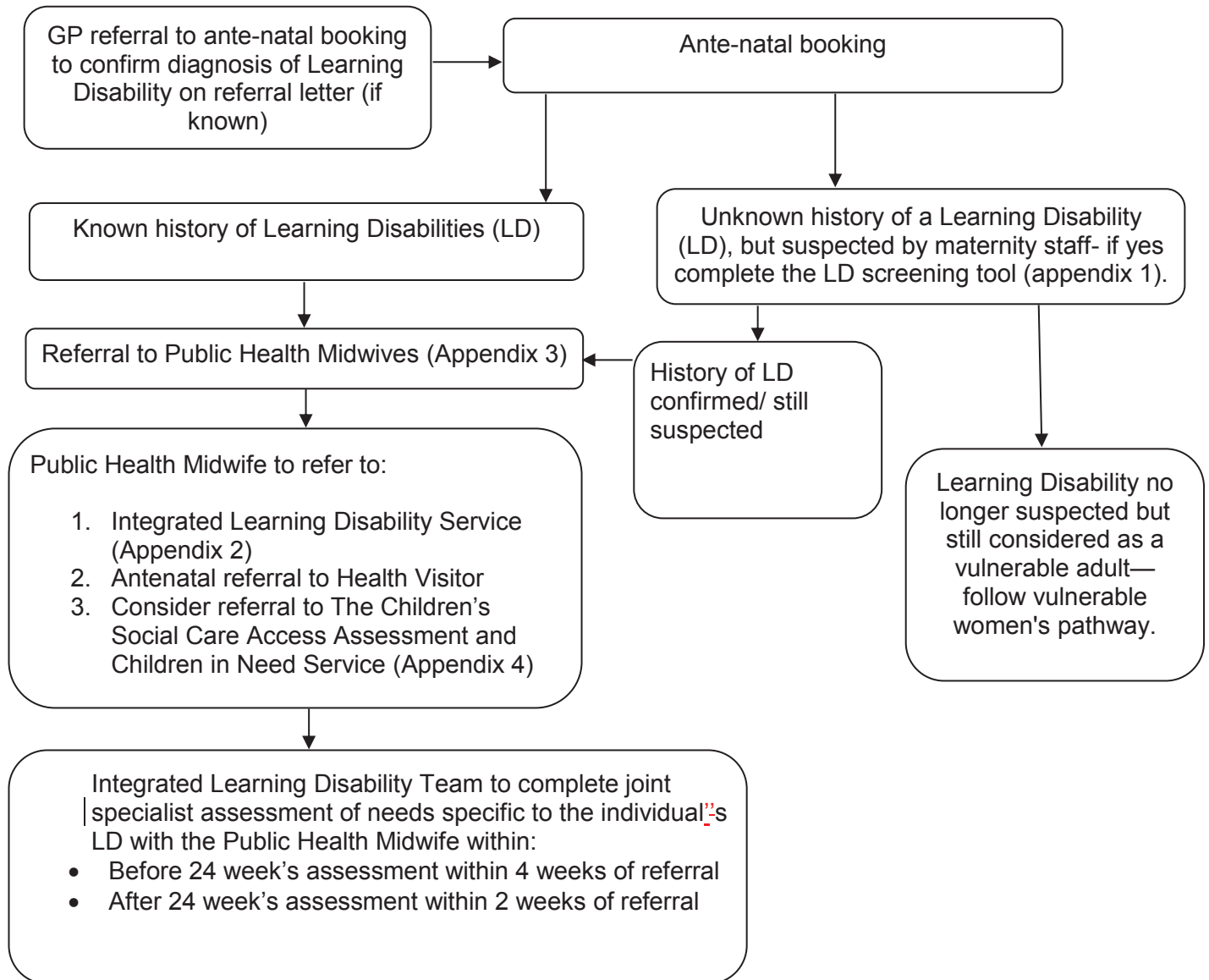


Learning Disabilities Maternity and Early Years Practice Guideline

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Learning Disability Maternity & Early Years Care Pathway



CARE PLAN DURING PREGNANCY

- Case Midwife to plan appropriate individual maternity care with advice and support from the Integrated Learning Disability Team.
- If Social Services are involved; Social Work lead to undertake pre-birth assessment to inform Child Protection status for unborn
- Joint visit by Health Visitor and case Midwife (supported by Integrated Learning Disability Team if required) to complete parenting capacity assessment and ensure smooth transition from maternity to health visiting services.
- Birth plan documents to be completed by 36th week
- If concerns around mental capacity to consent to medical treatment these are to be addressed by Obstetrician and case Midwife with support from the Integrated Learning Disability Team.
- Consider if discharge planning meeting post birth is required.

1. Introduction

Homerton University Hospital NHS Foundation Trust (HUHFT) recognises and accepts it's responsibility for ensuring a personalised and appropriate response to the needs of parents with a

learning disability ensuring effective plans are in place at an early stage. HUHFT is aware of the importance of early intervention in improving outcomes for both children and parents. This guidance should facilitate a more positive experience of integrated services for parents and their children during pregnancy and the early years following birth.

The aim of this guidance is to offer practitioners within maternity and early years services good practice reference points to consider when working with people with a learning disability who are to become parents.

1.2. Definition of a learning disability

The Department of Health (2001: Valuing People) suggests that learning disabilities are one of the most common forms of disability; affecting up to 1.5 million people in England alone. It is suggested that the following are critical to understanding these individuals that they have:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence);
- a reduced ability to cope independently (impaired social functioning)
- the onset of disability is considered to have started before adulthood, with a lasting effect on development

1.3. The Government's view on learning disabilities and other expectations

Early preventative support clearly is essential to this statutory principle and to the principles set out in, for example, Children's Act 2004, Think Family 2009, The National Service Framework 2004,

Recent legislation and guidance indicates that parents with a learning disability have a right to support that enables them to have a normal family life with person-centred support (Human Rights Act 1998, Equality Act 2010, Valuing People Now 2009, Health and Social Care Act 2008 and 2014). The foreword to the Good Practice Guidance on Working with Parents with a Learning Disability (DH 2007) states in England that:

'People with learning disabilities have the right to be supported in their parenting role, just as their children have the right to live to live in a safe and supportive environment.'

The guidance recognises that parents with learning disabilities can be good parents if provided with positive support.

The five key features of good practice in working with parents with learning disabilities are:

1. Accessible information and communication
2. Clear and co-ordinated referral and assessment procedures and processes, eligibility criteria and care pathways
3. Support designed to meet the needs of parents and children based on assessments of their needs and strengths
4. Long-term support where necessary
5. Access to independent advocacy.

The Good Practice Guidance says that it is essential to have:

'Collective ownership (across adults and children's services and across health, social care, housing and non-statutory sector) of the need to provide early support (page 45).

2. Scope

This guidance applies to all staff working within the Homerton University Hospital NHS Foundation Trust primarily those who work in Maternity and Early Years Services.

3. Roles and Responsibilities

All staff will be responsible for ensuring that they are knowledgeable in the expected care and management of women with a learning disability throughout their pregnancy and during their transition to parenthood

4. Guidance

4.1. Accessible information and communication

As maternity/early year's services are not always informed of a woman's learning disabilities, communication and support needs should be identified through the maternal history taking process or the first contact with the woman.

Easy read resources and other accessible sources of information along with face-to-face information sharing, should be used routinely to support communication with women with learning disabilities.

4.2. Clear and Co-ordinated referral and assessment procedures and processes, eligibility criteria and care pathways

Any health or social care professional who is already engaged in supporting a woman with learning disabilities should inform maternity/early services of their client's particular needs if she becomes pregnant.

Midwives or Early Years staff should be alert to behaviours that might indicate that a woman has learning disabilities. This should prompt the use of simplified language and further screening. A screening tool should be used to aid identification of women with learning disabilities (Appendix 1).

Adult and children's service practitioners who are involved in supporting the family must work closely together to ensure the needs of the whole family are considered and assessed.

4.3. Support designed to meet the needs of parents and children based on assessments of their needs and strengths

Women must be fully engaged and consulted about the way in which services will be provided throughout their pregnancy, labour and following birth. These discussions should be documented within her maternity notes and the completion of an antenatal plan should be included where additional support from other agencies is identified during pregnancy.

A full assessment of the needs and the support required for the parents to undertake parental responsibilities must be carried out, together with considering the needs of their children, born and unborn. Maternity services should undertake risk and needs assessment in relation to learning disabilities throughout the pregnancy pathway, taking into account that needs may change over time.

Women should have issues such as domestic abuse, substance misuse and mental health discussed with them as with any other pregnant woman.

Services should make 'reasonable adjustments' to ensure they are accessible for people with learning disabilities including times and settings for appointments e.g. longer appointment, first or last appointment, establish a routine.

Opportunities for parents-to-be around skills training, help in the home, finance, budgeting or benefits may be offered through the Integrated Learning Disability Service. Any assessments must include details of the woman's understanding of her health and social care needs in relation to her pregnancy, screening and surveillance tests, keeping herself healthy including diet

and exercise, substance misuse, baby care and potential parenting issues. Discussions should also include sexual health and future pregnancy planning.

4.4. Long-term support where necessary

Where a need for long-term support with parenting tasks is identified, it should form part of the community care and/or child in need plan.

Early identification of support needs will help prevent unnecessary difficulties arising but it should be recognised that some support needs may be on-going and this should be reflected in care planning.

4.5. Access to independent advocacy

Advocacy and self-advocacy services should be offered to help parents access and engage with services.

Independent advocacy should always be provided where children are the subject of a child protection plan and/ or care proceedings are instituted. This should be offered at an early stage.

4.6. Hospital-based care

Maternity services should plan the hospital stay in advance as much as is possible, including early sharing of information regarding the woman's support needs and visits to the ward.

Staff caring for the woman in labour should refer to and implement her birth plan ensuring that communication support needs are met and that continuity of carer is provided. Support agencies should be informed of the birth.

Staff caring for the woman after the birth should refer to and implement her care plan and co-ordinate parenting support to meet her needs. A longer hospital stay should be considered to facilitate learning and to ensure home support arrangements are in place prior to discharge.

Staff should engage with and observe mother and baby interactions to identify any support needs. Where current or anticipated needs are identified, these should be documented and social services informed.

4.7. Antenatal care

Any health or social care professional who is already engaged in supporting a woman with learning disabilities should inform maternity services of her client's particular needs if she becomes pregnant.

Easy read resources and other accessible sources of information e.g. CD/DVD/ Websites, along with face-to-face information sharing, should be used routinely to support communication with women with learning disabilities.

As maternity services are not always informed of a woman's learning disabilities, communication and support needs should be identified through the maternal history taking process.

Midwives should be alert to behaviours that might indicate that a parent has learning disabilities. This should prompt the use of simplified language and further screening. The screening tool should be used to aid identification of learning disabilities (Appendix 1).

A multidisciplinary approach should be applied; partners, keyworkers, advocates, social worker, family members and friends. Adult learning disabilities services should be contacted to provide advice and support, and to undertake further assessment where appropriate, a referral should be made within the early stages of pregnancy (Appendix 2).

Where the parents have learning disabilities a staged booking process should be considered to allow information to be provided in manageable amounts and understanding to be reinforced. Extra time and support for appointments, the opportunity to have the information repeated, information presented in a form that the woman can understand, and involvement of family carers should be considered for these appointments.

The designated midwife should inform the woman's health visitor of the pregnancy.

Care should be tailored to the needs of the woman and include more frequent appointments, longer appointment times, home visits and orientation visits to the maternity unit. The woman's birth plan should be referred to and discussed further, during an orientation visit to the labour ward.

Continuity of care/carers should be ensured as far as possible.

4.8. Postnatal care in the community

The frequency and length of postnatal visits by community midwives and health visitors should be tailored to the woman's needs. Visits should include the ongoing assessment of the woman's understanding and competence in relation to parenting skills and infant care. Any support needs or concerns should be documented and the multi-disciplinary team informed.

Liaison with the health visitor or where appropriate other support agencies e.g. the adult learning disabilities team, must be undertaken prior to handover of care.

5. Promoting the children's best interest

Children have the right to be protected from harm and for their interests to be paramount (Children Act 1989 and 2004). They also have the right to receive the necessary support in order that, wherever possible, they remain living with their parents.

Where there are concerns that the unborn child of parents with learning disabilities are at risk of significant harm, good practice will be promoted by:

- clarity about rights, roles and responsibilities, including legislative basis for action and the entitlement of parents to support under both children's and community care legislation.
- in depth assessments, including appropriate specialist input from both children's and adult services.
- information sharing between relevant agencies and professionals.
- involvement of parents, and the provision of independent advocacy.
- ensuring relevant liaison between midwives, health visitors and the named midwife and named nurse for safeguarding children.

6. Training and awareness

6.1. All staff working within the Homerton University Hospital NHS Foundation Trust who provide maternity care and early years services including the Integrated Learning Disability Service should be made aware of this guidance.

6.2. Staff working within maternity care and early years services will receive learning disability awareness training pack with a specific focus on good practice for parents with a learning disability

6.3. The guideline will be audited to monitor compliance.

7. Review

This guideline will be reviewed in 3 years' time. Earlier review may be required in response to exceptional circumstances, organisational change or relevant changes in legislation or guidance.

8. Monitoring/Audit – Mandatory: detail arrangements for the implementation and application of the guideline. This must include details on how compliance could be audited; how it will be monitored, who by and how frequently

Measurable Guideline Objective	Type of Monitoring/Audit	Frequency of monitoring	Responsibility for performing the monitoring	Monitoring reported to which groups/committees, inc responsibility for reviewing action plans
Implementation of guidelines	Review of incidents, safeguarding alerts and breaches of guidance	Every 6 months		Joint Children's and Adults Safeguarding Board

9. Sources of Evidence; References / Bibliography

Cleaver, H., Unell, I., Aldgate, J. (2011) *Children's Needs – Parenting Capacity. Child abuse: Parental mental illness, learning disability, substance misuse, and domestic violence. 2nd Edition.* Norwich: TSO

Department of Health (2004) *Core document: The National Service Framework for children, young people and maternity services.* London: DH

Department of Health (2009) *Valuing People Now: a new three-year strategy for people with learning disabilities.* London: DH

Department of Health and Department for Education and Skills (2007) *Good practice guidance on working with parents with a learning disability.*

Mencap (2007) *Inclusive support for parents with a learning disability.* London: Mencap

Parliament (2005) *Mental Capacity Act.* London: HMSO

Parliament (2004) *The Children's Act.* London HMSO

Parliament (2010) *The Equalities Act.* London HMSO

Parliament (2004). *The Health and Social Care Act.* London HMSO

Parliament (2014) *The Health and Socials Care Act.* London HMSO

Appendices – these must be numbered/identified and referred to as appropriate throughout the document

Appendix 1 – Screening Tool

Appendix 2 – Integrated Learning Disability Service Referral Form

Appendix 3 – Referral to Public Health Midwives

Appendix 4 - Referral to Access Assessment and Children in Need Service

Resources

1. The Parents Booklet

Written for, and by, parents who have learning disabilities, this booklet tells you what happens if Children's Services feel your child is at risk of harm.

The booklet explains in easy to understand words and pictures:

- Who normally makes decisions about child protection
- What happens when Children's Services get involved
- The Child Protection Process
- What happens at different meetings
- Emergency Protection Orders
- What happens in court
- Different legal orders
- Adoption and Fostering processes

<http://www.voiceability.org/images/uploads/Parents%20brochure%202011.pdf>

2. Working Together with Parents Network

Support provided to professionals working with parents with learning difficulties and learning disabilities, and their children:

- Resources available
- Information for parents and professionals

<http://www.bristol.ac.uk/sps/wtpn/>

Appendix 1.

This tool can support it identifying whether a person may have learning disability, it is not a diagnostic tool. It is recommended that this is completed with the person involving others, with consent from the person when necessary e.g. family, carers, and professionals.

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

1. HISTORY

Is there historical information documenting learning disabilities? Find out about their educational history

- a) Ask the person if they went to a special school, or had extra support within mainstream school? Did they have a statement of special educational needs?
- b) Ask the family information about special education, developmental delay, needing additional help etc.
- c) Information from other agencies that suggests developmental delay e.g. GP or Hackney Learning Disability Service.

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. It is appropriate to contact CLDS

You can also ask the following questions

2. TRAVEL

Does the person have difficulty travelling on their own?
Do they come 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. Coping with appointments and routines.

- a) Is the person overwhelmed by routine demands e.g. missing many appointments, erratic appointment keeping – late, early, wrong day etc.

- b) Inability to keep track of medical appointments and medication
- c) Difficulty sequencing tasks or prioritising demands and activities

5. GIVING INFORMATION

Does the person provide vague or over-simplified information about basic facts, e.g. unclear about health symptoms?

6. UNDERSTANDING COMMUNICATION

Does the person have difficulty understanding more complex or abstract communication? Do they use complex words themselves that they don't seem to understand?

7. MONEY SKILLS

Ask the person, carer or relative if they have difficulty with using money.

Do they run out of money soon after being paid/receiving benefits, poor budgeting skills, and difficulty estimating costs?

8. SELF CARE

Does the person have difficulty carrying out self care?

Do they have difficulty recognising the connection between taking care of their personal care needs and good health?

9. LEVEL OF SUPPORT

Is there a central role of another person providing help not normally expected for an adult, e.g. help with using transport, doing shopping, and 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



Learning Disability Service Referral Form

Thank you for referring to our service. The Learning Disabilities Service is available to adults who have a learning disability. We make diagnosis of a Learning disability based on an impaired intelligence (IQ below 70) and an impaired functional ability (Assessment of motor and process skills (AMPS)). There must be evidence that a person has significant impairment of intellectual and adaptive functioning to receive a service from this team.

As an integrated health and social care team, we provide treatment and care support to residents of Hackney and / or those service users who have a GP in Hackney. The health team also provide service to service users who have a GP or are resident in the city.

Please complete this form as fully as you can as if information is missing we may need to return the form to you. If you would like to discuss anything with us whilst considering this referral please call us on:
0208 356 7444

Details about the person being referred.

Title:	First Name:	Middle Name:	Surname:
Address:		Landline Number:	Mobile Number:
Postcode:		NHS Number (if known):	
Date of Birth:		Male <input type="checkbox"/>	Female <input type="checkbox"/>
First Language:	Other Languages	Are there risk factors to staff in relation to visiting this person? Please explain.	
Religion: (if known)	Ethnicity:	Nationality:	
	British Citizen Yes <input type="checkbox"/>	No <input type="checkbox"/>	
Special Educational Need: Yes <input type="checkbox"/> No <input type="checkbox"/>	Marital Status:		
	Name of school or College attended:		
Will an interpreter be required at any visit? Yes <input type="checkbox"/> No <input type="checkbox"/>			
Type of interpreter required (e.g. language):			
Has the person consented to this referral Yes <input type="checkbox"/> No <input type="checkbox"/>			

OR

Does the person lack capacity to consent and you are acting in their best interest?

Yes No

Please explain.

Reason for referral.

Please tell us the purpose of making this referral

Please tell us what your expected outcomes are which you would like to be achieved upon making this referral:

Why do you think this person has a learning disability?

Please attach any reports (e.g. psychology report; Statement of Educational Need) and evidence that the person has a significant impairment in his/her cognitive and adaptive functioning (which has not been caused by neurological illness or injury or mental health problems after the age of 12years old). This may help us understand the nature of the person's learning disability.

Have you attached previous neurology and/or psychiatry clinic letters/reports

Yes No

Have you attached an EMIS summary report Yes No

In your view, is this person vulnerable or at risk in any way?

For example, loss of accommodation, harm to self or others, domestic violence, exploitation.

Yes No

Please give details.

Does the person you are referring see him/herself as having a learning disability?

Yes No

What is the persons current medical history:

Is the person you are referring being investigated for any physical health problems at present?

Yes No

If yes, please describe:

Details of Main Carer

Name:	Address:
Date of birth:	
Telephone Number:	Postcode:
Relationship to client:	

Details of person's GP

Name:	Address:
Telephone Number:	Postcode:

Details of professionals / others currently involved

Please give details of anyone else who knows the person well or is involved in their care (e.g. family member, friend, day centre worker, and child development team)

Name	Contact/Address Details	Role

Your details

Name: (Please Print)	Address:
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Telephone Number:	Postcode:
Your Role:	
Best times to contact you (if needed):	
Your signature:	
Date of referral:	Date referral received (Internal only)

Please return to:

**Learning Disabilities Services
Maurice Bishop House
Hackney Service Centre
1 Hillman Street
London E8 1DY
Or
Send via fax: 0208 356 7200**

Appendix 3

Public Health Midwife Referral Form					Confidential	
Please Tick						
Area A	Area B	Area C	Area D	Area E	Area F	
Personal details <i>(please enter details legibly in block capitals)</i>						
First name:		Surname:				
NHS Number:		DOB:		Age		
Address:		Postcode:				
Telephone:		Mobile Telephone:				
Preferred language:		Interpreter required?	Yes		No	
Ethnicity:		Nationality:				
Religion:		Marital status:				
GP details <i>(please enter details legibly in block capitals)</i>						
Name:						
Address:						
Post code						
Telephone:			Fax:			
Referrer details <i>(IMPORTANT-please enter details legibly in block capitals)</i>						
Name:			Designation:			
Address:						
Post code						
Telephone:			Fax:			
Reason for referral <i>(brief summary of issues)</i>						
Is the patient aware of this referral? <i>(please tick)</i>		Yes		No		
Is this referral for a booking? <i>(please tick)</i>		Yes		No		
Obstetric history						
Obstetrician:		Midwifery Team:		Next appt:		
Date booked:		Named midwife:				
EDD:		Date of Delivery:		Gravida:		Parity:
Attitude to pregnancy/baby:						
Signature of referrer:			Date:			

DO NOT FAX THIS TO THE CHILDREN'S CENTRES. You may leave the completed form in the Public Health Midwives tray in Antenatal Clinic @ Homerton Hospital. You may also fax the form to the Referral Centre at Homerton Hospital-: 020 8510 5727. Please ensure you have stated clearly whether this is a booking request.

OA_PHMW-referralOct 2009

Agency referral to Hackney Children's Social Care

Referral form for use by all agencies.

PLEASE NOTE THAT A WRITTEN REFERRAL FORM IS REQUIRED IN ALL CASES. WHERE A TELEPHONE REFERRAL HAS BEEN MADE BECAUSE OF THE URGENCY OF A SITUATION THIS MUST BE FOLLOWED UP WITHIN 48 HOURS BY A COMPLETED REFERRAL FORM UNLESS AGREED OTHERWISE.

Name and contact details of person making the referral			
Name:			
Name of agency/organisation:			
Address:			
Telephone Number:		Fax Number:	
Email Address:			
Date written referral is being made:			
Date telephone referral made (if applicable) and to whom:			
Relationship of person making the referral to the child/family:			

NAME(S) and DATE(S) OF BIRTH of the child(ren) being referred (please list here all children in the family):	
<i>'For Homerton Staff, please include NHS Numbers for each child referred'</i>	
Child(ren)'s preferred language if not English speaking:	
Ethnic origin and Nationality if known:	
Details of wider social and professional network (e.g. significant family / friends, GP, health visitor, schools, professionals working with members of the household)	

Name	Role/ Relationship	Address	Telephone number	Email

Name of parent(s)/carer(s) with whom child(ren) live(s): Please include date of birth of parents if known

--

Parent(s)/Carer(s) preferred language if not English speaking:

Address:

--

Telephone number(s):

Any other relevant family details:

--

Why is a referral being made? What are the concerns? (Please be as specific as possible, giving dates, examples of incidents etc):

--

Is the referral for information only?

Is there evidence that any children in the family are being subject to significant harm?

If 'YES' please specify:
Actions taken by referring agency/involvement with the family:
Please outline your involvement with the child/family and any ongoing support that is being provided. Detail any past concerns or known involvement of statutory agencies. If a CAF or other assessment document has been completed please attach a copy to this referral.
What outcomes are anticipated by the referral?
Does the person with parental responsibility know that a referral to Children's Social Care has been made?
If 'No' please explain why:
If yes, does the person with parental responsibility consent for members of the family's network to be contacted to obtain further information?
Any other information that would be helpful in deciding the priority of the referral and/or understanding the actions Children's Social Care is being asked to take in respect of the child(ren) being referred?
<p>Please note: For Homerton University Hospital Staff when sending children social care referrals to Hackney First Response Service</p> <p>If you have a secure email address e.g. another@nhs.net please use your secure email address to email your referral to Hackney FRT/CSC secure email address csreferrals@hackney.gcsx.gov.uk</p> <p>If you do not have a secure email address please fax your referral to Hackney FRT fax no: 020 8356 5516.</p> <p>Should you need any assistance in completing this form or wish to follow up your referral please call the First Response Service on 020 8356 5500.</p> <p>If your referral has not been acknowledged by Children's Social Care within three working days please make contact to confirm it has been received.</p> <p>For Homerton University Hospital Staff, please email a copy of this referral to the Homerton Safeguarding Children Team huh-tr.Childprotection@nhs.net .</p> <p>Thank you.</p> <p>Pauline Grant and Irene Willie, Named Nurses for Safeguarding Children</p>