Best Practice Guidelines for Taking a Blood Sample from People with Learning Disabilities







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### **Acknowledgements**

This report was produced with the kind assistance of Tracy Reed (Primary Healthcare Facilitator), Glynis Rodgers (Community Learning disabilities Nurse) and Jayne Whalley (Community Learning Disabilities Nurse).

With input from Aileen Harrison (Community LD Nurse), Amy Donovan (Community LD Nurse), Jane Newport (Community LD Nurse), and Tracey Thompson (Community LD Nurse).

## Blood Pathway: Best Practice Guidelines and Outcomes for the use of a Care Pathway to support People with Learning Disabilities to have a Blood Sample Taken

Inequalities in health care for adults with learning disabilities is a recognised and well documented social issue, (Disability Rights Commission, 2004; NHS Scotland 2004; Valuing People 2001, 2007; Mencap 2007). Barriers to health care for the LD population have been identified when attempting to access mainstream services, with communication issues lack of primary care staff training and challenging behaviours preventing people with learning disabilities receiving the health care they are entitled to (Howells 1996; Lennox, Diggens & Ugoni 1997; Mencap 1998; Bollard 1999; Melville, Finlayson, Cooper, Allan, Robinson, Burns Martin & Morrison 2005).

Specialised learning disability (LD) nurses within Sefton PCT experienced these problems first hand when attempting to access primary care services for blood sample procedures for their clients. They identified issues such as historical factors; traditionally the LD nurse had taken responsibility for the taking of bloods. Lack of primary care staff training; phlebotomists and practice nurses were inexperienced in working with individuals with LD and were unequipped to communicate with them or understand their health needs. Challenging behaviour; due to services inability to offer appropriate care clients behaviour was perceived as unmanageable. Issues around consent were also reported as a barrier to accessing mainstream services.

The inability to access mainstream services resulted in people with learning disabilities served by Sefton PCT not receiving the blood tests they required for issues such as; a change in health status, annual checks, medication monitoring, genetic testing and blood group testing. The consequences of these inequalities led to the possibility of unidentified health needs, misdiagnosis, and at the organisational level government guidelines for people with learning disabilities not being followed.

Valuing People (2001); "Health policies such as improved access to services ... will be particularly important for narrowing the gap between learning disabled people and the population as a whole"

"... Evidence of avoidable illness and premature death amongst people with learning disabilities is a major cause for concern ..."

Our health, our care, our say (2006); "...we need to do more on tackling inequalities and improving access to community services..."

The necessity for a structured blood pathway for adults with learning disabilities offering clear clinical guidelines and continuity of care led to the development of an integrated care blood pathway.

This report describes the design and implementation of the blood pathway as a guidance tool for best practice. With clinical outcomes and future directions identified by the qualitative analysis of feedback data collected from health professionals.

### **Integrated Care Pathways**

An integrated care pathway (ICP) is a document which describes a process within health and social care.

It is intended to be used as a clinical tool, incorporating guidelines, protocols and locally agreed evidence based best practice with the focus on a person centred approach. The everyday use of an ICP embeds these concepts in individual client care.

An ICP also allows for the continual assessment and audit of variations from the planned care.

There are many government documents which mention ICP's and patient journeys.

- Putting patients first (1998)
- Quality care Clinical Excellence (1999)
- Improving Health in Wales: A Plan for the NHS and its Partners (2001)
- Wanless review of Health and Social Care in Wales (2004)
- Designed for Life: Creating World Class Health and Social Care for Wales in the 21<sup>st</sup> Century (2005)

### Taking a Blood Sample; A care Pathway Approach

The ICP blood pathway team was set up in 2004. It originally consisted of Tracy Reed (Primary Healthcare Facilitator), Glynis Rodgers (Community Learning Disability Nurse), Aileen Harrison (Community Learning Disability Nurse), Serena Jones (Senior Community Nurse) and Wendy Storey (Practice Nurse Facilitator). The current team also includes Jane Whalley (Community Learning Disabilities Nurse). The development process included input from primary care and specialised learning disability teams, ensuring a multidisciplinary approach to the project.

#### Why was a blood pathway needed?

Several areas were identified that were preventing people with learning disabilities from having blood samples taken, resulting in their health needs not being addressed due to discriminatory practices.

- GP's banning individuals from their practices
- Primary care workers lack of knowledge around people with a learning disability and their health care needs
- Confusion around issues of consent
- Mainstream services perceiving the LD nurse to be responsible for the taking of bloods
- Mainstream services not equipped to work with individuals displaying challenging behaviour
- Individuals with needle phobias
- Inflexible appointment times
- Individuals fear of hospitals and clinical environments

#### What was the evidence base?

- Pooled local knowledge and best practice from the experience of LD
- Implementation and improvements in practice in line with government guidelines set out in Once a Day (1999); Valuing People (2001); Our health our care our say (2006).

#### What was the next step?

- The blood pathway and accompanying care plan was developed, by the core team.
- The information was disseminated via GP's forums, practice managers meetings training sessions and an away day presentation in conjunction with The Cheshire and Wirral NHS Partnership, at which the project was officially rolled out.

The blood pathway and care plan can be seen as appendix 1 and 2.

Training sessions were presented to health professionals, with the intention of addressing the issues faced by a person with learning disabilities when they have been referred to have a blood sample taken. The training focused on;

- The definition of, and implications of having a learning disability
- The specialised needs of an individual with a learning disability when they are having a blood sample taken
- Embedding government policy and best practices (Valuing People 2001), into the Blood Pathway

Certificates of attendance were given.

Training session guidelines can be seen as appendix 3

The training was evaluated to allow the core team to continually improve the sessions.

Evaluation forms can be seen as appendix 4

As part of the training programme communication exercises were used. The exercises were intended to illustrate the communication difficulties faced by people with a learning disability, and highlight this area as one of major importance when ensuring a service is accessible to this client group.

The communication exercises can be seen as *appendix 5* 

### **Analysis of Data**

This report looks at the blood pathway some three years on, and attempts to identify the effects it has had on the lives of service users with a learning disability, and the health professionals they come into contact with.

Health care professionals, with experience of using the blood pathway took part in a focus group. They gave feed back on their experiences of working with people with a learning disability who needed to have a blood sample taken. The core team involved in the design and implementation of the pathway were also consulted and interviewed, both on a group and individual basis, in order to elicit their experience of the blood pathway.

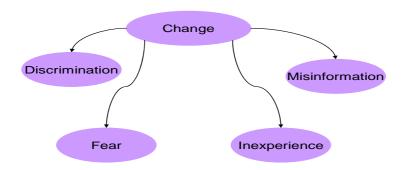
The main sub-themes to be drawn out of the data were as follows;

"The need for change", "Clinical judgement", "Consent", "Benefits", "Person centred", "Confidence", "Continual development"

The following section looks at each sub-theme individually. Each sub-theme is shown with key words and quotes from the health professionals who have been consulted. The collection of data is then drawn together and clinical outcomes are discussed.

#### The need for Change

Several areas were identified that highlighted the need for change in the existing system.



"GP's don't understand why people with LD can't consent"

"GP's don't understand LD"

"Problems with a GP meant that a service user didn't have their bloods for four years"

"District nurses need to know ... yes it will take longer"

"It was working ...there was new staff and the information was not passed on

... the support workers should have picked up on it ...needed to take ownership ... the bloods were three weeks late"

"GP needs pushing if you need bloods immediately ... it ended up he was with

H. Pylori ... that could have been what his behaviour was about"

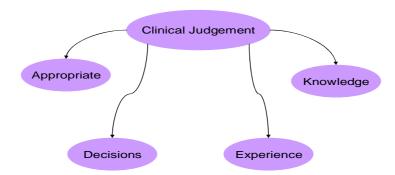
"They are afraid ... don't know what to expect (district nurse and phlebotomist)"

"People have been banned from the surgery ... scaring other patients ... because they can't sit and wait, they can't cope with that"

"...get banned from the GP surgery, be restrained, other patients would be complaining"

#### **Clinical judgement**

The nurses expressed that the pathway allowed them to continue to use their clinical judgement.



"Desensitization ... not all clients need it ... but I've been told to tick the boxes ... but I can record what I didn't do and why ... then I'm covered" "We know when a clinical setting isn't going to be appropriate"

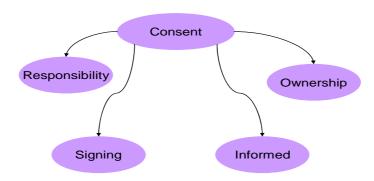
<sup>&</sup>quot;The nurses can make decisions"

<sup>&</sup>quot;The service user doesn't understand  $\dots$  family thought I was mad  $\dots$  had to tick box  $\dots$  but wrote down why  $\dots$ "

<sup>&</sup>quot;For a needle phobia it's different"

#### Consent

It was identified that there were still issues around consent, although it was felt that the pathway allowed these issues to be looked at and not ignored.



<sup>&</sup>quot;There are still lots of issues around consent"

<sup>&</sup>quot;No one actually wants to sign the form ... people don't want to take responsibility"

<sup>&</sup>quot;We need more consent issues cleared up"

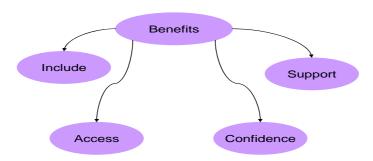
<sup>&</sup>quot;We have had MCA (Mental capacity Act) training but others haven't and don't understand issues of consent"

<sup>&</sup>quot;There are two forms now"

<sup>&</sup>quot;GP's don't understand why they (the service user) can't just be signed for"

#### **Benefits**

The nurses identified what they saw as positive outcomes of the introduction of the pathway.



"Needed to include other services, before there was just us"

"Mainstream services needed more confidence, they can meet people with LD now ... they get our support ... always make sure there are enough staff there"

"Large portion of service users who wouldn't have had bloods ... now get them taken"

"H. pylori identified"

"You can use meds that other wise you couldn't use"

"Fungal infection treatment"

"Before there was nothing ... they would just get banned from the GP surgery, be restrained, other patients would be complaining"

"Large number more blood tests being done now"

"Everyone thought there would be no chance with him ... but we did it dead quick ... no problem"

"some of the phlebotomists really good now ... find out something about them (the service user) before they go ....she knows that lady likes perfume so she takes a bottle and gives her a spray after she has done the blood test"

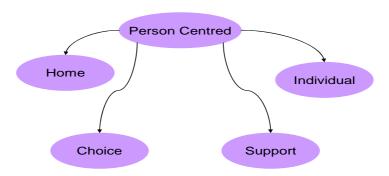
"Some of them will stay and have cup of tea ... its like desensitization as you go"

"She will not ware the uniform now ... and keep the blood bottles in her pocket"

"More people are accessing a service ... its more rare now that someone will call the team"

#### Person centred

A more person centred approach was identified on the part of main stream services. It was felt that the primary care staff were beginning to better understand the needs of people with learning disabilities.



<sup>&</sup>quot;Very rare restraint ... use distraction ... only takes a few seconds ... so it's better at home"

<sup>&</sup>quot;Good choice ... some family don't want it done at home ... its like associating home with something bad ...can use the day centre"

<sup>&</sup>quot;One phlebotomist will go out at night"

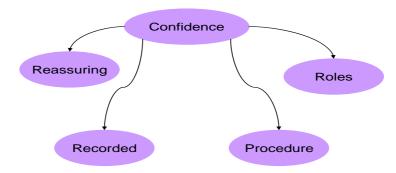
<sup>&</sup>quot;Go at a time that's good for him, when he's in bed he's more relaxed"

<sup>&</sup>quot;Go at specific good times... they are more relaxed....two o'clock after dinner"

<sup>&</sup>quot;Desensitization is too abstract sometimes"

#### Confidence

There was an increased level confidence expressed by the health professionals.



<sup>&</sup>quot;Service users family feels more confident ... they know what is going to happen"

<sup>&</sup>quot;More reassuring for family when they know what different roles are"

<sup>&</sup>quot;More confident asking for things ... we have got something wrote down to follow"

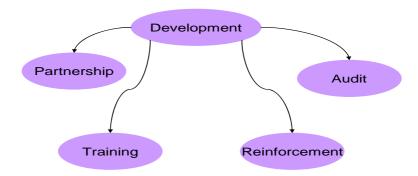
<sup>&</sup>quot;Easier for new staff"

<sup>&</sup>quot;Something to follow"

<sup>&</sup>quot;See where you are going next"

#### **Continual development**

The focus group and interviews also identified some areas in which the pathway could be improved / added to.



<sup>&</sup>quot;They will be able to use the pathway without the LD team "

<sup>&</sup>quot;Once something works they can re-use the care plan"

<sup>&</sup>quot;We need to join in partnership .... liaise with them (mainstream services) ... for training so they understand more what LD is ..."

<sup>&</sup>quot;Can't we have positive reinforcement wrote into the path ... if it's on paper then people will do it ..."

<sup>&</sup>quot;They will be able to use the pathway without the LD team"

<sup>&</sup>quot;Make audit sheet more blank...we can add what we need to"

<sup>&</sup>quot;So we know whose responsibility it is to take bloods"

<sup>&</sup>quot;Its difficult to know who should be doing it"

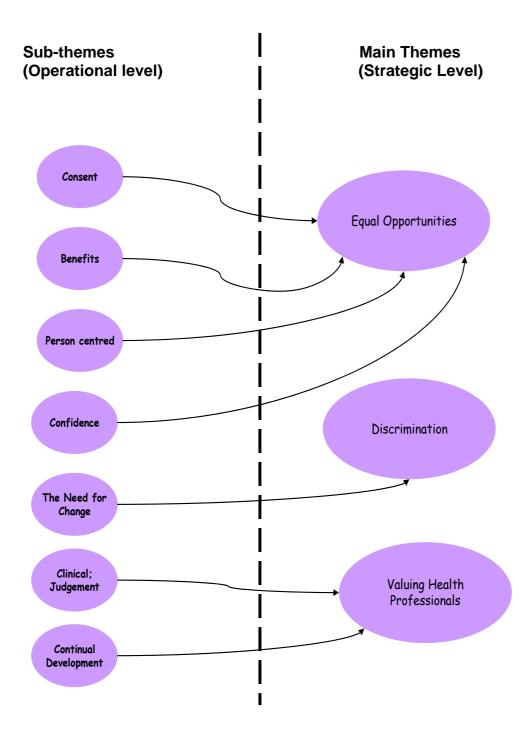
<sup>&</sup>quot;Need a central person,

<sup>&</sup>quot;Be easier if we had got a key person"

<sup>&</sup>quot;You call them and get told you can't talk to that person directly you have to go through someone else"

## **Clinical Outcomes**

From the sub-themes identified in the previous section three overall main themes can be established and employed to represent the clinical outcomes of the implementation of the blood pathway in Sefton. These main-themes are displayed below.



#### **Discrimination**

The main theme of discrimination is referring to the situation prior to the introduction of the blood pathway, showing support for the evidence base originally identified by the core team when they were developing the project.

This outcome suggests that prior to the introduction of the blood pathway there were discriminatory practices acting as a barrier to mainstream service for people with a learning disability. Key data here was the repeated reference to a lack of understanding from primary care staff, for example GP's not understanding why people with a learning disability would become anxious in waiting rooms.

# "Problems with a GP meant that a service user didn't have their bloods taken for four years"

The subsequent "challenging behaviour" would then be used as a reason to exclude individuals from services. It was also felt that primary care staff needed to accept that people with a learning disability have different health care needs and their appointments would need a different approach.

"District nurses need to know...yes it will take longer"

### **Equal opportunities**

The data clearly shows an improved system following the introduction of the blood pathway.

# "Large portion of service users who wouldn't have had their bloods taken...now have them taken"

The clear guidelines set out in the pathway ensure continuity of care and improved access to mainstream services for learning disabled service users. Importantly here a person centred approach is also clearly visible with primary care health workers beginning to individualise their services in order to accommodate the special needs of the learning disabled person.

"Go at a time that's good for him, when he's in bed he's more relaxed"

## **Valuing Health Professionals**

Criticisms of the Integrated Care Pathway system can focus on the notion that a clear pathway to follow dispenses with the benefits of experience and facilitates a lack of clinical judgement. It is promising therefore to see evidence of clinical judgement still playing a role in the pathway, with health professionals using their experience to adapt the pathway to individual clients, while recording variances to allow for future audit and development of the ICP.

"We know when a clinical setting isn't going to be appropriate"

"Desensitization ... not all clients need it... I can record what I didn't do and why"

#### **Conclusions**

Overall the data collected suggested that the Sefton ICP for taking a blood sample from service users with a learning disability has had a positive effect on the lives of individuals.

A more person centred approach has been adopted with the nature of the pathway system facilitating a continuity of care. The introduction of the ICP is beginning to ensure that mainstream services are encouraged to take positive action towards inclusion of their service users with learning disabilities.

The themes extracted from the data suggest that specialist learning disability staff have been given a clear pathway to follow in order to access main stream services. The pathway is based on knowledge and experience while drawing on government directives, and remains flexible and dynamic.

The core team are now in the process of addressing issues highlighted during this research in order to improve the existing pathway. Main areas to be addressed include the introduction of a more comprehensive auditing tool, the identification of key named primary care staff, addressing the remaining issues around consent and further partnership based training.

The Sefton Blood Pathway meets the Gold Standard for development of Integrated Care Pathways as agreed by the ICP network 2003 (National Leadership and Innovation Agency for Healthcare, 2005).

#### References

Bollard, M. (1999). Improving primary health care for people with learning disabilities. *British Journal of Nursing*. 18. 1216-1221.

DOH (1999) Once a Day. NHSE. London.

DOH (1998) Signposts for Success in the Commissioning and Providing of Health Services for People with Learning Disabilities. DOH. London

DOH (2001) Valuing People – A New Strategy for Learning Disability for the 21<sup>st</sup> Century. DOH. London.

DOH (2007) Valuing People Now – From Progress to transformation. DOH. London.

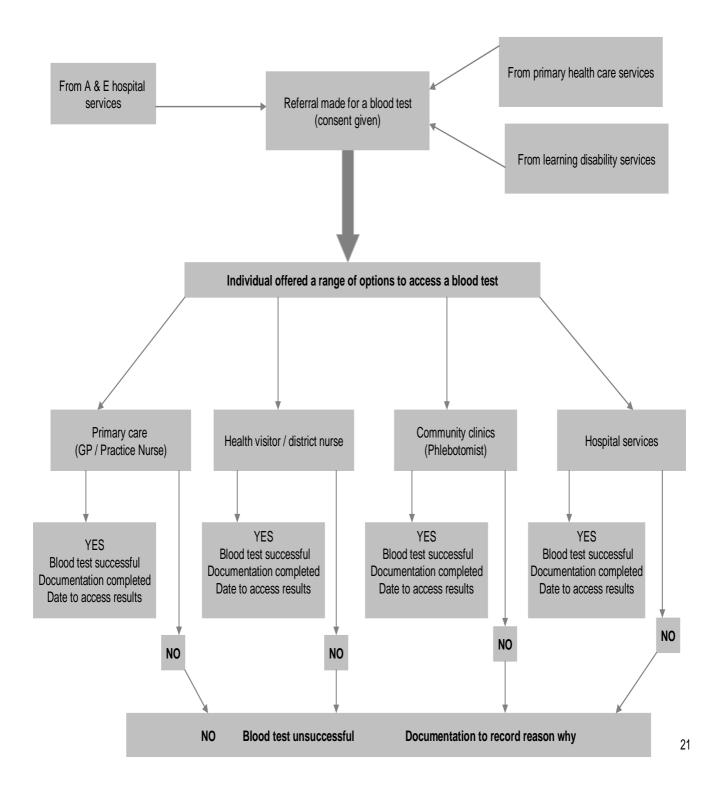
Howells, G. (1986) Are the medical needs of mentally handicapped adults being met? *Journal of the Royal College of Medical Practitioners*. 36. 466-453.

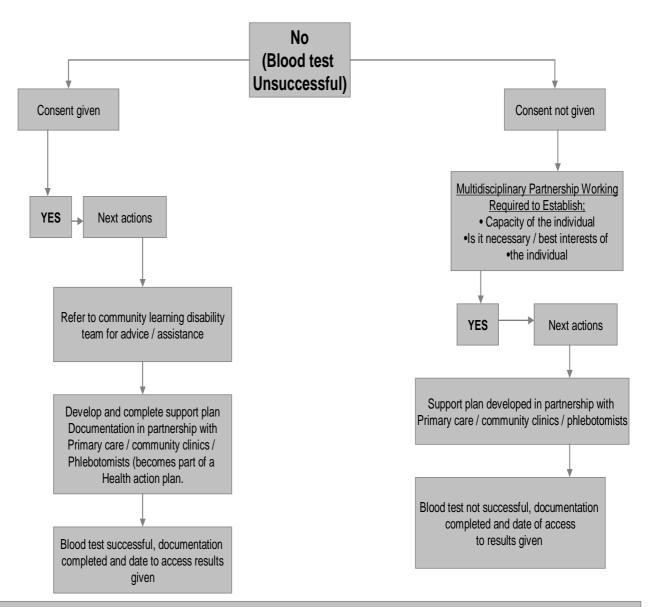
National Leadership and Innovation Agency for Healthcare. *Integrated care pathways A Guide to good practice*. (2005)

Lennox, N. G., Diggens, J. N. & Ugoni, A. M. (1997). The general practice care of people with intellectual disability: barriers and solutions. *Journal of Intellectual Disability Research*. 41. 380-390.

Mencap (1998) The NHS – Health for all? People with learning disabilities and Health Care. Mencap National Centre, London.

Melville, C. A., Finlayson, K., Cooper, S. A., Allan, L., Robinson, N., Burns, E., Martin, G. & Morrison, J. (2005). Enhancing primary care services for adults with intellectual disabilities. *Journal of Intellectual Disability Research*. 49 (3). 190-19





#### Reasons why a blood test might be unsuccessful

- 1. Consent not given 2. Environment / location and signage at venue 3. Phobias 4. Time of day for the blood test
- 5. Individual refuses to attend venue 6. Transportation difficulties 7. Gender issues 8. Use of sedation may be required
- 6. The individual may have multiple disabilities / sensory impairments or exhibiting behaviours that challenge services

## Community Learning Disability Team



Name of Individual:	Identified Lead Person	
People responsible for this Action Plan:	Date of Procedure(s):	

#### Ensure effective communication takes place with everybody involved throughout the process

While this suggested Support Plan covers many of the areas that you should consider when supporting a person with a learning disability through an invasive procedure, it should not be regarded as exhaustive. The needs of the individual throughout this process will obviously vary greatly. This document therefore, should be used flexibly and those of you who know the above named individual well should make additions and alterations to meet his unique needs.

Best practice guidelines for taking a blood sample for people with learning disabilities

## All possible blood tests that you can be referred for

Blood test	What is it	Why	Reason
T.F.T.s	Thyroid Function	Secretes hormone Thyroxine which is	Thyroid disorders are more
	Test	concerned in the regulating of the metabolic	common in people with
		rate	Downs Syndrome than the
			rest of the population
L.F.T.s	Liver Function	Prescribed Erythromycin for on going skin	Routine monitoring to be
	Test	problems	completed to ensure liver is
			working correctly
Renal	Kidney function	To determine the ability of the Kidney to	To ensure that the kidney is
		remove certain substances from the blood	working correctly
FBCs	Full Blood Count	To ensure that the number of blood cells in	To ensure that the range is
		the body is correct e.g. Red blood cells,	within normal limits.
		White blood cells and platelet count.	
Paracetomol			
Cholestrol/	Cholesterol is a	In a balanced state it serves as a useful	If excess cholesterol is
lipids	fatty natural	function	present it can put a strain on
	substance		the heart
	produced in the		

	body		
Fasting Lipids	As above but if your doctor has asked for a fasting lipids sample you should not eat or drink anything except water from midnight the night before attending for test		
Fasting Glucose	May be random or fasting. If fasting you should not have anything to ear or drink except water from midnight the night before attending for the test	To determine whether or not your blood glucose is within normal limits	To screen for, diagnose and monitor Diabetes

Lithium	Is a drug which may be prescribed by your doctor	Used for the prevention of manic depressive psychosis or to treat mania	Regular blood tests will be done to assess the level of lithium in the blood. This will ensure the dosage you are receiving is safe and effective. These tests may be weekly to start, then monthly
Phenytoin levels	Drug given on prescription by a doctor	May be used to control epilepsy	To check levels of phenytoin in order to assess adequate dosage.  N.B. Record time of last medication on form
Helicobactor pylori	Type of bacteria that may be responsible for the majority of peptic ulcers	One cause of peptic ulceration is bacteria infection with Helicobactor pylori	To detect if bacteria is present to allow treatment as necessary
Bone Denisty	?		

F.S.H.	Hormone that regulates the growth and development of eggs and sperm	Usually done more in women than men to check hormone levels in women who suspect/have symptoms of the menopause	To determine if menopause has begun or to diagnose menstrual and infertility disorders
Genetic Chromosomal			
ESR	Blood test to detect inflammation	Extra protein is released from the site of inflammation and circulates in the blood stream	To help diagnose diseases and monitor certain conditions
EDT			
B12	Vitamin involved in many body functions	Lack of this vitamin may cause anaemia as it affects the production of red blood cells	The test can detect if you have a lack of this vitamin or reduced amount. If so, you may receive vit B12 injections to replace
Folate	Folic acid vitamin	A lack of folic acid (folate) is one cause of anaemia	To detect levels to allow treatment if needed
Ferritin	Is a protein that stores iron in the body	If your doctor suspects you have too much or not enough iron in your system	To learn about the levels of iron stored in your body

G.F. Test	Glandular fever is a viral infection	Glandular fever is a common illness in adolescents and young adults	Blood test sometimes done to confirm the diagnosis
Rheumatoid factor	Is a test that measures the presence and level of rheumatoid factor in the blood	If you have symptoms that may be rheumatoid arthritis	To help diagnose rheumatoid arthritis
Warfarin	Belongs to a group of medicines known as anti-coagulants	Warfarin is used to prevent and treat the formation of harmful blood clots within the body	Regular blood tests are needed to ensure the dose of Warfarin is correct for you
CRP	c-Reactive protein	The level of CRP increases when you have certain conditions which may cause inflammation	To help diagnose diseases and monitor certain conditions

	<u> </u>	

## **Reasons for Blood Taking**

III health Annual Checks Medication Monitoring Genetic Testing Blood Group Testing	Please State:
Which Blood Test(s) have been requested by the GP	

## **Action Plan**

People involved with this Action Plan

Name	Relationship	Contact Number

N.B. For those individuals identified as having limited or no network of support **OR** 

Have additional associated difficulties in accessing primary health care service

Please make a referral to the Community Learning Disability Team for Assessment, Advice or Assistance

## **Checklist**

<u>Lead Person To:</u>	Yes	No
Discuss procedure with individual		
Reason for Blood test explained		
Process for blood taking explained		
Consent:		
Is Client is able to consent?		
Has consent been given by client?		
If unable to consent, has Form 4 been completed?  • Is the form attached		
Are there any concerns around consent issues?		

Do you need to refer to the Community Learning Disability Team	

Sedation:	Yes	No
Will sedation be required?		
Why? (Please state)		
Request sedation medication from the GP		
<u>Preparation</u>		
Will individual attend clinic/hospital? (Delete)		
Will familiarisation visits need to take place prior to procedure date?		
Will individual require a home visit?		
Why?		
<ul><li>Physical Disability</li><li>Sedation</li></ul>		
Phobic issues		
<ul> <li>Previous attempts failed</li> </ul>		
Other (specify)		

Preferred time of day for blood test? (Please state) Will individual want a local anaesthetic? (Emla cream) Has sedation medication been obtained? Please state (medication prescribed) Is the dosage clear? Are the instructions clear? Has local anaesthetic been obtained if required? If familiarisation was required: Has client been introduced to clinic/hospital staff? Has client been introduced to reception staff? Has client viewed clinic room?

Has client viewed equipment?

Has client been shown where the toilets are?

Has an appointment been booked?

#### N.B. Points to consider:

Time of day: (especially if sedation required/fasting bloods)

Waiting times.

Length of appointment: (double appointment)

Are familiar staff on duty?

## **Any special requirements?**

Removal of uniforms required?

Gender preferences?

Risk Issues?

Other requirements? Please state

# Care Plan Has care plan been written? Has care plan been agreed with client? Has care plan been agreed with support network? Action Plan circulated to relevant people (please list) Care Plan circulated to relevant people (please list) Copy of care plan attached? For completion by Phlebotamist or Practice Nurse on day of procedure only Is the Client consenting? If "no"...has Form 4 been completed?

Verified by blood taker?	
Was blood taking successful?	
If "yes" has aftercare sheet been provided?	
If "no" please state reasons why unsuccessful	
Action To Be Taken	
Inform requesting medical officer	
(Refer to Community Learning Disability Team) Inform Community Learning Disability Team	

Refer to G.P. for sedation/increased sedation	
Procedure to be attempted in clients own home	
Any Other, Please State	

SignatureDate		
Name in block capitals	Designation	

## Care Plan (example)

### Preparing the individual

Joe's understanding of the procedure and what it entails is very limited and this is the reason why Form 4 needs to be completed. From my understanding of Joe he does not like change and he finds it very difficult to cope with new situations. Preparing Joe for a sample of blood to be taken will involve Joe being in a familiar setting, surrounded by people and voices he is familiar with. Ensuring that he is safe and that his surrounding (home environment) is made secure around him. That the basic human requirements e.g. food and drinks are provided and he is given TLC. Joe will be given medication that will relax him and may make him feel sleepy. Dr Smith has suggested and Serena has agreed that Diazepam should be used as Joe has already experienced this medication. We know that Joe can tolerate this medication and he has not experienced any side effects or long-term problems from taking Diazepam previously. Dr Smith will prescribe a once only dose of this medication and this will be coordinated so that the medication will be given 30 minutes prior to the district nurse coming out to take the blood sample. It is important to inform

**Joe** that he may feel tired and sleepy and it is fine if he wants to go to bed to sleep. **Joe** needs to be monitored regularly after the Diazepam has been administered.

A symbols pack is available to inform patients of the blood taking procedure. However, the Speech and Language Therapist **Lesley White** has advised that **Joe** has been introduced to presentation of information in a visual format in the past and this has not been successful. He is therefore not used to receiving information visually and it would not be understood.

### The procedure

- 1. Diazepam will be administered at a set time by **Joe's** parents. Lead person will coordinate and inform his parents of the time.
- 2. **Joe** will have the support from his parents and **The Resource Centre** on the date of the procedure and this will provide him with security
- 3. Lead person/ Community Nurse will also be there if parents/careers would like this support.
- 4. The blood taker will come to the clients home and take a sample of blood from **Joe**.
- 5. The blood sample will be taken from **Joe's** arm and this depends which arm is best suitable for the procedure. The blood taker will make that decision on the day.
- 6. **Joe** may feel unsteady, tired, light-headed, and thirsty throughout the day and will require additional observation and support.

#### Care needs

**Joe's** care needs will be similar to how he is supported now. **Joe** may need additional support when walking around or using the toilets. This is to ensure his safety, as he may be unsteady on his feet while the effect of the medication is wearing of. **Joe's** safety is paramount. Remaining in the family home would benefit **Joe** as he is familiar with his surroundings, he has a bed there if he wants to go to sleep, he has his own stimulus or his lights in his bedroom which help him to feel relaxed and calm.

### After procedure

- 1. The blood taker will send the sample(s) to the Lab.
- 2. **Dr Smith** will receive the results within 10 working days
- 3. **Joe's** parents can phone up the doctor's surgery and receive the blood results or make an appointment to see **Dr Smith**.
- 4. **Dr Smith** will send Community Learning Disability Nurse a copy of the results to place in **Joe's** records
- 5. Lead person will discuss the procedure with **Joe's** parents and adapt the care plan if necessary.
- 6. This care plan can then be placed in all relevant files and can be used again when there is a need for a blood test. This may need to occur annually.

Discussion	
All parties agree to the above document and also the consent form 4 document.	
Mr Bloggs:	Date:
Father	
Mrs Bloggs:	Date:
Mother	

Serena Jones: Senior Community Learning Disability Nurse	_ Date:
<b>Dr Smith</b> :	Date:
Lesley White:Speech and Language Therapist	Date:
Jane Dodd:Key Worker	Date:





### Sefton Primary Care Trust Southport and Formby Primary Care Trust

## Agenda for

## **Training Session**

2 – 2.10pm	Lunch Introduction to Trainers Leaflets
2.10 – 2.20	What is a Learning Disability
2.20 - 2.30	Valuing People
2.30 - 2.45	Communication exercise 1 (ice breaker
2.45 –3.00	Consent and Form 4
3.00 – 3.35	Communication exercise 2 (Voices)
3.20 – 3.35	Pathway for having a blood test Checklist Support Plan Photo's
3.35 – 3.40	Issues to consider when taking blood
3.40 – 4.00	Scenario
4.00 – 4.10	Questions, Answers and Feedback
4.10 – 4.15	Evaluation form

## **Appendix 4: Evaluation Form**





## **Blood Taking Training Session**

## **Evaluation Form**

Name	e:	Date:
Profes	ession:	
	se provide comments on each of the topics co her positive /negative or changes you would li	
1.	. Introduction:	
2.	. (a) What is a Learning Disability:	_
3.	. (b) Valuing people:	

4.	Communication (exercise 1):
5.	Consent:
6.	Communication (exercise2):
7.	Areas to consider when taking blood:
8.	(a) Pathway:
	(b) Support Plan:
	(C) Photo's:

9.	Scenario's:
10.	Handouts:
11.	About the setting:
	(a) Venue/Environment:
	(b) Duration of session:
	<del></del>
12.	Further training needed: (Please specify):
13.	Would you feel confident in contacting the Learning Disability service for further help in the future:

-	edures that you consider People with Learning ance in accessing Primary Heath Care Services:
Thank you for your time	
Glynis, Tracy and Serena	



## Communication exercise 2

## **Group 1**

$$2 \times 1 = 2$$

$$2 \times 2 = 4$$

$$1 \times 3 = 6$$

$$2 \times 4 = 8$$

$$2 \times 5 = 10$$

$$2 \times 6 = 12$$

$$2 \times 7 = 14$$

$$2 \times 8 = 16$$

$$2 \times 9 = 18$$

$$2 \times 10 = 20$$

$$2 \times 11 = 22$$

$$2 \times 12 = 24$$

## Repeat until procedure is over



## **Group 2**

Hi my name is Mary.

I am going to take some blood from you today.

Your GP has asked for this blood test.

Have you got the form?

Have you had blood taken before?

Did you have any problems?

Can you sit on the chair and pull up you sleeve on your right hand

I have just bought a green car and it has a green flower in it

I have everything ready all I need to do is put this ligature on your right hand

Can you keep your hand straight for me please

You will feel a sharp scratch

That's it, I have finished and I will send your blood off today and you will get your results from your GP in 5 working days. You can phone up and get the results if you want.



## Group 3

I don't know what I am doing here
I don't know who this person is
I didn't hear what her name is
She wants my blood for what?
She is going to puncture my skin and leave a big hole in it
Will she sell my blood?
Is she a vampire?
Will she contaminate my blood?
I will be bad then
Nobody will want me and I will do bad things
Its that person's fault but I will get the blame



#### Communication exercise 1

Please can you translate the following instructions into simple jargon free language and identify the end product

- 1. Survey your intended area of use to ensure there is a suitable free space, suitable contours, underground services and possible hard spots.
- 2. Once the appropriate location is found erect the apparatus temporally in order to obtain the appropriate pitch and locations of support.
- 3. Mark each area that requires the support. Once done demount the apparatus and locate to a suitable location.
- 4. Excavate the marked areas to a depth of appox. 250mm. The diameter of the excavation to be 1.5 times the diameter of the apparatus. (If the support should be rectangular then the width should be 1.5 times the longest width)
- 5. Once the erection is complete (one per support) place a suitable base aggregate into the hole, to a depth of appox. 50mm
- 6. Erect the apparatus as required into the openings.

- 7. Ensure the apparatus is level. If not, remove further matter from the excavation as necessary until the apparatus is level. (Remember to ensure a 50mm depth of the base aggregate is maintained following the removal of the addition matter).
- 8. Pour and consolidate concrete with a mix of 2:7:1 into the remaining area of the excavation.
- 9. Once complete allow a period of 2 days to ensure the concrete cures.
- 10. After day 2 the apparatuses is ready to use!!!!!

## **Appendix 6: Training Programme**

What is a

**Learning Disability?** 

**Mersey Care** 



**Mersey Care** 



#### What is a Learning Disability?

- Term adopted by the Department of Health in 1992 to replace Mental Handicap
- · Labels It can be unhelpful and damaging to label people by what they cannot do
- · People first not the disability
- · Clinical definition :
  - an IO below 70
  - Onset before 18 years of age
  - Impaired social functioning
  - Impaired adaptive behaviours



**Mersey Care** 



#### Definition

Valuing People : A New Strategy for the 21st Century

- A significantly reduced ability to understand new or complex information, or to learn new skills (impaired intelligence)
- A reduced ability to cope independently (impaired social functioning) which started before adulthood with a lasting effect on development



**Mersey Care** 

## South Sefton NHS

#### Continuum of Ability/Disability

- As with the general population, people with learning disabilities are a very diverse group with varying degrees of abilities
- This is referred to as a continuum; at one end of the scale are people with extreme disabilities and at the other are those with extreme abilities. Around the middle of this scale are the majority of the population



The following terms are frequently used to describe the degree of a person's learning disability: MILD, MODERATE, SEVERE, PROFOUND



**Mersey Care** 



#### What This Means

- · People with severe learning disabilities are those that need significant help with
- People with mild/moderate learning disabilities will usually be able to live independently with some support
- · The things that a person with mild or moderate learning disabilities would need support with are likely to be :
  - Home making

  - Occupation and/or employment

    Dealing with interpersonal situation
  - Personal care/hygiene
- Communication of need
- A person with severe to profound learning disabilities, is likely to need higher levels of support with the above tasks/activities



**Mersey Care** 

South Sefton NHS

Areas to consider with regard to Blood Sample Taking (The impact of a person's learning disability)

- Additional and/or associated health problems and impairments, e.g. visual and hearing problems, communication and understanding of language, mental health issues, exhibiting behaviour which challenges services
- Phobias re: needles, injections, blood or uniforms of healthcare staff -
  - Maybe due to past experiences

  - Residential and institutional practices

    Lack of or no explanations on what is going to happen
  - Individuals being 'held down'
  - Medical model of care
  - Emphasis on the negative and not the positive



#### **Mersey Care**



#### Areas to consider with regard to Blood Sample Taking (The impact of a person's learning disability) cont

- Capacity and consent areas
- Language and communication issues
  - Address the individual and not the carer
  - Tone of voice Run through the procedure (individual, carer and staff)
  - Be prepared and know when to stop
  - Does the person know why they are here? What the blood test is for?

  - Will it hurt?
  - Results When?

  - How long will it take and what equipment will be used?

    After the blood test How will the person feel? sick/faint?
  - Aftercare What to do or what not to do



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#### Areas to consider with regard to Blood Sample Taking

- The environmental setting Important to plan
- Movement Consider an individual's ability
  Holding No! But why?
   i) against Consent Guidance iii
- - N.B. But need to determine what additional support will be required for the individual and to prevent stick injuries
- Planning and preparation Use of topical anaesthesia
- Use of sedation and aftercare
- Good Practice Multi-disciplinary working between Primary Care and Learning Disability
- Know who to seek advice and support from, i.e. Learning Disability Services



#### **Mersey Care**





#### Improving Health for People with Learning Disabilities

People with learning disabilities have greater health needs than the rest of the population. They are more likely to experience mental illness and are more prone to chronic health problems, epilepsy and physical and sensory disabilities.

The Government's Objective 5:

Good Health (Valuing People : A New Strategy for Learning Disability for the 21st Century)

states:

'To enable people with learning disabilities to access a health service designed around their individual needs, with fast and convenient care delivered to a consistently high standard, and with additional support where necessary.'



#### **Mersey Care**





#### Improving Health for People with Learning Disabilities

- That people with learning disabilities have the same right of access to mainstream health services as the rest of the population
- Health facilitators will be appointed from each local community learning disability team to support people with learning disabilities in getting the healthcare they need
- To ensure that all people with learning disabilities are registered with a GP and have their own Health Action Plan
- Action to reduce health inequalities
- Action to challenge discrimination against people with learning disabilities from minority



#### **Mersey Care**



#### Improving Health for People with Learning Disabilities

- NHS to ensure that all mainstream hospital services are accessible to people with learning
- Mental Health NSF will bring new benefits to people with learning disabilities
- New role for specialist learning disability services, making most effective use of their expertise
- National Service Framework (for coronary heart disease, older people, diabetes and longterm conditions), the National Cancer Plan and any other health initiatives, all apply equally to people with learning disabilities

