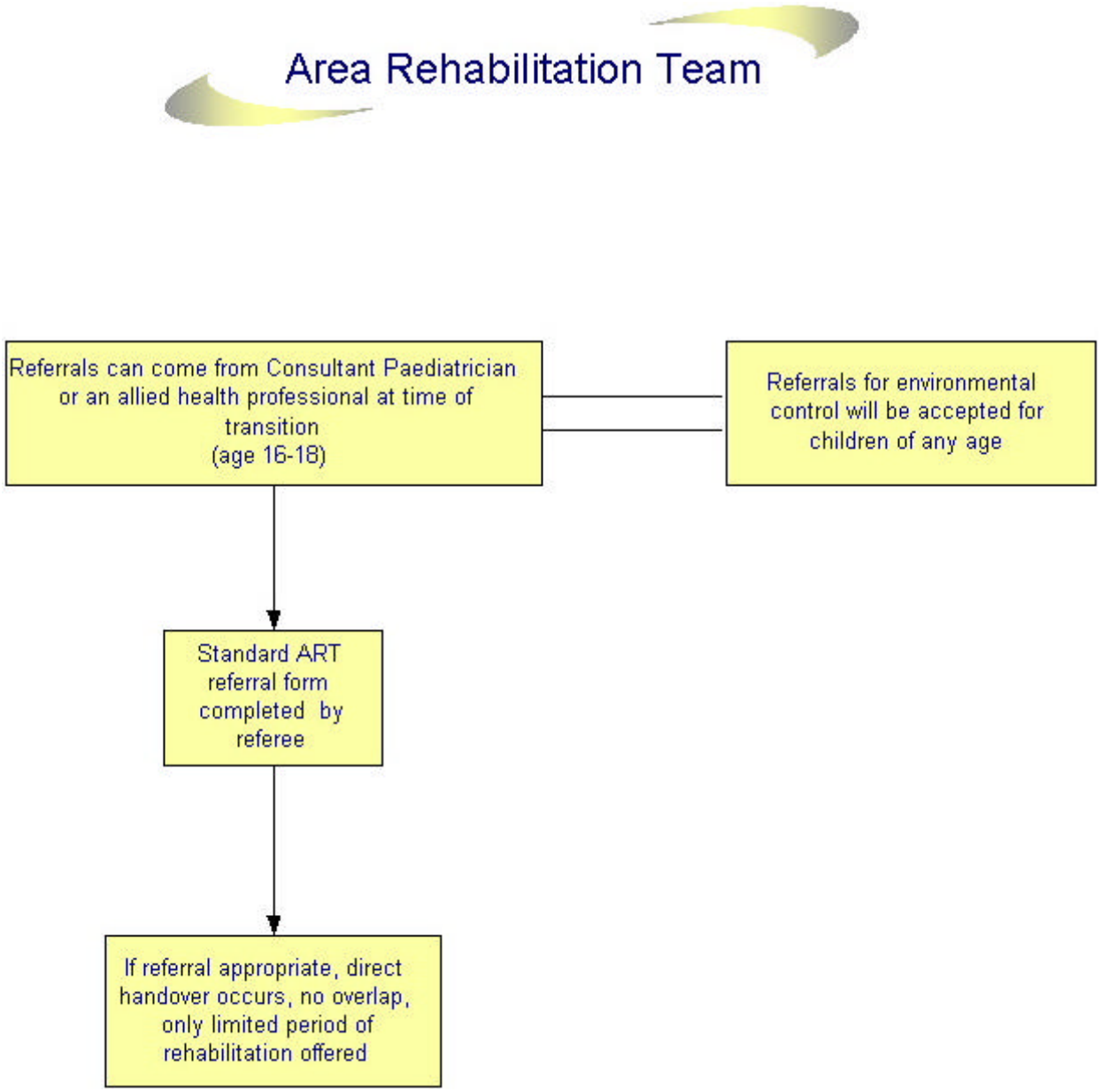
The quality of the planning depends more on the skill of the facilitator than on choosing the 'right' style. This skill should be grounded in proper training and study, and develops over years of work with people in many different situations. The concepts on which person centred planning is based are not complex but applying these concepts in a real situation, where roles are confused, views are in conflict and commitment is in doubt demands enormous skill, discipline and self-awareness.

North Transition Clinic

Appendix 14



APPENDIX 15


Area Rehabilitation Team
Referrals can come from Consultant Paediatrician or an allied health professional at time of transition (age 16-18)
Referrals for environmental control will be accepted for children of any age
Standard ART referral form completed by referee
If referral appropriate, direct handover occurs, no overlap, only limited period of rehabilitation offered

Appendix 16

Health Transition Process