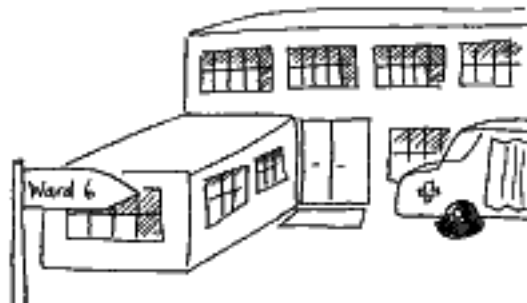


Looking at the support that social care staff give to people with learning disabilities when they go into hospital

2006-2007



Research report

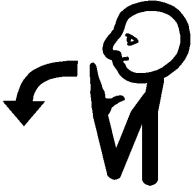
This is an easier to read version of our report called
"The nature of support provided by social care
organisations upon the admission of people with
learning disabilities to hospital"

By the Association for Real Change (ARC Cymru) for the
Welsh Assembly Government

What is in this report?

| | |
|---------|---|
| Page 4 | Thank you to people who have helped |
| Page 5 | What is this report about? |
| Page 6 | Understanding what we mean |
| Page 6 | Who did we talk to? |
| Page 7 | Policies, reports and plans |
| Page 8 | Plans in Wales |
| Page 11 | What Local Health boards, NHS Trusts and Local Authorities said |
| Page 11 | What did they say? |
| Page 12 | Plans |
| Page 12 | "No we do not have a plan" |
| Page 13 | "Yes we have a plan" |
| Page 14 | What should a plan do? |
| Page 14 | How can you make your plans better? |
| Page 15 | What did Learning Disability Teams say? |
| Page 15 | An example of a good plan |
| Page 17 | What social care service providers said |
| Page 17 | Who answered our questions? |
| Page 18 | How long did people stay in hospital? |
| Page 19 | How much help did support staff give people in hospital? |
| Page 20 | What help did support staff give in hospital? |

| | |
|---------|--|
| Page 22 | Who pays for the support staff? |
| Page 23 | Were support staff asked to give consent? |
| Page 25 | What happens when someone arrives at hospital? |
| Page 27 | What happened after someone left hospital? |
| Page 29 | How good was the care in hospital? |
| Page 29 | Very good care |
| Page 30 | Very bad care |
| Page 32 | What we found out |
| Page 34 | What we think should happen |
| Page 36 | Extra information |



We would like to thank these people for their help:

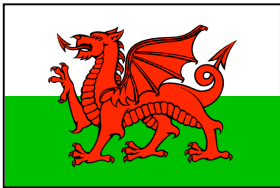
- All those who completed a questionnaire and/or answered telephone calls
- Those people and organisations who allowed the project to access their networks and members
- The learning disability contacts within the NHS Trusts
- Tony Shield and Tina Donovan (ARC Cymru Chair and Vice Chair)
- ARC Cymru national committee
- All Wales Community Living Network
- All Wales Forum for Parents and Carers
- Care Standards Inspectorate Wales (CSIW)
- Cartrefi Cymru
- Janet Cobb and the members of her email forum the Learning Disability Health Network
- Jill Lewis - Learning Disability Lead, Social Services Inspectorate Wales (SSIW)
- John Carter - Older People and Long Term Care Policy Directorate, Welsh Assembly Government
- Learning Disability Wales
- Mencap Cymru
- Rick Robson - Chair UK Access to Acute Network
- CHANGE picture bank
- Somerset Communication Symbols

What is this report about?



ARC gives help and advice to organisations that support people with learning disabilities.

Our members told us about problems that happened when they went to hospital with people with learning disabilities. You can read what they said at the back of this report. We told the Welsh Assembly Government what they said.



The Welsh Assembly Government asked us to find out:



- how many support staff helped people with a learning disability in hospital in one year
- what help support staff give in the hospitals
- how long they spent in the hospitals every day
- who paid them to be in the hospitals

They also wanted to know:



- if hospitals had any plans about what to do when someone with a learning disability goes to their hospital
- if the plans were working
- if there are people who work in hospital whose job it is to make going into hospital easier for people with learning disabilities

This report tells you what we found out.

Understanding what we mean

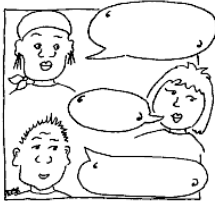


- When we talk about **healthcare staff**, we mean doctors, nurses and other health workers in hospital.



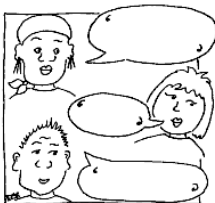
- When we talk about **support staff**, we mean social care staff who give people support to be independent at home.

Who did we talk to?



We talked to people who run care homes and supported housing, and adult placement schemes.

We only wanted to know about what happened when people had an appointment to go to hospital. We did not want to know about times when people had an accident unless they stayed in hospital afterwards.



We talked to the people who run health services. We also talked to Social Services.

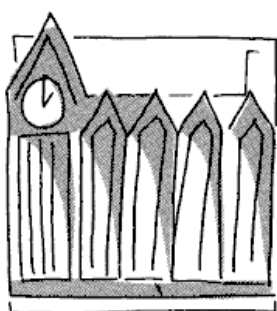
We asked them all if they had a plan about what to do when someone with a learning disability goes into hospital.

We sent them questions by post and email, or we talked to them on the phone.



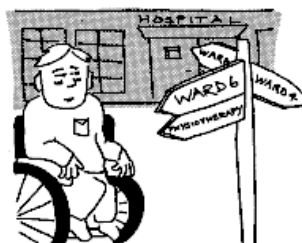
Even though we needed to talk mainly to people who run services, some parents wanted to talk to us and so did some people with learning disabilities. They were not happy about what can happen to people with learning disabilities in hospital.

Policies, reports and plans



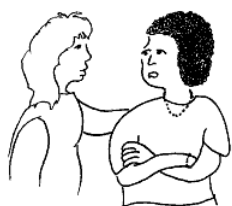
Many people are worried about what can happen when someone with a learning disability goes into hospital.

The government in England said that people with learning disabilities must get good treatment when they are ill.



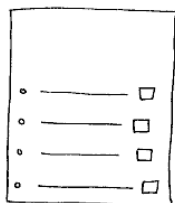
The National Patient Safety Agency said that people with learning disabilities are more likely have to go into hospital. They said health staff need more training to give people with learning disabilities more help.

The Access to Acute Network was set up to help people with learning disabilities and their carers. It has a lot of information about what should happen when people with learning disabilities go into hospital.



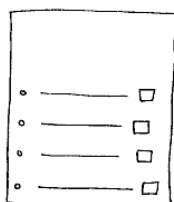
When a person with a learning disability goes into hospital, they may need to have support staff with them. Or they may need special help when they are in hospital like help with communication.

There is a lot of information about what must be done to make things better for people with learning disabilities when they get ill.



There have been reports from people like MENCAP and the Disability Rights Commission. These reports say that there have been big problems for some people with a learning disability when they have gone into hospital.

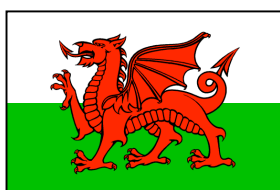
Plans in Wales



Fulfilling the Promises said a lot of things about health. It said hospitals should have a plan to tell health staff what they should do when someone with a learning disability goes into hospital.



Fulfilling the Promises also said that health staff should get training about people with learning disabilities and what special help they might need.



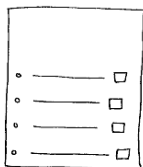
The Welsh Assembly Government has said that things must get better for people with learning disabilities when they get ill. It has said that Health Services and Social Services must change how they work:



The **Unified Assessment Process** will help Health Services and Social Services work together better. Health Services and Social Services will get better at sharing information about you. This means they will be able to make better plans about the health and social care services you need.



Designed for Life is a plan about how health services can work better in Wales. The Welsh Assembly Government wants everyone to get good treatment when they are ill.



Fulfilled Lives, Supportive Communities is a plan that fits in with Designed for Life. It is a plan to make Social Services work better.



The Annual Health Check is for everyone on the learning disability register. You can go to your doctor for a health check every year. If you are having any problems, your doctor can spot them earlier.



The Statement on Policy and Practice for Adults with a Learning Disability is a new policy for Wales. It has particular things to say about health.

It says:



- people with learning disabilities get ill more often so they need more help



- people with learning disabilities should be able to get the same good treatment for health problems as anybody else



- health staff should give even more help to people with learning disabilities to make sure they get the right treatment



- Social Services, Health Services and other service providers should have information that people with learning disabilities and their carers can understand



The **Disability Discrimination Act** is a law that says statutory services like health must treat people the same.

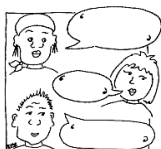
It says that if people who have disabilities need more help, they should get it.



The Disability Equality Duty is part of this law. It says that Health Services like Local Health Boards and hospitals must make a plan to show how they are helping people with disabilities.



If Health Services are going to get better for people with learning disabilities, we think they must start asking people with learning disabilities how they can make them better. And keep on asking them!



What Local Health Boards, NHS Trusts and Local Authorities said:

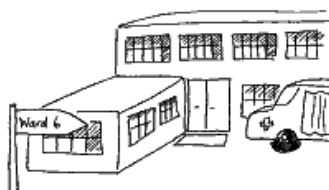
The NHS ('National Health Service') in Wales is run by Local Health Boards.



There are 22 Local Health Boards in Wales.

Local Health Boards run everyday healthcare like doctors' surgeries, community nurses and dentists.

There are 14 NHS Trusts in Wales.



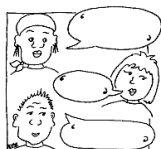
The NHS Trusts run the hospitals, ambulances and special health services for the Local Health Boards.

NHS Trusts are in charge of 135 hospitals in Wales.



There are also 22 Local Authorities who run Social Services.

The Local Health Boards and Social Services work together to plan services for people who need help.

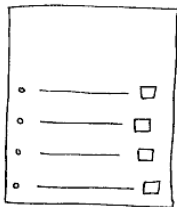


What did they say?

The Local Health Boards did not think that it was up to them to make plans about what to do when people with learning disabilities go into hospital.

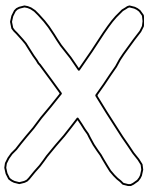


It was very hard to find the right person to talk to about plans for people with a learning disability in hospital. There is a list of names of the hospital staff who knew about plans at the end of this report.

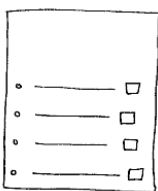


Plans

19 NHS Trusts and Local Authorities answered our questions.



"No, we do not have a plan"



- 13 said that they did not have a plan for people with a learning disability who went into hospital.
- 12 of the 13 thought that it would be a good idea to have a plan for people with a learning disability.
- 3 of the 13 are talking about making a plan for people with a learning disability.
- 2 of the 13 said they had general plans about what should happen when anybody goes into hospital. They use them for people with a learning disability too.
- Some did not want to make plans for people with a learning disability. They said that they already have enough plans. They said they did not want to make special plans for one group of people.



"Yes, we have a plan"



- Some NHS Trusts and Local Authorities share a plan.
- 2 NHS Trusts share a plan with each other.
- Some people sent us copies of their plans. This was very useful.
- The people who have plans say that everyone who works there is told about them.
- The people who have plans say that the Local Authority Learning Disability Teams can see them too.
- 2 of the plans can be seen by people with a learning disability or their carers. None of them are made easy to read for people with a learning disability.
- 5 people said that their plans were useful.
- 2 people said their plans worked well.
- 1 person said their plan did not work well.
- Some people did not know how well their plans were working.
- 1 person wrote a report about their plan in 2005. They found that



- Hospital staff were not keeping to the plan
- People with a learning disability were not treated well in the hospital
- Some hospital staff did not understand about people with a learning disability

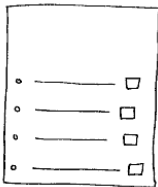
- Some hospital staff did not work well with support staff.

What should a plan do?

People who did not have plans said that a plan should:



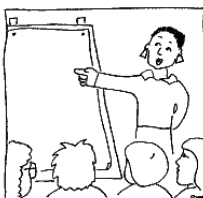
- Tell everyone what they are supposed to do when someone with a learning disability goes into hospital
- Give good advice.
- Help people get better treatment.
- Make it easy when people leave hospital
- Help hospital staff understand how to support people with a learning disability better.



How can you make your plans better?

We asked people who had plans what would help to make their plans better.

They said:



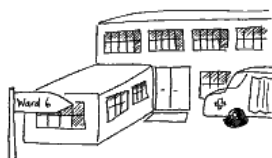
- We need the top managers and learning disability specialists in a Trust to work together.
- We need more training.



- We need a special worker who knows about learning disabilities to help us sort out problems
- We need all the top managers in Wales to work together to make it work.

What did Learning Disability Teams say?

Learning Disability teams said:



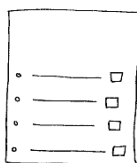
- Often nobody tells us that a person with a learning disability has gone into hospital.
- Sometimes people with a learning disability are sent home from hospital too soon.
- Sometimes hospital staff think that care homes and supported housing are the same as nursing homes, and that support staff are the same as nurses.



An example of a good plan

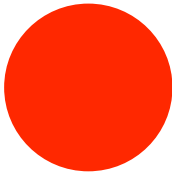


Christopher Griffiths is a nurse who works with people with a learning disability. He works for Bro Morgannwg NHS Trust. He is working to help hospital staff understand how to look after people with learning disabilities well when they go into hospital.

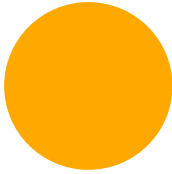


He has made a plan for people with a learning disability to use when they go in to hospital. You can see Christopher's plan at the end of this report.

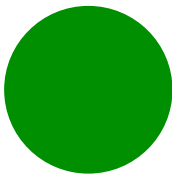
The plan is like a traffic light:



- The plan has a Red section. This is for things that the hospital must to know about a person. For example, the hospital needs to know if a person takes medicines.

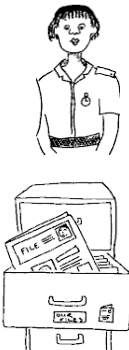


- The plan has an Amber section. This is for things that the hospital should know about a person. For example, the hospital should know if a person needs help to eat or go to the toilet.



- The plan has a Green section. This is for things that the hospital can do to make a person happy in hospital. For example, things that a person likes to do.

Christopher has also made sure that:



- everyone knows there is a nurse on each ward who knows about learning disabilities
- every person with a learning disability has a Personal Health Profile. This is an easy to read paper that tells all the hospital staff about someone's health and what treatment they need
- all the nurses have some training about people with a learning disability

What social care service providers said:

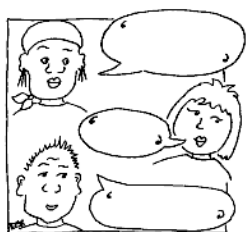
Who answered our questions?

Even though 266 people answered our questions we could not use all the answers because



- some people who answered did not support people with a learning disability
- Some people sent their answers in too late.

We used 244 answers.



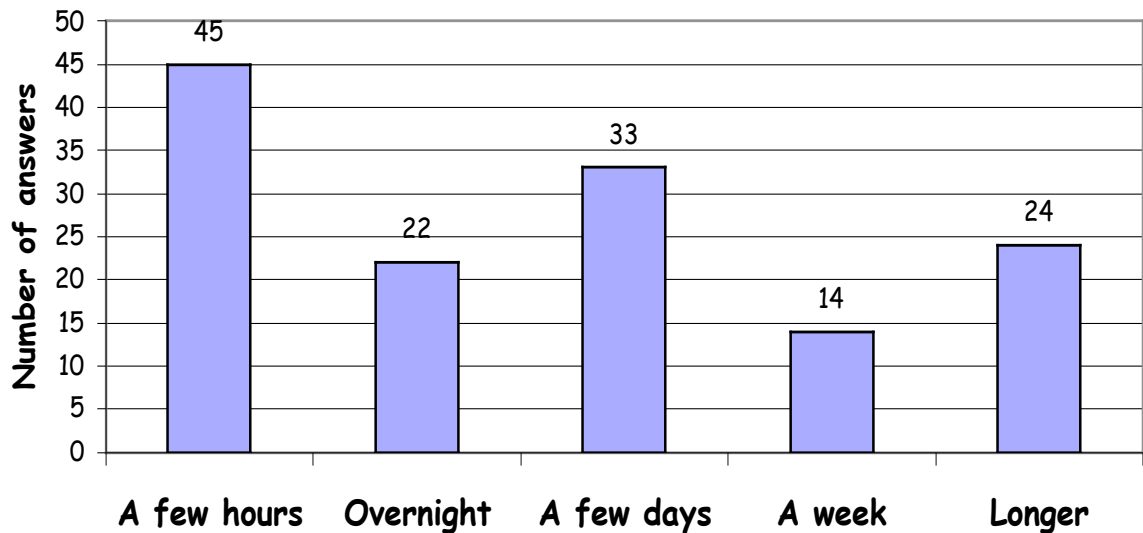
These answers are about 29 different hospitals.

146 people who answered our questions had supported someone going into hospital last year.

They said most people who went into hospital were over 18 years old and under 65 years old.

How long did people stay in hospital?

How long people stayed in hospital

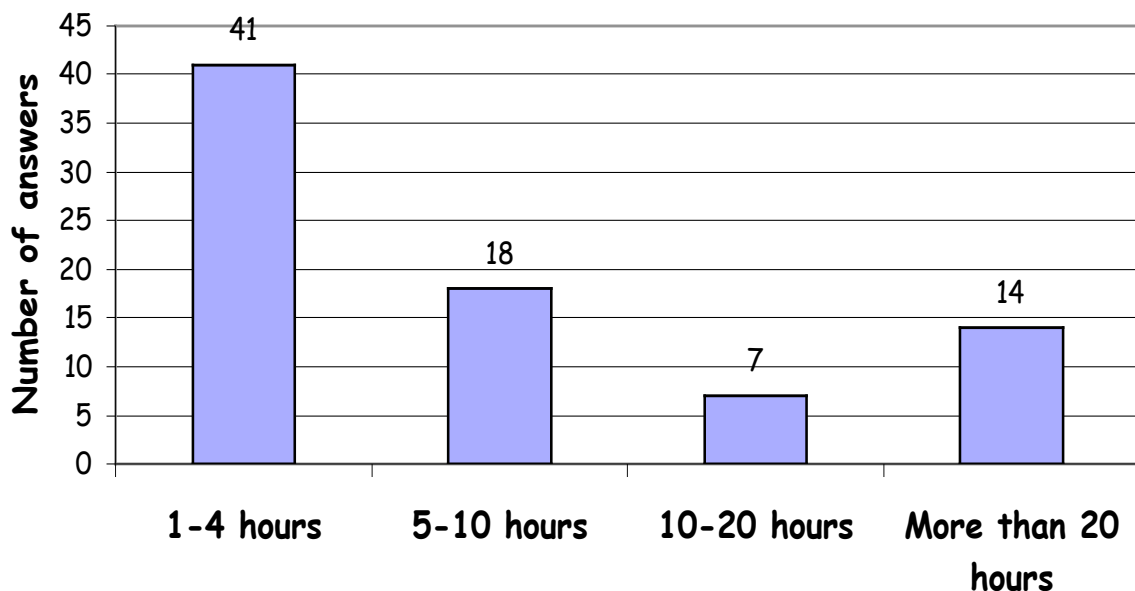


138 answered this question. People stayed in hospital for different amounts of time. 45 people went into hospital for less than a day, but 24 people stayed in hospital for longer than a week. Some people stayed in hospital for longer than a month.

How much help did support staff give people in hospital?

We got 80 answers to this question. Half of the answers said staff supported people in hospital for a few hours every day. 14 people got support for just about 24 hours a day.

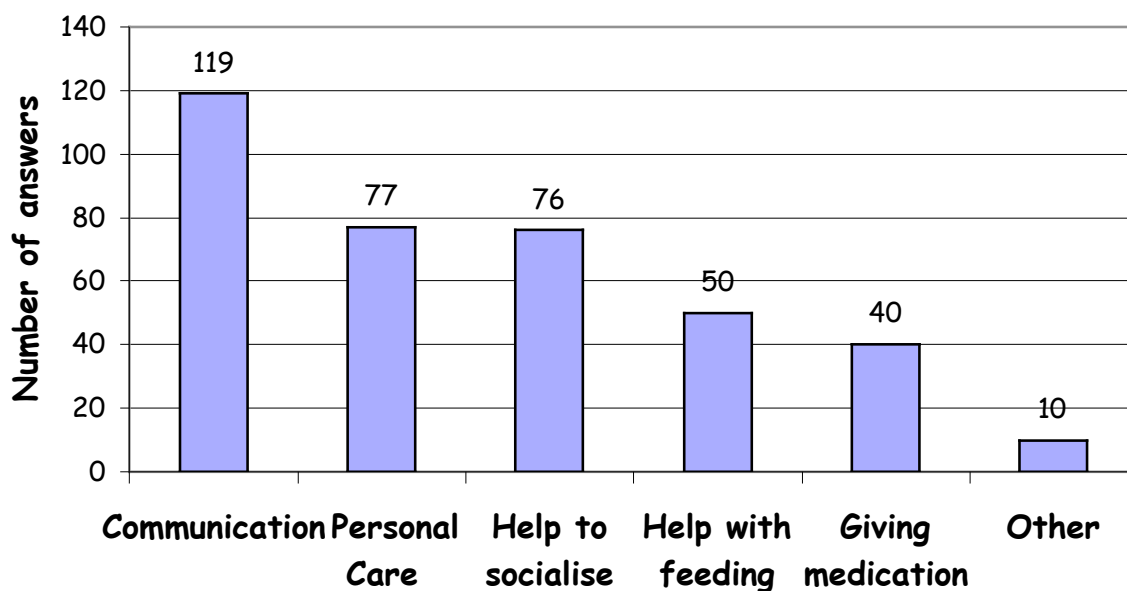
How much help support staff gave every day



We think it is likely that more people got support from staff while they were in hospital. This is because we got more answers when we asked about the kind of support they got.

What help did support staff give in hospital?

Kinds of help



Support staff helped with a lot of things:



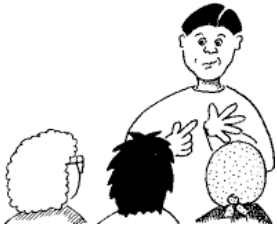
- 119 staff helped people to say what they wanted. Staff said that doctors and nurses were not good at talking to people with a learning disability.



- 77 staff helped people with washing, dressing or going to the toilet.
- 76 staff helped people to use the TV, play games and to socialise
- 50 staff helped people to eat and drink.

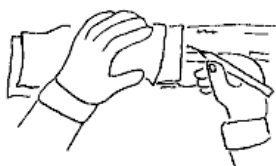


- 40 staff helped people to take their medicines. Support staff should not do this. When a person with a learning disability is in hospital only hospital staff should give medicines.



- 3 staff helped doctors and nurses to understand why someone with a learning disability acts like they do, especially if their behaviour was challenging. We think more support staff probably did this too, but said it was "helping with communication". Sometimes doctors and nurses do not understand that a person with a learning disability might act differently to other people.

Who pays for the support staff?

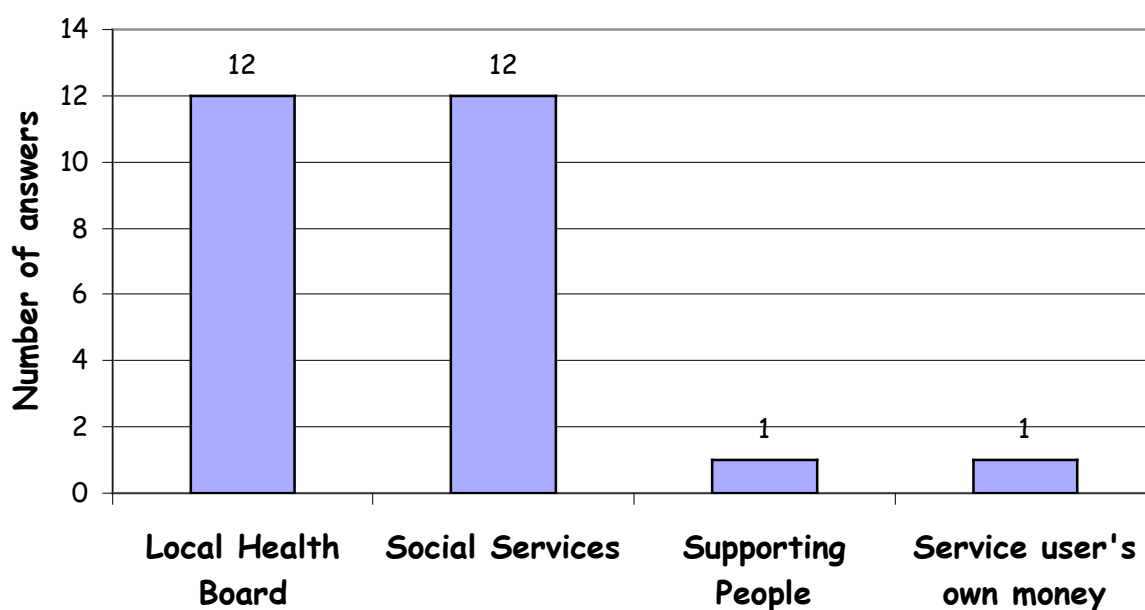


When a person with a learning disability goes into hospital Social Services often stops paying for staff to support them. This is because when people go into hospital, they say hospital staff are already paid to look after them.



But often, support staff and hospital staff both think that the person needs help from someone who they know and who knows what special help they need.

Who paid for the support staff to be in hospital?



Only 23 service providers out of 127 who supported people with learning disabilities in hospital got money for them to be there.

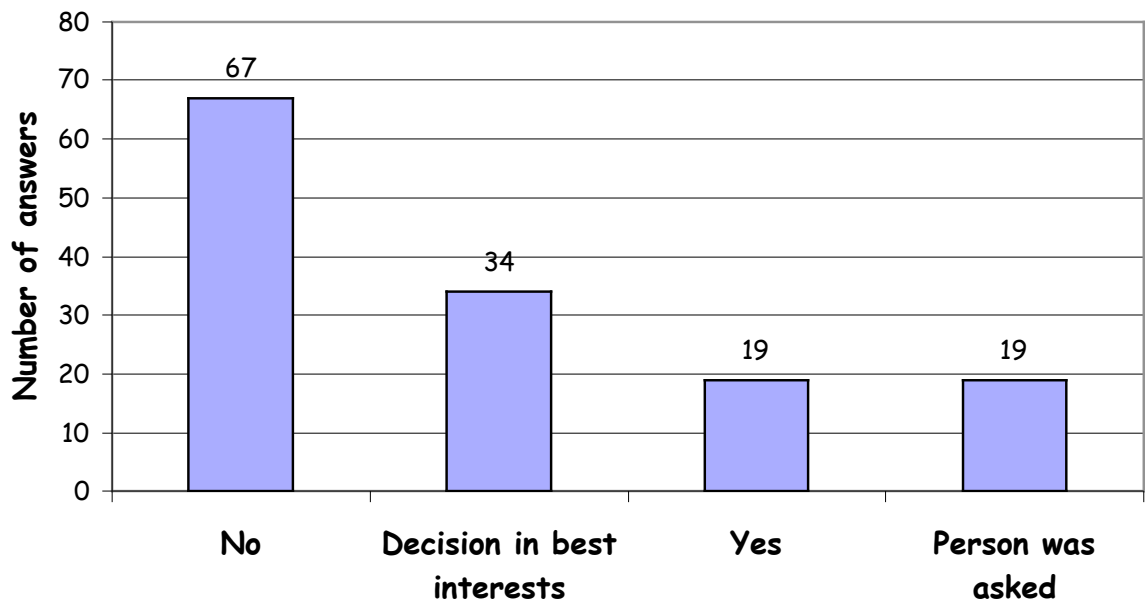
Most people who did get money got it from the Local Authority or the Local Health Board. One person paid for their own support.

Were support staff asked to give consent?



"Consent" means to agree. In hospital, "giving consent" means agreeing to medical treatment. Sometimes support staff are asked to give consent for the person they are supporting. This is wrong.

Were support staff asked to give consent?



Most staff were not asked to decide about treatment for the person they were supporting.

If a person cannot make their own decisions, a decision is made for them "in their best interests". This means that everyone agrees that this is the best thing to do.

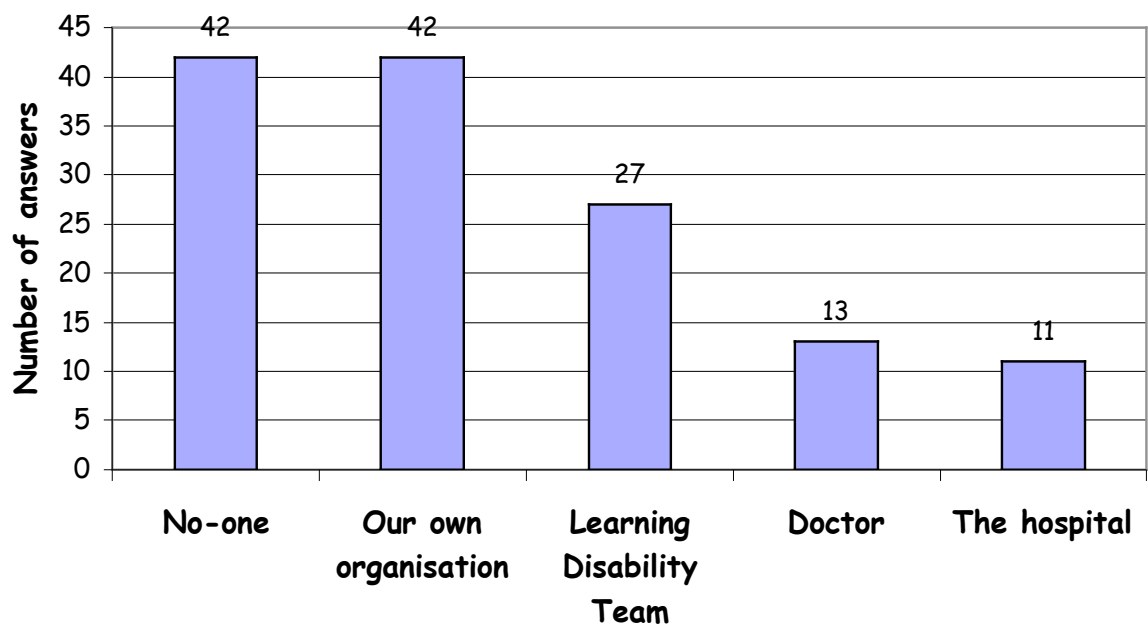


19 staff were asked to decide about treatment for the person they were supporting. They should not be asked to do this. Doctors should ask the person with a learning disability themselves. Some doctors do not seem to know this.

We hope all hospital staff will learn about who can give consent when they do their training about the Mental Capacity Act.

What happens when someone arrives at hospital?

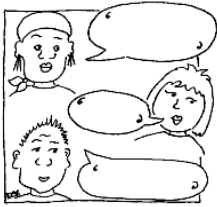
Who else helped when the service user was going in to hospital?



When someone with a learning disability went into hospital there was often no plan about what help they would need.

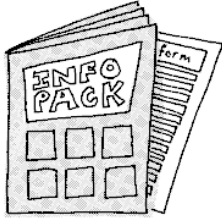
- 42 people had no help at all.
- 42 people had help from their own service provider.
- 27 people had help from the Learning Disability Team.
- 13 people had help from their doctor.
- 11 people had help from the hospital.





Some people said:

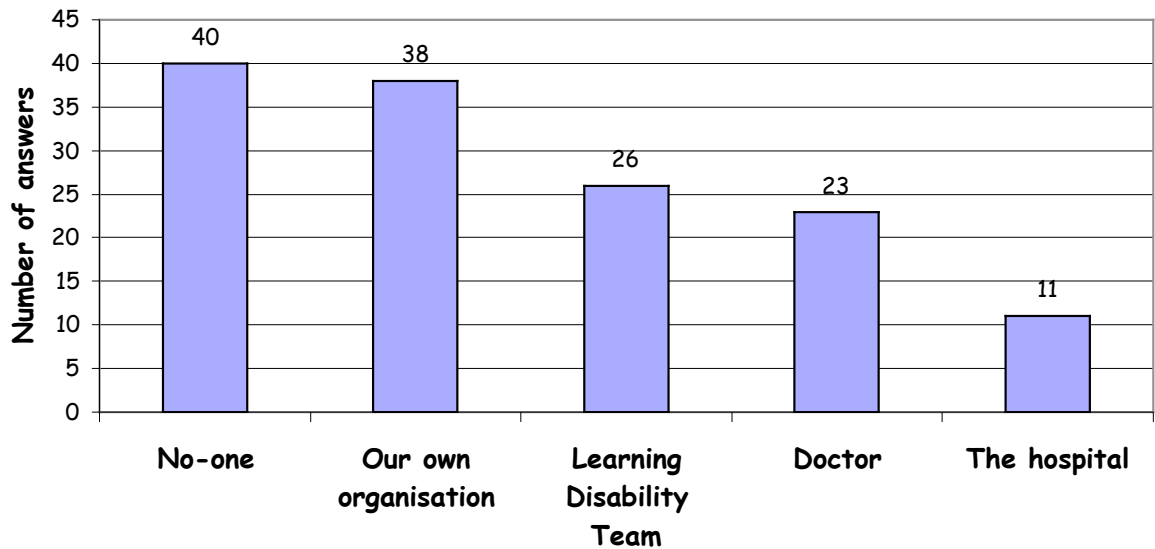
- There was no arrival plan
- We need to know more before we arrive.
- It would help if we could visit the hospital before we go in.
- It would help if support staff could give information about a person with a learning disability before they go into hospital.



Some people were very pleased about the planning that was done to make it easier for someone to go into hospital.

What happened after someone left hospital?

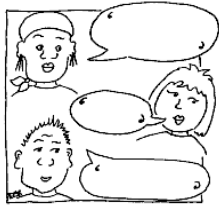
Who else helped when the service user was leaving hospital?



When someone with a learning disability left hospital there was often no plan to help them back at home.

- 40 people had no help at all
- 38 people had help from their own organisation
- 26 people had help from the Learning Disability Team
- 23 people had help from their doctor
- 11 people had help from the hospital.





Some people said:

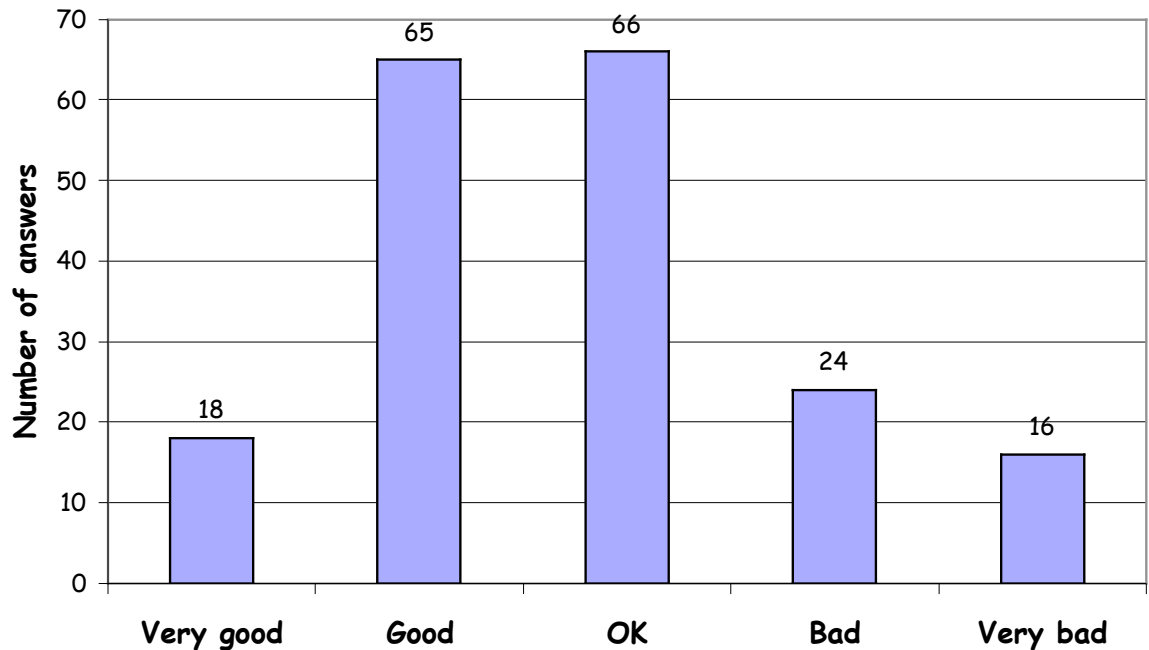
- The hospital staff did not want us there because they did not like the way the person with a learning disability acted.
- The plans for leaving hospital were not clear.
- There were problems when we left the hospital.
- It would help if we had more time to plan care after the hospital stay.
- We need meetings to talk about leaving hospital.



Some people said that the planning was good. The hospital gave them a lot of information to help support the person properly back at home.

How good was the care in hospital?

How good was the care that hospital staff gave?



Very good care



18 people said that the care in hospital was very good.

The people who said care was very good care said things like:

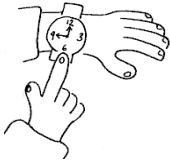
- The dentists were very good
- The nurses were very good. The doctors were not so good.
- The hospital staff listened to what we said.

People said there was very good care in 9 different hospitals. 2 of these hospitals said they had a plan for people with a learning disability.



Only 2 service providers who said care was very good got money to pay for support staff to be in the hospital.

3 people said one particular hospital gave very good care. This hospital had a plan for people with a learning disability.



Some people who said care was very good only spent a few hours in hospital. Other people who said care was very good spent 2 weeks in hospital.



Some people who had very good care sometimes had a lot of help from support staff every day. Other people who had very good care did not have so much help from support staff.

Very bad care



16 people said that the care in hospital was very bad.

The people who said care was very bad said things like:

- No one cared. No one helped with going to the toilet. The person with a learning disability was fed fatty food and put on a lot of weight. Now this person can not stand.



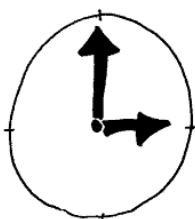
- The hospital staff leave all of the care to support staff.
- Hospital staff did not listen to support staff.
- There was no plan to care for a person with a learning disability.

People said that the care was very bad in 8 hospitals.

3 of these hospitals had a plan for people with a learning disability.



Only 1 service provider who said care was very bad got money to pay for support staff to be in the hospital.



People who had very bad care often spent longer in hospital.

People who said that the care was very bad often had a lot of support in hospital every day.

Some people said the care was very good and some people said the care was very bad at the same 3 hospitals!

What we found out



How people with a learning disability are treated in hospital is important because they are more likely to go into hospital than other people.

146 service providers said they helped someone with a learning disability in hospital last year.



We found out there is some very good work going on to help people with learning disabilities when they go into hospital.



But service providers told us there are still a lot of problems.

There were more problems when people went into hospital for a long time.

There were more problems when people needed a lot of support to be in hospital

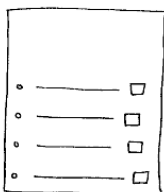
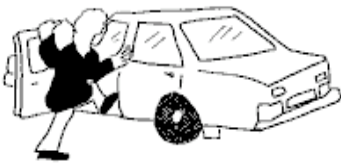


Many of these problems are the same problems that you can read in other reports.

We also found some other problems.

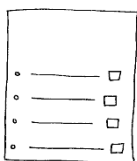


- There is no plan about who pays for support staff to help a person with a learning disability in hospital.



- Hospital staff often need help to talk to a person with a learning disability. Support staff can help with this. This is a very important job.
- There are even more problems when a person has complex health needs that mean lots of different agencies need to work together to do the best for that person.
- Leaving hospital can cause problems for service users and service providers. There are often no planning meetings about what the person will need when they go home.
- Hospital staff and support staff do not always work well together. Someone said "Hospital staff do not respect support staff". Hospital staff need to ask themselves "What can this person tell me about what this patient needs?"
- Some support staff are asked to do things that hospital staff should do. Support staff should not give medicines while in hospital. They should not be asked to give consent.
- Hospital staff and support staff need to understand each other better. Then they can plan what is best for a person with a learning disability when they leave hospital.
- Hospitals need a plan for when someone with a learning disability goes into hospital. A plan could help a person with a learning disability to get better care.
- Hospital staff need training about people with learning disabilities. This would help people with learning disabilities to get better care.

What We Think Should Happen



We think that every hospital should have a plan about what to do when people with learning disabilities go into hospital.



We think that hospitals should share the best plans so that every hospital has a good plan. The Unified Assessment Process means health services must learn how to share information well. Perhaps some of the new ways of sharing information can be used to share the best plans.



We think that the Disability Equality Duty means that hospitals should have a plan anyway.

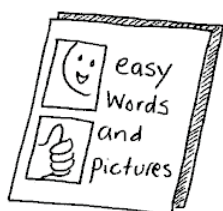


We think hospitals need a special plan for people with learning disabilities, not just a plan for everyone. People with learning disabilities often need special help.



We think that people with learning disabilities should help to make the plans.

We think that the plans should be looked at and thought about every year to see if they are working and how they could be made better.



We think that everyone should be able to see the plans.

We think that the plans should be easy to read.

We think that people with learning disabilities like to have people they know supporting them in hospital.



We think that it should be easy for service providers to get money so that a person's support staff can stay with them in hospital.



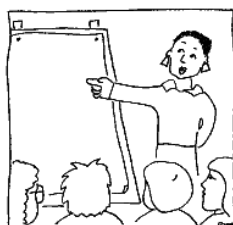
We think everyone should know the rules about who can give medicine to people in hospital.



We think that everyone with a learning disability should have a book about themselves that they can show to hospital staff. The book should tell the hospital about what that person needs and likes.



We think that hospitals should have a special person who can help hospital staff and people with learning disabilities if there are any problems.



We think that hospital staff should have training to understand people with learning disabilities better. People with learning disabilities should help with the training. They are the best people to tell hospital staff what it is like to be a patient with a learning disability.

Extra information at the back of this report

- Information that helped us to write this report
- The questionnaire we sent to social care organisations
- The questionnaire we sent to Local Health Boards, NHS Trusts and Local Authorities
- "What support staff do when service users are in hospital" - what ARC Cymru members told us
- A good plan - The Bro Morgannwg NHS Trust planning sheet
- A good plan for North West Wales
- Another plan for North West Wales
- A good plan from the Countess of Chester Hospital
- Another good plan from the Countess of Chester Hospital
- A good plan for adults and children with learning disabilities
- A good plan from Sheffield
- A good plan - Cartrefi Cymru's plan for support staff (not easy read)
- Contact details of people who know about learning disability services in NHS Trusts

Information that helped us to write this report

BBC (2007) Learning disability care slammed

<http://news.bbc.co.uk/1/hi/health/6266923.stm>

(Accessed 17th Jan 2007)

Dept of Health (2007) Promoting equality - Response from Department of Health to the Disability Rights Commission Report, Equal Treatment: Closing the Gap London HMSO

Department of Health (2001) Valuing People - A New Strategy for Learning Disability for the 21st Century. London, HMSO

Disability Rights Commission (2006) Equal Treatment: Closing the Gap

http://www.drc.org.uk/library/research/health_and_independent_living/health_formal_investigation.aspx

Disability Rights Commission, Gary Zarb (2006) Using the Disability Equality Duty to Tackle Inequalities in Health and Social Care.

www.drc.org.uk/files/The_DED_and_Independent_Living_Sep06.rtf

Foundation of People with Learning Disabilities (2006) 'Our Health, Our Care, Our Say': Issues to consider for the health of people with learning disabilities and learning disability services'

Mencap (2003) Treat me Right www.mencap.org.uk

Mencap (2007) Death by Indifference www.mencap.org.uk
(Accessed 15th Nov 2006)

National Access to Acute Network www.nnldn.org.uk/a2a
(Accessed 21 Jan 2007)

National Patient Safety Agency (2004) Understanding the patient safety issues for people with learning disabilities London, NHS



Hospital Support research project

Questionnaire for Organisations/Managers/Senior Staff

This research, commissioned by the Welsh Assembly Government, is reviewing the Planned Hospital Admissions for people who have a learning disability.

Planned admission means that the appointments, tests, operation or treatment, including dental work carried out **in hospital settings**, had been booked in advance. Please provide answers that apply to planned admissions.

Accident and Emergency treatment and admission for mental health problems are outside the scope of this study although comments can be made in Question 13.

You will need to complete a separate questionnaire for each individual who has had an admission and a separate questionnaire for each separate visit any single individual may have had.

Name of organisation:

Location of hospital that your comments relate to:

Information about the individual's age: Please circle which of these age brackets applies to the individual

Under 18 18 – 65 Over 65

Question 1: Has someone you support who has a learning disability had a 'planned admission' into hospital in the past 12 months? (*Please circle*)

Yes No (If no please go to Question 10)

Question 2: How long did this person spend in hospital? (*Please circle*)

A few hours Overnight A few days A week Longer (*please state*)

Question 3 Were your staff asked to support the individual while they were in hospital?

Yes No (If no please go to Question 7)

Question 4: How much time did your staff spend supporting the individual while they were in hospital PER DAY? *(Please circle)*

Less than an hour 1 – 4 hours 5 – 10 hours

10 – 20 hours More than 20 hours

Question 5: Did you receive any funding to enable you to offer this support?
(Please circle)

Yes No (If no please go to Question 7)

Question 6: Where did this funding come from? *(Please circle all that apply)*

Local Authority Local Health Board Own Organisation

Supporting People Charity Funding Individual's own funding

Other *(please state)*

Question 7: What type of support, if any, were your staff asked to provide while the service user was in hospital? *(Please tick all that apply)*

☐ Assisting with communication

☐ Providing personal care (for example toileting/bathing/dressing)

☐ Support with feeding

☐ Administering medication

☐ Support with 'social interaction' assisting with the use of TV, radio, playing games, etc.

☐ Any other type of support *(please state)*

☐ None

Question 8: At any stage of the hospital admission were your staff asked for consent on behalf of the individual? *(Please circle)*

Yes Yes the person was under the age of 18 No

The individual was asked to consent

A decision was made acting in their best interests

Question 9: Did your organisation or staff receive any support BEFORE or DURING the admission to hospital from any of the following? *(Please circle all that apply)*

| | | |
|-------------------------|------------------------|-----------------------------|
| Own Organisation | Individuals GP/surgery | Learning Disability Team |
| Health service/hospital | | Other <i>(please state)</i> |
| None | | |

Please list what type of support you received below

Question 10: Did your organisation or staff receive any support ON DISCHARGE/ AFTER the hospital from any of the following? *(Please circle all that apply)*

| | | |
|-------------------------|------------------------|-----------------------------|
| Own Organisation | Individuals GP/surgery | Learning Disability Team |
| Health service/hospital | | Other <i>(please state)</i> |
| None | | |

Please list what type of support you received below

Question 11: Overall how do you rate the level of support provided to the service user by the hospital professionals? *(Please circle)*

| | | | | |
|-----------|------|---------|------|-----------|
| Excellent | Good | Average | Poor | Very Poor |
|-----------|------|---------|------|-----------|

Question 12: In the light of your own experiences do you have any views about how pre-admission planning; care arrangements in hospital and the discharge arrangements could be improved?

Question 13: If you have experiences outside the last 12 months that you feel are relevant to this project please record these here (you can write on the back on the questionnaire if required).

*Please send the completed questionnaire **by 18th May** to the following address:*

FREEPOST RRGY-LRRY-XYRZ
ARC Cymru,
3a Mentec
Ffordd Deiniol
Bangor
LL57 2UP

Thank you for taking the time to answer this questionnaire



Llywodraeth Cynulliad Cymru
Welsh Assembly Government



Cefnogi darparwyr gwasanaethau
i bobl gydag anabledd dysgu
Supporting providers of services for
people with a learning disability

Welsh Hospital Project

Questionnaire for Local Health Boards/Trusts/Local Authorities

Please state your name and your organisation -

Question 1: Do you have protocols in place to support people who have a learning disability during planned hospital admission? *(Please circle or highlight)*

Yes No (If no please go to Question 11)

(Is it possible to supply the project with a copy of this protocol? See note at the end of the questionnaire)

Question 2: How long has the protocol been in effect?

Question 3: When was it last reviewed?

Question 4: Is an 'easy read' version available for people who have a learning disability themselves? *(Please circle or highlight)*

Yes No

Question 5: How do you make health staff aware of the protocol?

Question 6: Do you make social care staff aware of the protocol? If 'Yes', how?

(Continued)

Question 7: Do you make people who have a learning disability and their families/carers aware of the protocol? If 'Yes', how?

Question 8: How do you rate the usefulness of the protocol? *(Please circle or highlight)*

Excellent Good Average Poor Very Poor

Question 9: How do you rate the effectiveness of the protocol? *(Please circle or highlight)*

Excellent Good Average Poor Very Poor

Question 10: What do you think could be done to improve the usefulness and effectiveness of the protocol?

(If you have answered Yes to question 1 you have now completed the questionnaire – please see note below about protocols)

Question 11: If you do not have a protocol do you think that one would help with hospital admissions for people who have a learning disability? *(Please circle or highlight)*

Yes No

Question 12: Briefly state why you gave your answer to Question 11 in the space below.

If you have a protocol in place please send it and the questionnaire electronically to david.grundy@arcuk.org.uk or to the following address: FREEPOST RRGY-LRRY-XYRZ

ARC Cymru,
3a Mentec
Ffordd Deiniol
Bangor
LL57 2UP

Many thanks for taking the time to complete this questionnaire

What support staff do when service users are in hospital – what ARC Cymru members told us (2006)

We asked our members to tell us what the problems are when the person they support goes into hospital. This tells you what some of the common problems were.

When a service user goes into hospital, service providers say:

- **either** hospital staff are happy that a support worker is there and the support worker helps with things like communication and personal care
- **or** hospital staff do not think support workers have anything important to say about the treatment or care that a person is going to have.

One service provider said:

"A service user was admitted to Llandough Hospital having suffered a type of seizure. Understandably the service user was quite distressed and confused about having to stay in unfamiliar surroundings.

"The service user asked if a member of staff could stay with him. The nursing staff also raised concerns with regard to the service user being left unsupported by staff during his stay in hospital. Staff were concerned as were the hospital staff because of service user being so distressed agitated and confused. Arrangements were then made for the service user to be supported by his staff between the hours of 8am-9pm daily. The service user and the nursing staff were happy with these

arrangements and it made the service user's stay as pleasant and stress free as possible.

"The staff sat with the service user during the day and helped with the communication between hospital staff and service user. The staff also accompanied the service user when he had to undergo various tests/scans etc.

"The nursing staff treated the service user with dignity and respect and explained to him exactly what would be happening during his stay."

Another service provider said:

"A service user was in hospital for a while. The care staff wrote down what she needed and what her preferences were, like only ever drinking cold drinks. This was not even looked at".

Support workers often go into hospital to be with service users without being paid. They do this to make sure that the service user will get proper care.

Support workers feel that hospital staff just do not understand what people with a learning disability need. They feel hospital staff are afraid of being attacked by someone if their records say they have "challenging behaviour".

They said:

- *"Health professionals do not seem to realise how frightened someone would feel, having to go into hospital".*
- *"We've had cases with a person with a learning disability being admitted to hospital and being placed in incontinence*

pads straight away, whether that person required them or not".

Service providers felt that many hospital staff just do not have the time to give proper care and attention to a patient with a learning disability.

One support worker visited the service user she supported in her own time. She said to her manager:

"If I don't go in, she'll starve!"

Patients with a learning disability can get worse care from hospital staff if they do not understand what people with learning disabilities need.

Service providers told us about important routine tests not being done because service users had shown "challenging behaviour" in the past.

Service providers said that hospital staff do not have the training to properly understand people with a learning disability:

"During October, November and December 2004 a service user I supported was going back and forth to his GP and was being treated for constipation but nothing was working. He was admitted to the University Hospital of Wales in Cardiff during December 2004 for 4 days where he had an x-ray taken of his stomach and was treated for constipation a day later and then sent home.

"During the next week his condition got worse and his legs started to get swollen and he was having difficulty getting about and up stairs. He was then admitted to the hospital

again where he had further tests and was found to have cancer of his bowel, which had spread to his liver. We were told that he would be admitted to Holme Towers in Penarth and that he may pass away quite soon. He then passed away on 8 December 2004, a couple of days later. I and my staff team were not very impressed at the lack of examination that he received during his first visit to hospital. We understand that nothing could have been done to treat him as the cancer had spread too far."

While hospital staff may expect support staff to stay to help them to 'deal with' a service user, Local Authorities often stop paying for that support once the service user is in hospital. They say that the hospital gives people 24 hour care anyway.

One service provider said:

"On several occasions over the last couple of years, support staff have NOT been allowed to maintain support when the service user goes into hospital. This is caused by disputes between Local Authorities and Health Authorities about who pays for the support workers time. If the support staff are sent away, and the admission is protracted, there is often some form of 'retainer' paid by a local authority to the provider, but usually this does not cover the normal pay earned by the support worker, and is for a specific period. This obviously causes financial hardship for the organisation and may lead to loss of staff, especially if providers are unable to arrange alternative work. The danger is that, when the service user is discharged, there may not be a staff team available to provide support, resulting in bed blocking".

Service providers said that having staff who you know is very important to service users. It is so important that service

providers look for the money to pay for the support staff to be there from their own budgets:

"Although our contractual arrangements with Local Authority Social Service Departments state that the moment a Service User goes into hospital we stop supporting them and they become the responsibility of the Health Authority, we ALWAYS continue to provide support and fund it ourselves if necessary. We have had arguments with Social Services before about the need for Service Users to have people they know and trust around them and the fact that, in almost every case, the nursing staff have little or no experience of people with LD and are extremely grateful for any help that they can get. In one case in Denbighshire the LA eventually agreed to part fund our staff's continued input for a young man who was terminally ill."

While many hospital staff are very glad that a support worker stays with the service user in hospital, providers say that sometimes no-one listens to the support worker:

"The consultant looked at me and said 'So what's your role in all this?' I said I was his support worker. He said 'Well, I don't think we need you here do we?' I went to the other side of the room and he turned to talk to the client. After a while he called me back and said 'So what's going on here then?' because the client wasn't answering him. I said 'He's profoundly deaf and only lip reads through the medium of Welsh' After that he said I'd better stay around".

"A young lady we support, who has a profound learning and physical disability, was admitted to the Princess of Wales (Bridgend) as we thought she may have dislocated her shoulder. The injury was caused by the person self injuring due to the pain and discomfort of a chronic constipation problem. Her constipation was being treated via the use of enemas, but the district nurses were unwilling to give the type of enema advised by her consultant as they had concerns about the long term use. They had no direct access to the consultant, which held things up.

"Anyway, this injury was assessed and treated by x-ray and pain relief medication. Whilst she was an in-patient we asked if she could have a scan to address the root cause of her distress i.e. the constipation. This was not forthcoming and she was discharged only to have a prolonged period of distress and self injury leading to another admission as her constipation had worsened to impaction. In the hospital the staff appeared to be dismissive of the need for an assessment and treatment for the constipation as I don't feel they fully comprehended the connection between this and the persons self injurious behaviour. They seemed only to be interested in the shoulder injury and not the underlying cause".

Someone else said:

"Often when people we support are in hospital the support staff are not listened to, possibly because they do not have a medical background.

Not wanting to be negative, we have had occasions where staff we have had in hospitals have been excellent, but sadly this is the exception rather than the norm".

Another view about people who can show challenging behaviour was:

"We don't want to paint a negative picture of people with learning disabilities, but they need to understand that sometimes people can get very disturbed in a new environment".

And again,

"We called ahead to Casualty to say we were coming in with a service user with autism who required 3/1 support. We asked if we could be fast-tracked to see the doctor as this service user could get violent. The receptionist laughed in our faces when we got there and we had to wait".

It seems that the people who have the biggest problems are people who have problems speaking. Hospital staff often look uncomfortable and unhappy about dealing with people who do not speak. They rely upon support staff to help them out.

"A person with a learning disability was in hospital for many weeks during which time they were not given a bath. This person challenges and self harms if touched by people she does not know and trust, and the hospital staff were afraid to go near her. Support workers were with her 24/7 but they were not allowed to use the hospital hoists to give this person a bath because they were not insured. The hospital staff were not providing medical

treatment or intervention for the person as she was not complying. They were therefore not able to determine whether anything was wrong or not. Why couldn't the hospital have provided the medical service at home, because the person would have been in familiar surroundings and would have been less stressed? It would have been impossible for the hospital to create the specialised environment that this person was used to anywhere other than in their own home. There are people with more profound learning disabilities living in the community now".

Another worry for service providers is what happens when people leave hospital. They feel there is a no proper planning and this can lead to a lot of distress when a person is sent home from hospital. Providers have asked for clear guidance to be written about planning for leaving hospital. There are too many last minute phone calls that say 'He's on his way'.

"Sometimes people are just put into an ambulance but have no idea what is happening to them or where they are going".

At the moment, Trusts only have to have a discharge meeting when the patient is being dealt with under the Mental Health Act.

When things do go wrong, providers do not always use a hospital's complaints procedure. One service provider met with the senior nursing staff after they made a complaint. The hospital listened to what they had to say and changed their policy.

They worked with the hospital to make things work better. This provider said making a complaint can make a difference, but sometimes hospital complaints procedures are too complicated.

Another provider said

"We made a formal complaint about their care and treatment. They did everything they could to put us off. They said we couldn't complain and that it had to be someone from his family. We went to the Chief Executive in the end".

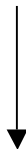
Hospitals must give good care to all their patients, if they have a disability or not. It is up to the hospital to find out what the patient needs and to give them the right support while they are in hospital.

Often, hospitals can not do this.

- They often do not understand what people with a learning disability need.
- Hospital staff need training about learning disability.
- Hospital staff need to understand what support staff are allowed to do and what they are not allowed to do.
- Hospital staff need to understand how important it is for service users to have staff who they know, especially if service users have problems talking.

HOSPITAL INFORMATION

RED



Things you must know.

AMBER



Things which you should
know about me.

GREEN



Things I would
like to happen.

Name:.....

RED

Important Information About Me

Name:

GP:

Know as:

Address:

Address:

Tel No:

Tel No:

Date of Birth:

Next of Kin:

Relationship:

Tel No:

Carer:

Relationship:

Tel No:

Professionals Involved:

Relationship:

Tel No:

Relationship:

Tel No:

Care Manager:

Tel No:

Religion:

Religious Requests:

Current Medical Conditions:

Current Medication:

Brief Medical History:

Allergies:

Medical interventions:

Level of understanding:

Behaviours which may challenge or cause risk:

Completed by

Date

Relationship

AMBER

Things Which You Should Know About Me

Communication:

Understanding:

Eating and Drinking:

Medication:

Going to the toilet:

Seeing / hearing:

Moving around:

Personal Care:

Level of Support:

Keeping safe:

Sleeping:

Pain:

Completed by:

Date:

Relationship:

GREEN

Things That Would Make My Stay More Enjoyable

Things I Like

Things I Don't Like

Completed by: Date:

Relationship:

Adapted from the Red, Amber, Green Hospital Assessment:
Gloucestershire Partnership NHS Trust (Elliot & Dean 2004)



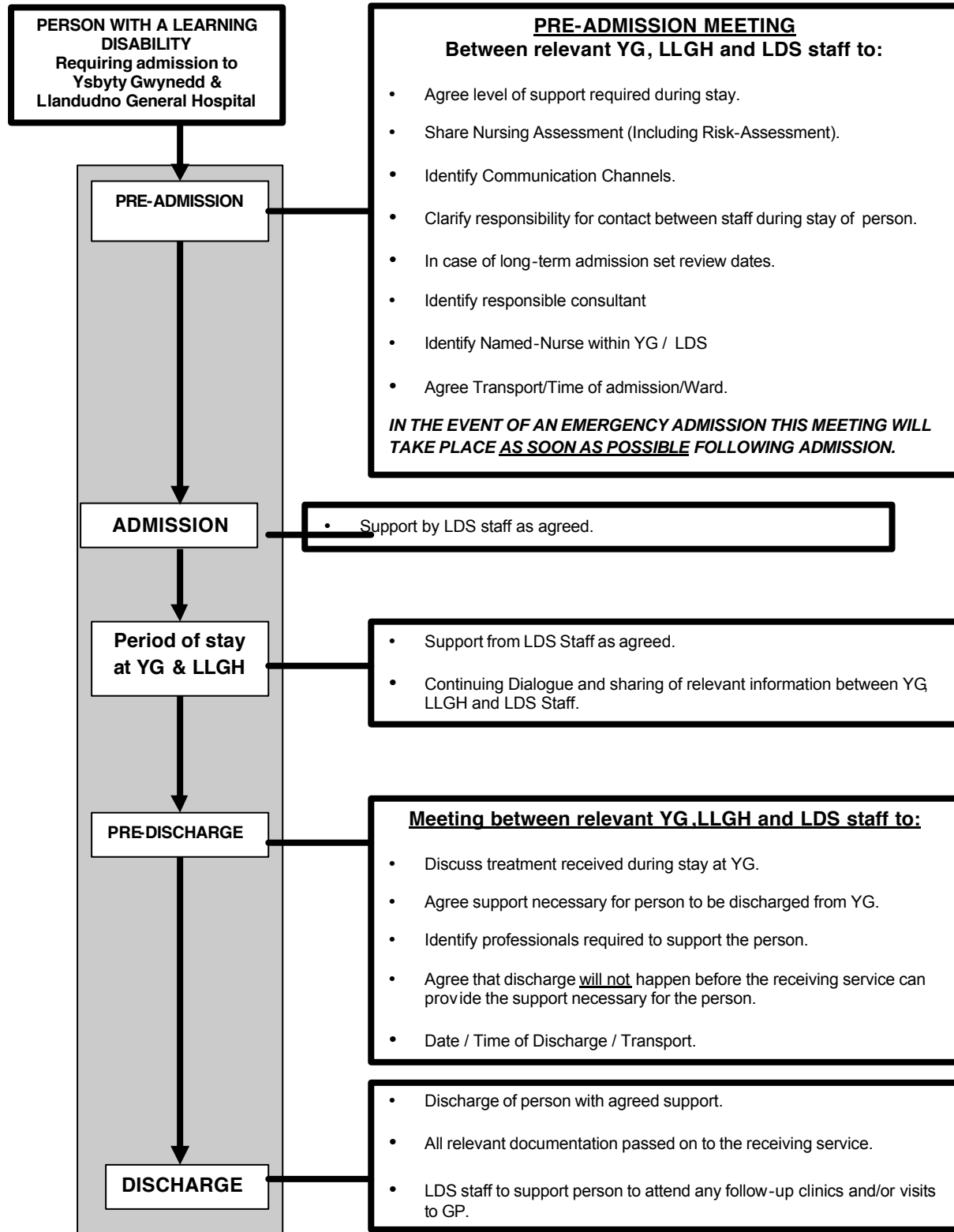
Title: N100 - Protocol for the Admission of a Person with a Learning Disability to Ysbyty Gwynedd & Llandudno General Hospital

| Rev | Date | Purpose of Issue/Description of Change | Planned Review Date |
|--|---------------|--|---------------------|
| A | March 2001 | Initial Issue | March 2002 |
| | May 2002 | Reviewed & Updated | May 2003 |
| | August 2003 | No amendments necessary | August 2004 |
| | February 2005 | No amendments necessary | February 2006 |
| | March 2006 | No amendments required - Policy extended to 'Llandudno General Hospital' | March 2008 |
| Responsible Officer | | Approved by | Date |
| Mrs E Hugheston-Roberts Nursing Practice & Professional Development Manager Peter Jones, LDS Clinical Governance Coordinator | | Executive Directors | 14 March 2001 |
| | | Executive Directors | 19 June 2002 |

PROPRIETARY INFORMATION

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Protocol for the admission of a person with a learning disability to Ysbyty Gwynedd & Llandudno General Hospital



CONFIDENTIAL

ADDITIONAL INFORMATION DOCUMENT

ANY ALLERGIES? (Use
red ink)

Date of completion of document:

Completed by (Name & designation):

PRIMARY CONTACT FOR ADDITIONAL INFORMATION

NAME:

ADDRESS:

RELATIONSHIP:

TELEPHONE:



**THE PURPOSE OF THIS DOCUMENT IS TO PROVIDE HOPITAL NURSING
STAFF WITH A QUICK REFERENCE GUIDE TO THE NEEDS OF AN
INDIVIDUAL WHO HAS A LEARNING DISABILITY.**

*The document has been designed around the elements highlighted by the Welsh Assembly
Government's initiative "FUNDAMENTALS OF CARE" which aims to improve the quality of
fundamental aspects of Health & Social Care in Wales.*

THIS DOCUMENT DOES NOT TAKE THE PLACE OF ANY MEDICAL OR NURSING NOTES

1. COMMUNICATION & INFORMATION



Full name _____

I like to be called _____

My first language is _____

I live:

On my own

☐

In my family Home

☐

In my own home with support

☐

In a Residential Home

☐

A Nursing Home

☐


Other:

My Telephone number is _____

My religion is _____

I do not smoke

☐

I am a smoker

☐

I communicate in the following ways:

Verbally

☐

Using signs

☐

Using a key-board

☐

Using sounds

☐

Using gestures

☐

Using pictures

☐

Other

☐

Details:

I **do not** have a sight impairment

☐

I do have a sight impairment

☐

I **do not** have a hearing problem

☐

I do have a hearing problem

☐

I wear Spectacles all the time

☐

I have a hearing-aid

☐

I wear spectacles for reading

☐

N/A

Sometimes

Most times

Always

My learning disability means that I will need more time to understand what is going on

☐
☐
☐
☐

2. RESPECT



As an individual citizen, I expect that my right to **dignity, privacy and informed choice** be protected at all times and that the care provided will take into account my individual needs, abilities & wishes.



My learning disability may mean that I will occasionally behave in a way that might puzzle or concern other people

☐

More information:

3. ENSURING SAFETY



I do not usually require supervision

☐

I usually require occasional supervision

☐

I will require constant supervision by someone who knows me well

☐

Additional information:

4. PROMOTING INDEPENDENCE



Mobility



I am physically mobile and **do not require any assistance** ☐

To get about I need:

A walking aid ☐

A wheelchair ☐

1 person to assist ☐

2 people to assist ☐

More info.

Activities / Occupation



I usually like to:

Watch TV ☐

Artwork ☐

Talk to people ☐

Be on my own ☐

Read Books / Magazines ☐

Listen to Music ☐

Be with people that I know ☐

Be with other people ☐

Others:

Choices

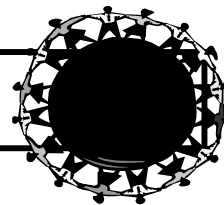
I am usually able to make choices about my everyday needs – **Ask me!** ☐

I usually need help to make decisions ☐

I usually rely on others to make decisions on my behalf ☐

More Info:

5. RELATIONSHIPS



CONTACTS / PEOPLE WHO KNOW ME

| Relationship | Name | Address | Contact No | When Available |
|---|------|---------|------------|----------------|
| Family member (Please specify) | | | | |
| Carer / Key worker / Link Nurse (Circle as appropriate) | | | | |
| Community Learning Disability Nurse | | | | |
| Community Care manager / Social worker | | | | |
| GP | | | | |
| | | | | |

6. REST & SLEEP



I usually go to sleep at / when _____

I usually sleep very heavily ☐

I am usually easily disturbed from sleep at night ☐

More Info (Including any special adaptations/ sleep patterns / habits / positioning etc.):

7. ENSURING COMFORT, ALLEVIATING PAIN



Medication



I regularly take the following medication:

| Name | Dose | Reason |
|------|------|--------|
| | | |
| | | |
| | | |
| | | |
| | | |

I do not need any special help to take my medication

☐

I need the following help to take medication:

Known medical conditions / Syndromes (Including Psychological / mental health needs)

I have not been diagnosed with a medical conditions or syndrome

☐

I suffer from a diagnosed medical condition or syndrome

☐

Name (s) of condition (s) / syndrome (s)

More Info:

| Condition | Yes | No | Information (and dates) |
|-------------------------------|-----|----|-------------------------|
| Anaemia | | | |
| Arthritis / Muscle disease | | | |
| Asthma | | | |
| Breathlessness | | | |
| Bronchitis / Chest infection | | | |
| Diabetes / sugar in urine | | | |
| Excessive bleeding / bruising | | | |
| Fainting | | | |
| Heartburn / Hiatus hernia | | | |
| Heart disease | | | |
| High blood pressure | | | |
| Jaundice / hepatitis | | | |
| Rheumatic fever | | | |
| Seizures | | | |
| Serious illness | | | |
| Swollen ankles | | | |
| Major accident | | | |
| Mental health problems | | | |
| Water / urine problems | | | |

FAMILY HISTORY

| | | | |
|----------------|--|--|--|
| Asthma | | | |
| Cancer | | | |
| Diabetes | | | |
| Heart problems | | | |
| Osteoporosis | | | |
| Strokes | | | |

Any other information:

I have **never had a general anaesthetic** ☐

I have had a general anaesthetic before ☐

More Info:

I have had the following tests in the past 3 months:

| | Yes | No | Date |
|--------------------|--------------------------|--------------------------|----------------------|
| Full Blood count | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/> |
| Chest X-Ray | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/> |
| Thyroid Function | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/> |
| ECG | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/> |
| EEG | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/> |
| Rhesus | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/> |
| Ultrasound | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/> |
| Urea & Electrolyte | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/> |



Any other tests and dates:

IMMUNISATION STATUS (Including dates of boosters etc.)

| Tetanus | Influenza | Hepatitis B | Other |
|----------------------|----------------------|----------------------|----------------------|
| <input type="text"/> | <input type="text"/> | <input type="text"/> | <input type="text"/> |



My recent blood pressure was:

My Current Weight is:



Body Mass Index:

When I am not well I might:
(Expressions, particular behaviours etc.)

8. PERSONAL HYGIENE, APPEARANCE & FOOT CARE



I am usually able to look after my own needs in relation to personal hygiene, my appearance & foot care

☐

I usually require some assistance to look after my personal hygiene needs

☐

I am usually dependent upon others to care for my Personal hygiene, appearance & foot care

☐

Further Info:

9. EATING & DRINKING



I can eat and drink independently

☐

I need assistance to eat and drink

☐

I have Dysphagia problems

☐

I use an adapted plate

☐

I use an adapted mug

☐

I use adapted utensils

☐

I need a special diet

☐

More Info.

I like to eat _____

I like to drink _____

Further Info:

10. ORAL HEALTH & HYGIENE



I am usually able to look after my own Oral Health & Hygiene ☐

I usually need assistance to look after my own Oral Health & Hygiene ☐

I am usually dependent upon others to care for my Oral Health & Hygiene ☐

I wear dentures ☐

ore Info:

11. TOILET NEEDS



I can usually go to the toilet independently ☐

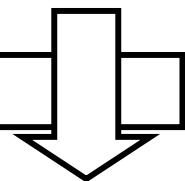
I usually need to be reminded to go to the toilet ☐

I usually go to the toilet with assistance ☐

I usually need to wear pads ☐

ore Info:

12. PREVENTING PRESSURE SORES



I am not usually at risk of getting pressure sores ☐

I am at risk of getting pressure sores ☐

ore Info:

ANY ADDITIONAL INFORMATION

For Hospital Staff....

Was there any information that was not contained in this document that would have helped you during this person's time at hospital and would possibly help should this person need to be admitted again?

Was this document useful?

Yes

☐

No

☐

**If I am ready to be discharged from Hospital
please let this person know:**

Name:

Relationship:

Contact No:



THANK YOU

**GUIDELINES FOR ADMISSION OF PATIENTS WITH
A LEARNING DISABILITY**

**Jill Heaps, Practice Development Nurse,
Surgical Directorate
Karen Reece, Matron
Medical Directorate**

**Devised September 2003.
Reviewed 18.04.05
Next review date 18.04.08**

Guidelines for admission of patients with a learning disability

1. Notification

1.1 ANY patient with a learning disability admitted to the trust through any route i.e. elective admission or emergency admission at any time of the day or night **MUST** be notified to the relevant matron/bleep holder.

1.2 In-hours the relevant matron/bleep holder will be informed.

Out - of - hours the Hospital Co-ordinator will be informed.

The co-ordinator will then notify the relevant matron at the next opportunity;

within 12 hours weekdays

by 9am Monday morning if admission is at the weekend.

1.3 Accident & Emergency

Patients with a learning disability admitted to the A&E Department should be notified to the matron or designate.

A&E matron or designate must inform relevant matron or co-ordinator of an admission of a patient with a learning disability to their area.

1.4 Elective pre-admission clinic

Surgical Pre-admission clinic will notify the relevant matron by e-mail of the pending admission and relevant details of a patient with a learning disability.

1.5 Medical Assessment Unit

When a patient with a learning disability is admitted directly to MAU the team leader must inform the relevant matron or hospital co-ordinator.

If/when the patient is transferred to another medical ward the team leader must notify the admitting ward and matron.

2. Informing Process

2.1 The Patient Care System - Learning Disability Field -should be completed and the name of matron notified of admission plus the date and time of notification all completed.

3. Matrons' responsibilities to patients with learning disabilities

3.1 When possible, within the first day of admission, the matron should go to the ward and introduce themselves to the patient with a learning disability and their carer

3.2 Matron should check that any special needs are documented in the patient care plan and that the relevant staff are aware of these.

3.3 Matron should aim to facilitate a seamless patient journey by regularly visiting the patient and carer.

3.4 Matron should keep records, for audit purpose, of the number of trust admissions to their area of patients with learning disabilities.

Jill Heaps, PDN Surgical Directorate
Karen Reece, Matron, Medical Directorate

June 2003

Ratified by Lead Nurse Forum September 2003.

AREA

MATRON

[illegible]

Karen Reece, Matron, Medical Directorate
June 2003

**GUIDELINES FOR SUPPORT OF CARERS
OF
PATIENTS WITH A LEARNING DISABILITY**

JILL HEAPS, Practice Development Nurse,

**Reviewed: January 05
Next review: January 07**

Approved by: Patient Services Strategy Group

Introduction

Carers can be vital to the safe delivery of appropriate treatment and care of a patient with a learning disability.

It is usually the carer who has the expert detail of the most effective methods of communicating with, and therefore management of, the treatment regime of a patient with a learning disability.

Whilst it is imperative that staff meet the requirements of both informed patient consent and individual patient confidentiality issues, the potential valuable input from carers must also be recognised.

- The Operational Policy for the Deployment of Temporary Staff Appendix 6 **'GUIDANCE FOR THE NURSE IN CHARGE WHEN A CARER, PAID OR UNPAID FROM AN EXTERNAL AGENCY, TRUST OR FAMILY ATTENDS THE TRUST WITH A VULNERABLE ADULT WITH A LEARNING DISABILITY'**
details the role of carers whilst the patient with a learning disability is in hospital.
- **GUIDANCE ON ACQUIRING A CARER BADGE FOR USE BY A CARER WHEN SUPPORTING A PATIENT WITH A LEARNING DISABILITY WHILST IN HOSPITAL**
Which identifies a carer of an in-patient with a learning disability. In this way the carer can be supported by staff whilst in hospital so ultimately enhancing the patient's stay.
- **GUIDANCE ON ACQUIRING A BLEEP FOR USE BY A CARER WHEN SUPPORTING A PATIENT WITH A LEARNING DISABILITY WHILST IN HOSPITAL.**
There are a number of bleeps available for use by carers so they can take the patient around the hospital premises yet still be contactable by ward staff when required to return for treatment.

GUIDANCE FOR THE NURSE IN CHARGE WHEN A CARER, PAID OR UNPAID FROM AN EXTERNAL AGENCY, TRUST OR FAMILY ATTENDS THE TRUST WITH A VULNERABLE ADULT, WITH A LEARNING DISABILITY / NEED

1.0 Paid carers

It has been agreed by the Lead Nurse Forum that if a paid carer attends the Trust with a vulnerable adult e.g. an adult with a learning disability, it is in the best interests of the patient that their carer /s remain onsite to aid in the care required.

This does not mean that

- ◆ The carer delivers the care required
- ◆ The carer is responsible for the patient

The carer's key role is to assist where necessary, to promote familiarity and so reduce fear and anxiety that the patient may be experiencing. The carer may also be key to communication with the patient.

It is the responsibility of the Nurse in Charge to ensure that all planned care and treatment, for the patient, is delivered appropriately and that

- ◆ The carer receives a rest break
- ◆ The carer is kept informed of progress on a need to know basis

The Trust will bear the cost of the carer which can be charged to the ward /Dept who is responsible for the patients episode.

The procedure for agreement to reimburse a carer or their employer must be followed.

- Prior to elective admissions a discussion between the paid carer/carer's employer and the nurse in charge will decide on the patient requirements for carer support.
- The nurse in charge will notify the relevant Matron of these arrangements via e-mail so there is a written record of the agreement.
- When the patient is admitted the carer hours worked will be recorded on the relevant form. See *'Record of 1:1 Supervision, appendix 1 of Trust Guidelines for the 1:1 Supervision of Patients who are Unable to maintain their Own Safety.'*
- It should be noted in the patient records that the patient has a paid carer with them.
- The carer's employer will submit an invoice to the ward for reimbursement.
- In the event of an emergency admission of a vulnerable adult, the Nurse in Charge will still report the agreement for patient requirements for a paid carer to the relevant Matron.
- Out of hours this agreement should be reported to a Hospital Co-ordinator and to the relevant Matron at the first opportunity.

2.0 Family or Friends in a Caring Role

An unpaid carer may also fulfil the role of assisting with a vulnerable patient where necessary, to promote familiarity and so reduce fear and anxiety that the patient may be experiencing. The carer may also be key to communication with the patient.

This does not mean that

- ◆ The carer delivers the care required
- ◆ The carer is responsible for the patient

It is the responsibility of the Nurse in Charge to ensure that all planned care and treatment, for the patient, is delivered appropriately and that

- ◆ The carer receives a rest break
- ◆ The carer is kept informed of progress on a need to know basis
- ◆ The carer feels free to leave the ward area in the knowledge that their family member will be cared for appropriately

These Guidelines are to be used in conjunction with the
TRUST GUIDELINES FOR THE SUPERVISION OF PATIENTS WHO ARE
UNABLE TO MAINTAIN THEIR OWN SAFETY. Nov 03

GUIDANCE ON ACQUIRING A CARER BADGE FOR USE BY A CARER WHEN SUPPORTING A PATIENT WITH A LEARNING DISABILITY WHILST IN HOSPITAL

Aim

To access a CARER badge to ensure appropriate support is given to a carer accompanying a vulnerable in-patient

Scope

Patients with learning disabilities are usually accompanied to hospital by a carer, either a relative or paid carer.

It is usually in everyone's best interests that a carer stays throughout the whole in-patient episode.

To ensure that the carer is supported whilst in the hospital they are identified by a CARER badge.

Process

- 12 CARER badges will be held by Amanda Green, Patient Advice and Liaison Services (PALS) Manager
- The PALS Manager will issue a CARER badge at the request of a ward manager or appropriate matron (or designated other).
- If the patient is to come into the Trust as an elective admission then the CARER badge can be pre-booked for the anticipated day of admission.
- The PALS Manager should be contacted by telephone 6066 to arrange a mutually convenient time to collect the badge.
- The collecting nurse will sign for the badge giving an approximate length of time for expected use.
- When the CARER badge is given to the carer the nurse must emphasise that this badge is the property of the Countess of Chester Hospital.
- The carer should be asked to sign an agreement (*Appendix 1*)
- It should be worn only within the hospital premises and not taken home even if the carer is going home to return the next day.
- When the patient is discharged or no longer has an accompanying carer the CARER badge must be returned to the PALS Manager again at a mutually convenient time.
- The ward is responsible for the safe keeping of the badge and must ensure that it is returned in a timely manner.
- The PALS Manager will keep a record of CARER badge issue and details.
- The issue of these badges will also enable an audit of the number of carers supported by the Trust. Consequently it is important that badges are not retained on a ward or passed from one patient carer to another.
- Out of hours or at the weekend a Hospital Co-ordinator can access a CARER badge from the box file in the PALS Manager office by completing the relevant documentation.

Wearing the badge

- Will identify a paid or un-paid carer who is supporting an in-patient with a learning disability.
- Will signal to the ward/departmental team that the Carer's needs should be met.
- The carer should be offered drinks
breaks to go for meals
use of the staff toilet
- Will **not** mean that the carer is responsible for the patient or that they carry out the planned treatment.
- The ward staff remain responsible for the care and treatment of the patient with a learning disability just as they do for all the patients in their care.

Jill Heaps
November 2003

Appendix 1

Countess of Chester Hospital

NHS Trust

NOTICE FOR CARERS

- This badge is the property of the Countess of Chester Hospital
- This badge must only be worn within the Countess of Chester Hospital premises
- On no account should the badge be worn outside the hospital premises.
- The badge must be given to ward staff whenever you leave the hospital.

I have understood and agree to the above conditions.

Carer signature..... Date.....

Carer's address.....

.....

.....

Telephone number

Patient name.....

Ward

GUIDANCE ON ACQUIRING A BLEEP FOR USE BY A CARER WHEN SUPPORTING A PATIENT WITH A LEARNING DISABILITY WHILST IN HOSPITAL.

Aim

To provide appropriate support to the carer of an in-patient with a learning disability.

Scope

Patients with learning disabilities are usually accompanied to hospital by a carer, either a relative or paid carer.

There are circumstances when the patient is better managed if they are not restricted to the ward. The carer may need to walk the patient around the hospital yet remain in touch with the ward.

The carer may also need to leave the ward for a period of time but be contactable by the ward staff.

Having a bleep should ease these circumstances.

Process

- 2 bleeps will be held by Amanda Green, Patient Advice and Liaison Services (PALS) Manager
- The PALS Manager will issue a bleep at the request of a ward manager or appropriate matron (or designated other).
- The PALS Manager should be contacted by telephone 6066 to arrange a mutually convenient time to collect the bleep.
- The collecting nurse will sign for the bleep giving an approximate length of time for expected use.
- When the bleep is given to the carer the nurse must emphasise that this bleep is the property of the Countess of Chester Hospital.
- It should be used only within the hospital premises and not taken home even if the carer is going home to return the next day.
- When the patient is discharged or no longer has an accompanying carer the bleep must be returned to the PALS Manager again at a mutually convenient time.
- The ward is responsible for the safe keeping of the bleep and must ensure that it is returned in a timely manner.
- Out of hours or at the weekend a Hospital Co-ordinator can access a bleep from the box file in the PALS Manager office by completing the relevant documentation.

Appendix 2

Countess of Chester Hospital

NHS Trust

NOTICE FOR CARERS

- This bleep is the property of the Countess of Chester Hospital
- This bleep must only be used within the Countess of Chester Hospital premises and grounds.
- On no account should the bleep be used outside the Countess of Chester Health Park
- The bleep must be given to ward staff whenever you leave the hospital.

I have understood and agree to the above conditions.

Carer signature..... Date.....

Carer's address.....

.....

.....

Telephone number

Patient name.....

Ward

PROTOCOL FOR ADMISSION TO HOSPITAL FOR ADULTS WITH LEARNING DISABILITIES

3 INTRODUCTION

- 1.1 The responsibility for medical and nursing care provided to people with learning disabilities will remain with the hospital at all times during their inpatient stay.
- 1.2 People with learning disabilities have the right to the same level of medical and nursing care as that provided to the general population. This care must be flexible and responsive and any diagnosis or treatment must take into account any specific needs generated by their learning disability.

4 INITIAL CONTACT WITH HOSPITAL SERVICES

The health care needs of people with learning disabilities are usually met by their GP and the Primary Care Team at their Health Centre. Occasionally however it may be necessary for a referral to secondary services. It is at the point of referral that a person with a learning disability needs to be identified in order to ensure that advance planning is undertaken to address any specific needs and where necessary to modify investigations or treatment to meet those needs.

- 4.1 GP's will be encouraged to identify a person with a learning disability when they are referred to hospital services and provide brief information about other professionals involved in their care.
- 4.2 Medical Secretaries and clerical officers are often the first line of contact in the referral process. Where it is known that a person has a learning disability, secretarial or clerical staff will attach a coloured sticker to the cover of the patients medical notes. This will highlight to secretarial, clerical, nursing, medical and other professional staff that the person may require specific care or support and they need to look inside the front cover of the medical notes for further instructions.
- 4.3 Inside the front cover of the medical notes will be a telephone contact number for the learning disability specialist/consultant nurse. Upon referral to hospital services medical secretaries and clerical officers will be asked to notify the specialist/consultant nurse whenever a person who is known to have a learning disability is sent an appointment date for attendance at the hospital.
- 2.4 Once the specialist/consultant nurse has been informed of their appointment date, they will contact the patient and where appropriate any carers, professionals or services involved with that person, and discuss any specific problems that may be caused by their attendance at hospital. Any such problems can then be addressed prior to their appointment.

- 3.1 Referrals may come from sources other than GP's such as community nurses or clinical nurse specialists. In these cases the protocol is as outlined previously. Clerical officers and medical secretaries are instrumental in the success of this aspect of the protocol.

4 ROUTINE PLANNED ADMISSIONS

- 4.1 If the person is to be admitted to hospital then where possible/appropriate they will be sent a date to attend the hospital for pre-clerking.
- 4.2 At the pre-clerking visit the person will be offered the opportunity wherever possible, to look around and familiarise themselves with the hospital prior to the admission. It may be possible to borrow video or audio tapes about the hospital where available if the person is not able to attend hospital prior to admission.
- 4.3 Along with the appointment date and other hospital information, the patient will be sent a detailed pre-admission questionnaire which will require completion by either the patient or a carer and returned to the pre-clerking clinic or to the specialist/consultant nurse prior to their admission. The information will provide the basis of their care plan on admission.
- 4.4 If the pre-admission questionnaire is not completed prior to admission then it will be necessary to complete one at the time of admission.
- 4.5 The person will be asked to bring into hospital any 'Life Book' they possess which may assist hospital staff to provide more individualised care during their stay. Where possible/appropriate some documented information generated during their stay in hospital may be incorporated into the 'Life Book' for future reference if the person has to come into hospital again at any time.
- 4.6 Having made contact with the person prior to their admission, the specialist/ consultant nurse will act as a co-ordinator between the nursing staff in the hospital, community based professionals and services, and the patient and then- regular carers).
- 3.7 The specialist/consultant nurse will be able to coordinate the community pre-admission preparation work with the patient to help them understand hospital procedures and treatment.
- 4.7 Where appropriate advice and training will be offered to hospital staff on how to enable the learning disabled person to gain the maximum benefit, with least distress, from their stay in hospital. Support with communication and assisting understanding will be a priority.
- 3.9 Hospital staff will be encouraged to contact the specialist/consultant nurse at any time before or during admission, for advice and support.

- 3.10 The specialist/consultant nurse will visit the ward to see the patient and ward staff during their stay. This should enable issues to be addressed before they become problematic or disruptive.
- 3.11 If a patient has profound or complex disability, then the specialist/consultant nurse would offer more intensive advice and support to staff than for other patients with learning disabilities. This would **not** involve hands on support unless point 3.12 applies.
- 3.12 In exceptional circumstances, when a patient has challenging behaviour, the specialist/consultant nurse may assist with "hands on" practical support to manage the challenging behaviour, in order that hospital staff can medically treat the individual.

Challenging behaviour in this instance would be defined as behaviour of such an intensity or duration, that it severely affects the individuals opportunity to receive treatment and/or presents a risk of harm to the individual, other patients or staff.

- 3.13 The specialist/consultant nurse will work closely with hospital and community staff to develop effective discharge plans and coordinate support of the patient post discharge.

3 EMERGENCY ADMISSION

- 3.1 Staff on Accident and Emergency or Emergency Admissions Unit Departments will *notify* the specialist/consultant nurse when a patient with a learning disability is admitted to hospital through either of these departments.
- 3.2 4.2 If the admission takes place during the day, then contact will be made with the ward that day where possible. If the admission is out of hours, then contact will be made as soon as possible.
- 3.3 In exceptional circumstances when a patient has a challenging behaviour as detailed in point 3.12, "hands on" support may be accessed "out of hours" through the hospital bed manager/site manager.

4 OUTPATIENT APPOINTMENTS/DAY CASE SURGERY

- 5.1 The specialist/consultant nurse will be available to offer support and advice to outpatient staff and those involved with day case surgery.
- 4.1 The specialist/consultant nurse will be able to co-ordinate community work with the patient to prepare them for their outpatient appointment or day case surgery.
- 5.3 In exceptional circumstances, the specialist/consultant nurse may meet patients for outpatient appointments or day case surgery (for example see point 3.12)

PROTOCOL FOR ADMISSION TO HOSPITAL FOR CHILDREN WITH LEARNING DISABILITIES

5 INTRODUCTION

- 5.1 The responsibility for medical and nursing care provided to children with learning disabilities will remain with the hospital at all times during their inpatient stay.
- 5.2 Children with learning disabilities have the right to the same level of medical and nursing care as that provided to the general population. This care must be flexible and responsive and any diagnosis or treatment must take into account any specific needs generated by their learning disability.

6 INITIAL CONTACT WITH HOSPITAL SERVICES

The health care needs of children with learning disabilities are usually met by their GP and the Primary Care Team at their Health Centre. Occasionally however it may be necessary for a referral to secondary services. It is at the point of referral that a child with a learning disability needs to be identified in order to ensure that advance planning is undertaken to address any specific needs and where necessary to modify investigations or treatment to meet those needs.

- 2.1 GP's will be encouraged to identify a child with a learning disability when they are referred to hospital services and provide brief information about other professionals involved in their care.
- 6.1 Medical Secretaries and clerical officers are often the first line of contact in the referral process. Where it is known that a child has a learning disability, secretarial or clerical staff will attach a medical alert sticker to the outside of the notes and information sheet inside the front of their notes. This will highlight to secretarial, clerical, nursing, medical and other professional staff that the child may require specific care or support and they need to look inside the front cover of the medical notes for further instructions.
- 6.2 Inside the front cover of the medical notes will be a telephone contact number for the neurology nursing team. Upon referral to hospital services medical secretaries and clerical officers will be asked to notify the neurology nursing team whenever a child who is known to have a learning disability is sent an appointment date for attendance at the hospital.
- 6.3 Once the neurology team has been informed of their appointment date, they will contact the family and will arrange a home visit if this is required. They will also contact other professionals or services involved with that child and their family to discuss any specific problems that may be caused by their attendance at hospital. Any such problems can then be addressed prior to their appointment.

- 3.1 Referrals may come from sources other than GP's such as community nurses or clinical nurse specialists. In these cases the protocol is as outlined previously. Clerical officers and medical secretaries are instrumental in the success of this aspect of the protocol.

4 ROUTINE PLANNED ADMISSIONS

- 4.1 If the child is to be admitted to hospital then where possible/appropriate the neurology link nurse will organise a home visit to prepare a profile of the child and a member of the neurology nursing team will visit the ward area and go through the profile with the nursing staff and other professionals as is required or appropriate.
- 4.2 The child and family will be asked to bring their personal profile/life book into hospital which may assist hospital staff to provide more individualised care during their stay.
- 4.3 Having made contact with the child and their family prior to their admission, the neurology nursing team will act as a co-ordinator between the nursing staff in the hospital, community based professionals and services, and the child and their families.
- 4.4 The neurology nursing team will be able to coordinate the community pre-admission preparation work with the child and their family to help them understand hospital procedures and treatment
- 4.5 Where appropriate advice and training will be offered to hospital staff on how to enable the learning disabled child and their family to gain the maximum benefit, with least distress, from their stay in hospital. Support with communication and assisting understanding will be a priority.
- 4.6 Hospital staff will be encouraged to contact the neurology nursing team at any time before or during admission, for advice and support.
- 3.7 The neurology nursing team will visit the ward to see the child, their family and ward staff during their stay. This should enable issues to be addressed before they become problematic or disruptive.
- 4.7 If a child has profound or complex disability, then the neurology nursing team would offer more intensive advice and support to staff than for other children with learning disabilities. This would **not** involve hands on support unless point 3.9 applies.
- 3.9 In exceptional circumstances, when a child has challenging behaviour, the neurology nursing team may assist with "hands on" practical support to manage the challenging behaviour, in order that hospital staff can medically treat the child.

Challenging behaviour in this instance would be defined as behaviour of such an intensity or duration, that it severely affects the child's opportunity to receive treatment and/or presents a risk of harm to the individual, other children or staff.

- 3.10 The neurology nursing team will work closely with hospital and community staff to develop effective discharge plans and co-ordinate support of the child and their family post discharge.

3 EMERGENCY ADMISSION

- 3.1 Staff on Accident and Emergency or Emergency Admissions Unit Departments will notify the neurology nursing team when a child with a learning disability is admitted to hospital through either of these departments.
- 3.2 If the admission takes place during the day, then contact will be made with the ward that day where possible. If the admission is out of hours, then contact will be made as soon as possible or a message left on the answer machine service.
- 3.3 In exceptional circumstances when a patient has a challenging behaviour as detailed in point 3.9, "hands on" support may be accessed "out of hours" through the 089 bleep holder.

4 OUTPATIENT APPOINTMENTS/DAY CASE SURGERY

- 4.1 The neurology nursing team will be available to offer support and advice to outpatient staff and those involved with day case surgery.
- 4.2 The neurology nursing team will be able to coordinate community work with the child to prepare them for their outpatient appointment or day case surgery.
- 5.3 In exceptional circumstances, the neurology nursing team may meet a child and their family for outpatient appointments or day case surgery (for example see point 3.9).

CARE PROTOCOLS

- **PROTOCOLS FOR ADMISSION TO HOSPITAL FOR ADULTS WITH LEARNING DISABILITIES**
- **PROTOCOLS FOR ADMISSION TO HOSPITAL FOR CHILDREN WITH LEARNING DISABILITIES**

PROTOCOL FOR ADMISSION TO HOSPITAL FOR ADULTS WITH LEARNING DISABILITIES

1. INTRODUCTION

- 1.1 The responsibility for medical and nursing care provided to people with learning disabilities will remain with the hospital at all times during their inpatient stay.
- 1.2 People with learning disabilities have the right to the same level of medical and nursing care as that provided to the general population. This care must be flexible and responsive and any diagnosis or treatment must take into account any specific needs generated by their learning disability.

2. INITIAL CONTACT WITH HOSPITAL SERVICES

The health care needs of people with learning disabilities are usually met by their GP and the Primary Care Team at their Health Centre. Occasionally however it may be necessary for a referral to secondary services. It is at the point of referral that a person with a learning disability needs to be identified in order to ensure that advance planning is undertaken to address any specific needs and where necessary to modify investigations or treatment to meet those needs.

- 2.1 GPs will be encouraged to identify a person with a learning disability when they are referred to hospital services and provide brief information about other professionals involved in their care.
- 2.2 Medical secretaries and clerical officers are often the first line of contact in the referral process. Where it is known that a person has a learning disability, secretarial and clerical staff will attach a coloured sticker to the cover of the patients medical notes. This will highlight to secretarial, clerical, nursing, medical and other professional staff that the person may require specific care or support and they need to look inside the front cover of the medical notes for further instructions.
- 2.3 Inside the front cover of the medical notes will be a telephone contact number for the learning disability specialist/consultant nurse. Upon referral to hospital services medical secretaries and clerical officers will be asked to notify the specialist/consultant nurse whenever a person who is known to have a learning disability is sent an appointment date for attendance at the hospital.
- 2.4 Once the specialist/consultant nurse has been informed of their appointment date, they will contact the patient and where appropriate any carers, professionals or services involved in that person and discuss any specific problems that may be caused by their attendance

at hospital. Any such problems can then be addressed prior to their appointment.

- 2.5 Referrals may come from sources other than GPs such as community nurses or clinical nurse specialists. In these cases the protocol is as outlined previously. Clerical officers and medical secretaries are instrumental in the success of this aspect of the protocol.

3. ROUTINE PLANNED ADMISSIONS

- 3.1 If the person is to be admitted to hospital then where possible/appropriate they will be sent a date to attend the hospital for pre-clerking.
- 3.2 At the pre-clerking visit the person will be offered the opportunity wherever possible to look around and familiarise themselves with the hospital prior to the admission. It may be possible to borrow video or audio tapes about the hospital where available if the person is not able to attend hospital prior to admission.
- 3.3 Along with the appointment date and other hospital information, the patient will be sent a detailed pre-admission questionnaire which will require completion by either the patient or a carer and returned to the pre-clerking clinic or to the specialist/consultant nurse prior to their admission. The information will provide the basis of their care plan on admission.
- 3.4 If the pre-admission questionnaire is not completed prior to admission then it will be necessary to complete one at the time of admission.
- 3.5 The person will be asked to bring into hospital any 'Life Book' they possess which may assist hospital staff to provide more individualised care during their stay. Where possible/appropriate some documented information generated during their stay in hospital may be incorporated into the 'Life Book' for future reference if the person has to come into hospital again at any time.
- 3.6 Having made contact with the person prior to their admission, the specialist/consultant nurse will act as a co-ordinator between the nursing staff in the hospital, community based professionals and services and the patient and their regular carer(s).
- 3.7 The specialist/consultant nurse will be able to co-ordinate the community pre-admission preparation work with the patient to help them understand hospital procedures and treatment.
- 3.8 Where appropriate advice and training will be offered to hospital staff on how to enable the learning disabled person to gain the maximum benefit, with least distress, from their stay in hospital. Support with communication and assisting understanding will be a priority.

- 3.9 Hospital staff will be encouraged to contact the specialist/consultant nurse at any time before or during admission for advice and support.
- 3.10 The specialist/consultant nurse will visit the ward to see the patient and ward staff during their stay. This should enable issues to be addressed before they become problematic or disruptive.
- 3.11 If a patient has profound or complex disability, then the specialist/consultant nurse would offer more intensive advice and support to staff than for other patients with learning disabilities. This would **not** involve hands on support unless point 3.12 applies.
- 3.12 In exceptional circumstances, when a patient has challenging behaviour, the specialist/consultant nurse may assist with "hands on" practical support to manage the challenging behaviour, in order that hospital staff can medically treat the individual.

Challenging behaviour in this instance would be defined as behaviour of such an intensity or duration that it severely affects the individuals opportunity to receive treatment and/or presents a risk of harm to the individual, other patients or staff.

- 3.13 The specialist/consultant nurse will work closely with hospital and community staff to develop effective discharge plans and co-ordinate support of the patient post discharge.

4. EMERGENCY ADMISSION

- 4.1 Staff on Accident and Emergency or Emergency Admissions Unit Departments will notify the specialist/consultant nurse when a patient with a learning disability is admitted to hospital through either of these departments.
- 4.2 If the admission takes place during the day, then contact will be made with the ward that day where possible. If the admission is out of hours, then contact will be made as soon as possible.
- 4.3 In exceptional circumstances when a patient has a challenging behaviour as detailed in point 3.12, "hands on" support may be accessed "out of hours" through the hospital bed manager/site manager.

5. OUTPATIENT APPOINTMENTS/DAY CASE SURGERY

- 5.1 The specialist/consultant nurse will be available to offer support and advice to outpatient staff and those involved with day case surgery.

- 5.2 The specialist/consultant nurse will be able to co-ordinate community work with the patient to prepare them for their outpatient appointment or day case surgery.
- 5.3 In exceptional circumstances, the specialist/consultant nurse may meet patients for outpatient appointments or day case surgery (for example see point 3.12).

PROTOCOL FOR ADMISSION TO HOSPITAL FOR CHILDREN WITH LEARNING DISABILITIES

1. INTRODUCTION

- 1.1 The responsibility for medical and nursing care provided to children with learning disabilities will remain with the hospital at all times during their inpatient stay.
- 1.2 Children with learning disabilities have the right to the same level of medical and nursing care as that provided to the general population. This care must be flexible and responsive and any diagnosis or treatment must take into account any specific needs generated by their learning disability.

2. INITIAL CONTACT WITH HOSPITAL SERVICES

The health care needs of children with learning disabilities are usually met by their GP and the Primary Care Team at their Health Centre. Occasionally however it may be necessary for a referral to secondary services. It is at the point of referral that a child with a learning disability needs to be identified in order to ensure that advance planning is undertaken to address any specific needs and where necessary to modify investigations or treatment to meet those needs.

- 2.1 GPs will be encouraged to identify a child with a learning disability when they are referred to hospital services and provide brief information about other professionals involved in their care.
- 2.2 Medical secretaries and clerical officers are often the first line of contact in the referral process. Where it is known that a child has a learning disability, secretarial or clerical staff will attach a medical alert sticker to the outside of the notes and information sheet inside the front of their notes. This will highlight to secretarial, clerical, nursing, medical and other professional staff that the child may require specific care or support and they need to look inside the front cover of the medical notes for further instructions.
- 2.3 Inside the front cover of the medical notes will be a telephone contact number for the neurology nursing team. Upon referral to hospital services medical secretaries and clerical officers will be asked to notify the neurology nursing team whenever a child who is known to have a learning disability is sent an appointment date for attendance at the hospital.
- 2.4 Once the neurology team has been informed of their appointment date, they will contact the family and will arrange a home visit if this is required. They will also contact other professionals or services involved with that child and their family to discuss any specific

problems that may be caused by their attendance at hospital. Any such problems can then be addressed prior to their appointment.

- 2.5 Referrals may come from sources other than GPs such as community nurses or clinical nurse specialists. In these cases the protocol is as outlined previously. Clerical officers and medical secretaries are instrumental in the success of this aspect of the protocol.

3. ROUTINE PLANNED ADMISSIONS

- 3.1 If the child is to be admitted to hospital then where possible/appropriate the neurology link nurse will organise a home visit to prepare a profile of the child and a member of the neurology nursing team will visit the ward area and go through the profile with the nursing staff and other professionals as is required or appropriate.
- 3.2 The child and family will be asked to bring their personal profile/life book into hospital which may assist hospital staff to provide more individual care during their stay.
- 3.3 Having made contact with the child and their family prior to their admission, the neurology nursing team will act as a co-ordinator between the nursing staff in the hospital, community based professionals and services, and the child and their families.
- 3.4 The neurology nursing team will be able to co-ordinate the community pre-admission preparation work with the child and their family to help them understand hospital procedures and treatment.
- 3.5 Where appropriate advice and training will be offered to hospital staff on how to enable the learning disabled child and their family to gain the maximum benefit, with least distress, from their stay in hospital. Support with communication and assisting understanding will be a priority.
- 3.6 Hospital staff will be encouraged to contact the neurology nursing team at any time before or during admission, for advice and support.
- 3.7 The neurology nursing team will visit the ward to see the child, their family and ward staff during their stay. This should enable issues to be addressed before they become problematic or disruptive.
- 3.8 If a child has profound or complex disability, then the neurology nursing team would offer more intensive advice and support to staff than for other children with learning disabilities. This would **not** involve hands on support unless point 3.9 applies.
- 3.9 In exceptional circumstances, when a child has challenging behaviour, the neurology nursing team may assist with “hands on” practical

support to manage the challenging behaviour, in order that hospital staff can medically treat the child.

Challenging behaviour in this instance would be defined as behaviour of such an intensity or duration that it severely affects the child's opportunity to receive treatment and/or presents a risk of harm to the individual, other children or staff.

- 3.10 The neurology nursing team will work closely with hospital and community staff to develop effective discharge plans and co-ordinate support of the child and their family post discharge.

4. EMERGENCY ADMISSION

- 4.1 Staff on Accident and Emergency or Emergency Admissions Unit Departments will notify the neurology nursing team when a child with a learning disability is admitted to hospital through either of these departments.
- 4.2 If the admission takes place during the day, then contact will be made with the ward that day where possible. If the admission is out of hours, then contact will be made as soon as possible or a message left on the answer machine service.
- 4.3 In exceptional circumstances when a patient has a challenging behaviour as detailed in point 3.9, "hands on" support may be accessed "out of hours" through the 089 bleep holder.

5. OUTPATIENT APPOINTMENTS/DAY SURGERY

- 5.1 The neurology nursing team will be available to offer support and advice to outpatient staff and those involved with day case surgery.
- 5.2 The neurology nursing team will be able to co-ordinate community work with the child to prepare them for their outpatient appointment or day case surgery.
- 5.3 In exceptional circumstances, the neurology nursing team may meet a child and their family for outpatient appointments or day case surgery (for example see point 3.9).

References

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Focus group for acute health care for people with learning disabilities, Sheffield (1999).

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Health of the Nation (1995) 'A Strategy for People with Learning Disabilities'.

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NHS Executive (1999) 'Once a Day', NHS Executive, London.



POLICY: SUPPORTING PEOPLE WITH LEARNING DISABILITIES TO ACCESS SECONDARY CARE ON A PRE-PLANNED AND EMERGENCY BASIS

CARTREFI CYMRU

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| Status: | Approved |
| Date status agreed by Senior Managers: | Jan 05 |
| Date status agreed by Council of Management: | March 05 |
| Author: | Margaret Flynn and Adrian Roper |
| Next review to be conducted by: | Date: June 2006 |
| | |

Any amendments to the policy are detailed on the Policy Information/ Amendment Tracking Form at the end of the Document.

This Protocol will require local agreements and amendments to be effective.

POLICY: SUPPORTING PEOPLE WITH LEARNING DISABILITIES TO ACCESS SECONDARY CARE ON A PRE-PLANNED AND EMERGENCY BASIS

Margaret Flynn and Adrian Roper

March 2005

Background

General hospitals vary in terms of scale, the kinds of needs they meet and the ways they meet these. Some of these ways are planned e.g. visits to out patients' facilities, to day care and admissions for elective surgery. Other admissions are unpredictable, such as those via Accident and Emergency Departments. This policy concerns both kinds of admissions.

Four presumptions inform this policy:

1. Hospital discharge planning must start from the premise that patients will return to their homes and to their pre-hospitalisation lives;
2. The support needs of vulnerable adults on admission to, and discharge from, hospital are varied and wide reaching and cannot be met solely by the NHS;
3. The participation of patients in their hospital discharge planning is critical to realising the best outcomes;
4. Willingness to engage with vulnerable adults* in hospital, their families and paid care-givers, is essential if they are not to be disadvantaged in the hospital discharge process.

* Adults who have been assessed by local authorities and are receiving services from the statutory, independent and voluntary sectors.

Improving health and health services, tackling health inequalities and ensuring effective services to people at risk of serious disadvantage are key NHS priorities (e.g. Welsh Assembly Government 2003). There is emerging evidence, however, that the secondary health care experiences of people with learning disabilities fall short of those of their non - learning disabled peers i.e. health professionals may overlook or minimise patients' symptoms as they may wrongly assume that these are a reflection of their learning disabilities; such patients may be denied investigations and treatment which are available to non-learning disabled patients; and they may misinterpret individual disorientation and distress as patients are transferred to and from departments/wards/hospitals and from one team of clinical staff to another, and respond by sedating them (Department of Health 1997, 1999, 1999a; Cumella and Martin 2001, Disability Rights Commission 2004). This echoes Cartrefi Cymru's growing experiential knowledge of supporting our tenants in hospital (e.g. Flynn et al 2003), i.e. we find that hospital staff:

- are often inexperienced in supporting adults with learning disabilities during episodes of acute care;
- are often inexperienced in communicating with patients with learning disabilities and in interpreting the ways in which they may indicate that they are in discomfort and distress;
- often act on incorrect assumptions about people's treatment needs that are unrelated to the reasons for their admission e.g. a former tenant, who required assistance with eating and drinking (which was not provided), had a peg feed tube inserted;
- may disregard a patient's basic needs such as hunger and thirst;
- may expect Cartrefi Cymru staff to sign consent to medical treatment forms;

- may fail to use the experiential knowledge of Cartrefi Cymru support staff;
- may assume that experienced Cartrefi Cymru support staff are ineligible to be members of, or to contribute to the work and deliberations of, Multi-Disciplinary Teams and assessments regarding patients' future care needs;
- expect Cartrefi Cymru staff to provide continuous support from admission through to hospital discharge.

This policy indicates Cartrefi Cymru's commitment to improving the experiences of people with learning disabilities in secondary care and commitment to purposeful collaboration with colleagues in health care and local authority service commissioning.

General Policy – Health and Well-being

It is Cartrefi Cymru's policy to be a health-conscious service and to support people in ways which promote good health and well being, including ensuring access to all services deemed necessary to secure this and to act as advocates for them in negotiating and receiving health services.

Cartrefi Cymru aims to minimise the anxiety that is associated with hospital appointments and admissions, and to ensure that service users are successfully treated so that they may return to their homes and familiar ways of life.

We will achieve these aims by:

- (i) establishing formal agreements with funders to clarify that funding will be sought to support service users in hospital. In the interim, we will respond to emergency requirements for in-hospital support for up to seven days. If funding is not confirmed within five days, two days notice will be served on the funder and copied to the hospital ward, senior hospital managers and the associated Health Board. All new contracts will take account of the importance of supporting service users in hospital;**
- (ii) sharing this policy with all Health Boards and Hospital Chief Executives;**
- (iii) informing people's relatives, friends and advocates of the lead support role we will assume where a service user supported by us is being admitted to hospital. However, if we have supported a tenant for less than 12 months, we will be guided by their relatives, friends and advocates;**
- (iv) competently supporting service users attending outpatient appointments/ pre-planned admissions to hospital, and specifically, by ensuring that:**

- at the point of admission, they are always accompanied by a member of staff who knows them and is well briefed about their (i) medical history and (ii) ongoing health care needs;
- the accompanying member of staff has contacted the hospital/ out patients department beforehand to outline the user's special requirements e.g. to explain that the user has a condition, such as autism, which requires special understanding; negotiating more time for the appointment because communication with the user is likely to take longer and require particular care; and/ or to request a pre-appointment/ admission visit to familiarise the user with the hospital

(and find out what the likely treatment will be, if this is unknown to staff) for example;

- the accompanying member of staff is prepared to describe to clinical staff what Cartrefi Cymru support staff have done to prepare the user and what has been explained so far. Such explanations should involve the user, whether or not hospital staff are familiar with their means of communication, e.g. 'Although N. does not speak, we always speak directly to him/ her and we explain things as we go along...' The staff member will remain with the user to assist with explaining procedures/ interpreting the users communications/ and with undressing/ dressing, for example. The staff member will take notes of what clinicians say. They should check out with the clinicians that their notes are accurate e.g. 'May I just check that I've got this right? N's diagnosis is...and the treatment you suggest is...'
- the accompanying support staff brings along users' favourite means of occupation such as listening to a DVD, looking at magazines, sewing, doing puzzles or drawing, for example, to make the experience of waiting more agreeable.

For users admitted on a pre-planned basis:

- the accompanying member of staff will bring sufficient, labelled medication for the duration of the visit (*this is critically important for users who take anti-convulsant medication*) – prepared with the assistance and contact details of the pharmacist. Staff will be prepared to discuss with admission staff how all medication should be managed, stored and administered, along with copies of (i) written information regarding the user's medication and doses (see Annex A), (ii) brief, basic information about the user e.g. their favoured way of being addressed ('He is known as Michael...'); contact address and phone number of the host Cartrefi Cymru service and senior manager; GP; next of kin; religion; means of communication; support needs in respect of toileting/ washing/ feeding/ drinking/ swallowing/ oral hygiene/ mobility/ use of aids; and information that the staff team believes is *essential to know* in order to realise good clinical outcomes and effective discharge planning (see Annex B); and (iii) the Hospital Admission Report (see Annex C for form and guidance);
- the accompanying member of staff will provide a list of the Cartrefi Cymru staff who will support the user for the duration of the stay, detailing the ways in which they may assist nursing staff e.g. with personal and oral hygiene (including care of dentures); with choosing what to eat; with eating/ drinking/ dressing/ undressing; responding to users' need to use the toilet, taking users to the toilet, helping them to use bedpans, commodes, urinals; maintaining their continence; or changing their continence pads and disposing of pads promptly; washing and drying bony areas (shoulders, elbows, heels, sacrum) and buttocks, and checking the condition and colour of skin; assisting users to change their position in bed or in seating. *It should be noted that these activities will be negotiated with ward staff;*
- the accompanying member of staff will ensure that the user's aids and equipment are available, clean and properly maintained;
- the accompanying member of staff will contribute to ward round discussions, clinical and case reviews and keep a record (for Cartrefi Cymru) of the decisions made. This record should be shared with other Cartrefi Cymru support staff, *and with clinicians* if their treatment decisions appear to conflict with those of their colleagues;

- the accompanying member of staff will adhere to Cartrefi Cymru's Confidentiality Policy and the provisions of legislation;
- the accompanying member of staff will be attuned to the importance of users receiving an effective service and will respectfully alert the ward manager (and the Cartrefi Cymru manager) to concerns regarding the user's care;
- on admission, the accompanying member of staff will ask for (i) a copy of the hospital's discharge policy so that they can begin the process of talking to the user about planning their discharge, and (ii) the name of the person with responsibility for co-ordinating all stages of the user's progress in hospital, including discharge, and the name of the associate co-ordinator for when the lead person is off duty;
- the hospital discharge policy will be shared with the Cartrefi Cymru service manager who will arrange to meet with the hospital discharge co-ordinator at the earliest opportunity. They will both play an important advisory role in (i) supporting the hospital discharge process, including the negotiation of home aids – hoists, grab rails, bath and shower seats - for example, as well as home supports arising from hospital treatment and (ii) endorsing the invaluable knowledge and expertise of Cartrefi Cymru support staff.

Cartrefi Cymru aims to preserve people's lives and reduce disability by securing prompt emergency treatment and transport to Accident and Emergency Departments to ensure that service users are successfully treated so that they may return to their homes and familiar ways of life.

We will achieve these aims by competently supporting service users admitted to Accident and Emergency Departments, and specifically, by ensuring that:

- all Cartrefi Cymru support staff and managers acknowledge the importance of accompanying service users who have had an accident, sustained a traumatic injury or have experienced a sudden change in their medical status. We recognise too the dangers in both over-interpreting and under-interpreting the gravity of symptoms which are potentially threatening to life or functioning;
- if a service user is not with support staff at the time when they require emergency treatment (perhaps a day service or employment training scheme contacts us) the support team and the service manager will be informed at the earliest opportunity. A member of staff will be identified to go directly to the Accident and Emergency Department, taking the user's medication and information about this (and if there is time, a favourite possession, which may be comforting for the user to have);
- if the service user is discharged home, the accompanying member of staff will check with clinical staff that it is safe to use a car to expedite the return home;
- the support staff/ manager will ascertain from reception staff where the service user is and offer to accompany him/ her as she awaits or receives treatment. If clinicians decide to admit the user to a ward, staff will remain with the user and inform Cartrefi Cymru colleagues and the next of kin at the earliest opportunity. In hospital, users will require their own medication, toiletries, towels, nightwear, and any aids they use on a daily basis. The transfer of these should be negotiated with the support team. At the earliest opportunity, the supports identified to people in hospital on a pre-planned basis (see above) will prevail;

- the service manager will arrange for Cartrefi Cymru staff to support the service user during their waking hours. The ward staff will have the service's contact details should assistance be required from Cartrefi Cymru staff during the night. If the prognosis is poor the service manager and colleagues will meet with the hospital discharge coordinator with a view to identifying and agreeing the end of life care options.

The roles of the support staff supporting users of Cartrefi Cymru services

It is the policy of Cartrefi Cymru that staff supporting users in hospital:

- carry Cartrefi Cymru identifying information with them at all times and show this to clinical staff;
- are familiar with the user's medical history and will provide clinical staff with copies of the information set out in Annexes A-C;
- demonstrate respectful communication with the service user, showing both compassion and empathy as unfamiliar ward routines and activities are explained for example;
- will seek explanations from clinical staff about their procedures and treatments and explain these to the user in ways that are understandable and seek to involve them in these discussions. (Bearing in mind that under stress, the user may not hear, understand or remember what has been said.);
- will contribute to discussions in ward rounds/ reviews/ discharge planning, showing courtesy at all times;
- will offer such assistance to clinicians as will expedite the user's treatment and improve their experience of being in hospital e.g. by offering continuity across wards/ staff teams and even hospitals;
- will assume a lead interpreting role on behalf of the service user e.g. 'When Huw does that, it means that...'
- will respectfully check out with clinicians that (i) they are familiar with earlier decisions (as recorded in the Hospital Admission Report) and (ii) the user is at risk of treatment such as sedation when support staff are absent. Staff will abide by all hospital rules and will accept the authority of responsible clinicians – except where they believe, in good faith, that challenging hospital rules or authority is the only way to prevent a service user from being at risk of unnecessary death, impairment or avoidable distress. In such an eventuality, the staff member will contact the Cartrefi Cymru service manager, the on-call senior manager and the care manager;
- report any concerns regarding the care of the user to the ward manager and to the Cartrefi Cymru service manager;
- maintain Cartrefi Cymru's Hospital Admission Records and have copies on the ward (for changeover purposes) and in the tenancy;
- know whether the service user has made a Will, and separately, a Living Will;
- assist the users to either do things for themselves or with the necessary support as *agreed with the ward staff*;
- decide with the user what they might wish to eat, bearing in mind the importance of variety and their known preferences/ allergies, and provide what assistance is required;
- assist nursing staff in toileting, washing, skin care and oral hygiene routines, taking specific needs and privacy into account;

- act to promote the user's welfare by finding enjoyable and familiar ways of occupying their time;
- maintain contact with people's next of kin and/ or friends and be tactful with them if they wish to visit a user who is very poorly;
- ensure that fresh drinking water is always available to the user.

Cartrefi Cymru staff supporting users in hospital *will not*:

- sign consent to medical treatment forms (and will refer clinicians to the Welsh Assembly Government's 2002 guides – see References);
- administer medication, except where this is agreed and administered in the presence of a clinician;
- engage in manual handling tasks alone (unless this is part of an agreed rehabilitation programme for which Health and Safety checks have been undertaken by the Service Manager or a trained Cartrefi Cymru officer);
- assume that they are aware of the implications of the user's changed health status for their support needs. These will always be negotiated with ward staff.

Making sense of Cartrefi Cymru's experiences of supporting adults with learning disabilities in secondary care

It is the expectation of Cartrefi Cymru that support staff will summarise their experience of supporting users in hospital at the end of a period in hospital. This will draw most particularly on the Hospital Admission Report with its daily recordings of events, procedures, concerns, experiences and decision-making. These summaries will be sent to the Regional Managers (within a week of the period in hospital) so that Cartrefi Cymru can begin to formally log the company's experience of supporting people in secondary care and prepare annual summaries for the hospitals concerned, the local authority concerned, and the Welsh Health Boards. In turn, at the end of each period in hospital, Cartrefi Cymru will invite the ward managers with whom we have worked to comment upon the quality of the support we have offered. It is the Cartrefi Cymru's hope that such rich feedback will play a part in improving the secondary care experiences of vulnerable adults.

Formalising Agreement

On admission, a copy of this policy should be signed by the ward manager and the Service Manager at the earliest opportunity.

Service Manager

Print name

Date

Ward Manager

Print name

Date

Learning Disability Hospital Trust Contact Information

Please note – these people are the Learning Disability Lead for each Trust. In most cases the individual hospitals and wards should be contacted for any specific information or questions.

| Name of Trust | Contact Person |
|---|---|
| 1. Bro Morgannwg NHS Trust 01656 752752 | Christopher Griffiths Consultant Nurse Learning Disabilities Chris.Griffiths@bromor-tr.wales.nhs.uk Telephone 01656 753403 |
| 2. Cardiff and Vale NHS Trust 029 2074 7747 | Via above |
| 3. Carmarthenshire NHS Trust 01269 841343 | No response |
| 4. Ceredigion & Mid Wales NHS Trust 01970 623131 | Chris Walsh Deputy Head of Nursing Chris.walsh@ceredigion-tr.wales.nhs.uk Telephone 01970 6355414 |
| 5. Conwy & Denbighshire NHS Trust 01745 583910 | No response |
| 6. Gwent Healthcare NHS Trust 01633 623623 | No response |
| 7. North East Wales NHS Trust 01978 291100 | Sonia Winley Health Liaison Nurse (Flintshire) Sonia_Winley@flintshire.gov.uk Kim Scandariato (Wrexham) (both) 6th Floor, Phase 4 County Hall Mold Flintshire CH7 6NN Tel: 01352 701081 |
| 8. North Glamorgan NHS Trust 01685 721721 | InformationGovernanceDepartment@ngram-tr.wales.nhs.uk |
| 9. North West Wales NHS Trust 01248 384384 | Peter Jones, Clinical Governance Co-ordinator, Learning Disability Services Peter.Jones@nww-tr.wales.nhs.uk North West Wales NHS Trust Staff Resource Centre Bryn-y-Neuadd Llanfairfechan Conwy LL33 OHH 01248 682608 |

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| 10. Pembrokeshire and Derwen NHS Trust 01437 764545 | No response |
| 11. Pontypridd & Rhondda NHS Trust 01443 486222 | Paul.Davies@Pr-Tr.Wales.NHS.uk Paul D Davies Acting Director of Nursing Pontypridd & Rhondda NHS Trust Royal Glamorgan Hospital 01443 443301 |
| 12. Swansea NHS Trust 01792 651501 01792 702222 | <p>The Trust does not have one lead/contact person who is responsible for the admission of people with a learning disability.</p> <p>Contact people are:</p> <p>Moyra Griffiths- Patient Experience Manager Glenda Lewis-Practice Developemnt Nurse, Elderly Care Jill Luckwell-Divisional Nurse/Service Manager – Elderly Mentally Ill Jenny Sanders- Divisional Nurse - Women and Children's Services Juanita Rees- Lead Nurse for Child Protection</p> <p>Glenda Lewis also has a protection of vulnerable adults role.</p> |