

## **Supporting Material**

## **Target 1**

### **Residential campus provision**

#### **Numbers of people on the list**

There are 5 people on our list - although one is the responsibility of North Tyneside Learning Disabilities team.

#### **Plans for each individual**

First two of 5 (although we have already achieved discharge for one person originally included within our campus population) could be discharged next month into an existing ISL vacancy and a specialist residential care service.

They do not have person centred plans but advocates involved for all and person directly involved in decision making processes.

Third person dependent upon shared ownership option. Full staff team in place. Timescale likely to be January 09. Person centred plan in place and advocate linked.

Person's 4 and 5 are currently living on-site in Northgate bungalows. Working group formed to consider service development, provider and possible relocation issues.

Both people are frail. Improvement in environment at the Bungalows as a result of a monitoring review by Les Pickering and PCT colleagues. Person centred plans have been refreshed and both indicate they wish to remain where they are. What is very clear is that every avenue is being considered to identify a positive change. However, it is also clear that there are plans to redevelop the Northgate site around the bungalows. This will mean massive change for the residents including being situated next to forensic patients. It is argued this is not acceptable and that they need to move in order to preserve the best aspects of residents' lives. It is suggested that this be taken forward on the basis of a move from the bungalows as a whole. The aim would be to minimise disruption whilst maintaining and promoting further the positive aspects of life together on the Northgate site now. The feasibility of this option will be debated and progressed through the North of Tyne Campus Group

Funding is committed for all people remaining in campus

#### **Is this covered in a Citizens First theme plan?**

Yes In Health Theme Plan

#### **If not, what more do we need to do?**

Needs to be reported as part of Health Theme Plan feedback February 2009

Campus re-provision needs to be reported more regularly to the Executive Group

## **Target 2**

### **2.1**

At the paid supporters day the following points were noted:

At the paid supporters day the following points were noted:

The Good Health Sub Group stressed the experience of pilot practices – the work was ongoing up to June 2007 so the experience was quite recent. It had been found that there were significant inconsistencies between CTLD lists and practice lists - in particular inaccurate coding – miss- reading and miss- coding. Everyone agreed there is an IT structure in place - therefore in this sense there is a system in place and so we are technically amber but there is an implicit assumption in this statement that the system will also be accurate which experience from the pilot practices (all of whom were regarded as being pretty forward thinking as regards learning disabilities) suggests is not the case. "Cleaning up" this data has to be a major priority to address as follow up action in primary , including referral and access to appropriate support in secondary care , can depend on the accuracy of coding used.

**ACTION: LES PICKERING/PCT IT COLLEAGUES**

The Good Health Sub Group , through its former chair , had argued for extra resources for a short period say about six months to ensure that CTLD and practice records tallied and that people were assessed as having a learning disability. However, this had not been taken forward. There is no consistent system in place. However, it may be that alternative models such as key characteristics checklist may be used to identify and then code people and if this is used on the back of the GP DES programme could lead to a quick gain in accuracy without expensive and time consuming use of psychology led CTLD resources. This needs to be explored

**ACTION:** LES PICKERING/MORAG HUNTER

Additional comment from CTLD feedback here was that GPs and others struggle to recognise difference between learning difficulty and learning disability. Clearly this may well be an issue to address in the GP training around DES payments

**ACTION:** LES PICKERING/MORAG HUNTER

At the simplified question follow up day People were asked if their GP knew they had a learning disability and people said yes and that they received the same treatment as anyone else

**Is this covered in a Citizens First theme plan?**

Yes

**If so which one**

Health Theme Plan and this is given high priority to address

However, at the moment we have only identified action relating to people with learning disability as opposed to

- Older family carers
- People from minority ethnic groups
- Carers of people from minority ethnic groups

**If not, what more do we need to do?**

As above

2.2 Self advocates were more positive about this than paid supporters' feedback

Self advocates felt that in the main primary care teams do try hard. One comment stressed they may not have time to have trained to understand people with a learning disability

CTLD response indicated

- No accessible information – i.e. reinforcement of point made by self advocates day for 2.3
- no health checks being undertaken
- No identified link workers with GP practices
- People with mild learning disability in particular may miss out because of the GP payments DES announcement

From the VP Now consultation response it is worth noting that the Board said

- The use of the primary care services framework should be given higher prominence. It is an excellent piece of work that must be used to produce national consistency.
- The responsibilities of primary and secondary care need to be made clear and explicit

**Is this covered in a Citizens First theme plan?**

Yes

**If so which one**

Health

**What more do we need to do?**

Implement DES guidance

2.3

Self advocates reported some did access mainstream services but that information was hard to understand

It was noted we have a very good dysphasia service

Paid supporters day and follow up consideration also identified

- specialist diabetes services

- podiatry

as other services to be covered by this question

**ACTION: MORAG HUNTER /KINGSLEY STRAKER /BILL NORMAN**

There was a very strong feeling that people with learning disabilities need additional support - its one thing to say they are being treated no differently but this is s no excuse not to identify and address the additional needs and action required to make people with learning disabilities equal

Since the consultation day, Les has taken a summary of Healthcare For All to the PCT executive team who have been very supportive of action required. They stressed the need to do more for all people with disabilities. We need to ensure that the specific needs of people with learning disabilities are explicitly identified and addressed. Contacts have already been established with colleagues with governance responsibilities. There is a need to get them more explicitly committed to this work

**ACTION: LES AND KINGSLEY**

CTLD feedback stressed

- Again , information not user friendly
- Consideration of longer appointment times not automatic
- No follow up from GP/service to patients who have been sent an appointment to ensure understanding and attendance

At the simplified question follow up session people were asked if they had been to health checks and people replied with a wide variety such as stopping smoking, breast cancer screening, Health checks for seizures

From the VP Now consultation response it is worth noting that the Board said

- Initiatives to promote the reduction of health inequalities must **not** be short term e.g. if we have a Strategic Health Co-ordinator post it must be a permanent one. We have seen a number of superb initiatives across this region cease because of restructuring, the disestablishment of health co-ordinator level posts or the cessation of short term funds.

**ACTION: LDDF pilot must secure long term funding outcome**

- There needs to be greater emphasis on the need for creative health promotion and the importance of the voluntary sector in this role
- Another respondent said she has a good doctor – she can explain things to her doctor but she could see this might be different if she could not say what was wrong with her. This emphasises the different treatment even WITHIN learning disabilities that people receive – i.e. if you can talk you still get a better deal that if you cannot. We have identified the “How to Talk to Me” part of a Health Action Plan as being especially important for people with communication difficulties

**Is this covered in a Citizens First theme plan?**

Yes

**If so which one**

Health

**What more do we need to do?**

See above

**2.4**

A varied response from self advocates very much reflecting what the CTLD say below

- Some said dentists were good at explaining things
- Others said very Difficult to get a dentist – have to use specialists, inaccessible buildings

There was particular concern re pharmacists at the self advocates day

At the paid supporters day discussion stressed this refers to whether people with learning disabilities get access to MAINSTREAM health services such as ordinary dentists. Mainstream professionals will tend to refer to specialist services if there is any evidence of a person having or could have a learning disability

People tend to be referred to CTLD in post operative care situations

There are of course examples of good practice but this does not happen through systematic application of informed practice. It was stressed that this does not detract from the good practice that does go on and again the need to capture, promote and build upon these examples was agreed to be a vital enabling task

CTLD feedback reinforced these perceptions. They highlighted

- Very variable – some effective, others are not
- Often people with learning disability do not access mainstream dentists. they access community dentist supported by community nurses - this can vary also

At the simplified question follow up session, people were asked if they felt comfortable going to see their dentist, chemist or other people about health. There were some numbers but mainly yes

**Is this covered in a Citizens First theme plan?**

Yes

**If so which one**

Health

**What more do we need to do?**

- The main task here is to make the best practice the norm across the city.
- We need to make contact with what ever local bodies for Opticians , Dentists and Pharmacists

Do NTW know of anybody they are aware of who they use (d) at Prudhoe and Northgate - who could serve as good practice to be promoted locally?

2.5

At the self advocates day people struggled to understand what this question meant fully. However ,one support worker supporting someone at the event noted that that people with learning disabilities need to make the most of new health facilities and this should be considered in the design and running health centres e.g. providing the equipment i.e. hoist , specialist bed to allow people to be examined in the health centre

One carer also asked us to use her personal experience to draw out issues around people's care when in hospital. These can be summarised as

- People with learning disabilities have the same physical needs anyone else in hospital. Basic nursing tasks e.g. –personal care , prevention of pressure sores apply just as much to people with learning disabilities – especially people who communicate without words
- People who communicate without words often have very subtle communication that takes time to understand - staff may not have the time to build up this understanding hence the communication element of a Health Action plan being even more important for this group of people
- People who communicate without words still need stimulation - again an important element of a Health Action Plan
- Staff need to understand that what they interpret as aggression may well be because a person is in severe pain or is very afraid of and cannot express themselves - anyone would be interpreted in this way if they could not communicate with words
- Patients are often a vital cog in the flow of communication between professionals who care for them whilst in hospital. This can disadvantage people who communicate without words - they cannot tell one professional what another said - at worst this can lead to inappropriate treatment

At the simplified question follow up session people were asked if you have been to hospital for treatment were you given any choice? The response was no. A second question asked Do you feel people took the time to explain things and there was a varied response here – some yes some no and a “sometimes”

**Is this covered in a Citizens First theme plan?**

Yes

**If so which one**

Health

**What more do we need to do?**

There is a lot more that we need to look at here

**Health care for All**

ACTION: IMPLMENT HEALTHCARE FOR ALL RECOMENDATIONS - LES THROUGH PCT

### **Issues for Liaison Nurse**

See carer's experience above

### **Unified health records – good practice from elsewhere**

- In other parts of the Region there were unified health records and wondered if this would be possible to implement in Newcastle also. It was agreed this need to be researched further
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ACTION: GOOD HEALTH SUB GROUP

### **Discharge policy**

- To what extent has the 2003 national Discharge policy that included a specific Learning disabilities section been implemented in Newcastle

ACTION: SECONDARY CARE WORKING GROUP OF THE GOOD HEALTH SUB GROUP

### 2.6

Les has identified cross references to other services as part of the work to develop the five year PCT plan - this stressed how learning disabilities need to be included as part of each of the strategic objectives . The action now will be to ensure these plans happen

ACTION: ENSURE PEOPLE WITH LEARNING DISABILITIES ARE EXPLICITLY CONSIDERED AS PART OF PCT FIVE YEAR PLAN

### **Is this covered in a Citizens First theme plan?**

Yes

### **If so which one**

Health

### **What more do we need to do?**

See above

### 2.7

At the self advocates day one person said they had seen letter about their health

At the simplified questions follow up session there was split vote to the question Would you like to see your health record – a mixture of yes and no's

### **Is this covered in a Citizens First theme plan?**

No

### **What more do we need to do?**

PCT Head of IT Ian Davidson has been contacted.

Main actions are now

- We need to make clear to him and his colleagues what additional needs people with learning disabilities and how these need to be taken forward
- Define what would make a health record accessible
- Justify how important this is under people rights
- Invite Ian to come to a Good Health Sub Group meeting to present on what could be achieved and how we might influence this

ACTION: LES AND KINGSLEY

### 2.8

At the self advocates day one person said "A lot of talk about this; very little progress"

There have been a number of approaches to engage BME communities debated by the LDPB. At the paid supporters day how existing BME families are engaged were discussed. A number of issues were identified.

This is seen as a Partnership Board priority. LDDF identified to take forward but so far not a joint approach because of changes in Equality and Diversity officer lead at PCT

### **Is this covered in a Citizens First theme plan?**

Yes

**If so which one**

BME communities Voices and Choices

**What more do we need to do?**

Perhaps this provides an opportunity to engage BME communities i.e. health might be a good “hook” to promote engagement

Need to discuss through with Anne Stokle and Alison De DeValle as leads in CTLD

WE need to identify a lead person who will take this forward long term

**ACTION: BILL NORMAN**

2.9 At the paid supporters day the following was stressed

- People with profound disabilities are one of the underpinning priorities throughout Citizens First
- Day centre manager leading on work from social care perspective
- Link with Long term conditions at PCT level and needs to be explored

At the simplified questions follow up session the question was asked of people with high support needs - Have you had any problems accessing help when you were ill. There was a yes reply here but unfortunately the respondent did not specify what problems there had been

**Is this covered in a Citizens First theme plan?**

Yes

**If so which one**

Voices and Choices

**What more do we need to do?**

The following actions were agreed

- Define who we mean by this group as some people will have lots of needs but would not be seen as high support in terms of profound disabilities
- Explore lead within CTLD – Could Communications service take this on

**ACTION: MORAG AND COLLEAGUES/LES**

- Consider a high support needs self advocate paid champion
- The Board needs to define a lead officer for high support needs - an underpinning theme

**ACTION : BILL NORMAN TO TAKE BACK TO LDPB****Target 3**

3.1

Action plan developed from Commission reports - available if required

Report approved through PB's Executive Group

Also reported to PB as part of Safety and Quality Theme in March 2008

Rejig of strategic Commissioning function and section in Adult Services bring together quality monitoring strands into integrated whole

NTW plans are reported quarterly to PCT

**Is this covered in a Citizens First theme plan**

Yes

**If so which one**

Safety and Quality

**If not, what more do we need to do?**

Make sure the Executive Group gets reports from NTW

Make sure the integrated monitoring function within Adult Services addresses Post Cornwall/Sutton plan and that this is reviewed on a quarterly basis

Make sure all of the PB guidance on safeguarding has been actioned

**ACTION : BILL NORMAN AND EXECUTIVE GROUP**

### 3.2

At the self advocates day a support worker noted that

Individual comment: there is no clear policy in place and support workers are often asked to sign consent forms on behalf of other people

There is a clear difference of opinion here as at the paid supporters' day it was argued that

- There are clear consent policies
- Clear evidence of this with both NTW and NUTHT
- There is a robust IMCA service and clear evidence of MCA training

CTLD said they agreed with this statement

#### **Is this covered in a Citizens First theme plan**

Yes

#### **If so which one**

Health

#### **What more do we need to do?**

- We need to be sure we can gather together evidence - this is the immediate action
- Review numbers of people trained re MCA in particular and set ongoing targets
- Identify a process for measuring staff understanding ( and therefore application in practice ) as opposed to mere awareness

#### **ACTION: GOOD HEALTH SUB GROUP TO REVIEW AND REFINE ACTION REQUIRED**

### 3.3

At the paid supporters day there was debate as to whether people with learning disabilities need to be identified in making complaints - there was an argument re why should they be – would this not be seen as discriminatory though the evaluation of ethnic monitoring was cited in response . Moreover, the recommendations from Healthcare For All suggest this is necessary.

So Patient Satisfaction Surveys are taken on a random sample basis. People with learning disabilities may be part of these. The question is whether the fact they may need additional support to complete has been identified - however acute colleagues stress that all patients are asked that question.

Moreover it was stressed that

- There is regular feedback to Trust board on complaints and patient satisfaction
- The trust are part of a national patient survey programme
- The PCT carry out their own survey

Nevertheless , there are many reasons why people might not complain in the first place so the Board needs to be satisfied

- People feel confident to complain if they want
- The process is accessible to them
- Concerns that do not reach complaint level are aggregated to detect trends

This needs to be added to the Good Health Sub Group's agenda

There is a need to think about verbal complaints and how these are recorded or rather, not how they might be recorded needs to be thought about – there is a need to capture all forms of informal feedback

There is also a distinction between those who use services regularly and who thus build up relationships and those who only access services as necessary – it is the latter group to whom we must first target action  
CTLD said agree but no experience in this area

#### **Is this covered in a Citizens First theme plan**

Not explicitly though it could be covered in the quality monitoring aspect of Safety and Quality

#### **What more do we need to do?**

There is arguably a lot of work to do based around gaining a better understanding of what happens now , what might be barriers and how these need to be addressed

#### **Gathering people's experiences**

- Engage PCT complaints lead

**ACTION: LES /KINGSLEY**

- How do PALS gather material that does NOT reach formal complaints procedure? We need to speak specifically to them and engage them in procedure? Take advantage of this being a North of Tyne wide service and two new PALS officers with specific learning disability remit having just been appointed
- Look at Liaison Nurse as being a link with PALS

**ACTION:SUB GROUP IN FINALISING LIAISON NURSE POST HEALTH ASSESSMENT**

**FRAMEWORK SUBMISSION**

- Review complaints procedures to make accessible
- Identify if Complaints Monitoring form picks up disability

**ACTION :KINGSLEY STRAKER**

- Use NTW health promotion days and other techniques to gather peoples stories
- Verbal complaints gathered at ward level

**ACTION : EVELINE/ELAINE TO DISCUSS WITH COLEAGUES**

3.4

At the self advocates a support worker noted that

“I think progress has been made across the health services and it has appeared to work better to help protect people from abuse”

At the paid supporters day it was argued that

- There are clear policies in place
- Safeguarding Adults has a clear multi agency system –policies available if required
- CTLD said CN advisor delivers safeguarding training and liaison in this area
- We adhere to safeguarding policy for Newcastle

**Is this covered in a Citizens First theme plan**

Yes

**If so which one**

Safety and Quality

**What more do we need to do?**

Review nature and frequency of safeguarding training within PCT

**ACTION : KINGSLEY STRAKER**

## Target 4

### 4.1

At the self advocates day it was argued by one person that people who are needing discharge have no where to go to and no services to support them

It was felt we are Red on this one but with aspects of clear progress towards amber i.e.

- There is a discharge protocol
- North of Tyne Campus Group have agreed a definition of delayed discharge
- North of Tyne Campus Group are stressing there should be tighter adherence to admission policy to help prevent unnecessary admissions

However, there are no arrangements for private hospitals

### Is this covered in a Citizens First theme plan

Yes

### If so which one

Voices and Choices – Local services for local people initiative

### What more do we need to do

North of Tyne Campus Group to identify potential discharges

### 4.2

At the self advocates day a support worker argued that

Disagree. I think there could be more. As from my experience the people I support have sometimes had to wait a long time for services

This disagrees with what was said by paid supporters and appears more in tune with CTLD feedback

Paid supporters' feedback noted the following here

- Mapping has been undertaken to identify gaps in current service provision/local infrastructure
- Review of specialist services and how they work together had been done but not implemented yet
- However a previous review led to establishment of BAIT and the current Putting People First derived scoping review of all joint working and how services should be structured will address this
- Argument is here we are a very solid Amber and can produce the evidence

CTLD written feedback argued the following

- Not enough out of hours support
- CTLD waiting lists reflect the fact more staff may be needed

### Is this covered in a Citizens First theme plan

Yes

### If so which one

Health

### What more do we need to do?

We need to look to see how we can move to Green

### **ACTION : KINGSLEY TO DO BENCHMARKING EXERCISE**

Make sure the Putting People First scoping review takes into account the priorities we need from specialist services and in particular, their relationship to general health care services

Make sure the Putting People First scoping review looks at effectiveness of services

### **ACTION: GROUP TAKING PUTTING PEOPLE FIRST SCOPING REVIEW FORWARD**

### 4.3

From the self advocates day it was argued that

- We need more demonstrable evidence of progress and
- one support worker noted that "They need more mainstream and specialist services to help make an easier transition and to enable the people we support to be supported nearer their own homes instead of having to go to specialist hospitals - miles away"

From paid supporters feedback the following was argued

We would say we were comfortably Red here with aspects of amber

The red conditions are

- Year 9 transition review takes place for all young people with full interagency involvement (*DFES*)
- There is a record and linked pathway in each locality of young people likely to need additional mainstream and specialist health supports or services in the coming five years
- Every child has a named personal adviser

We think we are also doing the following that qualifies as amber

- CTLD is a lifespan service
- Person centred planning underway at aged 14 years
- There is advanced planning for children with high support needs

CTLD written feedback argued the following

We understand that plans are in place. Needs to be multi agency with a worker identified

#### **Is this covered in a Citizens First theme plan**

Yes

#### **If so which one**

Growing Up

#### **What more do we need to do?**

Make sure we have evidence of progress and that this information can be captured routinely

#### 4.4

From the self advocates day two comments illustrated the range of opinion

- I think I could and would get support to do so
- Not really. We need to include family/supporters /relatives/changes are slow to develop

From paid supporters feedback the following was argued

There are three aspects we need to look at here

- Involvement in Partnership Board processes
- Involvement in general health care
- Involvement in specialist services

Discussion on the days largely centred upon Partnership Board because of the recruitment of the paid champions and so forth. Therefore in giving ourselves Red it was an evened out score across all three areas

#### **Involvement in Partnership Board processes**

There is a good start here through the Good Health Sub Group

There is a coherent structure in Good Health Sub Group - however there is no structure for what SUPPORTS this group's work

Everyone acknowledged that there need to be a lot more done starting with the development of the Health Champion

#### **Involvement in general health care**

- Acute hospital work

#### **Involvement in specialist services**

There is also work through

- NTW – Clinical work involvement which is going to be implement systematically over the next seven months

#### **Is this covered in a Citizens First theme plan**

Voices and Choices and Health

#### **What more do we need to do?**

#### **Involvement in Partnership Board processes**

- Follow up on Citizens First Launch Day suggestions e.g. drama group promotion
- Make Health Champion the priority champion to recruit
- Set up some form of Health Reference group once Health Champion recruited

#### **ACTION : GOOD HEALTH SUB GROUP**

##### **Others**

This is the Now action - Audit primary and secondary care against recommendations of Healthcare For All

4.5

From paid supporters feedback the following was argued

We should be rated solid Red

We think we can provide evidence e.g.

- through commitment to Putting People First derived scoping review initiated through Jackie Sochocka
- Citizens First itself

We are moving towards amber with the objective of an integrated management approach arising from Putting People First derived scoping review

**Is this covered in a Citizens First theme plan**

No

4.6 From paid supporters feedback the following was argued

- We are a weak red here and this needs some priority action
- No linkages between commissioning for learning disabilities and older people
- Not as well joined as it should be but it is getting better e.g. links with early onset dementia team
- Databases are in place
- Services audited against national pathways
- Need to get closer to OP services to make this a strong red

**Is this covered in a Citizens First theme plan**

Yes

**If so which one**

Voices and Choices and Health

4.7

From paid supporters feedback the following was argued

Solid Red

- Evidence of NE Autism consortium though everyone acknowledged this has been slow to start up
- There is also a NE Team and a commissioning strategy from the SHA out for consultation
- We do have one aspect of amber in that we are planning with people

We would look to make progress to this being amber in the next year

**Is this covered in a Citizens First theme plan**

Yes

**If so which one**

Health

**What more do we need to do?**

Implement Action Plan from commissioning strategy

4.8

From the self advocates day a support worker commented that there were not enough services

From paid supporters day the following was argued

We are Amber but not green in that we don't have evidence of specialised, localised commissioning.

However, excellent evidence of progress here in

- We have a Challenging Behaviour Strategy
- Behavioural Assessment Intervention Team – dedicated team in place for two years
- Separate Sub Group chaired by BAIT lead
- Timetabled PB Review as part of Health theme

To move to green we need to make the priority actions in the strategy happen fully

**Is this covered in a Citizens First theme plan**

Yes

**If so which one**

Health

**What more do we need to do?**

Tie in CB group work with North of Tyne Campus Group work

4.9

From paid supporters feedback the following was argued

We are a weak red and this needs to have priority action. Arguably, our weakest response to any statement.

This has not been part of the Good Health Sub Group's remit – there is an urgent need to identify where this action need to be taken forward

The priority action must be to move ourselves to a clear Red status this year

**Progress**

- We have had discussion re Green Light but these are only at preliminary stages
- NTW LD Contract monitoring meetings now have MH provider lead at the meetings
- Clear intention of model is to mainstream majority of people with small number of protected beds on the MH site

**Is this covered in a Citizens First theme plan**

Yes

**If so which one**

Health

**What more do we need to do?**

Move to clear Red this year

Les to consider if we need MH Commissioning lead at NTW contract meetings also

How can LD representation on LIT be taken forward? - It may be that particular sub groups' membership might be more appropriate

**ACTION : KINGSLEY AND LES TO DISCUSS WITH MH COMMISSIONING LEAD**

Ensure Primary care mental health workers are providing accessible services

Action now – should be to confirm protocols are in place

Action later this year – should be to confirm protocols are operational

**ACTION: LES PICKERING /DENISE WATSON (MH COMMISSIONING LEAD )**

4.10

From paid supporters feedback the following was argued

We are currently red but with green ambitions here in that we have a workforce plan with a clear set of actions and tasks that will be completed by the time of the first annual assessment

**Is this covered in a Citizens First theme plan**

Yes

**If so which one**

Safety and Quality ( under quality of support provided )

**What more do we need to do?**

Secure commitment from NTW HR and senior management to provide information and play a full role in the development of the plan

## **Consultation Process**

## Newcastle Learning Disabilities Partnership Board

### Health Assessment Framework response

#### Summary

A number of serious and consistent themes have emerged from this process:

- The need to convince services that being treated the same does not necessarily constitute equality. It is necessary to treat people with learning disability differently i.e. to identify what needs to be done over and above what is done for other groups in order to gain equal outcomes .
- Better engagement with GPs
- Better engagement with ALL health professionals
- Accurate, specific data on people's needs and service access gathered as routine
- Need for training of key professionals
- Accessible information and the need to prioritise how this is developed is vital
- Key concepts around access – consent and the Mental Capacity Act need to be given more high profile promotion

These are reinforcements of issues already identified in Health Theme Plan identified below. However, the process has also identified we should be doing **more** around

- For virtually every answer there were pockets of good practice being cited. We are failing to capture this and promote it. This needs to be addressed as a priority by the Partnership Board and ALL its partners.
- Specialist services leading good practice – see carers comments below
- Other **primary care** professionals' engagement and role - responses are variable and inconsistent – especially Dentists
- Capturing people's health stories and some methods of doing this
- Responsibility for progressing issues outside of the Good Health Sub Group's remit – especially around linking with Older People and Mental Health NSF/ joint commissioning work

#### Carers Centre's Comments

The following comments are from the Carers Centre which are more general comments rather than targeted at any one statement/question.

They emphasised the importance of the following

- GPs identifying all people on their practice lists
- Specialist staff in learning disability services need to lead by example – they need to show the way with other health professionals
- Health Action Plans
- Training for health professionals

#### Consultation process

The following consultation has been used to reinforce messages in this response

Self advocates	Consultation day Follow up with specific groups at Day Centre using simplified questions
Carers	Invited to consultation Day Specific consideration by Carers Centre
Paid supporters	Consultation day. Specific consideration by CTLD
All	Consulted upon Health as number one priority throughout consultation on Citizens First – February to May 2008

#### Suggestions for improvements

Area	Comments	Where from
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Questions	<p>The questions are about circumstances outside most people's experiences - learning disabled or not and therefore impossible to answer accurately if at all. Just because people are involved in some way with learning disability does not mean that they are familiar with all aspects of the services available. To involve learning disabled people in a broad based fact finding exercise like a Health Check is not appropriate. The insights are much more relevant and useful when they are talking about services that they know well</p> <p>Perhaps the questions need to be broken down with specific issues at the end of the report to reflect people's experience</p> <p>The questions are mainly written for professionals working in the various aspects of care and support for people for people with learning disabilities of various kinds</p>	Carers Centre
	<p>Questions should be rewritten and broken down into simple chunks</p> <p>Echoing the Carers Centre - concentrate on questions that mean something to people!</p> <p>When we used simplified questions for follow up session people understood how the questions related to them – these were based upon modifications done by colleague in Northumberland. Serious consideration should be given to using these next year</p>	Valuing People Development Worker
Preparation	<p>Keep question in mid throughout year and have a central point at which comments can be passed to Agree a date now in September next year for review Get a more central venue now Could have themed days on each of the areas</p>	Valuing People Development Worker
Facilitation	<p>Multi media support – pictures of local GPs and Hospitals Watch DVDs of going to hospital for example to get people in mood Interactive work e.g. taking blood pressure</p>	Valuing People Development Worker

### General background

Newcastle Learning Disabilities Partnership Board is just launching its three year strategy called Citizens First

This identifies nine themes to carry forward the work of Valuing People

Health is one of the themes and is designated the number one priority for the Board



The theme is reported every fourteen months to the Board

A theme plan has already been prepared by the Partnership Board's Good Health sub group, whose remit largely covers access to general health care. It is chaired by the North of Tyne commissioner for learning disabilities. The theme plan is reproduced below

Principal progress since the original drafting of Citizens First has included

- Health Action Co-ordinator post about to be recruited
- Liaison Nurse agreed to be funded by PCT, recruitment to begin in November
- LDDF funded Accessible Information audit and pilot gap address
- Suitable Health Action Plan format that could be used identified
- Development of Ten Top Tips for engaging hospital staff
- Expansion of Dignity in Care to Learning disabilities
- A paid self advocate Health champion to be recruited from December/January

Theme	Health
<p><b>Introduction :</b></p> <p><b>What does the theme cover?</b></p> <p>This is a central objective of Valuing People. People with learning disabilities have poorer health outcomes than general population. This is because of :-</p> <ul style="list-style-type: none"> <li>• Lack of good information and support for adopting healthy lifestyles</li> <li>• Ineffective access to general health services and a lack of health related advocacy support to make the most of opportunities to access appropriate services at appropriate times</li> <li>• People with learning disabilities more susceptible to a range of conditions than the general population</li> <li>• Health services being by and large ill prepared to know ,how to deal with people with learning disability</li> </ul> <p>The paper stated that people with learning disabilities should get the same, good quality, health services as everyone else the objective being <i>"to enable people with learning disabilities to access a health service designed around their individual needs, with fast and convenient care delivered to a consistently high standard, and with additional support where necessary."</i></p> <p>The two main requirements that Valuing People said must happen to help address these inequalities were Health Action Planning and Health Facilitation</p> <p>All people with learning disabilities were to have health facilitators by 2004 and all people were to be offered Health Action Plans by June 2005.</p> <p>Since Valuing People, there has been lots of guidance and reports in (see below for a selection) indicating nationally that not a lot of progress had been made and, if anything, the situation is getting worse in accessing secondary care.</p> <p>So , this theme covers</p> <ul style="list-style-type: none"> <li>• Making sure people get equal access to general health care services – primary ( including dentists , opticians as well as GPs ) and secondary care and</li> <li>• Refocusing specialist services ( like services for people with autistic spectrum disorder ) provided to people with learning disabilities to fulfil the principles of Valuing People</li> </ul> <p><b>What do we want as outcomes?</b></p> <ul style="list-style-type: none"> <li>• People will have clear plans about how to be and stay healthy</li> <li>• People will have their <b>right</b> to good health services honoured fully</li> <li>• People will have good support to help them get and use health services</li> <li>• People will have support and information to choose to take control of their health if they wish</li> <li>• People will play a big part in training professionals about the health needs of people with learning disabilities</li> <li>• People will take a big part in making all of the above happen</li> </ul>	

What have we got to take into account	
National	Local or Regional guidance
	
<p>The <b>main</b> reports and guidance include</p> <p>Signpost for Success – DH 1998</p> <p>Once a Day DH , 1999</p> <p>All means All – Valuing People Support Team, 2002</p> <p>CTLD Review Toolkit – 2002</p> <p>Discharge guidance 2003</p> <p>Treat Me Right – Mencap, 2004</p> <p>Equal Treatment , Disability Rights Commission 2006</p>	<p>Strategic Health Authority Performance Management Framework ( Health Assessment Framework)</p> <p>Strategic Health Authority Regional Public Health Strategy</p> <p>Newcastle Health Improvement Strategy</p> <p>NHS Disability Equality Scheme</p>

Death by Indifference Mencap 2007 GP Toolkit , DH 2006 Primary Care Service Framework , DH 2007 Specialist Health services Commissioning Guidance DH 2007 A Life Like No Other – Healthcare Commission 2007 Good Practice in Learning Disability Nursing Services DH 2007	
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**What's happening in Newcastle**  
**Traffic Light Colour - RED**  
 Despite a strong and committed sub group who have made substantial progress over areas they can influence or control, we are now over two years past the Valuing People target dates in making and delivering Health Action Plans for Newcastle mean this must be Red and the highest priority for the Board to get right.

**Progress To Date – What has really gone well**

There has been substantial progress made through the work of the Partnership Board in some key areas toward reaching the targets set out in Valuing People. This developmental work is imperative and must be in place to ensure delivery of the targets.

**Systems in place**

- The Partnership Board approved an Action for Health framework in February 2006. ( full, summary and Easy Read available from Bill Norman )
- There is a committed Health Sub Group in place including specialist NHS Trusts, Acute trust , carers , self advocates and supported living providers
- Regionally , Strategic Health Authority Framework Health Assessment Framework pioneered for all areas in the North East to use
- Primary Care Services Framework was published in July 2007 nationally and could be adopted as an effective tool in Newcastle
- Primary Care Trust Local Delivery Plan for 2007-08 includes plans and funding for Health Action Plan Co-ordinator post

**Capacity Issues**

- PCT Commissioner role that has been vacant for seven months, due to management restructuring within the PCT, is now filled.
- Temporary posts to undertake Community Services review of Community Learning Disabilities specifically has been appointed to.
- Health Action Coordinator post ( the equivalent of the Strategic Health Facilitator role outlined in the Primary Care Services Framework ) is ready to recruit to
- Health Action Plan formats have now been redeveloped
- Some Newcastle health professional staff have undertaken Inclusion North training
- The recently completed resettlement process for the last of the residential patients from Northgate and Prudhoe Hospitals has significantly enhances the specialist services available to people with learning disabilities within the City adding four new staff members to the CTLD, establishing a BAIT team of eight highly skilled staff, specialist palliative care nursing and nursing for assessment of continuing healthcare.
- Also provided through resettlement are the resources for community healthcare interventions facility which will prevent the inappropriate admissions to Northgate hospital though this development has still to be implemented.

**GP Registration**

- All people known to services are registered with a GP

## **Partnerships**

- Link to Health Services' Disability Equality Schemes and Health Improvement Strategy
- Excellent links with Newcastle Hospitals Trusts including their Equality and Diversity programme
- Voluntary sector commitment to health
- Liaison Nurse role identified as a priority action to improve understanding and support for secondary care staff
- Health Information partnership working

## **Initial Work**

- Much has been learned much from the initial work undertaken on a pilot project involving three GP practices which is leading to a new approach to the maintenance of accurate GP registers
- Inclusion North training on HAPs and Health Facilitation February 2007
- Dignity in Care programme extended to people with learning disabilities
- Analysis of what health information is being used by health professionals carried out by Better Days
- We have identified appropriate health information for a website that can be used by self advocates , carers and professionals

## **Future Steps – What do we still need to do**

As part of Citizens First the Partnership Board and Good Health group identified areas for future working. An Action Plan to make this happen is attached. These are the major areas we still have to tackle :

## **Capacity**

With the appointment of a Lead Commissioner and a prospective Health Co-ordinator it should be possible to:

- roll out the development of Health Action Plans or agreement of Health Facilitators
- to ensure consistency of quality of HAPs when they are being devised and implemented
- identify training requirements and training delivery
- enable primary care to take a higher profile role in implementation
- ensure the Good Health Sub Group is led by the PCT
- re-address the issues around IT resources necessary to support implementation of pilot project for HAPs and subsequent roll out
- look to implement the specific actions around Learning Disabilities in its Disability Equality Scheme Action Plan
- review the role and remit of Community Team Learning Disabilities in order to identify the best use of CTLD expertise to support the preferred model for Health Action Plans and Facilitators

## **Evidence base**

We have some useful but limited research on people perceptions of health but not their use of health services. We need to look to commissioning research to indicate how we compare in terms of health service access and peoples experiences of health services to other areas.

## **Technical**

Work with PCT and Trust IT services is required to give a more effective process to enable GPs to identify people with learning disabilities within practices, based on the work in the pilot project.

## **Ownership**

This is of great importance to ensure that there is support for and subsequently effective roll out of actions. We need:

- agreement across **all** stakeholders on the range of HAP formats and how they will be used
- to explicitly link our work to person centred planning

## **Support to secondary care staff**

The specific liaison role has been identified as being more important than training by NUT Hospital Trust staff

### Health Checks

The national policy promise was to introduce comprehensive health checks for people with learning disabilities is still to be delivered. However, introducing health checks does not have to wait for national agreement if the NHS Primary Care Contracting framework to commission these services locally is used

### Health promotion and screening

Health Promotion is important to drive the personalisation agenda. We need to:

- Identify and prioritise gaps in health information
- Address the health inequalities issues by identifying leads in Primary Care Trust to gain ownership and commitment to resources
- Start talks with Cancer and other screening programmes leads

### Specialist services

- Recent guidance needs to be reviewed by newly appointed lead commissioner

### Summary

Much has already been achieved in the delivery of improved healthcare for people with learning disabilities within the City but there are still significant tasks to be undertaken, particularly those related to the original Valuing People targets. However, the PCT and local healthcare providers are now in a much stronger position to work with others on the Partnership Board and the Good Health Group to deliver the outcomes described in the attached work plan.

National Policy			
Gap	Objective	Who	Principal Risks
Commitment to use Primary Care Service Framework	To agree plan for implementation of primary care service framework By June 2008 with particular emphasis	The Primary Care commissioner and LD Commissioner <u>Supported by:-</u> Good Health Sub Group, Supported Living Forum	Delay in taking forward Disability Equality Scheme commitments

Capacity			
Roll out development of Health Action Planning	To offer Health Action Plans to all people with learning disabilities By December 2010	HAP co-ordinator <u>Supported by:</u> strategic non learning disabilities services lead in PCT	Without the extra capacity from HAP co-ordinator post we will not be able to move this on

	To recruit Health Action Plan Co-ordinator By May 2008	Lead LD Commissioner at PCT <u>Supported by</u> NTW Trust	
	To offer Health Action Plans to all people with learning disabilities	HAP co-ordinator <u>Supported by</u> Primary Care and LD Commissioners CTLD Good Health Sub Group Three year timescale 500 per year Starting April 2008	Dependent upon HAP co-ordinator appointment and Primary Care engagement.
Implementation of Health Facilitators	To agree health facilitators for all people with learning disabilities	As above	Dependent upon HAP co-ordinator Process needs formal engagement of providers, carers organisations and PCT  Original AFH Framework timescale 18 months overdue
To ensure consistency of quality	To devise and implement system to monitor quality of Health Action Plans and Health Facilitation	Health Action Plan Co-ordinator <u>Supported by</u> PCT Service Quality lead , Good Health Sub Group By September 2008	Dependent upon HAP co-ordinator
Training	To ensure all health professionals working in target services are trained in awareness of people with learning disabilities' needs and what they have to do to access support if needed	Training leads in PCT and NHS Trusts <u>Supported by</u> Good Health Sub Group Health Action Plan co-ordinator June 2009	Target services are those services which people with learning disabilities are more likely to use Training tiers concept need to be implemented Dependent upon HAP co-ordinator Resources not identified or secured
	To ensure all other health professionals	Training leads in PCT and NHS	

	are trained in awareness of people with learning disabilities needs and what they have to do to access support if needed	Trusts <u>Supported by:</u> Good Health Sub Group, Health Action Plan co-ordinator by June 2012	
PCT Disability Equality Scheme Action Plan relating to learning Disabilities	Establish a programme to ensure that the elements relating to learning disabilities in the PCT Disability Equality Scheme Action Plan are implemented.	PCT LD Commissioning leads <u>Supported by</u> Other PCT Commissioning leads PCT Quality Lead Good Health Sub Group	Risk of Equal Treatment not being responded to locally if this doesn't happen
Newcastle Hospitals Trust Disability Equality Scheme Action Plan relating to LD	Establish a programme to ensure the need of people with learning disabilities are considered as part of the DES work	NUTH Trusts Equality and Diversity sub group	Lack of communication between partners
Community services Review	Examine the effectiveness of all the specialist NHS services provided in the community in Newcastle and make changes to ensure that they deliver the service in line with current best practice and in a way which maximises the benefit to local service users	PCT Project Lead <u>Supported by</u> Northumberland Tyne and Wear NHS Trust Adult Social Care Good Health Sub Group Timescale – February 2008 – June 2008	Timing of review compared to HAP implementation

<b>Evidence Base</b>			
Research into local peoples experience	To undertaken systematic study of people health experiences	Good Health Sub Group	Possible LDDF bid

<b>Technical</b>			
Implementing an improved LD Registration process	To secure dedicated time and support to ensure consistent recording and review process operated within all Primary care services in the City.	PCT Commissioning Lead <u>Supported by</u> , PCT IT , NTW IT Health Action Plan Co-ordinator , Good Health Sub Group By May 2008	Robust primary care LD register date is critical to whole VP programme

<b>Ownership</b>			
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Broad ownership of the Health Action Plan (HAP) concept	Agreement on range of HAP formats and how they will be used	People with learning disabilities through sub group member and all partnership board stakeholders	Must be a realistic timescale that we know is achievable
	Adopt the Health Action Plans format developed for users of the CTLD as a model for all HAPs	CTLD/NTW Commissioning Team Supported Living Forum Carers Centre NSNN By June 2008	
HAP Links to Person Centred Planning	To review linkages between sub groups	Valuing People Co-ordinator <u>Supported by</u> Person Centred Planning Co-ordinator Health Action Plan Co-ordinator	Confusion/overlap between initiatives
People taking control	To identify and explore opportunities for people with learning disabilities participation on local Expert patient programme	PCT Expert patient programme lead <u>Supported by</u> , Good Health Sub Group	Lack of accessibility to programme
To establish wider input of people with learning disabilities into Good Health Sub Group processes	Establish alternative vehicles to get service user voices heard	Self advocate Health champion, <u>Supported by</u> Good Health Sub Group , User Forum , Better Days , Health Action Plan Co-ordinator, Good Health Sub Group By August 2008	Time to support self advocates

<b>Support to Secondary Care Staff</b>			
Support to secondary care staff	To create a nurse liaison post to provide support advice information , specific training to secondary care staff in caring for people with a learning disability in hospital	PCT LD Commissioning lead <u>Supported by</u> NHS Trust Equality leads All Partnership Board	Not filling post quickly
	To make sure People with learning disabilities take a big role in training of health professionals	LD Liaison Post <u>Supported by</u> Training Leads, PCT& NHS Trusts Good Health Sub Group	

<b>Health Promotion and Screening</b>			
Identifying and prioritising gaps in health information	To identify 'easy to understand information' gaps in target services	Good Health Sub Group <u>Supported by</u> NTW Patient Information Centre, PCT Health Promotion, Other Partnership Boards  By June 2008	Build upon work from Better Days Bid for LDDF
	To commission and disseminate 'easy to understand' information to fill gaps in current availability	Good Health Sub Group <u>Supported by</u> Northumberland Tyne and Wear NHS Trust Accessible Information Partnership Josephine Project , LDF North Tyneside,  Programme over time Start July 2008	Build upon work from Better Days  Need commitment from services to develop as part of their budgets
	To use NTW website as a host for easy read health information , information for professionals and carers	Good Health Sub Group NTW , Supported by NTW Patient Information Centre, Other Partnership Boards	Possible; LDDF bid
Health Promotion programme	To identify and commission projects to enable people to get healthy	All voluntary sector members of the Board , Health and Wellbeing partnership  Rolling programme	Fundamental commitment and buy in to "non traditional" forms of health promotion delivery  Cohesion within Voluntary sector to offer united package

Health Improvement Strategy	<p>To ensure people with learning disabilities needs are reflected in the implementation of the Newcastle Health Improvement Strategy</p> <p>To ensure people with learning disabilities needs are reflected in the work of the Health and wellbeing of partnership</p>	<p>PCT LD Commissioning Lead  <u>With Support from,</u>          Director of Public Health , Health and Wellbeing Partnership,          Good Health Sub Group</p> <p>Ongoing</p>	<p>Cannot happen without commitment to leadership of sub group from PCT</p>
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<b>Development of Specialist Healthcare Services</b>			
Specialist services needed to meet Valuing People requirements	<p>To plan for the implementation of the healthcare components of the NHS North East strategy in accordance with its framework. This will need to be broken down into several secondary objectives once the process for implementation of framework agreed regionally</p>	<p>LD Commissioning lead at the PCT  <u>Supported by:</u>          PCT Quality Lead          SSD Adult Social Care Commissioning Team          Good Health Sub Group          Ongoing</p>	<p>Capacity to deliver at all levels</p>
<p><b>Main things we need to know to be sure this is working</b>            Initially, the most important things we need to know on a regular basis to be sure this theme is being delivered by the NHS are:-</p> <ul style="list-style-type: none"> <li>• The percentage of the people on the learning disability register who have a formally identified healthcare facilitator</li> <li>• The percentage of the people on the learning disability register who have had a formally arranged health check</li> <li>• The number of Health Action Plans offered</li> <li>• The number of Health Action Plans produced</li> <li>• The number of times Health Action Plans are used when people access services</li> <li>• The number of times that people are admitted to specialist learning disability hospital beds</li> <li>• The number of NHS and non- NHS staff trained in the use of health action plans</li> <li>• The number of complaints from people with health action plans about the way service providers have/have not used them</li> </ul>			