



**BUCKINGHAMSHIRE  
INTERAGENCY PROTOCOL**

**WORKING WITH PARENTS WITH LEARNING  
DISABILITIES**



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Professionals from Buckinghamshire NHS and Buckinghamshire County Council have collaborated with this protocol and the planning for a resource leaflet for parents, the setting up of a website and a Professionals Network.

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## 1. INTRODUCTION

This document grew out of awareness among Buckinghamshire Children's Services Social Care Teams and the Buckinghamshire Adult Learning Disabilities Service that their work with parents with learning disabilities needed to be founded on a shared value base, and needed better co-ordination and managerial support. National policy in England commits Government to 'supporting parents with Learning Disabilities in order to help them, wherever possible, to ensure their children gain maximum life chance benefits' (DH, 2001).

The protocol aims to take a family centred approach, which recognises the centrality of the child's needs, and the principle that they should be the paramount concern of all staff, while appreciating that when a parent with learning disabilities receives inadequate and inappropriate support, the child's wellbeing will suffer. Services therefore need to provide support for the whole family and not just an identified person.

### 1.1 Parents with Learning Disabilities: The Evidence Base

The exact number of parents with learning disabilities in Buckinghamshire or nationally is not known. The 2001 White Paper on Learning Disabilities Services, Valuing People (DoH, 2001) estimates that the incidence of learning disabilities is around 5% of the general population. Changes in the political and social climate mean that more young people with learning disabilities grow up with similar aspirations as their non-disabled peers in areas such as employment, education and family life. Therefore it is likely that the numbers of people with learning disabilities who have children is growing.

In Buckinghamshire in July 2003 Magda Sereda, Consultant Clinical Psychologist, and Kate Frost, Trainee Psychologist, undertook "A County Wide Audit of Parents With a Learning Disability and a Qualitative Exploration of the Experience of Those Working With Them". They established that there were 23 families across the Community Learning Disabilities Teams where a parent had a learning disability and were using the services of the team. Referrals were primarily prompted by Child Protection concerns. Three themes emerged most often; the lack of resources available, the timing of the intervention being late, the need for a longer-term view of input to these families and lastly the difficulties in working with different philosophies between services.

National research evidence suggests that, for a variety of reasons, parents with learning disabilities are more likely to come into contact with Children's Services, Social Care than other parents. Their children are more vulnerable to developmental disabilities (McGaw, 1994); the parents are likely to be living in poverty, with restricted social networks (Bebington and Miles, 1989); the families also experience high rates of removal of children by statutory authorities – up to 40-60%. In many cases contact between parents with learning disabilities and services prove frustrating and disappointing for both

sides. Staff often feel ill prepared for dealing with these parents (Genders, 1998), parents and their advocates feel discriminated against, and that they are offered inadequate or competence-inhibiting support (Booth and Booth, 1994; Llewellyn 1995)

There are examples of good practice (McGaw, 2000), and evidence that parents with learning disabilities can improve their parenting skills with appropriate support (Feldman, 1994). Booth and Booth (1994) and McGaw (2000) advise that effective interventions with parents with learning disabilities should involve good interagency co-ordination; build on parents' strengths, while acknowledging their disabilities; include provision for long-term support, actively involve parents; are preventative as well as reactive; and are implemented and supported by trained staff (Tymchuk, 1992).

In May 2006, Bristol University's Norah Fry Research Centre published "Finding the Right Support Study". It found that an increasing number of adults with learning disabilities are becoming parents. In about 50% of cases their children are removed from them, usually as a result of concerns for well-being and/or an absence of appropriate support.

Some key findings of the Norah Fry research:

- There are a range of barriers to the provision of appropriate support to parents including negative, or stereotypical, attitudes about parents with learning disabilities on the part of staff in some services.
- Effective support involves a wide range of strategies, including early identification of parents with learning disabilities; support during pregnancy; assessment of support needs; skills training; help at home; parenting groups; flexible support to meet families individual and changing needs; helping parents to engage with children and family services; and multi agency working.
- The provision of easy to understand information on all aspects of parenting and advocacy support are also critical, especially during Child Protection and Judicial proceedings.
- Professional working in services for adults with learning disabilities need training in Child Protection issues; those involved in children's or generic services need training about adults with learning disabilities and their support needs.
- Many adults with learning disabilities are deemed 'too able' to qualify for the support services they need. Eligibility criteria for services need to take account of their additional needs for support for parenting.
- The development and spread of good practice in this area requires action at different levels; the individual parent and family; local services and at national (policy) level.

The Norah Fry research (2006) found that a wide variety of agencies and professionals are engaging with the issues around supporting parents with learning disabilities and their children including community nurses, social workers, health visitors, midwives, psychologists, speech and language therapists, occupational therapists and advocates. Many professionals are

trying to help parents overcome these barriers so that they can parent with support. To achieve this professionals are:

- Raising awareness of parents with learning disabilities and their support needs with non learning disabilities specialist services.
- Developing multi-professional and multi-agency support for them and their families.
- Empowering parents with learning disabilities.

## 1.2 Scope

This protocol is intended to assist the following groups:

- I. All staff working in Children's Services.
- II. Staff working in Maternity or Children's Services in Health, e.g. Midwives, Health Visitors, Child Development Centres and Children's Centres.
- III. Any staff of any discipline working in the field of learning disabilities.

It is recognised that our organisational structures are constantly changing and this protocol will need revision and amendment as new initiatives and structures emerge.

## 1.3 Aims

- a) To improve and develop services to families in which there are dependent children with parents with learning disabilities, avoiding, where possible multiple assessments by different workers.
- b) To establish good co-operation and communication between Children's Service Teams and Learning Disabilities Teams in order to achieve improved access to resources and collaborative decision making.
- c) To ensure safe management of risk while providing a responsive service to families that is sensitive to their special needs.

## 1.4 Definition of Learning Disabilities

'Learning Disabilities' is a nationally adopted term. Other terms used to describe this group include 'learning difficulties' and 'mental handicap'.

A person may be considered to have learning disabilities when all of the following apply (WHO 1992; BPS Professional Affairs Board, 2001):

- I. Significant impairment of intellectual functioning. This might be manifest in a reduced ability to understand new or complex information. It may be associated with problems with literacy and numeracy, though difficulties in these areas would not always mean that an individual would be labelled as having learning disabilities. If the individual has had a formal cognitive assessment, their IQ score would be below 70. However, a diagnosis of learning disabilities cannot be made on basis of IQ score alone.

- II. Significant impairment of social functioning, so that the individual requires significant assistance to provide for his/her survival and/or community adaptation needs.
- III. An impairment that is manifested during the developmental period, i.e. before the age of 18 years.

The Norah Fry Research (2006) recommended that one strategy for positive practice when assessing support needs would be to undertake a multi professional/agency and competency based assessment. This would be rather than an IQ based model. It would be based on assessments, taking account of the comprehension levels of parents (so that professionals know how best to communicate with them) and allowing sufficient time, so that assessments can be properly explained to the parents.

## **2. GENERAL PRINCIPLES**

### **2.1 Service Goals**

#### *2.1.1 Children's Services*

The aim of Children's Services Social Care is to keep families together wherever possible, and to provide appropriate resources and services to achieve this. The Five Outcomes of the Every Child Matters agenda apply to children whose parents have learning disabilities. The Five Outcomes are as follows:

- Be Healthy
- Stay Safe
- Enjoy and Achieve
- Make a Positive Contribution
- Achieve Economic well-being

Where children's needs cannot be met by their parent's decisive action should be taken to ensure their safety and well being.

#### *2.1.2 Adult Learning Disabilities Services*

Services provided to adults with Learning Disabilities by the Community Learning Disabilities Teams are grounded in the principles of Valuing People – A New Strategy for Learning Disability for the 21<sup>st</sup> Century, published by the Dept. of Health in 2001 (CM5086).

The four key principles guiding the work of the teams are:  
Rights, Independence, Choice and Inclusion.

A central aim of adult learning disabilities services is to support people with learning disabilities to access valued roles and opportunities in their communities (subject to the services' eligibility criteria) in addition to promoting their independence. Further aims are to maximise client's own health and well-being and to be helped to access mainstream services and

wherever possible to be included in the local community. Staff also strive to support clients make meaningful choices and to express preferences about their daily lives such as who they live with and where.

Staff also offer support and training to families, carers and other staff to help build up their skills and awareness when working with adults with learning disabilities. In their work with parents with learning disabilities, they aim to support the individual in their parenting role, using their expertise to tailor that support to parents' special learning needs.

Workers in these services recognise that there are circumstances where children cannot remain with their parents. They are aware of Child Protection and Adult Protection issues and would always have a responsibility to alert Children's Services colleagues if they had any concerns in these areas. There is an ongoing need for training in this area.

## 2.2 Children in Need

All children in families in Buckinghamshire where there is a parent with learning disabilities are included in Buckinghamshire's profile of Children in Need. They are entitled to an assessment of their needs under the Children Act 1989, and if providing care, under the Carers (Recognition and Services) Act 1995. Parents with learning disabilities are also entitled to a Community Care Assessment, under the Community Care and NHS Act 1990. However, we should note that a number of families where parents have learning disabilities do not want or need professional help and might view such input as stressful and intrusive (Llewellyn, 1995).

## 2.3 Working in Partnership with Parents

*'Trying to adapt services...to support me as a parent is like doing a jigsaw where you can almost see the picture, but where the pieces just don't seem to fit'* (A Jigsaw of Services, D.O.H. 2000).

Family members usually know more about their family than any professional could possibly know and well-founded decisions about a child should draw upon this knowledge and understanding. Family members should normally have the right to know what is being said about them, and contribute to important decisions about their lives and those of their children. Agencies and professionals should be honest and explicit with children and families about professional values, responsibilities, powers and expectations, and about what is and is not negotiable.

A CAF (Common Assessment Framework) when undertaken by any professional is completed in partnership with the family and looks at strengths and support networks as well as needs. A CAF is completed when a practitioner becomes aware that there may be unmet needs for an unborn child or at any point later. If there are child protection concerns at any point CAF is superseded by local safeguarding board procedures.

Such commendable intentions around working in partnership with parents with learning disabilities need to take into account the special challenges this client group might present. A parents' intellectual impairment may mean they have difficulties with understanding complex language, with attending to the essential part of the message, or with concentration. They may have difficulties with memory or with verbal expression. Opportunities for information sharing and decision making need to be set up by services with the parents needs in mind. They might need to hold more frequent, shorter meetings, use non-verbal reminders, enlist the support of a trusted friend, carer or advocate. Advice on these matters may be sought from specialist learning disabilities workers and advocates.

### *2.3.1 Family Group Conferences*

In recent years Family Group Conferences nationally have developed in a number of areas as a positive option for planning and the involvement of children and their families in the assessment and Child Protection process. There is a growing body of research about the positive impact and outcomes of Family Group Conferences

Family Group Conferences are a process through which family members, including those in the wider family, are able to meet together and to find solutions to difficulties that they or a child or young person in their family are facing. Family Group Conferences are not just a one-off meeting. They are an approach to planning and decision making which uses the skills and experience of the wider family, as well as professionals. The definition of who is in a family should come from the family itself. It includes parents and extended family, as well as friends, neighbours, and community members if they are considered part of the child's '*family*'. Since mid 2006, a Family Group Conferencing Service has been available in Children Services in Buckinghamshire. The main objectives are to prevent the need for children becoming Looked After or becoming the subject of a Protection Plan.

### 2.4 Staff Development

It is recognised that working with such complex situations requires a high level of skill and knowledge. Workers should be encouraged to take advantage of appropriate training events that are available. We also hope to develop local training initiatives for Buckinghamshire staff. At present training in working with parents with learning disabilities is an unmet need for many health and social care staff. It is planned to set up a Professionals Network in mid 2007. This will provide an opportunity for staff development, identification of training needs and an ongoing special interest group.

### **3. PRACTICE GUIDELINES**

#### **3.1 Pregnancy and Birth**

##### *3.1.1 Initial Contact*

The first point of contact for a mother with learning disabilities, who is pregnant, is likely to be members of the primary care team. She is likely to disclose news of her pregnancy to her GP or practice nurse, who would arrange for her to have a booking interview with a community midwife.

At this stage the following questions might arise:

- Does this mother-to-be have learning disabilities that mean that she might need more support during her pregnancy and the birth?
- Does she need support in other areas of her life? What about other family members?
- Are there any concerns about her safety, that of the baby or other children in the family?

##### *a) Learning Disabilities and need for additional support during pregnancy*

- Not all mothers with learning disabilities will need additional support during pregnancy and birth. They may have had previous children, and/or receive adequate support from their own networks.
- Midwifery staff should use the screening tool (Chinn, 2005) to determine if a special learning need exists. (Appendix 1)
- Midwifery staff should use the Pregnancy Assessment Form (Martin, 2002) to determine need for additional support. (Appendix 2).
- If the mother-to-be does need additional support, staff should draw up a Pregnancy Support Plan.
- If required, refer to specialist Services for People with Learning Disabilities and/or advocacy services.(Appendix 3)
- The parents to be might benefit from opportunities to learn new childcare skills during the pregnancy period. This training could take place at home or at the Family Centre.

##### *b) Need for support for mother and/or other family members*

- During her contact with the primary health team the mother-to-be might disclose that there are other issues concerning her or her family that might require further support (for example, benefits, mental health issues, housing, family relationships, Education Welfare, Advocacy Services)

- The primary health team would then make further referrals to generic or specialist Learning Disabilities Services and/or Advocacy Services. (Appendix 3)

c) *Concerns about safety of mother or child(ren)*

- If staff have any safety concerns about mother and/or child/ren they should make a referral using the Common Referral Form to Children's Services Social Care .(Appendix 4). If the unborn child or other children in the family are already open to a key worker (Social Worker) in Children's Services Social Worker should be contacted directly with the concerns.
- When parents present with needs for additional support during pregnancy and birth or where there are concerns about safety, a pregnancy and Birth Planning Meeting should take place.

3.1.2 *Pregnancy and Birth Planning Meeting*

When?	By the 26th week of pregnancy
Where?	At hospital
Co-ordinated by?	Midwife or Social Worker
Who attends?	Mother, family members, Advocate, Midwife, Children's Services Social Worker, Learning Disabilities Care Manager (if involved), other Children's Services staff (if involved), Health Visitor.

If there are Child Protection Concerns or the need for a Learning Disability Worker is identified at any point in the pregnancy, a referral to the appropriate team should be made(Appendix 3 and/or 4). A pregnancy and Birth Planning Meeting can be held at any point but no later than 26 weeks.

3.1.3 *Aim of the planning meeting:*

- To co-ordinate with any ongoing Child Protection procedures if the unborn child is subject to a Protection Plan this meeting could be combined with a Child Protection Core Group meeting.
- To draw up a pregnancy and birth plan covering the following areas:

Antenatal care

- Attendance at classes
- Need for additional support

Consent issues

- Can the mother give consent for medical interventions?
- How should consent be assessed?

Plan of care at birth

- Projected length of stay in hospital
- Details of how partner and other carers might be involved
- Supervision of the baby (if required)

#### After the birth

- Involving partner and other carers
- Teaching goals in hospital
- Consideration of training, support needs for ward assistants
- If on the Child Protection Register to carry out the requirements of the Protection Plan

#### Childcare training

- Arrangements for further support to parents to learn childcare skills

#### Make additional referrals

- e.g. to Homestart, for an advocate, to children's services, to Community Learning Disability Team, request a Family Group Conference be held

### *3.1.4 Removal of baby*

If the Child Protection plan is for the baby to be removed after birth, staff should be sensitive to the feelings of the mother and her partner and other family members. This might be the only time that the parents spend time with their new baby. The plan should consider the following issues:

#### Spending time together

- Staff may need to consider issues around supervision, what extra support the parents might need to make this work for them, the baby and the ward. The Safety and well being of the baby is paramount.

#### Mementoes

- Taking photographs, footprints – who will arrange this?

#### Privacy

- If the mother has to stay in hospital after the baby has been removed, she should not be left on the maternity ward. She should be able to access a room to herself.

### *3.1.5 After the Planning Meeting*

It might be appropriate for a **Family Group Conference** to take place so the family can generate their own solutions and responses. The Children's Services Social Worker will refer for this.

A **written plan** should be circulated within two weeks of the meeting. A copy should go to the Midwifery Manager and Maternity Ward Manager.

The plan should be **forwarded to the mother's GP and the health visitor** assigned to that GP practice.

The child should be allocated a Children's Services Social Worker if not already in place.

### **3.2 Referrals between Adult Learning Disabilities and Children's Services Social Care Teams**

The pathway of care for a parent with learning disabilities may start within the Adult Learning Disabilities Service or Children's Services Social Care Teams. Once a named worker has conducted their initial assessment, and found out about current issues within the family, they need to consider whether to make a referral (Appendix 3 or 4).

#### *3.2.1 Issues for Adult Learning Disabilities Team workers to consider:*

Having undertaken an initial screen of the parent/s you need to consider:

Does the family need support that Children's Services Social Care Teams may be able to offer?

- a) Child's needs not being met within current support network
- b) Family needs specific extra help e.g. respite care
- c) Risks to child e.g. potential risk of neglect or abuse

If any of these circumstances are present the worker would need to consult with their manager, and make a referral to Children's Services Social Care.

#### *3.2.2 Issues for Children's Services Social Care Workers to consider*

Having undertaken an initial/core assessment (DH, 2000) you need to consider:

- Does the parent seem to be having problems with childcare that may be linked to the parent's learning disabilities?
- Does the parent seem to have individual needs linked to learning disabilities? The introduction of the screening tool (Appendix 1) should assist with this.

There is a training need here to ensure that workers from the Children's Services Social Care understand the impact of learning disabilities and the role of specialist services in supporting people with learning disabilities.

Workers should refer to the definition of learning disabilities in this document (1.3). If they have any doubts about whether a parent might be eligible for a specialist learning disability service, they should discuss this with someone from one of the specialist teams, namely a Care Manager, Team Manager or Senior Clinician.

Consultation is available with the Community Learning Disabilities Team regarding possible referrals where the parent/parent to be may have borderline learning disabilities.

### 3.2.3 *Advocacy for parents with learning disabilities*

With the parent's consent, specialist advocacy workers for people with learning disabilities should be involved at an early stage, to support the parent in communicating their wishes and views to the professional support system and to enhance their understanding. (See Appendix 5).

### 3.3 Joint Initial Assessment

For some families at this early stage, it may be beneficial for workers from different agencies to conduct their Initial Assessments jointly. This would avoid parents having multiple appointments with lots of new workers, and would facilitate sharing of information and assessment aims. Where possible, a new worker should visit with someone who already knows the family well.

The Initial Assessment (DH, 2000 Framework for the assessment of children in need and their families) should identify which professionals are already working with the family, e.g. GP, Health Visitor, Teachers, Educational Social Workers, etc.

The Children's Services Referral and Assessment team would initially agree on who would be the lead assessor and take responsibility for writing up and distributing the assessment. The assessors would agree on the aims of the assessment and the sort of information that they wanted it to collect, and make sure these are communicated to the family involved. The Initial Assessment report should end with conclusions and recommendations, which make clear whether further referrals will be made, and how more detailed assessments to be presented at the multi-agency meeting will be conducted (see Section 3.4). The recommendations would also identify what liaison should be undertaken with other professionals in the family's support network.

### 3.4 Multi-Agency Professionals Meeting

This multi-agency meeting is about service responses, and therefore the parents would not be present. Well organised and focused multi-agency meetings are a core part of joint working. Where there are Child Protection concerns, or issues relating to a Child in Need, a worker from Children's Services Social Care would be responsible for calling and administering multi-agency meetings. Thought should be given to who should be invited to meetings, and what documentation is needed for the meeting. Meetings should be kept as small and manageable as possible.

#### 3.4.1 *Aims of the meeting*

The **aims** of the multi-agency meeting are to:

- Plan more detailed assessment if required, e.g. a Core Assessment (DH, 2000 Assessment Framework), Community Care Assessment.
- Decide how to involve the parents in the assessment and keep them informed.

- Identify case co-coordinator/allocated Social Worker from Children's Services Team and Community Learning Disabilities Team.
- Identify a worker to feedback the decisions of the meeting to the parents, and go over the assessment plan with them.

#### *3.4.2 Chair of the meeting*

The chair of the meeting will be a Senior Practitioner/Team Manager from Children's Services Social Care. Their role will be to:

- Manage the meeting.
- Negotiate roles.
- Develop a timescale for agreed work.
- Recommend resources for assessment if necessary (e.g. transport and childcare) and to provide support to the family.
- Set up series of follow-up meetings to monitor progress of agreed tasks.

#### *3.4.3 Meeting with parents*

The feedback from the multi-agency meeting should be delivered in such a way that it takes account of the parents' communication and learning needs. There is an important role for advocates in supporting this work.

Where the unborn child or the child is subject to a Protection Plan/on the Child Protection Register parents will be fully involved with the Child Protection Conference process and the Core Groups. The latter take place every four weeks. Workers from the Learning Disabilities Team may be core group members.

### 3.5 Assessment of parents with learning disabilities and their children

#### *3.5.1 Timeframes*

Assessments should be completed within the agreed timeframe and copies of any reports should be circulated in good time for the next meeting. It should be noted that different services follow different statutory time limits for the completion of their assessments. Children's Services Social Care Workers have 35 days to complete their core assessment, while Care Managers in Learning Disabilities Teams have 28 days to complete the Community Care Assessment.

#### *3.5.2 Multi-agency assessments*

Assessments should be wide ranging and comprehensive, following the model described in the Framework for the Assessment of Children in Need and their families (DOH, 2000).

**Childs Developmental Needs** – e.g. health, education, emotional and social development. This would be assessed by Children’s Services Social Care Workers, with input as necessary from Health Professionals from the Child Development Team, and the Children and Families Consultation Service.

**Parenting Capacity.** Professionals from Health and Social Services Learning Disabilities Teams would be well placed to access the parent’s skills, knowledge and practices which relate to the support that the parents might need for themselves and to care for their children. Social Workers from Children’s Services Social Care will also contribute to this section, as they have many opportunities to observe parent/child interactions. They will be able to assess how parents’ cope with parenting tasks on a daily basis, and to review the social and relational networks that support parents in bringing up children.

**Family and Environmental Factors.** Professionals from all agencies will be able to contribute their perspectives relating to areas such as family’s use of community resources, social integration, employment, wider family, and family history and functioning.

### 3.6 Feedback and Planning Meeting

On the basis of the multi-disciplinary assessments the meeting will agree on the following:

- Do the children in the family have unmet needs?
- Are there any risks to children in the family?
- What extra support does this family need?
- Is there a role for a Family Group Conference

## 4. ASSEMBLING A SUPPORT PACKAGE

### 4.1 Family Centred Support and Outcomes

Support should be offered to the family as a whole. This might include support around general issues such as benefits and housing. Wherever possible support should be directed at helping parents care for their children. Clear goals and responsibilities should be identified for workers. Workers should proceed in collaboration with other support networks available to the family, including the extended family, friends and the wider community.

It might be unrealistic for certain parents with learning disabilities to change in particular ways within predetermined timeframes. In order for the child’s needs to be met, what might need to change in these circumstances are changes in the family environment and levels of support.

## 4.2 Eligibility

There are some parents who, before they had children, were able to cope independently and would not have met the eligibility criteria for specialist Learning Disabilities Services. However, the complexity of childcare tasks means that they will need extra help when they have children. Services should have the flexibility to take account of the changing circumstances associated with parenthood and this may mean that parents who were previously ineligible for services may become so as a result of such changes.

## 4.3 Quality Standards

Recent research (e.g. Booth and Booth, 1995; McGaw, 2000) has outlined good practice in working with parents with learning disabilities. Professional help works best when:

- There are not too many professionals involved.
- Parents are treated with respect, and involved in decisions affecting their lives.
- Support reinforces and develops the parents' own skills in childcare as well as other areas of life, such as further education, budgeting and making friends.
- Support makes use of community support, including the extended family.

## 4.4 Support Agencies

Agencies that may be involved in supporting families could include:

- Health visitors
- Peer support
- Family Centres
- Children's Centres
- Home start
- Parents as First Teachers
- Extended schools
- Child and Adolescent Mental Health Service (CAMHS)
- G.P.
- Advocacy Services
- Housing Services
- Young Carers

Support services must be sensitive to the culture and religion of families they work with. Services may need to organise specialist training and support packages for workers.

## 4.5 Funding of Support

Clear guidelines for funding of support for families need to be established. This should be addressed within a multi-agency professionals meeting. It does not make sense for different agencies to fund different workers to provide different sorts of inputs within a family home (e.g. a worker for the parent and a worker for the children). In the course of family life, parents are confronted with a range of tasks, and it is impossible to separate out support for parents that does not affect childcare issues as well (e.g. teaching a parent budgeting skills would mean better control of family finances, and reliable sources of cash to pay for family meals, children's clothes, family outings, etc.)

Support for parents with learning disabilities is likely to be long-term. There should not be the expectation that such parents can quickly learn the necessary skills and then have their support withdrawn. Agencies funding support need to acknowledge this. Withdrawing support after seeing some improvements in childcare skills means that such skills are unlikely to be sustained, and sets parents up to fail.

This is not to say that there will never be times in the family's lifecycle when less professional support is needed. Services need to be sensitive to the family's changing needs, especially around periods of family transitions.

## 5. ONGOING WORK

### 5.1 Multi-agency reviews

Where children are not subject to a Protection Plan/on the Child Protection Register multi-agency reviews will be convened by the case co-ordinator and should take place every three to six months. When additional issues emerge, multi-agency reviews should be scheduled on a more regular basis. Whatever meetings take place, the case co-ordinator should be informed and involved. Parents, their support network, and advocates should be involved in the review process.

Where children are the subject of Protection Plans there will be a Multi-Agency Core Group Meeting with the parents every four weeks. The Plan/Registration will be reviewed at a multi-agency conference including the parents at three months and then six monthly thereafter.

### 5.2 Ongoing support for parents after children have been removed from the family home

There will be circumstances where children will not be able to remain with their parents because of issues to do with vulnerability and risk, and difficulties in ensuring appropriate services. When this happens, services should sensitively manage the process of withdrawing support workers in cases where strong relationships have developed between parents and workers. Parents will receive continuing support from Community Learning

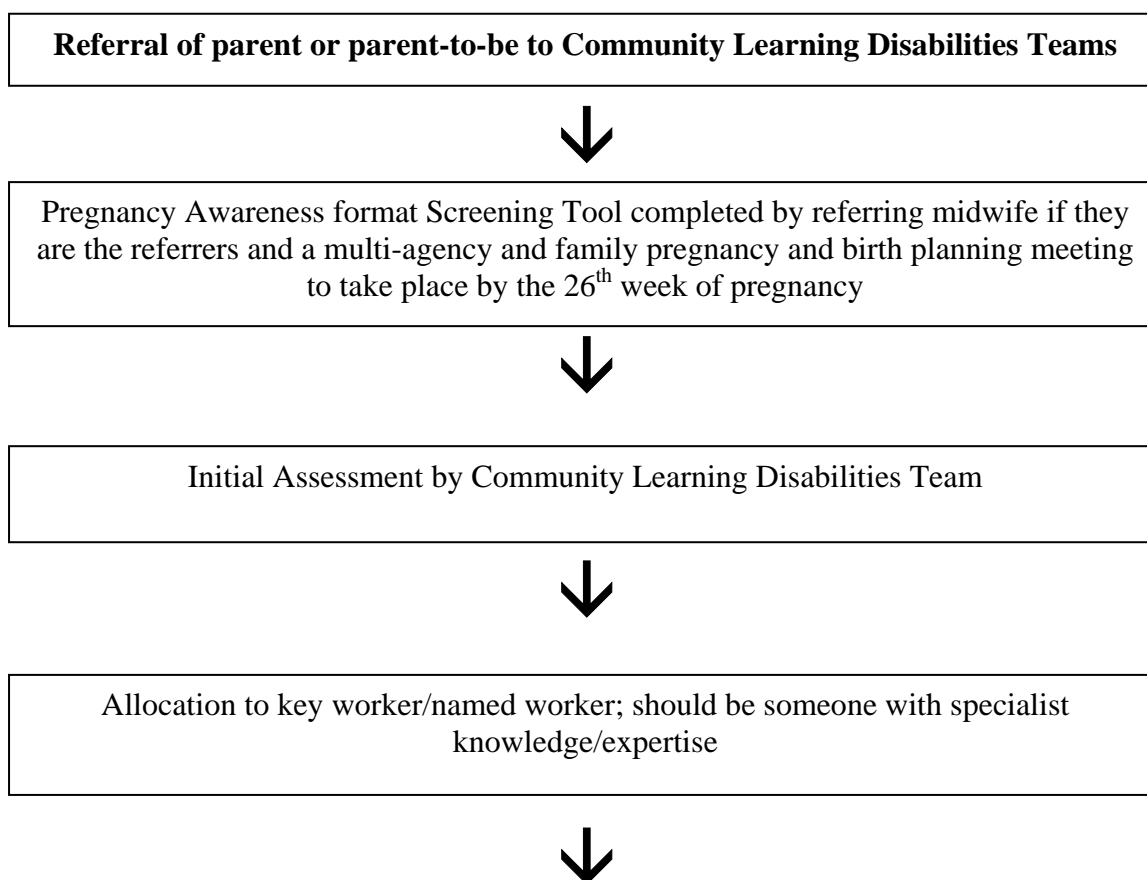
Disabilities Services if this is needed. The parent's care plan and support needs should be reviewed at this point.

## **6. PRACTICE GUIDELINES – FLOWCHARTS**

### **6.1 PATHWAY OF CARE STARTING WITH COMMUNITY LEARNING DISABILITIES TEAM OR MIDWIFERY**

In this section of the guidelines the practice flowchart begins with someone coming into contact with one of the Community Learning Disabilities Teams because parenting issues have just become 'live'. This might be when a woman becomes pregnant or when extra help is being sought by other agencies dealing with the family.

**N.B. If there are Child Protection/welfare concerns at any point a referral should be made to Children's Services Social Care.**



Consider referral to Children's Services Social Care

Q: Does family need support or assessment which Children's Services Social Care can offer eg:

- a) Needs extra help e.g. respite, nursery provision
- b) Risks to child – potential risk of neglect or abuse

If the answer is 'yes'

- refer to Children's Services Social Care using the Common Referral Form (Appendix 4)
- refer to advocacy



Children's Services Social Care Social Worker will visit and complete Initial Assessment within 7 days. This may be a joint visit with the Community Learning Disabilities Team worker if appropriate.



If a Core Assessment is required (DOH Assessment Framework for assessing Children in Need) a Multi-agency Professionals Meeting with e.g. Children's Services Social Care Social Worker, Learning Disabilities Care Managers, other Health Personnel (e.g. Midwives, Health Visitors, GP, Advocate), School etc will be held.

Aims:

- To plan assessment
- To decide how to involve parents
- The meeting will identify a key worker from Children's Services Social Care Team
- Resolve any funding issues

The meeting will be chaired by Senior Practitioner/Team Manager from Children and Families Social Services .

Their role will be to:

- Manage the meeting
- Negotiate roles
- Develop a timescale for agreed work
- Recommend resources for assessment if necessary (e.g. transport, childcare) and to provide support to the family
- Plan who will share the outcomes of the meeting with



Planning meeting with parents (and advocates)



Workers complete assessment within agreed timeframe e.g. Core assessment within 35 days led by Children's Services worker, Community Care assessment within 28 days, led by Learning Disabilities worker.



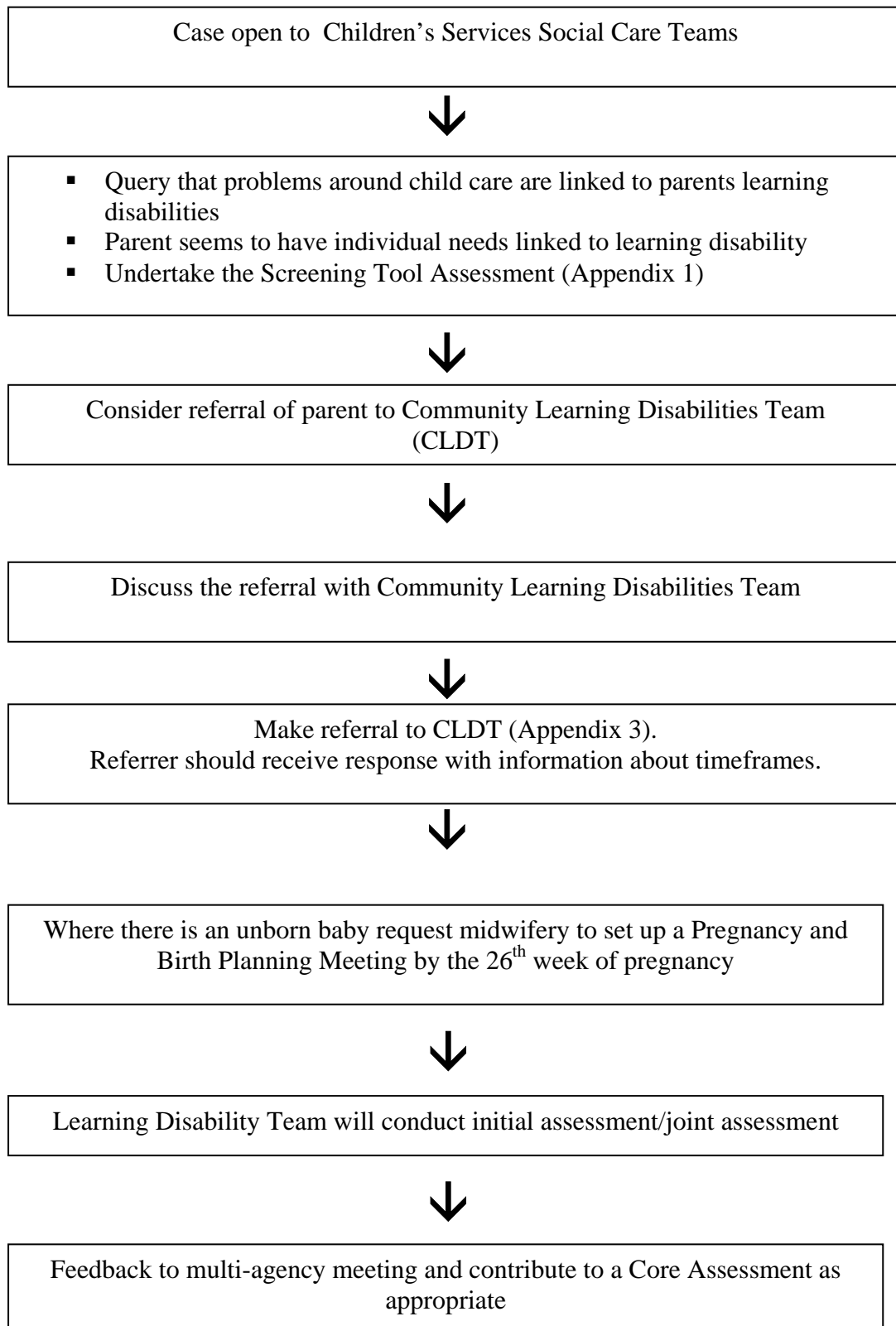
Feedback and Care Planning Meeting.  
Parents should be involved in this meeting. Assessment will outline: risks to children, what extra support family need, role of family group conference  
Consider convening **Family Group Conference**

If children removed from parents  
↓  
Adult services will co-ordinate support package to parents



Assemble support package.  
Organise training and support for workers if necessary. Agencies which may be involved: family centres, community nurses, peer support, outreach services, parents as first teacher, home start, children's centres, extended schools.

## 6..2 PATHWAY OF CARE STARTING WITH CHILDREN'S SERVICES SOCIAL CARE TEAMS



## 7. REFERENCES

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Department of Health (2000). *A Jigsaw of Services: Inspections of Services to Support Disabled Adults In Their Parenting Role*: The Stationary Office.

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Norah Fry Research Centre University of Bristol (2006). Finding the Right Support?

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APPENDIX 1

**Buckinghamshire Community Learning Disability Service**

March 2007

**Identifying whether a parent may have learning disabilities**

Please tick if there is any evidence to support the following:

**1. HISTORY**

Is there historical information documenting learning disabilities such as:

- a) Self-report, e.g. that they went to a special school, or had extra support within mainstream school? Did they have a statement of special educational needs?
- b) Information from a family member, e.g. information about special education, developmental delay, needing additional help etc.
- c) Information from other agencies.

If you have ticked this box you **DO NOT** need to complete the remainder of the form as it is likely that the person has been labelled as 'learning disabled' in the past.

**2. TRAVEL**

Inability or difficulties travelling on public transport independently and/or always coming to appointments accompanied by another adult.

**3. LITERACY**

- a) Inability to write in their first language
- b) Writing minimal information only
- c) Reading words but limited understanding of what is read

*(you could gently check this out)*

**4. DEMANDS**

- a) Being overwhelmed by routine demands e.g. missing many appointments, erratic appointment keeping – late, early, wrong day etc.
- b) Inability to keep track of grocery needs, difficulty sequencing tasks or prioritising demands and activities.

**5. GIVING INFORMATION**

Providing vague or over-simplified information about basic facts, e.g. unclear about symptoms of pregnancy, expected changes to body, about how many weeks into pregnancy or when pregnancy was confirmed.

**6. MONEY SKILLS**

Not able to make change for a pound. Running out of money soon after being paid/receiving benefits, poor budgeting skills, difficulty estimating costs.

**7. SELF CARE**

Not adequately recognising connection between need to take care of self and health of developing baby, e.g. awareness of behaviours that need to be avoided during pregnancy.

**8. UNDERSTANDING COMMUNICATION**

Difficulties understanding more complex or abstract communication. Using complex words themselves that they don't seem to understand.

**9. LEVEL OF SUPPORT**

Central role of another person providing help not normally expected for an adult, e.g. help with using transport, doing shopping, helping with managing money.

If you have ticked at least **three** of the boxes numbered 2 – 9 and suspect that these difficulties are primarily the result of someone having a learning disability (rather than mental health issues, or language or cultural issues) then you should liaise with other professionals involved to gather more information and consider seeking advice/support from specialist learning disability services

(This form was developed by D Chinn, Clinical Psychologist and M McKinstry, Community Nurse, Tower Hamlets Community Learning Disability Service)

## **Pregnancy Awareness Form**

From: Martin, H. (2002). Support for pregnant women with learning disabilities. *Nursing Times*, 98(10), p38.

### **The pregnancy awareness form**

The form allows the user to ascertain whether or not the questions are pertinent and probing enough, without being too complex. It consists of a brief questionnaire that aims to provide the practitioner with information and give the woman an insight into the challenges she may have to face.

It can also help the communication and contact between the generic and the specialist community teams for people with learning difficulties (CTLD) services, as during this period of time in a woman's life, both settings offer a valuable service.

After drawing up a draft form, I sought the opinion of a doctor working in family planning. Once I had gained approval for the form, I began to use it in my work (Box 1).

One question women often find difficult answering is: 'What does being pregnant mean to you?'. I expect answers such as 'getting fat' but all the women responded with: 'Don't know'. I was reassured when one woman told me she was worried about giving birth. But she was not typical (...)

### **A springboard for support**

I like to think of the form as a springboard for women with learning disabilities to obtain the support they require from the CLDT in conjunction with generic services. I anticipate that the form will be completed by the practitioner undertaking the pregnancy test who will be able to refer the woman, should this be requested, to the local CLDT for specialist input. It could also be used as the basis for care planning (Box 2).

A women with learning disabilities may be shocked to discover she is pregnant so, once the form has been completed, she may need time to think about the support she may want. This may require the practitioner to make follow-up arrangements, either through a face-to-face appointment or, where appropriate, a telephone call, to ascertain the response.

### **The future**

Ideally, for the pregnancy awareness form to be more widely used, it would have to be accompanied by a brief handout. A resource section could also be included. The pregnancy awareness form is being piloted in two GP surgeries and is reaching a limited number of women. The aim is to extend its use to all surgeries and even hospital departments, such as A & E and genitourinary clinics.

PREGNANCY AWARENESS FORM (Martin, 2002)

<b>Client Name:</b>	<b>DOB:</b>
<b>Address:</b>	<b>Tel. No:</b>
<b>GP:</b>	
How many weeks pregnant?	
Is this your first baby?	
Who will help you through your pregnancy and birth?	
What does being pregnant mean to you? What changes in your body will you notice?	
Did you plan this pregnancy?	
Have you been into hospital before?	
What are your main worries?	
How do you think you can be helped with these concerns/worries?	
How do you see your future after the baby is born?	
Do you have any professionals involved in your life?	
Any other concerns?	
Completed by:	Date:



Confidential Referral/Re-Referral Form  
Community Learning Disability Team



**Please return to the most appropriate team listed below:**

Aylesbury CLDT

Manor House

Bierton Road

Aylesbury

Bucks. HP20 1EG

Phone: 01296 565 317/8

Fax: 01296 565 934

Chiltern & South Bucks CLDT

9 Chiltern Court

Asheridge Road

Chesham

Bucks. HP5 2PY

Tel: 01494 810140

Fax: 01494 786492

Wycombe CLDT

Bucks County Council

Easton Street

High Wycombe

Bucks. HP11 1NH

Tel: 01494 475032

Fax: 01494 475008

**COMPLETE IN BLOCK LETTERS IN BLACK PEN**

Name: Preferred Name: Full Address:   Postcode: Tel No:	Male <input type="checkbox"/> Female <input type="checkbox"/>  D.O.B.  Ethnic Group:  Preferred Language:
Contact Persons/Carer:  Relationship to Client:  Name: Full Address:  Postcode: Tel No:	GP Name:  Surgery Address:   Postcode: Tel No:

Date of Referral:	Emergency: Yes <input type="checkbox"/> No <input type="checkbox"/>
Referred By:	Action taken if yes:
Designation:	
Referrer's Address:	
Postcode:	Tel No:
The Client has been informed of the referral	Yes <input type="checkbox"/> No <input type="checkbox"/>
The GP is aware of the referral	Yes <input type="checkbox"/> No <input type="checkbox"/>
If known, Swift/Record	Yes <input type="checkbox"/> Number..... No <input type="checkbox"/>
Health File:	Yes <input type="checkbox"/> No <input type="checkbox"/>
Medical File:	Yes <input type="checkbox"/> No <input type="checkbox"/>

Has the Client previously been seen by members of the CLDT?
Yes <input type="checkbox"/> No <input type="checkbox"/>
If yes, by whom:
Date:

Other agencies/keyworker, etc, involved (please tick ✓):		
		Name:
Rehab Worker	<input type="checkbox"/>	
Care Manager	<input type="checkbox"/>	
Day Centre Key Worker	<input type="checkbox"/>	
Dietician	<input type="checkbox"/>	
Assistants	<input type="checkbox"/>	
Resident Key Worker	<input type="checkbox"/>	
SIT	<input type="checkbox"/>	
Other	<input type="checkbox"/>	

Does the Client have an advocate?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
If yes, who:		

**Reason(s) for Referral**



Please complete as fully and clearly as possible to aid allocation process:

- 
- 
- 

We aim to see each Client within two months of receiving the referral. If the Client needs to be seen sooner, please give reasons:

Additional relevant information (eg, medication, etc):

Signature:	Designation:
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		<b>Buckinghamshire Multi Agency Common Referral Form Assessment Framework initial information Confidential</b>					
<b>Note: Shaded areas are for Social Care use only</b>							
<b>1</b>	SWIFT ID:		Date:				
Is the parent / carer aware of the referral? <i>Please tick</i>			Yes		No		
<b>2</b>	<b>Child / young person's name, address and responsible local authority</b>						
Family name:			Forename(s):				
Date of birth:			Gender:				
Address:							
Postcode:			Tel no:				
Current address		<i>if different from above:</i>					
Postcode:			Tel no:				
Social Care team:			Responsible LA				
<b>3</b>	<b>Child/young person's ethnicity</b>						
Child's ethnicity:			Code:				
Child's religion:			Child's first language:				
Parent(s) first language:			Is an interpreter or signer required?		Yes	<input type="checkbox"/>	
<b>4</b>	<b>Child/young person's principal carers</b>						
Surname	Forename	DoB	Relationship to child	Parental Responsibility			
				Yes		No	
				Yes		No	
<b>5</b>	<b>Other household members including non-family members</b>						
Surname	Forename	DoB	Relationship to child <i>Tick if also referred to Social Care and complete a separate referral form</i>				
				Ethnicity			
				Ethnicity			

<b>5</b>						<b>Other household members including non-family members (Continued)</b>					
<b>Surname</b>		<b>Forename</b>		<b>DoB</b>		<b>Relationship to child</b> <i>Tick if also referred to Social Care and complete a separate referral form</i>				<b>Ethnicity</b>	
										<b>Ethnicity</b>	
										<b>Ethnicity</b>	
										<b>Ethnicity</b>	
<b>6</b>						<b>Information on statutory status</b>					
<b>Child or other family member(s) is or has been on a Disability register?</b>								<b>Yes</b>		<b>No</b>	
If 'yes', please give details:											
<b>Child or other family member(s) is or has been on a Child Protection register?</b>								<b>Yes</b>		<b>No</b>	
If 'yes', please give details:											
<b>Child or other family member(s) has/have been Looked After by a local authority?</b>								<b>Yes</b>		<b>No</b>	
If 'yes', please give details:											
<b>Child/young person has a Statement of SEN?</b>								<b>Yes</b>		<b>No</b>	
<b>7</b>						<b>Significant family members who are not members of the child's household</b>					
<b>Name:</b>				<b>Relationship:</b>							
<b>Ethnicity:</b>				<b>SWIFT ID:</b>							
<b>Address:</b>											
<b>Postcode:</b>				<b>Tel no:</b>							
<b>Name:</b>				<b>Relationship:</b>							
<b>Ethnicity:</b>				<b>SWIFT ID:</b>							
<b>Address:</b>											
<b>Postcode:</b>				<b>Tel no:</b>							
<b>Name:</b>				<b>Relationship:</b>							
<b>Ethnicity:</b>				<b>SWIFT ID:</b>							
<b>Address:</b>											
<b>Postcode:</b>				<b>Tel no:</b>							

**8 Other SWIFT cases associated with the child / young person**

Name:		Case no:		Name:		Case no:	
Name:		Case no:		Name:		Case no:	

**9 Key agencies or other parties involved** *e.g. GP, HV, School, YOS, CMH, Police, EPS, EWS, etc.*

Name	Agency	Tel no	Currently working with the family
			Yes <input type="checkbox"/> <input type="checkbox"/>
			Yes <input type="checkbox"/> <input type="checkbox"/>
			Yes <input type="checkbox"/> <input type="checkbox"/>
			Yes <input type="checkbox"/> <input type="checkbox"/>
			Yes <input type="checkbox"/> <input type="checkbox"/>
			Yes <input type="checkbox"/> <input type="checkbox"/>

**10 Referrer**

Referred by:		Agency/relation to child/young person, etc:	
Address:			
Postcode:		Tel no and Fax no:	
Signature:		Designation:	
Date:		Method of transfer of communication to C&FSC: Tel / fax / letter	

**11 Reason for enquiry / referral / request for service** *use separate sheet if necessary*

Enquiry code:	type	
---------------	------	--

Name of staff member taking this referral:			
Signature:			Date:
<b>12 Feedback to referrer</b> <i>to provide acknowledgement of referral and feedback</i>			
Name:			
Signature:			Date:
<b>13 Further referral action</b> <i>Practice note: Ensure this referral is collated with previous referrals or files</i>			
No further action:		<i>Please tick</i>	
Provision of information and advice:		<i>Please tick</i>	
Referral to other agencies:		<i>Please tick</i>	
Please state which agencies:			
Initial assessment:		<i>To be completed within 7 working days</i>	
Party category:		Priority Code	
Reason for further action <i>(stated issues)</i>		Stated Issue Code(s):	
What further assessments are to take place?			
Receiving Worker's name:			
Signature:		Date:	

<b>Team Manager's comments:</b>
---------------------------------

<b>Team Manager's name:</b>			
<b>Signature:</b>		<b>Date:</b>	

This form, and its appendices, is available to download from Buckinghamshire County Council's Internet web site: [www.buckscc.gov.uk/care\\_of\\_children/referral.htm](http://www.buckscc.gov.uk/care_of_children/referral.htm)

**Appendix 1** Please answer all questions in Appendix 1, giving as much detail as possible.

<b>1</b>	Have you discussed your concerns with the family / parents?	Yes		No	
----------	---	-----	--	----	--

<b>2</b>	If you answered 'no', why not?

<b>3</b>	Why are you referring this child / young person?

<b>4</b>	Why are you referring now?

<b>5</b>	What are your main concerns?

<b>6</b>	What are the child's / young person's strengths?

<b>7</b>	<b>What are the family's strengths?</b>
<b>8</b>	<b>What is the likely impact of this referral for the child / young person and the family?</b>
<b>If you are referring from Health</b>	<b>Please complete Appendix 2</b>
<b>If you are referring from Education</b>	<b>Please complete Appendix 3</b>
<b>If you are referring from any other agency</b>	<b>Please answer any relevant questions for which you have further information</b>
<b>Appendix 2</b>	<b>For referrals from Health professionals</b>
<i>Please answer all questions, giving a brief overview.</i>	
<b>1</b>	<b>Does this child have health / developmental needs?</b>
<b>2</b>	<b>Does the child's parent or other family member have health needs?</b>
<b>3</b>	<b>Are there concerns about parenting capacity?</b>
<b>4</b>	<b>Are there any environmental issues contributing to the child's needs?</b>
<b>5</b>	<b>Please add any other information which may be useful.</b>

Signature:		Date:	
Name (please PRINT):		Designation:	
Contact address details:			
Postcode		Tel no:	

**Appendix 3** For referrals from Education professionals

*Please answer as many questions as possible, giving a brief overview. Continue on a separate sheet if necessary, or attach the relevant school documents.*

**1** Please comment on attendance / punctuality.

**2** Are there any concerns about the general health of the child? Please describe.

**3** Is the child cared for, clean and well presented?

**4** Does the child have friends in school? How does he/she relate to peers?

**5** How does the child respond or relate to adults? Is there any difference between male and female adults?

**6** Are the parents supportive? Do they attend parents' evenings, school events, engage in meetings or help with rewards/sanctions?

**7** Does the child do his/her homework?

**8** What are the child's attainments?

<b>Appendix 3</b>	<b>For referrals from Education professionals</b> ( <i>Continued</i> <i>from</i> <i>previous page</i> )
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<b>9</b>	Does the child have any special educational needs? Does he/she have an individual education plan (IEP)? How are needs supported?
----------	--

<b>10</b>	Does the child have any behavioural difficulties? Does he/she have a pastoral support programme (PSP)?
-----------	--

<b>11</b>	Has the child been excluded from school? Give details.
-----------	--

<b>12</b>	What is the likely educational impact of this referral?
-----------	---

<b>13</b>	What other educational services are aware of this child?
-----------	--

Signature:		Date:	
Name (please PRINT):		Designation:	
Contact address details:			
Postcode:		Tel no:	

**This form, and its appendices, is available to download from Buckinghamshire County Council's Internet web site: [www.bucksc.gov.uk/care\\_of\\_children/referral.htm](http://www.bucksc.gov.uk/care_of_children/referral.htm)**

What is advocacy?

Advocacy helps explain

to people what you

think, feel, need and

want so they understand.

Here is a list of organisations

who provide independent advocacy

**Age Concern**  
145 Meadowcroft  
Aylesbury  
HP19 3HH  
Tel: 01296 431911

**People's Voices**  
1 King George V Road  
Amersham  
HP6 5TT  
Tel: 01494 793143

**Aylesbury Vale Advocates**  
7 Temple Street  
Aylesbury  
HP20 2RN  
Tel: 01296 432313

**Talkback**  
Amersham  
Community Centre  
Chiltern Avenue  
Amersham  
HP6 5AH  
Tel: 01494 434448

For further copies of this leaflet Tel: 01296 382935

This leaflet can be made available

on tape

in large print

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مہیا کی جا سکتی ہے

આ લીફ્લેટ ગુજરાતી

Advocacy services in Buckinghamshire





### Who needs advocacy?

Anybody who needs support to:

- ▲ Make changes and take control of their own life
- ▲ be listened to and understood
- ▲ be valued and included in their own community.



### Who can have advocacy support?

Advocacy support is for anyone whether they are

- ▲ very old
  - ▲ very young
- whatever their:
- ▲ disability
  - ▲ religion
  - ▲ culture
  - ▲ gender.



### What is advocacy support?

Advocacy support can be:

- ▲ Talking things over to get more understanding: For example about what has been said by the housing officer or the consultant in the hospital.
- ▲ Finding things out together
- ▲ Speaking together at meetings: For example at an assessment meeting or a case conference
- ▲ Helping and informing people so that they can access their rights and entitlements.



### Who are advocates?

Advocates have to be

- ▲ Independent
- ▲ Trusted.
- ▲ In a position to represent the interests of the person and no one else's interests. For example, it is difficult for staff members to speak up for someone when they may have a divided loyalty with their job.

Advocates can be:

- ▲ volunteer or paid advocates
  - ▲ people with specialist knowledge like doctors, lawyers or solicitors
- a group of people with the same needs.