

"Getting Better"

Examples of the good practice

identified through the

North West

2010 Health Self-Assessment

by the

North West Health Equality

Group

Foreword

There is no doubt that incidents of appalling treatment to some people with a learning disability and their families continue to make the headlines and cause us all great concern.

Whilst these are a proper reminder to us all that we cannot be complacent they also hide the enormous amount of good work going on across all health services to try to ensure that people with a learning disability get proper access to, and quality of the health services they need.

Across the north west we have a reputation for being leaders in developing services for people with a learning disability and their family and whilst the recent self-assessment exercise carried out by PCTs showed areas for improvement it also highlighted many areas of good practice with staff, self-advocates and families working together to ensure better care and support.

This document sets out some of those best practices and gives all the opportunity to learn from the initiatives of others. We cannot afford to be complacent but equally we must acknowledge that much progress is being made.

I hope the contents of this document will inspire those who read it to double their efforts to improve services in this area.

John Boyington CBE
Chairman
North West Health Equalities Group

Introduction

Following the successful introduction of the first year Health Self Assessment across the North West, it was apparent that a lot of proactive work was taking place to improve the health experiences for people with learning disabilities. It was evident that the professionals involved were sometimes remiss in shouting out about all the good work that went on. In discussions with practitioners of all disciplines it was obvious that they did not see what they were doing as exceptional (i.e. it was normal practice for them). However, despite this practitioners did not have the time or indeed the confidence to share these achievements via the different professional journals that exist.

Therefore the idea for this catalogue of multidisciplinary good practice was developed. The "articles" within this document are the result. It does not portend to be an academic journal, but a showcase of some of the good work that has made a difference to the lives and health experiences of people with learning disabilities across the North West.

It is expected that a similar document will be collated; following year 2 of the Health Self Assessment, but that will be down to the willingness and contributions of practitioners following the validation process. One note of caution, if you wish to use any of this information, it is your responsibility to contact the individual involved as a matter of courtesy, and to acknowledge where your information has come from. You will need to also ensure that references are factual and current as these were not verified as part of the process.

Finally, I would just like to say thank you to all those who have contributed.

Sue Smith, Project Manager for the North West Health Equality Group.

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Bury PCP Charter

In the autumn of 2010 an audit was conducted across Bury funded Supported Living Providers to establish the degree to which Person-centred Planning was being implemented. The results were encouraging but left room for improvement. A number of concurrent developments followed which combined to influence the development of a Charter to support PCP.

1. As a result of the audit an LD Provider Forum was established to encourage and develop best practice in person-centred planning for Bury funded customers.
2. A set of seven minimum standards for PCP had been agreed by the Bury LDPB in 2005 and these were taken to the Forum to establish whether they were still fit for purpose in the light of practice moving on in Person-centred Thinking. Over a period of time, and with the involvement of the Bury LDPB, Bury People First, and the Personalisation Task Group of the Partnership Board, these standards were updated and expanded on to form ten governing principles for PCP. These were converted into Easy read format, with the support of Bury People First, with agreement at the Forum that there was only a need for the Easy read version to exist.
3. It was suggested that the development of a Charter for Providers might serve to support the development of good practice in PCP as well as acting as a public statement of support for PCP. The Forum members were unanimously in support of a Charter which had the ten principles at its heart.

At time of writing the plan is to launch the Charter in Bury in the autumn of 2011 with two separate events. Firstly, there will be a public launch of the Charter with a signing by Providers supporting it. Secondly, an information event will be held for people who use, or are likely to use services, and carers/family members to show them what they can expect from Providers if they purchase a service from them, or have a service commissioned on their behalf.

It is intended that the ten principles will be used as a means of guiding best practice in PCP and a quality measure for Quality Assurance processes. Future work also includes the development of a peer review system and the use of the forum to share good practice and to act as a 'critical friend' to its members. The wording of the Charter is likely to be as follows:-

'Person-centred Planning is a recognised way of helping learning disabled people gain more control over their lives.'

The Charter has ten principles developed in partnership between the Bury Learning Disability Provider PCP Forum, Bury Learning Disability Partnership

Board, and Bury People First. We agree to hold these principles as central to our planning with people. Page 2 lists all ten principles.

Principles of Person Centred Planning



Principle 1

The plan looks at the person as an individual. It shows all the things they want to do with their lives.



Principle 2

The person should have as much control as possible when making their plan.

They should be able to choose

- How the plan is made
- Where it is made
- Who is involved in making it



Principle 3

Those who are close to the person should be involved as much as the person wants them to be. This could include

- Family
- Friends
- Support workers
- Anybody who they trust



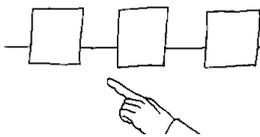
Principle 4

It is important that the person is fully involved in making their plan. People should be supported in a way that enables them to understand and contribute.



Principle 5

The plan should allow people to make important decisions about their lives. Those who are severely learning disabled should be given the chance to communicate this in a way that is suitable for them. Those who know the person well could help to make decisions with them.



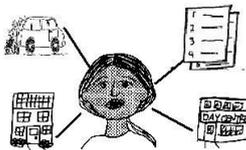
Principle 6

The person should set their own goals. They could get help with this if they need it. They should be able to choose the best way to check how things are going.



Principle 7

The planning process should be ongoing. The plan should be reviewed and the person should be able to add to or change the plan at any time.



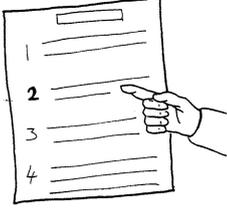
Principle 8

The plan should show what is good for the person. This should include what the person feels is important to them.



Principle 9

The plan must include any risks to the

	<p>person. It should show how the person will be supported through these risks.</p> <p><u>Principle 10</u></p> <p>The plan should show how personal goals will be achieved, including timescales, commitment, and supports required to make the plan happen.</p>
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North West Self-Advocacy: Staying Strong

Self-Advocacy is about people with learning disabilities coming together to speak up for themselves. The groups are led by people with learning disabilities working together, with support and training, to become more confident, to have their say and take greater control over their lives. Self-Advocates work locally, regionally and nationally to help ensure people with learning disabilities are treated fairly. We believe there are over forty active Self-Advocacy groups in the North West Region of England.

Nationally there is less money than recent years for Self-Advocacy groups to "speak up". Last year the Department of Health commissioned The National Self Advocacy Forum to write a report called *Staying Strong*. The report looked at how Self-Advocacy groups could stay strong and highlighted good practice across the country, offering information to support the future development of Self-Advocacy locally, regionally and nationally. The *Staying Strong* report can be downloaded from the National Forum Website www.nationalforum.co.uk

In July this year each region was asked by the National Forum to identify how things were going for advocacy groups in their area. The review looked at key areas including, self-advocacy membership, finance, workforce, and how groups were working with Learning Disability Partnership Boards.

The review consisted of telephone interviews with a sample of Co-ordinators of 17 local self-advocacy groups in the region. The key findings were that the 17 groups reviewed had a total membership of 581 self advocates.

The groups employed a total workforce of 56 people
33 members of the workforce had learning disabilities
23 members of the workforce did not have a learning disability.
12 employees were full time
44 employees were part time,
The 17 groups had a total of 49 volunteers.

The main funders of the groups were local councils and health agencies and some groups received funding from charitable trusts. Some groups were generating small amounts of income by offering training to the public and private sectors.
2 Groups were receiving less money from their main funders
11 groups were receiving roughly the same money from their main funders
4 groups were receiving more funding
Some groups were consulted about local issues at Partnership Boards and the Boards sub groups
Some Partnership Boards had regular councillor input so they knew about local issues
Most groups said they desperately needed more resources
Most groups wanted to make more connections to other advocacy groups locally regional and nationally
Some groups said longer term funding was needed so they could plan ahead.

It is clear that advocacy groups need to work harder to survive in the current economic environment and we believe some may not survive. Compared to other regions however;

the North West has a relatively strong self-advocacy movement. A reason for this situation might be the strong local and regional self-advocacy integrated planning infrastructure, despite the cessation of the National and Regional Valuing People Teams.

Currently self-advocate representation in regional planning is relatively strong in relation to:

- Housing
- Relationships Friendships and citizenship
- Finance
- Employment
- Health

Learning Disability Health issues are being championed on a regional basis in a number meetings and forums including:

The Regional Learning Disability Health Equalities Group is chaired by John Boyington CBE, CEO of Bury Health, with membership from Strategic Health Authorities, Local Authority and Health agency lead officers, family representation the North West Learning Disabilities Health Project Manager and members of the North West Training and Development Team.

The meaningful involvement of self-advocacy members in health Issues is continuously improving. Last year self-advocates were heavily involved in the interviews of lead officers in relation to the Health Self-Assessment validation process and were vital in the production of the North Wests Easy Read Health Self-Assessment Report led by Sue Smith. This work was cited as good practice by the National Forum Self Advocacy Group and recently presented to Ministers at the Learning Disability National Programme Board as an example of good work.

Other key structural supports for self-advocacy include the Annual Self Advocacy Regional Conference in Blackpool attended by over 120 Self advocacy delegates. At the event leading national regional and local figures attend to offer workshops, key note speeches and listen to self-advocate "big issues" and respond to rigorous and passionate questioning. In 2012 the conference will include Professor Jim Mansell of The Tizard Centre, Scott Watkins Mencap and formerly National Co Director of Learning Disabilities, The Regional ADSS lead for learning disabilities Liz Bruce and the National Self Advocacy co-chair Amanda Platts.

At the conferences, delegates vote for self-advocates they wish to represent them at the various regional planning meetings and at the national forum. Currently our two regional self-advocacy representatives are Karen Flood and Jonathan Hurley, whose role it is to represent the region at the National forum that in turn reports to the National Learning Disabilities Programme Board.

If you would like to find out more about National Regional and Local Self-Advocacy activity please contact: Dene Donalds NWTDT Regional Self-Advocacy Co-ordinator.
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Learning Together: The Benefits of Service User Involvement in Developing Clinical Outcome Measures

Following liaison with the Learning Together training group, the Psychology Department in Learning Disability Services, Lancaster, will be seeing improvements in the way they evaluate services in a client friendly way.

Caroline Maxted and Sue Knowles have been working within the Psychology Learning Disability Service as Trainee Clinical Psychologists for the past six months. It was felt that there was a need to review the outcome measure procedure currently used by the team and improve the mechanisms in operation to gain meaningful client feedback on the service. In order to address this, Caroline and Sue consulted with the Learning Together group at Lancaster College. This group consists of people with learning disabilities who provide training and consultancy to local services, including Lancaster University, on issues around working with, and recognising the needs of people with learning disabilities.

As part of the consultation process, Caroline and Sue attended the Learning Together Group's meetings to gain their ideas and feedback. This specifically focussed on methods of gaining feedback from service users with varying levels of ability and communication needs. Their input was vital in informing the psychology service's care pathway and both the layout and content of the evaluation sheets. Some of the members of the group were also willing to share their own experiences of psychological input and the evaluation process.

Caroline, who along with Sue consulted with the Learning Together Group, said, "We felt it was really important to get service user views on this, and working together with the Learning Together Group was a real pleasure. They came up with so many useful ideas and were so enthusiastic."

As a result of this process, the psychology service have redesigned their service care pathway and initial appointment letters, and have developed goal measurement sheets, practical information questionnaires and an adapted outcome measure for use with all clients who receive psychological therapy from the service. This outcome measure has been developed and is currently being piloted by another service in the North of England. This pilot will provide invaluable feedback on the service, which can aid service improvement and client / clinician collaboration.

This project has highlighted the importance of working alongside service users to develop systems and tools that address the needs of both clients and services; ensuring that service users are fully able to contribute to the evaluation process.

For further information on the outcome measures, please contact Sue Austen (Consultant Clinical Psychologist) on sue.austen@lancashirecare.nhs.uk
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Case Study Visiting the consultant

The care manager of a man with severe learning disabilities contacted the Learning Disability Hospital Liaison Nurse. She said that he had had a couple of failed appointments to see his consultant at the hospital because of his severe anxiety. This was causing him to be unable to wait any length of time and ultimately to leave the hospital before seeing the doctor therefore not receiving treatment for his problem which was now getting worse.

The Learning Disability Hospital Liaison Nurse spoke to the consultant's secretary, explaining the nature of Daniel's problem and requesting that Daniel had the first appointment of the day so that he didn't have to wait. She said she would arrange this with the consultant and report back. It was also requested that she make the clerk on the desk at Outpatients aware of Daniel's situation and that he would find it difficult to wait any length of time. The secretary later confirmed that she had arranged an appropriate appointment time for Daniel and his carer. This is the message received from the care manager:

'I thought you would like some feedback on Daniel's hospital last appointment. Spoke to his mum this morning who said it was first class treatment. At first Daniel had refused to go in the hospital and remained in the car so mum went in on her own to explain and was impressed that everyone was aware of what was happening, the consultant agreed to continue with the appointment managing to see Daniel at the end. So thank you for that it has allowed Daniel to be treated and also allayed lots of anxieties for mum and Daniel and also in the long run staff and myself'

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Health action plan research

Valuing People (DOH 2001) suggested that access to health could be improved by implementing the concepts of health facilitation alongside the implementation of health action plans to improve the health of people with learning disabilities. The health action plan would identify the health needs of the individual and how these needs could be addressed to improve the individual's life.

However, there was little guidance for people responsible for this implementation of health action plans and sparse information about whether health action plans were actually effective. There was a plethora of both national and international evidence relating to access to health for people with learning disabilities, some of which also reported on health screening and the outcomes. For example Kerr (2005) identified that of 181 people with learning disabilities screened 51% had unmet health needs and Lennox et al (2006) identified 17/23 people had skin abnormalities. However, this literature referred to small to medium size case studies only, with many studies having taken place outside of England. Only one study that I found related to health action plans, with a couple more discussing the benefits of patient held notes. These studies were locality based and none of them had reference to a larger national perspective.

As a result I completed a piece of practitioner research, for my PhD, to evaluate the experience of health facilitators in introducing health action plan nationally. In addition, to improve practice locally focus groups were completed with people with learning disabilities who had health action plans and supported living services health facilitators in my locality. The local and national practices were compared as part of the research and the results of the local research informed and changed practice regarding health action plans. This research was undertaken before the DES for health checks was introduced, but some areas were still embracing the concept of Local Enhanced Service for health checks.

This article will focus on the national part of the research.

Aims of the research

To determine whether health facilitators and people with learning disabilities consider that the introduction of health action plans have resulted in health improvements for people with learning disabilities living in England

To evaluate the experience of people with learning disabilities and health facilitators in my locality in delivering health action plan and compare this to the national findings to inform local practice.

Findings

In total 117 health facilitators, across England responded to the questionnaire.

The majority of health facilitators were nurses and less than one fifth of health facilitators were unpaid carers or family members. The size of the health action plan ranged between 10 and 50 plus pages. The mean number of plans completed was 24 with the number of plans facilitated ranging from 1-10 to over 300 by one health facilitator who was employed directly to complete health action plans.

There were a wide range of people involved in completing the health action plan, with 35% of respondents indicating primary care involvement in the plan. The majority of plans were in a written format (73%) but health facilitators had also developed individual plans in Braille, on a CD, tapes, and videos and in Urdu.

The data identified that almost three quarters (72%) of people had health checks to inform the health action plan and that more health needs were identified as a result. However, the research identified that not all screening was undertaken by primary care staff, with some learning disability nurses undertaking the health check due to issues engaging primary care in the process. Whilst *Valuing People* (2001) suggests that *"learning disability nurses are specialists in their field and should be a point of reference to others"*, this way of working by nurses carrying out health screening will not assist to develop collaborative practice and improve the knowledge of primary care staff (Michael 2008, Barr et al 1999). This demonstrates that clear leadership is required to ensure that learning disability nurses work to engage primary health care staff to complete these health checks so that access to health and primary care support in this becomes normal, usual practice. It is anticipated that the introduction of the DES would have altered this result. Indeed McGrath (2010) in completing a local study, identified that generic services can undertake health checks independently if training is given first and support is offered by the community team for learning disabilities. Unfortunately, despite the extension of the DES until 2012 less than 50% of people with learning disabilities nationally were offered a health check in 2010.

In 74% of respondents health gains were identified as a result of the health action plan. 13% said that they had not identified any gains and a further 13% did not respond. One respondent commented that as a result of health action planning 54 health gains were identified across the plans they had completed.

Health facilitators were not always prepared in undertaking health action plans. Feedback indicated that health facilitators, whether trained nurses or support staff needed the appropriate training on the process of health action planning for the concept to be successful. Training was most likely to be offered to non nursing staff. Some areas had developed comprehensive training that covered aspects of health alongside that of health action planning. Nurses themselves identified that they did require training as this was, in most cases a new and additional part of their role with one nurse commenting that they *"Haven't had training and none was available. There appeared to be an assumption that as a qualified nurse I'd already know what I was doing"*.

In addition respondents suggested that the health action plan provided education for staff (health and carers) about the health needs of people with learning disabilities. This was achieved in one case *" Through liaison with one lady's GP. This led directly to active engagement in working with the GP practice to reduce the number of home visits and work toward desensitization to attending the GP practice"*. The health action plan has also *" been an invaluable tool in educating practice nurses in specific health needs of people with learning disabilities and how to address health needs, communication skills etc"*.

Furthermore, the study identified that as a result of introducing health action plans communication has improved between professionals, between families and paid staff and more importantly with people with learning disabilities themselves about the health needs of

the individual with a learning disability. This was reiterated on a local level whereby health facilitators identified that the health action plan had proven beneficial in improving communication with families, primary health care professionals and indeed between staff themselves. One facilitator had used the plan to discuss the rationale for an individual's behaviour with the care team and achieved successful outcomes for the person's health. Another referred to having all the information at hand during a health professional's visit, which ensured that the individual received appropriate and timely treatment. This is of particular importance as GP's have criticised lack of carer knowledge when accessing their services (Powrie 2003).

Finally this study identified that although the majority of health facilitators (70%) identified that they felt supported in their role they identified several difficulties in implementing health action plans. Several respondents suggested that issues with implementation arose as there was no appropriate strategic health facilitation lead and often they felt there was an increase to their workload with no additional time to do health action plans.

Indeed, repeated criticism was that there was a lack of national leadership and guidance about the introduction of health action plans. Whilst some areas progressed well, others struggled, citing lack of support by their manager, their colleagues (in integrated teams), the PCT the LDPB and lack of guidance that could be used to support the work that they were trying to develop. The findings from this research were presented and helped to inform later guidance released on health action plans (DOH 2009) and helped to improve both the process and experience for people with learning disabilities on a local level.

The need for leadership continues to be an issue for learning disability nurses in general which was reiterated in *Learning from the Past: Setting out the Future* (RCN 2011) which confirms that there needs to be "*strategic leadership for all learning disability nurses in the mixed care economy*".

Key implications for practice

The key implications for practice on a national level are:

- 1) A mandatory health module should be developed for support workers to enable them to understand the health related aspects for people with learning disabilities in order for them to undertake their support role. There needs to be an adequate training/awareness raising programme regarding health action plans and health related issues for all people, regardless of qualifications, supporting people with learning disabilities. The context and depth of this training requires further examination, but it is evident from the findings of this research that nurses require training as well as carers and their families and health care providers. Furthermore, the importance of health screening or a health check to inform the health action plan needs to be an integral part of this training.
- 2) Clear guidance and leadership needs to be developed on a national and local level to not only ensure that the health agenda for people with learning

disabilities is developed but also that learning disability nurses get the same equitable levels of support to develop the health agenda within their practice.

- 3) Health screening for people with learning disabilities needs to be delivered by primary care staff in order for a transfer of skill, knowledge and improved practice to happen. A national review of the DES process should be completed to identify:
 1. Who undertook the health screening
 2. If this increased their knowledge
 3. What health outcomes were identified
 4. If health action plans were instigated as a result

- 4) Ownership for monitoring the introduction of health action plans, the monitoring of outcomes and implications for practice should lie with the Learning Disability Partnership Board, via inclusion within the new area Health and Well Being Boards. This should include a local review of progress resulting in target specific outcome measures within all service level contracts that offer support to people with learning disabilities in accessing health (community team for learning disabilities, supported living services, primary health care and secondary health care services). This should include penalties for non compliance.

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Learning Disability Registers and read coding as an 'active problem' within NHS Central Lancashire GP Practices

Barriers in access to health care and the consequences to individuals with a learning disability have been one of the key themes in recent public health policy (DH, 2004; 2006). None more significant than that highlighted within 'Healthcare for all' (Michael 2008) and the Health Service Ombudsman report 'Six lives'(2009). It is therefore crucial General Practice registers of patients with a learning disability, are maintained adequately in primary care to ensure people are easily identified, in order to recognise this an important prerequisite to improving access and to promote preventative strategies (Allgar et al, 2008) such as health checks (Lindsey & Burgess, 2006).



Within General Practice the focus on data required in accordance with the Quality Outcomes Framework (QOF) toward patients with a learning disability is the QoF indicator set that '*the practice can produce a register of patients aged 18 and over with learning disabilities*' (Amos, 2009). There are no set guidelines upon how evidence must be derived in applying such a read code to a patient, which presents a risk in practices inaccurately coding patients based on subjective or anecdotal information, possibly skewing prevalence data and leading to individuals being inaccurately coded.

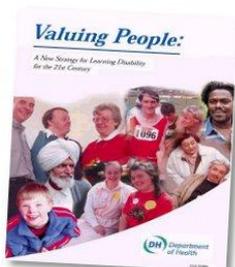
The recording of learning disability patients is part of the first step to identifying and meeting the needs of people with learning disabilities. Linked to this is the need to increase the number of people that receive a health check in primary care. However identifying people with a learning disability on any GP practice list is often a difficult and lengthy process (Allgar et al, 2008). This often leads to the recording of patients with a learning disability on practice registers as considerably less than would be expected with considerable variation between practices. There are also several problems associated with data collection and quality relating to the learning disabled population, in that no standard definition of learning disability is often applied and there seems to be an assumption that the identification of people with a learning disability is a relatively quick and straightforward task (Evans et al, 2004).



There are many codes and sub codes for learning difficulties/disability/mental retardation, which includes many people with specific learning difficulties who do not fit into the criteria for learning disability as defined in Valuing People (Dept of Health, 2001). When attempting to establish evidence of learning disability the presence of a low intelligence quotient, (e.g. IQ below 70) is not in itself sufficient. Therefore it is essential that consideration of a



persons adaptive functioning and communication skills are taken into account. Alongside this an approach which recognises a combination of Read-code identification, practice based knowledge, and the input of learning disability professionals, will lead to production of the most accurate registers (Whitaker S, 2004).



As Valuing People (Dept of Health, 2001) asserted there was an expectation general practices and learning disability services would work together to identify people with learning disabilities on practice lists and in doing so the problem of inaccurate read coding in general practice could be significantly reduced (Evans et al, 2005). It was agreed that this should be a focused and co-ordinated initiative for the community learning disability teams.

In recognition of the fact that identifying people may not be a quick or straightforward and in order to produce the most accurate registers in establishing evidence of learning disability a process of verification by the local learning disability professionals, was recognised as essential (Allgar et al, 2008). To avoid repeating this process each time information is required about the health status of people with learning disabilities and their access to health care, Giraud-Saunders et al, (2004) advocates the consistent use of a single Read code for learning disability. Therefore it was agreed that the local community learning disability team would provide support and guidance to GP practices (Giraud-Saunders et al 2003) in establishing evidence of learning disability before they read code any individual patients.

Whilst the Dept of Health advises that the code E3 should be applied (Dept of Health, 2001) it was recognised by the community team, that they are not at liberty to insist the E3 code is applied as the QoF guidance does not demand so of the GP practice (Amos, 2009). It is therefore the individual practices discretion to decide which code to apply. It is important though to promote and advise consistently that any code is applied as an 'active problem' and where possible the code E3.



Practices are supported by liaison with identified community nurses within all locality teams, who work alongside practice managers to proactively identify and read code patients. A senior nurse co-ordinates the initiative to ensure a consistent approach is adopted and reviewed across the NHS Central Lancashire footprint. The senior nurse works alongside both primary care and learning disability commissioners, the QoF team and local PRIMUS facilitator, in order to compare and contrast data collation and ensure consistency across practices is applied in the approach being advocated. The



interface between GP Practices and the community nurses is an ongoing scheme of work throughout the year with additional time devoted for quality monitoring in preparation for QoF data extraction on an annual basis.

Initially the activity was piloted within 1 large practice, and then extended to 28 practices within the Preston area (following further evaluation and the amalgamation of community teams established by the creation of NHS Central Lancashire, this is now established across the central Lancashire footprint). Soon after the initiative was extended to a further 28 practices in Preston, it became evident that not allocating any code as an 'active problem' led to multiple requests for validation of the same patients, when they moved practice. Similarly patients were 'lost' when leaving practices as the read code was not included in any transfer summary information.

If a community team was looking to establish such a programme of work, a lesson learnt would be to ensure robust systems are in place within the community teams in terms of how enquiries from GP practices are to be processed, alongside proactive recognition that this is an ongoing scheme of work.



Clarifying the process to be undertaken, along with clear roles and responsibilities of the practice and the community learning disability professionals, as well as being clear as to the criteria to be applied when establishing documentary evidence of learning disability is essential. It

is also important to establish from the outset the contact agreement with the Commissioning QoF team and local PRIMUS facilitator/team, in order to agree how comparison and contrasting of data collation and the involvement of your service, is to be implemented. Format a robust database system within the community team of those patients who have been verified/checked in order to reduce repeat requests for verification. It is also essential for the QoF and community learning disability team to establish the process of annual quality monitoring in order to measure the number of patients verified by the community learning disability team against QMAS extracted data.

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Annual health checks

Adults with a learning disability (LD) have poorer health than the general population. They have unmet health needs and live with preventable health problems, have shorter life expectancy (Hollins et al 1998).

As early as 1998, 'Signposts for Success' highlighted that people with LD have poorer health and advocated for annual health checks for this group of adults (DH 1998, DH, 2001, Mencap 2004). A Direct Enhanced Service (DES) was introduced in 2008/09 for annual health checks for people with LD, to begin within Primary Care (N.H.S.E. 2008). The health checks were to incorporate physical examination, discussion of behaviour, epilepsy, review of medication, health promotion and if required specific advice/health checks linked to a syndrome.

Annual health checks within G.P. surgeries were introduced to provide an opportunity to ensure health needs are identified and met, to offer health promotion advice, discuss and develop a clients Health Action Plan, review medication and also provides an opportunity to build relationships and desensitise any fears.

There are many barriers to accessing health care for adults with an L.D which include: understanding, (from the service user and Primary care staffs perspective), communication needs, (including how a person communicates and the language a Primary Care professional will use), accessing services, inconsistencies in care delivery and fear of health professionals.

In 2003, two L.D Nurses began a project in Oldham to improve the health needs of adults with a L.D. They developed links with one G.P practice. Contact was made with all patients on the L.D. register of that practice to invite them into the surgery for a health check. The Nurses visited each adult to inform them of the project and supported the Practice Nurse with Health Checks in the surgery. Approx. 30% of patients agreed and had a health check completed. The Primary Care Health Facilitator post began in May 2006 to continue with this development and liaised with a further 13 practices (approx 25% of practices in Oldham.)

As a pre-requisite of the D.E.S., the L.D Nursing Service facilitated L.D. Awareness training for G.Ps, Practice nurses and Managers. During one of these planned sessions concerns were expressed from the GPs regarding the use of the Health check recommended in the D.E.S. and an accessible Health check was developed. This was a joint venture overseen by the Clinical Lead for Practice Nursing with involvement from L.D. Nurses and Practice Nurses. As the L.D Nursing service has excellent links with the Speech and Language Therapists,

part of the Communication therapy team, Accessible Signage was incorporated into the document, named 'The Oldham Well Person Health Check.'

As part of the D.E.S., annual health checks have been offered in a person's home by some practices. This has been accepted by approx. 5 people that the L.D.S. is aware of. Reasonable adjustments are made to support adults with their health needs (DDA 2005).

The home visits have benefited adults whose behaviours can challenge, for those with mobility problems and the elderly.

The visits have helped improve access to Primary Care Services, and are more inclusive. Primary Care staff report that they have become more confident with the additional support requirements of the client group. The home visits allow for unknown health needs to be identified and appropriate treatment to be commenced. There has been an increase in routine medical tests for example blood tests have been completed in a person's home where they feel more relaxed and are more co-operative with the procedure. The home visits allow relationships and trust to be established between Primary Care and the individual. In some instances the L.D Nurses, have advised and supported Primary Care staff to ensure the home visit has gone ahead. There has been an increase in partnership working for all concerned.

The Dental service in Oldham also offers support to adults with an L.D within their home. The team complete home visits on an individual basis to provide dental examination and some treatment. There are limitations to the extent of treatment that can be offered in a person's home. However, relationships are built that enables de-sensitisation work to begin and encourage a person to use the facilities at the dental surgery. Families have reported that they have developed good links and trust with this service.

Other support offered to the G.P. Practices, has included, support to verify the L.D register, support to inform adults of the annual health check process, during a home visit, supporting adults during health check appointments (with their agreement) and arrange follow up appointments and referrals if required to the extended L.D Health service, (which includes Physiotherapy, Dietician, Drama therapy etc.)

The home visits have worked well, due to the willingness of many Practice Nurses who have strived to ensure they offer an inclusive service to adults with a L.D. The home visits have been offered either independently or jointly with either the Primary Care Health Facilitator or a L.D Nurse. It has been noted that some of the Practice Nurses involved have family members who have a L.D. and they are aware of the difficulties accessing health services for this group of individuals. They have been instrumental in advocating the need for health checks with their Primary Care colleagues and are seen as natural 'Champions'

In 2009/10 there was an 86% uptake of health checks completed in Oldham for adults with a L.D. in the Primary Care setting.

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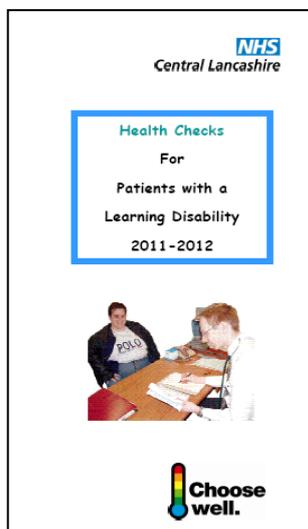
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Accessible information for DES health checks across NHS Central Lancashire



There has been a plethora of publications over recent years highlighting the need for information to be produced in a variety of formats, for people with a learning disability, when attempting to communicate information (Mencap, 2008; Office for Disability Issues, 2010; DH, 2010). Within the delivery of DES health checks there is a need for all service providers to make reasonable adjustments to ensure learning disabled people can access services in accordance with The Disability Discrimination Act (1995) to provide them, with information to promote their rights and choices and understand the treatment and services available when undergoing a health check (Giraud-Saunders et al, 2003).

In 2010 the department of health produced guidance focused on creating easy read, information, which used simple words and pictures to communicate complex messages (DH, 2010). It recommends that people with learning disabilities are involved in developing such publications, in order that people with a learning disability have greater control and understanding of their lives, particularly in relation to provision of health information which assists and guides them in preparation for having a health check. With incentives in place for GP's to deliver health checks for people with learning disability (BMA & NHS Employers, 2011), it is imperative patients identified as eligible for a health check, are afforded as much involvement in the process as possible and that they are informed of the process in advance to support a proactive and positive experience for all concerned.



The main purpose of any easy read/accessible documentation should be to provide people with information in order to make any necessary preparation and appropriate decisions (West & Reuben, undated). With this in mind it was clear that the community team in supporting GP practices in the delivery of health checks, needed to produce and provide accessible information letters/leaflets for the individual GP practices to share with those they were potentially inviting for a health check. A decision was taken that this should be incorporated within the scheme of work community teams were expected to

Family History	Yes	No	Don't know	Whom
Diabetes				
Heart Disease				
Asthma				
Cancers				

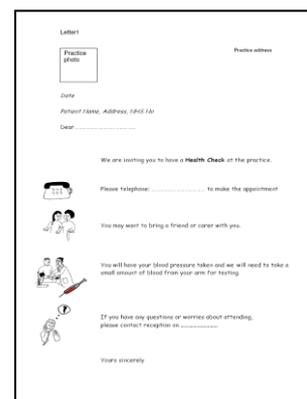
undertake as set out in the DES guidance (BMA & NHS Employers, 2011). The DES guidance (BMA & NHS Employers, 2011) also recommends that practices recognise the need to support patients to collate information prior to any health check taking place, in order to prepare patients for their health check appointment and reduce any anxiety related to the health check. It is expected that patients, with support from their carers, will arrive with relevant information related to their current health and medical history in an effort to be proactive and thorough in the

information provided to the practice.

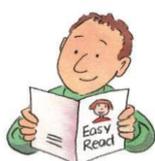
The community team produced a number of draft leaflets and information letters, which were critically appraised by local advocacy groups, who provided invaluable feedback on both amendments required and positive aspects of the documents. Within the DES training programme, GP practices were then provided with electronic copies of the 'preparation and invitation' letters and advised to contact the PRIMUS facilitator for upload onto their respective systems. (See appendix for copies). Liaison by the community nursing team with the local PRIMUS facilitator enabled documents to be interlinked to the practice electronic systems, enabling easily uploading of documents within the practice to the patients' electronic file and health check



The collaboration generated by producing such information between the community team, local advocacy groups and the individual GP practices, has enabled practices to deliver a consistent approach in the documentation they use in the preparation for and delivery of health checks. Feedback from those practices that have chosen to adopt use of the documentation has been extremely positive. They have relayed how using the documentation produced by the community team, has saved them a significant amount of time in not having to prepare the documentation themselves. It has also been reported that practice staff have recognised that by adopting such an approach, patients and their carers are enabled to provide more detailed and robust information about a person health as well as reducing any potential anxieties. Alongside this practice nurse have relayed how the documentation supports the process of assessing capacity to consent in accordance with the Mental Capacity Act 2005. A number of practices are now regularly approaching the community team for advice in producing or accessing other such information in relation to specific health conditions which whilst there is a plethora available they are not aware of.



Those who were involved in the production of the information were a senior nurse from the community team, primary care project worker (on a short fixed term contract), local advocacy groups, and the PRIMUS facilitation team. Dissemination of the information was undertaken at each DES training event by the trainers (community nurses and people with a learning disability). The DES information leaflets were distributed by the community team to all GP practices (DES and non DES registered), user and carer groups. The learning disability commissioning team distributed the leaflet to all local preferred provider services, reiterating the need to support people with a learning disability to attend and request a health check if they had not been invited.



The initiative has had a positive effect, on both the experiences people with a learning disability have had in being able to prepare for any health checks, and the relationship between the GP practice and community team. This is an approach which is now adopted for all schemes of work by the community learning disability team, in ensuring that people with a learning

disability are involved as critical readers of any documentation being produced which endeavours to provide them and their carers with information.

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Fighting Fit: Reducing obesity amongst adults with learning disabilities

Repeated studies have shown that the fitness levels of people with learning disabilities are much lower than the general population, and that most people perform very little physical activity and carry high amounts of body fat (Draheim et al., 2002; Emerson, 2005; McGuire et al., 2007; Melville et al., 2007; Messent et al., 1998; Robertson et al., 2000).

Obesity levels have been shown to be higher in people with learning disabilities than the general population (Hamilton et al., 2007; Bhaumik et al., 2008; Thomas & Kerr, 2011), putting them at higher risk of chronic health conditions associated with overweight and obesity (for example, cardiovascular conditions, diabetes, hypertension, certain cancers) and reduced life expectancy. Obesity can damage a person's wellbeing and quality of life (Butland et al., 2007).

Whilst much of the focus has been on physical activity, diet and nutrition also impact upon obesity levels. Evidence suggests that adherence to a healthy diet is low for people with learning disabilities (McGuire et al., 2007). Robertson et al. (2000) argue that the two most effective ways of improving the health of people with learning disabilities would be to increase levels of physical activity and to improve diet. It was therefore important to develop an effective weight loss intervention for people with learning disabilities.

Fighting Fit is Manchester Learning Disability Partnership's (MLDP) strategy to encourage and support adults with learning disabilities to lead a physically active lifestyle and to maintain or achieve a healthy weight. It became apparent that in Manchester there were some important health factors impacting on the number of people with learning disabilities being referred to physiotherapy for treatment:

- Many people needed general exercise to prevent deterioration, not treatment
- People had complex cognitive and physical problems, premature ageing and communication difficulties which made the use of mainstream leisure services an impossibility
- There were a large proportion of people who were seriously overweight and likely to present with serious secondary health problems
- The demand for physiotherapy increased and only those with complex physical problems could be treated due to staff resources

Fighting Fit has been co-ordinated by the physiotherapy team as a means of providing exercise to prevent deterioration in physical mobility, allowing the physiotherapists to concentrate on providing therapy to patients presenting with complex physical problems.

In 1999 permission was obtained to employ a senior physiotherapist to assess the obesity issues, the numbers of people, their social circumstances and the prevalence of avoidable secondary care issues arising from low activity and obesity. The physiotherapist came to post and spent the first few months assessing the size of the problem, and methods to reduce the risks to people with learning disabilities. At this time there was no other service of its kind.

The Fighting Fit team now consists of an Acting Fighting Fit Lead a Physiotherapy Technician and managed overall by a Practice Advisor for Physiotherapy. Fighting Fit has since developed a person centred comprehensive screening tool which in conjunction with the Independent Mobility Assessment form, effectively screens for:

- Height, weight & Body Mass Index
- Waist circumference
- Blood pressure
- Activity levels
- Information on the constituents of a healthy diet
- Medications which are likely to increase weight
- An assessment form for identifying those people who may be at risk of Sleep Apnoea and type 2 Respiratory failure
- Slips, trips and falls
- Communication and ability to consent

Following this screening, Fighting Fit then provides a number of interventions including:

- Signposting the person to their G.P. for further health screening or medication reviews
- Providing person centred information on health conditions, weight, healthy eating and physical activity
- A referral to a dietitian may be appropriate in some cases for people with certain health conditions
- 2 activity sessions and 1 gym session run by Fighting Fit
- Individual programmes
- Goal setting
- Long-term follow up
- Weight management training

The focus of Fighting Fit has now changed to try to empower people with learning disabilities through the provision of a new weight management training programme, which is currently under development following an 11 week pilot session earlier this year.

Fighting Fit focuses on increasing activity levels and improving diet in the hope of reducing obesity levels. There has always been an emphasis on evaluating the impact of Fighting Fit and two papers have been published in peer reviewed

journals measuring the impact of the initiative (Chapman, Craven & Chadwick, 2005, 2008). These papers examined the change in Body Mass Index (BMI) over time for two groups: an input group receiving individual support from the Fighting Fit team, and a non-input group consisting of people who were not receiving individual support. The initial paper showed statistically significant differences in the change in BMI for the two groups, with mean BMI decreasing over time for the input group whilst increasing for the non-input group. This suggested that the individualised input from the Fighting Fit team could be leading to reductions in BMI. At the six year follow-up reported in the second paper, the input group showed continued reductions in mean BMI whilst mean BMI in the non-input group which had initially risen, stabilised and then reduced (although remaining at a higher level than at baseline). This suggests a long term impact of individualised support and that the general awareness raising had begun to have an impact on obesity and overweight levels for people with learning disabilities locally.

There are few evaluations of weight loss interventions involving people with learning disabilities (Hamilton et al., 2007). The Fighting Fit research is one of the few published studies on this topic and has been well-cited in recent evidence reviews (Hamilton et al., 2007; Kremers et al., 2010; Jinks et al., 2010).

Fighting Fit has developed and continues to develop with the needs of the client group. Through receiving feedback we have been able to look at the areas of practice which have worked well and what still requires adjustment. Overall, people have enjoyed trying new activities such as the Nintendo Wii, cook and eat sessions, swimming, gym sessions and supermarket shopping. The use of pedometers is always very popular, and providing person centred charts, goals and incentives has also been successful. Our activity sessions have developed from sports based to games based activities as we found short bursts fun games which can be easily changed if not working well, help to maintain concentration levels. The pilot weight management training sessions highlighted to us that we may need to run several sessions catering for specific need whether that is prevention, treatment, dietary advice, exercise advice, specific health conditions and also the skill mix of the group needs to be taken into account in future.

Whilst Fighting Fit has been proven to be a successful weight management intervention, it has also highlighted that there are some people who are unresponsive who we also have a duty of care to. Those who live independently and with families are at particular risk. This is when we need to work together with our social care colleagues to determine capacity and whether the case needs to be raised as a safeguarding issue. In some cases we have to accept that there is no more that we can do.

Fighting Fit aims to develop further in the future. There is scope for more of a focus on dietary advice and nutrition. Melville et al (2011) found a significant decrease in body weight after a dietary prescription in adults with learning disabilities, which is an area Fighting Fit has not previously focused on. Further funding would allow us to increase our staff team and thereby enable us to provide more activity sessions, staff training, awareness raising and training for people with learning disabilities.

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Case Study: Supporting Catherine to follow a healthy diet

The piece of work that I completed that was successful was working with a lady with mild learning disabilities to manage her weight and educate her to eat a healthier diet and to promote exercise. I will change her name for confidential reasons and name her Catherine. Catherine lives alone in a warden controlled flat; she is separated from her husband, but still married and has regular contact with him. Catherine is very obese, according to, body mass index chart, weight loss resources Ltd, (2000) she eats a poor diet and lacks motivation to engage in activities and services. Catherine does have family that she visits across the city which tends to keep her spirits up, as she suffers with depression and currently takes long term medication for her mental health.

The outcome: For Catherine to lose weight, feel better in her general health, mood and be more pro active.

Plan of action: To meet with Catherine in her flat once a week for 8 consecutive weeks.

I gathered lots of information from the health promotion unit and utilised our resource from the community learning disability team such as resources from fighting fit (physiotherapy team), 'food should be fun and healthy', British heart foundation, (2006). I decided to put together a folder with two different sections for Catherine, so each week we could look through the leaflets and booklets and complete answers and keep a food diary. Depending on the topic I would relate this to a visual resource from health promotion unit this would hopefully enable Catherine to retain information better, and have a clearer understanding on the subject discussed. According to the mental capacity act, (2005) every adult has the right to understand information by using simple information such as visual aids. Some of the resource I hired out included globes of fat, medicine cabinet, and saturated fat in tubes. By the end of the 8 weeks I have covered a wide area of topics this included:

- Food and diet: eat well plate, food and mood, 5 a day, food facts, salt intake from food standard agency.
- Weight and exercise: physical activity and your heart, taking control of your weight, how do people put weight on, how do people lose weight.

Catherine agreed to keep a food diary and she also recorded her daily activities some of which she did not expect to be classed as exercise i.e., cleaning, walking, general house keeping, ironing, and shopping. According to get Manchester moving,(2011) exercise comes in many forms even taking the stairs instead of getting the lift is classed as exercising.

Catherine's GP was also involved with this process and the doctor monitored

Catherine's height, weight, and BMI before we started our sessions. Catherine also had her bloods taken to test for possible onset of diabetes, because Catherine is overweight and she eats a poor diet high in salt and sugar, she may develop diabetes in the future. (N.I.C.E guidelines obesity, 2010). I informed Catherine's care manager about the work I was going to undertake. I also discussed and then made a referral to the occupational therapy team, asking for Catherine to have support with cooking and using electrical appliances.

After the sessions had finished Catherine had gained a vast knowledge about healthy eating and knew the importance of regular exercise. I carried on visiting Catherine on a regular basis and every time I noticed Catherine always had healthy meals in the fridge and cupboard. I felt very pleased the work I had carried out had made a difference to Catherine, and I felt very proud of Catherine to carry on with her new regime.

One year later Catherine looks and feels better in herself "people are noticing I've lost weight" she tells me, Catherine's care manager even made a comment to me at work about her weight loss. I supported Catherine to visit her GP, and the doctor commented on how well Catherine looks and Catherine told her GP how good she feels. Catherine had another full M.O.T carried out and her blood results show she is thankfully not diabetic. This is more than likely due to the hard work Catherine has done over the last 12 months. Overall Catherine lost 3 1/2 stone. Catherine is now monitored by her GP annually; she continues to eat a well balanced diet and walks every day.

I have learnt that meeting on a regular basis with the people that we support is the most effective way to encourage and support someone to aim for a goal. I have also learnt that plenty of planning and researching key areas is needed, if the work you carry out is to be successful.

If repeating similar work again I would plan my sessions well in advance and I will possibly see if the person has a goal/ideal weight they would like to be. I would also review them one year later to enable them chance to hopefully see their positive progression.

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Case Study cancer treatment

The Learning Disability Hospital Liaison Nurse was contacted by the Specialist Macmillan Haematology Nurse for advice about Jack a man with learning disabilities who lives independently and who was recently diagnosed with cancer. She was unsure about J's ability to understand his condition and therefore his capacity to consent and comply with treatment. The L.D Hospital Liaison Nurse met Jack and assessed his communication and his capacity to understand his condition. She was also able to gather resources available from the Learning Disability service to produce accessible information leaflet which clearly and simply explained J's condition to him and his treatment options. By working together closely with the Specialist Haematology nurse and the Hospital Social Worker the Learning disability Hospital Liaison Nurse was able to suggest that Jack could understand his condition and make a decision about treatment and also advise about the best way to present information and support to him once he returned home from hospital.

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Ready Steady Go! A Health Promotion Course for People with Learning Disabilities;

An Adaptation for Young People in Transition to Adult Services

Cheshire and Wirral NHS Foundation Trust has nine Health Facilitators/health promotion specialists/hospital liaison workers in the Cheshire and Trafford footprint in Adult learning disability services and one Health Facilitator based in the Learning Disability/Child & Adolescent Mental Health Service.

The premise of good health begins with promoting well being and preventing ill health. Health promotion is an essential part of the Health Facilitator's role. The health promotion process enables people to make decisions and take actions for themselves around their own healthcare. It supports people to take control over their health and make positive changes that will influence their lifestyle and the wider population's health inequalities.

Ready, Steady, Go! is a course designed by the Adult Health Facilitator and Children's Health Facilitator in Central Cheshire. The course is specifically tailored to provide a supportive environment and give people with learning disabilities the information and assistance they need to exert more control over their own health. In addition the course will give all the relevant information to carers to enable that support to be long-lasting and effective.

The impetus for the development of the course is based in evidence of poorer health and greater unmet health needs for a person with learning disabilities than that of the general population (Michael, 2008) and the growing wealth of legislation that supports the right of a person with a learning disability to access the healthcare and support needed to lead a health life. However and unfortunately, access to the NHS for people with learning disabilities is poorer despite the services being available (Equality Act 2010; High Quality Care for All, 2008; Michael, 2008). Ready Steady Go! supports the building of positive relationships between students and health services. It provides the student with accessible information and experiences building an understanding around healthy lifestyles. The course supplies the student with accessible documents that will improve their patients' journey and carer's experiences within a health setting.

Michael (2008) stated that the professionals in health settings had to make reasonable adjustments in their environments to enable equal access to care and Valuing People Now(2009) identified that often lack of understanding affects the way a person is treated within services. This course supports an increase in knowledge and experience for hospital staff in caring for and communicating with a person with a learning disability. It cements the principles of the learning

disability awareness courses currently available for Acute Trust staff, facilitated by Adult Learning Disability Services.

It is important that the course be developed with the ability to be adapted for both adults and young people so that young people have the opportunity to become more empowered to make positive changes in their lifestyle and therefore reducing health inequalities. It is especially important for young people in transition so that their health needs are identified and the appropriate care and support in adult services can be accessed.

The course links with the philosophy of the new SEN Green Paper (2011). It enables and supports greater collaboration between many services and professionals and minimising to propensity for transition to be a confusing process that often loses sight of a young person's health needs. The course format encourages the public health role of school nurses, further develops the relationships of other agencies around the young person and gives the opportunity for a young person's health needs to be taken into account when considering the support required in adult life.

The Ready Steady Go! course comprises eight weeks of core modules, each lasting approximately two hours, with one session recommended per week. There is flexibility to access individual topics of specific interest, and in addition to the core elements there are supplementary sessions which may be applicable to explore dependent on the group demographics. The format of the Ready Steady Go! course utilised for young people was adapted to fit within a school curriculum and its presentation informal, built around what worked best for the students during a term that included work placement experience, school events and introductory visits to college placements.

The group members were identified as this year's school leavers at a local special school as it was highlighted that these would be students in most need of such health promotion focus. Experience has shown that the optimum number of participants for a programme like this varies according to participant capability, resources and accommodation. With this in mind following discussions with School staff it was agreed that these students and a Learning Support Assistant would be the most appropriate.

The course has been designed to be interactive and enjoyable for all participants including session leaders, with its main aims being the sharing new experiences and the improvement of knowledge that supports a healthier way of life. The main focus of the course for the school leavers was a better understanding of health, health examinations and experiencing a positive visit to the hospital. The order of sessions was flexible and each incorporates a number of aims, specific tasks to meet these aims, activities to do, and exercise sheets to complete and keep as a reminder of each session. Each week the exercise

sheets and any pertinent information from each subject are collected and build up into a personal folder for each person.

The eight week course comprised of the following sessions:

Introduction - What is Ready Steady Go!

- Health Action Plans & Passports

Health - Being poorly

- Going to the doctor/hospital

Good Health - Visiting the dentist

- Good mouth care

You and your body - Keeping safe

Leisure and activity

A visit to the hospital

Recap and evaluation

Each session was planned fully before the course commenced with other agencies including Primary Care Specialist Dental Service, Cheshire East Council, Child & Adolescent Mental Health Services, Specialist School Nursing and East Cheshire Acute Trust Patient & Public Involvement Service.

Each student was provided with a lever arch file, personalised with their photo and containing draft health action plans and passports. These were provisionally completed with the students, school and school nursing staff over the duration of the course and finalised with parents. Other agencies/professionals were asked to provide accessible leaflets that could be inserted into the student's files.

Every session was photographically recorded to enable the production of a weekly recap sheet with personalised photographs of the session to be placed in the file.

Each session, except the visit to hospital, was held on the school campus and identified as two hours in length, but two and a half hours blocked off the timetable to allow for travel between campus' and time to extend if needed. Breaks were negotiated with students depending on the activities being undertaken but one was arranged half way through the session. The facilitator

provided a small selection of healthy snacks each week, usually two types of fruit and bottles of smoothie and water. All timings were flexible and the Facilitators adapted each session according to students individual needs.

The sessions began with an introduction to health action plans and an overview of the course content. Health passports were completed with the students.

All the sessions were practical and activity based. Based on feedback from the students the three most popular sessions were; going to the doctors/hospital; leisure & activity and a visit to the hospital.

During the going to the doctors/hospital session the school nurse co facilitated the session and all the instruments used in an annual examination were available to handle and use on each other!

The leisure and activity session was facilitated by the Cheshire East Leisure Service. Two trainers facilitated a session that included an introduction to boxing and a dance exercise.

The visit to the hospital was organised with the Patient and Public Liaison Worker from the schools local acute Trust. The students took with them their own patient passports and we visited Accident & Emergency, X-Ray, Phlebotomy, A surgical ward and Out-patients. The students practised handing their passports to staff and hospital staff asked them questions about their passports.

An accessible evaluation sheet for each session was produced that contained personalised pictures of the relevant session for the student. These sheets were used in the recap session as a visual aid to gather the student's thoughts on the course and assess their comprehension of the sessions and to reflect on the whole of the course.

The evaluation identified that all the students enjoyed working with all the different agencies especially the nurse and taking part in the Cheshire East leisure session. There was no negative feedback though one student noted that they did not like going to the hospital but rated the session as ok.

The benefits and outcomes were identified as

- This year's students leaving school all have an up to date patient passport.
- Two students have fully completed Health Action Plans. One student's is still in production due to close family illness.
- Following completion of Health Action Plan for two students, it highlighted some actions for carers to pursue with the G.P. and another identified the need for a referral assessment to the Adult Community Health Team.

- The students have experienced a very positive visit to the hospital and met staff in various departments.
- The students have been given accessible relevant healthy messages that, on recap, all students retained the most important information given.
- Cheshire East leisure staff highlighted one student with a particular talent for boxing. The leisure staff actively sourced the local boxing club and the Health Facilitator supported the student and his family to access the club, liaising with both and sourcing a support worker. The student is now a member of the boxing club.
- Other agencies became familiar with interacting with students with learning disabilities, especially the health staff.
- Relationships between agencies have been made, improved and continued.
- The sessions have opened up other opportunities for health staff to support the teaching staff in the school curriculum.
- The school leavers in the following year are double numbers this year and the class dynamics slightly changed. Following discussion with the Head Teacher it was agreed that a different application within the curriculum might be more appropriate with the content remaining the same.

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Tameside and Glossop. Accessible Cycling Scheme

There was a need to develop healthy activities in which our Learning Disabled clients would engage. As a team we felt that these activities should be made as accessible as possible.

One activity looked at was cycling. Initially we had taster days where manufacturers brought their adapted cycles for clients to use and from this we were able to build a picture of what we needed from direct feedback from clients and from our own observations of what equipment could give even the most challenged client a chance to have a cycling experience.

The original plan was to have a few adapted bikes that we could base at a centre to be used by the team itself, however feedback from the taster sessions indicated a huge interest from not just those who could cycle but also people who wished to learn. Bikes were chosen for their stability, for being able to take two for support and supervision as well as ordinary bikes. This enabled us to offer a progression as people skills improved.

At this time we were able to work in partnership with youth services that had a project for young people and adapted cycles. We decided to combine both fleets and use the all the bikes for each session. We were able to facilitate some sessions for Sports Development in Tameside who recognised the potential for children and they came on board, securing funding for a greater variety of bikes. We secured the use of East Cheshire running track through the Youth services contact which has proved to be an ideal venue to run safe and secure sessions outdoors.

Other partners who have joined in this effort have been the Hyde Fire and Rescue Service who have contributed bikes and help in the form of volunteers from their youth scheme in the Tameside area who continues to support both at our session and the public session.

A great plus has been our inclusion as a group on the Tameside Cycling Development Group, which has enabled us to get access to the recently developed Cycle Circuit in Ashton. This has enabled us to explore Cycle training and maintenance training involving our clients. We hope this will lead to employment opportunities for our clients. The involvement in this group has allowed us to put disabilities high on the cycling agenda in Tameside and has resulted in inclusion in Family rides and the potential for clients to join cycle clubs in the area.

In the last year there has been formed the TITANS Disability Cycling Club, using the circuit on a Thursday night. This includes all ages and families cycling

together. This has in the last month doubled in size to a peak of 100 on the last session.

To date the fleet of bikes are used on four regular sessions during the week. These sessions are beginning to include clients from Physical disability and VI groups as word spreads about the opportunities that the fleet afford. These sessions can on a good week involve in excess of 250 people including family and carers. This does not include the one off sessions for special schools and disability awareness sessions run by Sports Development.

The initial objective was to have a meaningful healthy activity for clients where we could encourage fitness and mobility. Allied to this was the ability to progress people from supported cycling to more independent cycling. Equipment was purchased to account for those with challenges that limited them to use arms only. Side by side bikes have been procured for those with a visual impairment.

Wheelchair accessible bikes allow up to four wheelchair users to participate at one time and recently a family plus physically challenged young person took part in a Manchester to Blackpool run.

In the future we are looking to how we can further challenge clients with logs of achievement. Recording types of bike ridden, number of laps completed. Timed laps with arranged times to have time trials. Looking forward we hope to have more inclusion in mainstream events and raise the profile of this activity and how inclusive it can be.

Would we do anything differently?

If we had to start all over again we would look at storage more carefully and an indoor/outdoor venue.

We would afford more time for the testing of equipment as we found some bike less than suitable.

To look at shared goals for the different partners, we suffer from time with differing ethos of how the fleet should be used. An example of this are the disability awareness sessions where we feel disabled clients should be more involved to illustrate the need for the specialist equipment.

We were hampered by the timescales attached to the funding when the money needed to be spent quickly or lose the funding. Sometimes we were pressured into some hasty decisions which were regretted later on.

Look more carefully at the problems associated with getting people to the sessions. There is a group of clients unable to access because of transport difficulties.

We would have liked to generate greater involvement of disabled clients across the community.

Challenges.

- Keeping the fleet maintained and generating funding to repair and replace.
- Looking at winter provision i.e. indoor activities.
- Moving the activity to a community led management rather than service led.
- Setting realistic and attainable outcomes.
- Greater community participation in Cycling.

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The Big Painting Project: moving from discrete group to gallery residency.

The Big Painting Project was a therapeutic project run by Art to Life in Manchester. Devised to encourage greater physical movement, action, co-operation and decision making in its participants, the project was so successful in its aims that a week long residency for Art to Life was planned to showcase the work at an art gallery in Manchester.



Member in regular session

Aims

In addition to the original projects aims the residency intended to:

- Promote awareness of the work of the art groups to the wider public
- Share good practice within the organisation and with partner arts organisations
- Value the work by showing it in a contemporary art context
- Give members new opportunities thus increasing wellbeing through participation in the project.

Background

Art to Life has been running groups (under different names) since 1993, led by an artist and Occupational Therapy Technicians (OTT), from the Community Learning Disability Teams in Manchester Learning Disability Partnership.

Adults living in Manchester can be referred into the group where Model of Human Occupation Screening Tool (MOHOST) assessments are made and individual therapeutic goals set working across the six MOHOST domains of: motivation for occupation, patterns of occupation, communication and interaction skills, process skills, motor skills and environment. (Parkinson, Forsyth, Kielhofner, 2006) The creative projects are then planned with these goals in mind.

Members are encouraged to develop skills through both the creative and the social aspects of the group. For example: increased motivation through exploration and competence of art media is seen across all types of art projects. Regular attendance and routines, including tasks like taking photos and making drinks develop meaningful patterns of occupation. Social and communication

skills are improved through greeting, sharing materials and collaborative tasks or creative activities like music making. Functional motor and process skills are developed in all projects through activities like painting, drawing and weaving, to making tea and using a camera. The group also offers opportunities to try out and explore wider environments and the senses. Projects have taken place in parks, churches, galleries, on a canal boat and allotments.

A recent project began with a story telling session where image prompts and turn taking were used to engage the group to collaboratively write a story. Members then took sections of the story to illustrate through painting, drawing and sculpture. During the weeks they photographed their work and the photos were turned into a stop-motion animation. Members then worked with a visiting musician to make and play percussive instruments and record a sound track together.

The Big Painting Project asked group members simply to paint small and large cardboard boxes and then assemble them into sculptures, taking photos as they went. They did this as individuals and in groups of 2, 4, 6 and 10 over a period of 10 weeks. During the project, members had to share tasks, consider each other, make choices and decisions. Whilst during breaks and setting up, members took on responsibilities and helped others.

'We believe that active participation and engagement in the arts can lead to improvements in health and wellbeing for everyone. In addition, evidence shows that participation in the arts can provide a non-threatening and alternative way to engage in a healthier lifestyle.'(Angus, 2002)



Art to Life members painting during the exhibition

Methods

The exhibition was proposed as a residency for the groups. This was partly done to ensure members would get to see the work as getting support to cover activities other than an individual's usual timetable is often an issue. The Blank Media Collective who run the BLANKSPACE gallery were very open to our ideas and the zones of the gallery space accommodated different activities well so that we were able to run art sessions in a participatory exhibition. This is something that would be hard to manage in larger institutions alongside permanent collections. The artist and OTT risk assessed the space and BLANKSPACE made sure that the ground floor space was fully accessible with help from Full Circle Arts before the residency began.

The weekly sessions were run at their usual times as much as possible to avoid confusion but closed sessions were also scheduled for those who might find a group session open to the public too stressful. Maps, invites and letters were sent out a fortnight ahead detailing sessions, how to get there and what to bring.

The exhibition mainly took the form of a large box sculpture, sensory blankets and a painting wall to be worked on during the art sessions in the gallery. In line with the nature of the project the exhibition was made participatory to help visitors interpret the work and mechanics of the project experientially.

The work was presented as much gallery work is currently presented - unframed, with simple labels. It was presented in context as contemporary art not community art and was appreciated as such - 'I like the way that you didn't have photos of happy people on the labels' - losing the photo labels ensured the work was taken as equal.

What Happened

The residency at BLANKSPACE ensured that members were able to visit, view and interact with their work in a new context. The work changed and was recorded throughout the week, so members visiting at different times could see the exhibition grow and others responding positively to their own work. This meant that members gained a deeper understanding of the potential of their work and themselves

Members responded positively to the new space, working well, undistracted and comfortably. Those very stuck in their ways were buoyant and open to new activities. Others were curious about the gallery and the context they saw their work in which sparked questions about what else happens in the gallery space. All members moved around the space with a confidence usually displayed in more familiar settings.

This confidence seemed connected to their work being in the space, thus helping them own it and making it familiar. The public response was also very positive. Almost every visitor got involved in making a new sculpture and displayed pride in their achievement and absorption in the activity, there was occasional reticence but this seemed to be more to do with not wanting to change the sculpture already made rather than not wanting to get involved.



Sculpture made by visitors to the exhibition

Findings

The residency promoted the work of OT staff and members. It extended the project into a new space which brought with it opportunities for all, to share good practice and experiences and a new audience for the work.

The presentation of the work in a contemporary format, in a contemporary art space valued the work by putting it in context, for the viewer and maker, with other art being made now. This new context certainly did nothing to alienate or cause anxiety to the group members who experienced it. In fact motivation levels of all members increased during the gallery sessions.

We are now looking for more opportunities for members to work in alternative spaces.

"I think the secret is to not look at arts as something delivered by an artist or by an arts organisation. It happens best when it comes out of a dialogue between different sectors, and we need this hybrid way of working to develop. I think that the crucial connections are between the art, health, education and local government sectors, and it is entirely through the partnerships of those

sectors that we are going to get a form of practice articulated that is supportive of this work, helping it develop and also identifying what the best venues and situations are for the public as a whole to engage with the arts." (White, 2010)

The partnership between OT, artist and art gallery ensured a heightened quality of experience, opening new audiences and potential to all involved. We hope to build on this for future projects.

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A Case Study of Mary

Client's Brief history at referral

Mary presented with anxiety and this was preventing her engaging in the activities she once partook. It particularly impacted on her being able to visit her dad in a local nursing home.

Mary had special learning needs that had to be considered. She was a 59 years old lady when I started working with her.

Environmental (physical)

External:

Mary was not leaving the house and exhibited high levels of anxiety about falling when going out.

There were steep steps down from the property, which is a terraced property. However there was a rail either side of the steps.

Internal:

Mary lives with her brother.

Mary and her brother had shared their home with their dad, until recently when he was taken into a nursing home with a diagnosis of dementia. Mary's brother had been a paid carer for their dad.

Mary's brother and sister managed all activities of daily living for Mary and she managed her own personal care. However at the time of the referral Mary was not showering daily and needed regular prompting from family.

Environmental (social)

Mary's immediate family, that is her brother and sister, had been trying to get Mary a diagnosis of a learning disability. They felt this was important to ensure she received the correct long term care package they felt she needed.

Mary had undergone several Social Services Assessments prior to meeting with me. I was informed by Mary and her family that these were lengthy and difficult for her to manage. Her family reported finding the whole process very stressful and not in the least positive for either themselves or Mary.

Mary said she found the whole process with social Services very demanding emotionally. She therefore entered into the process of working with me with some trepidation, as did the family.

To date Mary has been given a diagnosis of a learning difficulty rather than learning disability. This is still being contested by her family. At the time of the referral Mary did not have any contact with others except her family.

Environmental (cultural)

Mary is a white woman who is very close to her immediate family. She has never married. Mary has always lived with her dad and brother, up until her dad being taken into nursing care.

Mary is very strong minded and is able to clearly identify her own preferences. However she becomes very upset when she feels people are not listening to her and not involving her sufficiently in her own care.

Mary prefers to be around older people, that is people of 40 year old upwards, and said she generally feels more at ease with older people.

Mary described how 'it took her time' to trust people and 'know if she felt alright with someone'. She has the capacity to inform someone if she no longer wants to work with a person. She has demonstrated this ability in the past.

Individual (political)

Mary receives disability living allowance because of her mobility restrictions. Mary uses a trolley indoors to transfer drinks etc.

Mary was using the furniture and walls to walk around the house at the time of referral.

Mary was very upset about the care she received from Social Services. She said she found it very difficult to even reflect on this experience. Mary said she felt that she was not believed and was repeatedly asked the same questions.

Individual (spiritual)

Mary is of Roman Catholic Faith. Her faith is very important to Mary. The priest was coming to her house monthly to give her Communion.

Mary identified that it is very important for her to build a trust in a person involved in her care or who she develops as a friend. Mary identified that she cannot be rushed and finds that this makes her very stressful.

Individual (cognitive)

Mary has learning difficulties.

Mary can at times appear a bit abrupt; however this is representative of her cognitive difficulties and limited insight into her own presentation of self. Nevertheless she is a very friendly person when one develops a rapport with Mary.

Individual (risks)

Mary was extremely isolated and had stopped visiting her dad in the nursing home because of her anxiety going out. Her dad is very important in her life.

There was a lot of family stress evident. This further impacted on not only Mary but her family. As her brother lives with Mary it was of concern to ensure stress levels within the home were addressed and managed productively.

Plan:

Therapeutic Rapport/Social Inclusion

To build a trusting relationship with Mary and encourage her to identify some goals in which she would like to achieve.

Physical Disability Management

To liaise with a physiotherapist, in order to identify and supply an appropriate walking aide for Mary to safely use outside. I was also look at a suitable aid for Mary to use indoors and upstairs, instead of using the furniture and walls. I felt that for Mary to achieve her goal of going out it was important to discourage Mary from furniture and wall walking in the house - to increase her confidence in using appropriate aids.

Graded Exposure Work

To help promote Mary's confidence in walking outside with a suitable walking aid. This would be through regular feedback and encouragement. I was also to promote correct posture and positioning using the frame. I was to help Mary identify the safety of using this aid if correctly used.

Whole System Approach

To involve Mary's family, where appropriate, in the work being completed. Her brother and sister are the main carers for Mary. A discussion with Mary would advise me on what she wanted me to share with them in her care planning needs.

Goals

Mary identified two initial goals:-

- i) To be able to independently visit her dad at the nursing home he was living.
- ii) To look into a befriender for Mary.
- iii) To look at volunteering.

Problems Incurred:

Mary reported that the relationship between her and her bother was 'breaking down'. She reported incidents of stressful situations where she and he had argued and she ended up going to her room and crying.

Mary suggested I have a meeting with her brother and sister. I arranged the meeting and was able to sensitively talk to both her brother and sister. I was able to help her brother identify his carers stress and loss issues he was experiencing since his dad went into a nursing home. I gave him information on how he could receive help for his own needs. This was well received by him and his sister.

I also spoke to Mary about ways of managing her own stress. I also considered her spirituality in looking at management strategies.

Outcome:

Mary has reported that her relationship with her brother has definitely improved and this is conducive to her well being in general.

Review of Goals:

Mary received a befriender from her sister's local church. This helped also meet her spiritual needs.

Mary decided against volunteering.

We then set about a plan to look into Mary being involved socially, with others but in a very low key approach. I discussed Age Concern and the sort of things they could offer. Mary agreed to attend a meeting with the manager at Age Concern if I accompanied her. This appointment took place and Mary expressed an interest in a social group at New Era.

An appointment was arranged where I would accompany her on her first visit and the manager would meet and greet us on our arrival. She would introduce Mary to others in the group. Mary informed me at the next appointment that she was looking forward to the visit.

Mary has gradually become more and more confident in her walking ability. She has been able to go alone to the nursing home, using Dial a Ride. She has also travelled with her brother in his car. She reported that they did not even argue.

Reflection:

Mary has had her needs met by an approach of rapport building, client centred care and multi agency working. These have all been beneficial in the success of this work and the client's and families overall experience of the service. I would hope it has gone some way towards mending the more negative experience of health care that the family previously described.

Mary has expressed the importance that she had been given time to gain trust in me, have an opportunity to change her mind and include her family where

appropriate. However this type of work takes time and a service such as IAPT(Improving Access to Psychological Services), where it is time limited, needs to be mindful of this need if good practice is to be demonstrated. This length of time needed impacts on my already substantial waiting list. I am a lone occupational therapist in the team and have no one to support me in my work. I feel an STR (Support Time Recovery Worker) worked would have been extremely beneficial in this work and I would have been able to 'hand over' this work to an STR worker, under supervision, once the goals were in place.

I conclude that occupational therapists are well placed to work with those with learning difficulties. We can offer a more practical based approach that moves away from being too intrusive and not too psychological based.

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Case Study: Dental Treatment

Jay is a 46 year old man that has complex learning disability. He has no verbal communication but can make his needs known using other expressions. Jay also displays behaviour that challenges, Jay needs 2-1 support to access community services. Jay's behaviour has declined over the past few months; staff feel he is in pain with his mouth/teeth. Jay would not tolerate a visit to the dentist. I liaised with the community dental team who agreed to carry out a domiciliary visit to meet Jay and assess the situation, Jay declined any intervention. A best interest meeting was set up and all healthcare professional attended along with a representative for Jay. Consent was discussed and all discussion was documented accordingly. The plan was to use general anaesthetic to enable practitioners to have a look in his mouth and treat him.

Treatment support from the community team for learning disabilities was needed; this team provides the vital support using physical intervention techniques to support service when they need treatment. My role as liaison nurse is to provide the vital link between acute services, senior practitioners, carers and staff. This link ensures that all staff play a key role on the day of treatment. Once the co-ordination has taken place and any additional pre medication has been prescribed then the treatment time will be arranged. This causes the least distress to the patient whilst maintaining dignity and respect throughout.

Jay's plan was in place all key persons were informed of their roles on the day. Pre medication given as prescribed to reduce anxiety and distress, treatment co-ordinated and treatment took place successfully. Jay had extensive dental decay ulceration and needed extensive dental work.

By carrying out this work Jay was successfully treated.

Jay's quality of life improved and behaviour eased, he must have been in agony and pain.

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Cervical cytology screening awareness for women with learning disabilities

Background

Cervical cancer is the twelfth most common women's cancer in the UK and the second most common worldwide. Around 3,000 women a year are diagnosed with cervical cancer and more than 1,000 women die from it each year in the UK.

Coverage for cervical screening in Sefton has been consistently below the target of 80%. There is considerable variation across practices in Sefton. Coverage is also low nationally, regionally and among comparison with Primary Care Trusts.

Improving the uptake of cervical screening by women with learning disabilities is in keeping with recommendations from '**Healthcare for All** (2008) (1,2) and '**Valuing People**' (2001 & 2009) (3). However, there is a wealth of research evidence which highlights that people with learning disabilities experience known inequalities in health, in particular the low uptake of screening programmes and difficulties with access to NHS health services (4,5).

NHS Sefton carried out health equity audits in 2007 & 2010 (**See tables 1 & 2**) re: uptake of cervical screening by women with learning disabilities. At the same time, a working group with membership from the NHS Sefton public health department and learning disability services within Mersey Care NHS Trust was established to deliver local actions to reduce any inequities found.

Purpose of this report

This paper outlines the situation with regards to cervical screening and women with learning disabilities in Sefton. It describes NHS Sefton's approach to addressing the identified barriers to accessing the screening programme and the outcome of the interventions adopted.

Where we are now?

England

National coverage has been declining year-on-year from 82% in 2000 to 78.6% in 2007⁹. The first year that coverage at a national level fell below target to 79.5% was 2006.

North West

Trends in coverage for the North West have closely followed the national trend. Screening coverage fell below the 80% target for the first time in 2006 (79.4%) and declined further in 2007 to 78.2%.

Sefton

Coverage in Sefton has consistently been below the 80% target. The 2007/08 figures show coverage of 73.9% ¹⁰. Also, in line with national and regional trends, coverage has been steadily declining over the last few years.

Table 1: Cervical screening coverage in Sefton, North West and England 2007/08

	2006/07	2007/08
England	79.5 %	78.6%
North West	79.4%	78.2%
Sefton	74.4%	73.9%
Target	80%	80%

The coverage data is taken from the National Annual Cervical Screening Report, produced by The Information Centre for Health and Social Care ².

Table 2: Cervical screening data relating to women with learning disabilities in 2007 and 2010

	2007	2010
Women eligible for cervical screening	431	405
Percentage of recorded test date	30%	30%
Percentage of women ceased from the screening programme	29%	12%
Percentage of women with no test recorded	41%	58%
Coverage rate	23%	20%

2010 results:

- More women had a last test within 3 years (up to 46% from 38%)
- 20% of women had their first test within the last three years.

Data taken from NHS Sefton Public Health Intelligence report Cervical Screening for women with learning disabilities 2007/2010

Where do we want to be?

Given the coverage rate of 23% in 2007 and 20% in 2010, NHS Sefton is committed to:

- Identifying and addressing the causes of the low coverage rate with the aim of increasing it
- Increasing the awareness and understanding of cervical screening by women with learning disabilities, their carers and health professionals
- Providing appropriate information to allow informed choice
- Raising the profile of cervical screening for women with learning disabilities
- Identifying and addressing the needs of these women relating to the cervical screening
- Demonstrating and sharing strategies taken to address the issues identified

How do we get there?

Identifying and addressing the causes of the low coverage rate with the aim of increasing it.

Knowledge is a denominating factor in decision making. Providing appropriate information allows informed choice. Two of the main barriers identified for the women were:

- Understanding the importance of cervical screening
- Understanding what having a smear test actually means

An approach to removing these barriers was to provide information to women in a way that was non-threatening but permitted clear understanding of the importance of cervical screening and the sample taking procedure.

Jo Jo Mind and Body Production consist of a group of actors who provide information to people with learning disabilities by using life sized anatomically correct male and female puppets, Joe and Joanne. The awareness sessions are interactive with the audience who then create and build the character of the puppet.

In December 2007 the Cancer Screening Lead (Consultant in public health), and the Cancer Screening Coordinator/Cytology Training Lead in NHS Sefton, the

Primary Healthcare Facilitator (learning disabilities) from Mersey Care NHS Trust, and the Director of Jo Jo Mind and Body Productions began to work in partnership to create awareness sessions for women approaching twenty five years and their carers.

Using the female puppet Joanne, a three-hour workshop was created that focused on

- the importance of cervical screening
- step- by- step process of having a smear test
- demonstration of the procedure for having a sample taken
- encouraging women with learning disabilities to take responsibility for their own sexual health & wellbeing

Increasing the awareness and understanding of cervical screening by women with learning disabilities, their carers and health professionals

Two venues in the north and south of the PCT were used to provide four half day interactive workshops in March and April 2009 and March and April 2010. Seventy women attended the session in 2009 and sixty six in 2010.

Women were invited by use of a contact list and sending the awareness flyer. GPs were informed of the awareness sessions and asked to support women who may present at the surgery for screening following the workshops. The flyers were displayed in the GP surgeries and general practice staff promoted the workshops opportunistically, as did staff in the sexual health clinics and within learning disability services. Furthermore, specific designated clinical time within sexual health services was also made available following the workshops to accommodate women who sought screening.

Raising the profile of cervical screening for women with learning disabilities

In tandem to the workshops, educational sessions relating to the cervical screening per se and the needs of women with learning disabilities are provided on a twice yearly rolling programme for clinical and non-clinical staff. Further, general learning disability awareness sessions are also delivered to staff by the learning disability nurses and people with learning disabilities.

Educational sessions for learning disability nurses relating to the cervical (and other) screening programmes were requested and accessed. This enabled them to support clinicians as required when taking a cervical sample.

Identifying and addressing the needs of these women relating to the cervical screening

A small focus group was held Monday 20th April 2009 which was attended by six women and their carers. This allowed the women and their carers to explore and

share their thoughts about the workshops and to highlight their needs related to cervical screening. The main themes were:

- Information: what cervical screening means. Lack of understanding by the women and their carers were a barrier to accessing the screening programme.
- Suitable access sites: not all venues meet their needs, particularly if there are any physical disabilities.
- Time: longer appointment times are often required with preparatory visits
- Staff who have an awareness and understanding of the needs of people with learning disabilities

Outcome

136 women attended the workshops in total. The overall cost for four workshops was just under £1,000 plus £300 for venues, staff costs and hospitality. They were well attended and very interactive, and highlighted the need to repeat and roll-out to a wider audience.

The audience shared their thoughts and feelings which, in the main were very positive. Many stated that the session addressed their fears and questions and they could now make the decision for themselves; and that they would make an appointment to have their sample taken. Importantly, most carers present felt more reassured about the reason for cervical screening for the woman in their care and the process.

The majority of the women who attended the workshops had never attended for cervical screening. This was because:

- 1) they had never been invited
- 2) they did not know they had been invited (lack of discussion and/or informed consensual decision making)
- 3) they had been invited but were informed by a clinician they it was not required when an appointment was requested
- 4) they did not want to attend - lack of understanding and awareness re: benefits of screening
- 5) their carer/support staff said they did not need it (screening)

In terms of influencing a decision to access screening and as a direct result of the workshop:

- Fifteen women attended the sexual health services clinics and successfully had the sample taken in 2009. The figure is yet unknown for 2010

- Seven women attended in the general practice setting in 2009. To date ten women have attended in 2010.
- A total of thirty two women to date have successfully attended for screening.
- Several of the carers were prompted to attend for their screening

The feedback from the focus group was as follows:

- The play was really helpful on getting the message across in a non-threatening way
- It educated the carers in addition to the women with learning disabilities
- The easy- read leaflets and posters were very helpful
- The (national) invitation needed to be altered to meet the needs of the women with learning disabilities
- Having nurses to talk to about having a sample taken was helpful - it allowed time to discuss things
- Seeing a sample being taken really explained how it was done
- A DVD of the workshop would be helpful
- Anything with pictures is easy to understand

Conclusions

The low attendance for cervical screening for women with leaning disabilities remains a concern. Efforts are continually being made to highlight and address the barriers encountered by the women all be they; educational, access issues, support or service provision.

Learning styles must be adapted to suit need. The workshop approach has proved to be beneficial to the target audience. The interest by others outside NHS Sefton has been forthcoming and is welcomed.

It is clear that the profile has to be enhanced and maintained. One hundred and thirty six women attending the workshops, out of which thirty two accessed the screening programme who more than likely would not have done so. Despite this success the coverage rate has fallen from 23% in 2007 to 20% in 2010. It therefore remains an area that requires persistent effort and commitment if the inequities in access to cancer screening programmes are to be addressed.

Education for all is paramount and has proved to be an essential component in highlighting the profile of cervical screening and the needs of not only women but all individuals with learning disabilities. A conclusion could be reached that the coverage rate for 2010 could be lower that 20% if the interventions used had not been offered.

Recommendations

The following recommendations are suggested to improve the coverage rate of women accessing cervical screening of in Sefton.

- Maintain awareness sessions for women with learning disabilities, their carers, clinical and non-clinical staff
- Continue to provide cancer screening awareness sessions for learning disabilities staff
- Continue to provide learning disabilities awareness sessions for all staff
- Identify and remove any barriers to screening
- Deliver a cytology screening service that is reasonably adjusted to the needs of all women with disabilities
- "Ring fence" monies to overcome barriers to accessing the screening programme

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Reflections on the involvement of a joint therapy team in a new build housing project for people with learning disabilities.

Introduction

Between 2008 and 2011 staff from the physiotherapy and occupational therapy teams in Manchester learning disabilities partnership were involved in the design and letting of a supported accommodation project for people with a range of learning disabilities.

Two identical properties were built, each consisting of wheelchair accessible bungalow accommodation for four people with high support needs on the ground floor, combined with two independent flats for people requiring minimal support. Therapy staff were involved at the design stage, providing the architects with evidence-based advice concerning necessary and desirable design features. They were also involved in ensuring that the right people were supported to move into the building and that the Mental Capacity Act (MCA) was adhered to.

The building – architecture, activity and accessibility

In developing the building, we balanced three needs; for a homely and domestic environment, for a functional and disability-friendly environment, for a safe working environment for support staff. Individual tenants had not been identified in advance, so the recommendations were of necessity very general.

Firstly, fundamental spatial and construction issues were considered. For example, bathrooms are a common source of risk and functional and dignity-related problems. Each downstairs bedroom was provided with an en-suite wet room with sufficient space to accommodate a tilt-in-space shower chair and carer support. Each had a secondary door into the corridor in case of the need for emergency access (e.g. in the event of someone having an epileptic seizure and falling against the door). Stud walls were avoided as grab rails cannot easily be fitted to these. Soil pipes from lavatory bowls all exited straight out to the rear as side-exiting pipes can prevent wheelchair access to the lavatory. Toilets were located in the middle of walls to enable carer access/sliding wheelchair transfers from both sides (Health Facilities Scotland 2007). Fixtures were robust, to accommodate the possibility of tenants being overweight, and care was taken to provide clear colour contrasts between fittings and background in case tenants had impaired vision (see below).

Similar attention to detail was applied throughout the house. A shared bathroom with a rise-fall bath and tracking hoist system catered for the possibility of baths being preferred. Bedrooms were designed for peninsula-positioned beds (i.e. not against the wall), with wheelchair turning circles allowed

for and overhead tracking hoist as standard. A staff bedroom with en-suite facilities and computer access was incorporated into the design.

Secondly, improvements were suggested which would support activities to add meaning and variety to service users lives. For example, although the kitchen in the supported accommodation was anticipated to be largely for staff use, a lowered surface was incorporated (700-800mm) so that service users could engage and participate in the food preparation process. The dining room was designed for flexible table positioning and flexible access possibilities to the kitchen. A dedicated but non-specific activity room with sink, storage and washable floor was provided to support the carrying out of recreational activities within the home. Suggestions were also made concerning accessibility and layout of the garden areas.

Thirdly, suggestions were made concerning sensory issues, accessibility and simplicity. Mixer taps were thus not used in the property, as these can be confusing. Helpful visual cues were provided as much as possible in the décor - for example, the walls and floors were painted different colours, glitter in wet room floors was avoided as possibly distracting, and thresholds were camouflaged where possible to avoid them being perceived as barriers. Bathroom suites and wall tiles were of different colours to ensure the facilities visually stood out. Internal windows were used to allow direct observation of communal rooms and their functions. Powerful and variable lighting was recommended, along with various options to limit who it could be controlled by and where from. Toilet flushes were chosen which were intuitive and simple to operate, but hard to get a firm grip on to "pull" to discourage this. Much advice in this section drew quite heavily on resources developed to help design accommodation for persons with dementia. Many of the themes in this advice are transferable as they do not relate to dementia *per se*, but have been developed to make buildings more friendly for people with compromised core intellectual processing speeds, limited knowledge and awareness, poor memory, and reduced or altered sensory abilities rather than dementia *per se* (Cunningham et al 2008).

The first floor flats were planned to provide much more independent accommodation for people without physical care needs, so whilst some of the principles discussed above were employed (for example related to visual contrasts in bathroom areas, or simplicity and robustness of fittings), these flats presented less of an issue. Separate access from the ground floor accommodation via wide stairs was provided. Each flat had a single bedroom, wet room and toilet, kitchen/diner and separate lounge. An intercom system was available for night time use.

These examples give a flavour of the kinds of discussions staff were involved in. In many instances, it was difficult to strike a balance. For example, how does

one choose between "ordinary" carpets and washable (but loud!) flooring, or between somewhat dull plain tiles versus "homely" patterned (but potentially confusing) tiles? Should electronically operated gates be provided to the property be provided given the high incidence of petty crime? There is no clear correct answer to many of these questions, but in most cases a new solution or an acceptable compromise was struck. Regular meetings were a vital, if time-consuming, part of the process.

At the time of writing, the buildings have been fully occupied for 6 months and reports concerning functionality and accessibility from tenants, relatives and support staff has been overwhelmingly complimentary. In retrospect, a lift to the 1st floor flats may have been a good idea, but aside from this, no major problems have emerged.

The people - choice, compatibility and capacity

It has become a truism to state that people with learning disabilities want to choose where they live; who they live with and be given the support they need to do so (Valuing People Now 2009). At the same time, however, practical pressures and limited understanding of the issues involved have made this historically difficult for learning disabilities services. Where choices do have to be made on other's behalf, The Mental Capacity Act (MCA) (2005) and subsequent Court judgements show the importance of ensuring that people's rights are upheld and that the service is protected from potential litigation. (Jones 2008).

In this case, once the building was complete, there was some pressure to fill the vacancies as quickly as possible. However this had to be balanced with ensuring that the right people moved into the home, exercising choice where possible. An independent moving team was set up for the project. Initial suggestions for possible tenants came from a range of sources (e.g. people themselves, care managers, health professionals, carers, placement panels). 26 people were nominated in total and, after initial screening, 18 people were assessed for the 12 vacancies.

The starting point was to address fundamental issues of choice and compatibility by assessing the person's wishes, needs, preferences and lifestyle. The team devised a needs/compatibility assessment to gain a "snapshot" of the person. This consisted of a simple tick list, covering, for example, food preferences, noise preferences, and preference for company/solitude and so on. Detailed information could be provided if desired on a particular element. The assessment could be completed by the individual or by those who knew them well. Discussion of the emergent patterns with individuals could be used to encourage choice, where possible. Tenancy agreements were presented to

people in an accessible form with key questions to check understanding of the issues.

Many, however, did not have capacity to decide where they wanted to live. The team ensured that all decisions were made in the person's best interests, taking their past and present wishes and the views of others into account, and that any proposed move would be the least restrictive option. (MCA, 2005 6.8). For example, "best interests" meetings involved the individual, a representative and any professionals involved. Occasionally there was difference of opinion - either between professionals / family or between professionals - and the best interest meeting format proved useful in resolving these. Particular needs could be set as conditions for the move - for example, it was one person's best interests for them to become a tenant as long as they could still attend the day centre and church.

Difficulties arose when trying to establish a procedure for signing tenancy agreements on behalf of people who did not have capacity. If a person lacks capacity and has no court appointed deputy, then an application has to be made to the court of protection to deputise on behalf of the person to sign a tenancy agreement. This proved to be a lengthy process which was overwhelming for many family members, and they needed support from the team - which used considerable resources.

Throughout, the team worked closely with senior management to develop a written procedure that is now being rolled out across the learning disabilities service. We hope this will ensure that many tenants with learning disabilities will be able to live in a home of their choice, supported the way they want to be, and with people they are compatible with. Where an individual lacks the capacity to make some or all of these choices, explicit application of the MCA and best interests' procedures can serve to protect all parties. The tenant (and the landlord) will be protected by a legal binding tenancy agreement.

In future projects, further work could to be done to ensure that all practical steps are taken to establish, promote and improve capacity. This may include using illustrations and photographs to aid people's understanding of the decisions that need to be made. It would also be useful if compatibility and MCA assessments of potential tenants were carried out as early as possible. Court appointed deputies could then be arranged in good time.

Conclusions

Members of the occupational therapy and physiotherapy teams were involved from the beginning of this ambitious housing project, in two very distinct ways. Initial practical advice concerning the physical environment tried to ensure that basic use of space was sensible and flexible, that the space encouraged rather

than blocked participation in everyday activities and that common minor pitfalls of décor and fittings were avoided. Some 18 months later, different team members carried out a thorough assessment of possible individual tenants. They helped to maximise people's involvement and capacity in accommodation choices, and helped ensure that best interest processes were comprehensively and legally pursued, despite occasional conflicts with understandable organisational pressures. Both areas of involvement have been useful and productive; for the future, closer integration between buildings advice and tenant support may prove useful.

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Central Lancashire Physical Intervention Partnership Approach

Rationale and outline of the work undertaken

Physical Intervention is a term used to incorporate breakaway techniques; physical guidance/touch control/Assisted Support and restraint techniques. The Department of Health¹ has issued guidance on systems and law pertinent to physical intervention and the British Institute of Learning Disability² have a scheme of accreditation for models of physical intervention. The Mental Capacity Act³ also has specific guidance in relation to restriction of liberty and restraint. It also outlines the statutory assessments and decision making required where people lack the capacity to consent. Furthermore common law in relation to protection of the person comes into play when restraint is used for the protection of others.

Physical intervention is one of the most invasive methods of intervention for challenging behaviour and came to the attention of Healthcare Commission (now Care Quality Commission) during their investigations in Cornwall⁴, Sutton and Merton⁵ and their national audit of Learning Disability Health Services¹. The Healthcare Commission made specific recommendations in relation to systems and use of physical intervention. Additionally recent events at Winterbourne View televised on the BBC Panorama programme; 'Undercover Care' in June 2011 has brought the use and abuse of physical intervention to the fore once more.

A consultation commenced in November 2007, a partnership approach was drafted and circulated to all commissioned learning disability service providers (30 organisations), community learning disability social work teams and community learning disability health teams for comment. The first version of this document was issued in September 2008 with a full review having been conducted with the same groups of staff through an annual event in September 2009 and September 2010. Amendments and developments have been made which reflect those comments received. The approach will continue to be reviewed at least annually on behalf of Central Lancashire Joint Commissioning Board for Learning Disability in partnership with local service providers by the Community Learning Disability Health Team.

Compliance with this partnership approach is a Central Lancashire Learning Disability commissioning requirement. Commissioned learning disability Service Providers will also need to meet any additional requirements of their insurers and/or from their training providers for the physical intervention model adopted.

The approach incorporates a number of principles that organisations sign up to. These are based upon person centred approaches, best practice in communication and interaction, applied behavioural analysis and approaches and the mental capacity and common law requirements. Furthermore the approach requires that providers only use models of physical intervention accredited by BILD.

The approach has two significant areas of work

1. The Quality Check - this is conducted by a member of the service not involved in the person's care or interventions that has additional training is applied behavioural analysis and approaches. It is a documentary analysis of the support provided against a standard benchmark resulting in a report of positive aspects and aspects requiring review that leads to the quality checker either supporting the provider service's decision or not supporting their decision to add / maintain physical within the person's support plans. Support can be given for any period up to a maximum of 12 months based on the findings of the documentary analysis. Where people's care is being considered by the Court of Protection more in depth analysis and reporting is provided to assist the court in its work.
2. The Audit of useage - quarterly audit of the frequency of use of each group of techniques. The analysis of audit data is conducted by the community learning disability health team and considered by a Physical Intervention governance group made up of commissioning, contracts and health team staff. At these meetings actions are agreed in relation to proactive intervention for situations that appear to be worsening and collate information for feedback, both positive and negative, within the provider organisation's contract review process

Outcomes / benefits of the project

Information from various parts of the approach has demonstrated that

- the addition of physical intervention to some people's care plans has been prevented
- the use of physical intervention techniques for many people has reduced or been maintained
- the care plans of some people have had physical intervention removed due to it no longer being necessary
- Some people have had social care or health care reviews brought forward or planned as a result of audit information
- Many services have improved their understanding of the person and their preventative approaches

- Many services have improved their ability to demonstrate both necessity and proportionality in the use of physical intervention techniques

The approach has ensured that physical intervention is used only with those people with learning disability who are already receiving good quality preventative interventions and where physical intervention is both necessary and proportionate.

Who was involved?

The service development was led by Consultant Nurse Learning Disability and Joint Commissioning Manager Learning Disability however it was a co-produced partnership development that involved colleagues within the community health teams of NHS Central Lancashire, commissioning, contracting and social work teams within Lancashire Social Services and 30 third sector providers to develop the approach

Lessons learnt and what if anything would you change if repeating the project

The project has been resource intensive and has required a different way of working for those who undertake the quality checks. The approach has been updated each year as have the internal administrative systems in response to new issues that emerge through the annual event or through dealing with a specific case in this way the learning is ongoing and the approach responsive to that learning.

Adaptations have been made to the process when it is known that the situation will be considered by the court of protection, to ensure that the providers have been supported to make necessary changes to meet the statutory requirements.

In relation to the support to people with learning disability, providers have verbally feedback the learning that they have had based on the process and the feedback received from the check itself. In this way their approach to the planning and delivery of support to individuals has changed as the learning has taken place.

If others were looking to replicate this development, it is necessary to ensure sufficient clinical and administrative time to undertake the functions, this would need to be based on an evaluation of the population and the relative use of physical intervention within that area.

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The Role of Patient Disability Adviser

The Role of Patient Disability Adviser at Wirral University Teaching Hospital Foundation Trust is unique and autonomous within the hospital and even within the general NHS. In many ways it serves an almost identical niche role as that of the Learning Disability Liaison Nurse but with a few differences.

It was created in 1999 as a temporary 0.5 WTE Senior Occupational Therapy role (BAND 7) to develop and lead best practice initiatives in response to the then Disability Discrimination Act (1995) now part of the Equality Act 2010. Emphasis of the role focused on 2 major responsibilities from the Act: Employment and Service Provision.

Originally a pilot project that ran for approximately 9 months, the role of the Disability Adviser encompassed qualitative initiatives for promoting the social model of disability within the modern NHS for the care of patients and staff who have a disability. This work focused on 4 clearly defined areas:

- 1) Environmental access for patients with disabilities,
- 2) Disability awareness training for members of staff,
- 3) Individual patient assessments including reasonable adjustments advice for patients with a learning disability
- 4) Assessing staff with disabilities, reporting back to line managers, Occupational Health dept and Human Resources.

Responsibilities also included coordinating and processing Access to Work requisitions for disabled members of staff.

The role was made permanent following the successful completion of the pilot project and remained within the domain of Occupational Therapy, given that core duties required a thorough working knowledge of physical and mental health conditions, comprehensive understanding of environmental adaptations and promoting person centered approaches to healthcare.

Following the publication of a number of national guidelines such as the Dept of Health's Valuing People Now, the 6 Lives Report and MENCAPs 'Death by indifference' an urgent need was highlighted for hospitals to develop best practice in the delivery of acute healthcare for patients with learning disabilities.

The Trust board recommended that the role should be redefined to focus purely on its primary strength, which was the understanding of the needs of patients with disabilities accessing acute hospital services. Therefore in July 2010, the

role became known as Patient Disability Adviser and remains within the governance of the Occupational therapy dept.

The Patient Disability Advisory role currently supports operational initiatives in making hospital services accessible to patients with learning disabilities and other vulnerable adults. The role has many similarities to that of a Learning Disability Liaison Nurse, namely, patient/ carer advocacy, collaboration between community care organisations and the acute hospital, enhancing communication between services, patients and professionals. Organising specific learning disability training, providing mediation and facilitating person centered planning at every stage of the patient journey. However there are some fundamental differences reflecting the professional background each post.

Unlike the Learning Disability Liaison Nurse, the patient disability adviser's remit is to encompass all disabilities, and is not exclusive for patients with a learning disability, although this patient group constitutes the majority of the workload.

Patients with sensory impairments, patients with mental and physical disabilities and other complex needs have been supported with individual adjustments to healthcare delivery, which has made qualitative differences to the patient experience.

The limitations of an OT orientated role is that specific nursing skills cannot be demonstrated, such as moderating techniques of taking blood pressure on a patient with a learning disability, advising on best nursing practices for invasive treatments for patients with learning disabilities etc.

The benefit of the post holder being an occupational therapist is that reasonable adjustment principals are central to the philosophy of the profession such as the ability to analyze function and dysfunction in a variety of settings. Practical advice on equipment provision and adaptations to the environment are also essential skills for the role. A keen understanding of the Social model of disability and the importance of a person centered approach is critical for this unique emerging role.

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Person Environment Occupation Performance Model (PEOP) (Charles Christiansen & Carolyn Baum)-Occupational Therapy Frame of reference.

*A mixed methods impact and outcome research study June 2010
By learning disability liaison nursing services*

The hospital experiences of people with learning disabilities and their carers

Background

In 2007, MENCAP's *Death by Indifference* report detailed the deaths of six people with learning disabilities who MENCAP felt died unnecessarily in NHS care, including hospitals. This prompted an independent inquiry into access to healthcare by Sir Jonathan Michael (2008). The inquiry found that people with learning disabilities have higher levels of unmet needs and receive less effective treatment; this is despite legislation, such as the Disability Discrimination Act and the Mental Capacity Act, which sets out a clear legal framework for the delivery of equal treatment. A report into the six deaths found significant failings in health and social care services (Local Government Ombudsman 2009). Despite work to improve the situation, people with learning disabilities and family carers still report experiences of care that fall short of expected standards (Department of Health, 2010). Research shows that people with learning disabilities experience poor quality care in hospitals, mainly due to the attitudes, knowledge and communicative style of hospital staff, the physical environment and discrimination (Gibbs *et al.* 2010, Backer *et al.* 2009, Hart 1998).

It is therefore important to monitor and evaluate the hospital experiences of people with learning disabilities. This project was commissioned the North West Regional Health Equality Group. The project aims were:

- To develop a patient satisfaction audit tool for people with learning disabilities
- To pilot the patient satisfaction audit tool in a number of sites within the North West region

This project was carried out by researchers from the Manchester Learning Disabilities Research Group².

Development of the patient satisfaction audit tool

Existing patient satisfaction questionnaires used in twenty areas across the United Kingdom were identified through:

- The research literature
- Reviewing information from a previous project on hospital access carried out by MLDP (Backer *et al.* 2007)
- The Learning Disabilities Health Network forum moderated by the Foundation for People with Learning Disabilities

² The Manchester Learning Disabilities Research Group consists of researchers and practitioners from Manchester Metropolitan University (MMU) and Manchester Learning Disability Partnership (MLDP)

- The A2A Network, a national forum for people interested in improving access to acute hospital care for people with learning disabilities

Areas which had developed questionnaires were contacted to discuss the development and administration of each questionnaire, response rates, how information from questionnaires has been used, and whether questionnaires could be improved.

A range of key stakeholders were consulted about the development of the pilot questionnaire: people with learning disabilities, hospital and community staff. Members of *Think Quality*, a group of people with learning disabilities who meet regularly to discuss issues relating to service quality, discussed the patient satisfaction questionnaire at two meetings. At the first meeting they gave their opinion on a selection of existing questionnaires. At the second meeting they gave feedback on a draft pilot questionnaire.

The MLDP Nursing and Speech and Language Therapy Practice Advisors, the Central Manchester University Hospitals NHS Foundation Trust (CMFT) Learning Disabilities Partnership Steering Group and the North West Regional Acute Health Network were also consulted about the pilot questionnaire.

Based on the stakeholder feedback, it was decided to design a questionnaire based on the NHS Surrey questionnaire which was designed in partnership with The Clear Communication People. The Clear Communication People were commissioned to adapt the NHS Surrey questionnaire. The pilot sites were also asked for feedback on the content and format of the draft questionnaire.

The pilot

The questionnaire was piloted in four sites across the North West Region over a four week period between January and March 2011. Feedback was gained from the link person at each site on the length of the questionnaire, the process of administration and how easy the questionnaire was to complete. Information from the questionnaires was entered into an Excel spreadsheet and then exported into Statistical Package for the Social Sciences (SPSS) computer package to conduct the analysis.

Key findings

Thirty-six questionnaires were returned as follows:

Site A	<i>11</i>
Site B	<i>16</i>
Site C	<i>4</i>
Site D	<i>5</i>
Total	<i>36</i>

Feedback from the pilot sites indicated that:

- The questionnaire provides useful information. All pilot sites wanted to continue to use it (or an adapted version) to monitor the experiences of people with learning disabilities
- Most sites did not have a means of identifying all people with learning disabilities as electronic 'flagging' systems have not yet been set up. Without accurate information about the numbers of people with learning disabilities admitted to each site over the pilot time period it is not possible to determine how large the response rate was, or how representative the sample is of the local populations of people with learning disabilities
- Potential sources of bias include:
 - The means of administration (e.g. if the questionnaire is completed with a nurse people may be reluctant to give negative responses)
 - The sites which took part in the survey may be particularly interested in supporting people with learning disabilities which may lead to more positive experiences
 - The use of a tick symbol for 'yes' responses may have meant that some people with learning disabilities interpreted this as the 'correct' response, leading to more positive responses
- The questionnaire was too long
- Several sections of the questionnaire were not relevant to outpatient or A&E visits
- Some questions were not applicable to all hospitals (e.g. having magazines and day rooms on wards)

Analysis of data from the questionnaires showed that many responses were largely positive (for example, relating to staff communication and information). In the overall ratings of hospital experience, if 'OK' and 'average' are interpreted as a positive response, only one negative response was made by a person with a learning disability and a supporter. It is important to consider the influence of potential sources of bias described above which may have led to positive responses. However, some negative experiences were reported and a larger sample size with more sites might lead to more varied responses.

There were some interesting patterns:

62.5% of inpatients felt that they were included in making plans for going home; however, 37.5% did not feel included.

73% of inpatients felt that their religious and cultural needs were met; however, 27% did not feel that they were met.

More than half of inpatients who responded (58%) were bored whilst they were in hospital.

Hospital staff used a range of communication methods to help people understand information. The most commonly reported were, speaking to people in words they understood, showing people what would happen and using objects.

Whilst inpatients were generally positive about the amount of choice they had, they reported less choice over having their own room (56% reported having no choice) and their treatment (41% reported having no choice). In terms of the help they needed in hospital, respondents were largely positive. However, of those that needed help, 33% did not get help to get out of bed and into a chair, 42% did not get help to move around the ward and 55% did not get help to use the television and radio.

59% of inpatients who responded did not know who to complain to.

When compared to the generally positive overall ratings of support received by people with learning disabilities, their supporters were more critical of the support that they received as carers, with 25% rating the support that they received as 'poor' or 'very poor'.

Due to the small sample size, many questions being relevant only to inpatients and the largely positive responses, comparison of most responses for different sites was not carried out. However, as the question on how hospital staff helped people to understand was well answered this was analysed by site (Table 1). Site A appears to use a wider range of methods to help people understand than the other sites (although this finding must be viewed with caution due to the small sample sizes in each site).

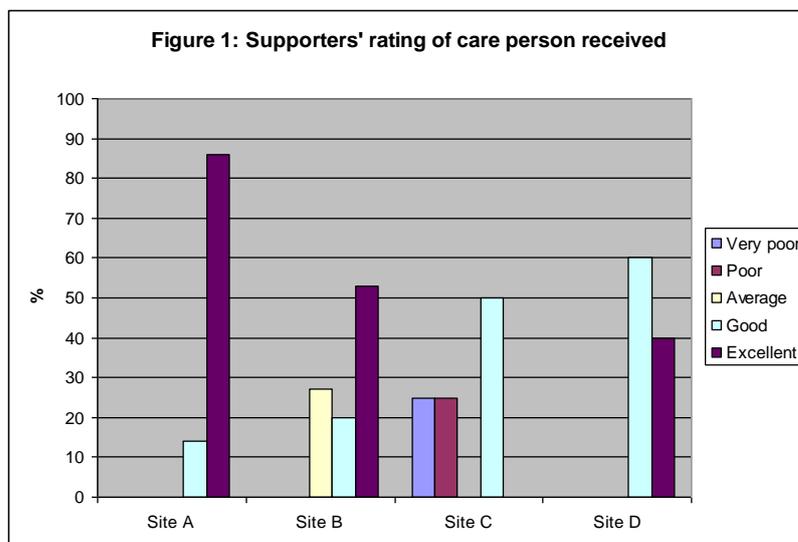
Table 1: Percentage of people responding 'Yes' in each site

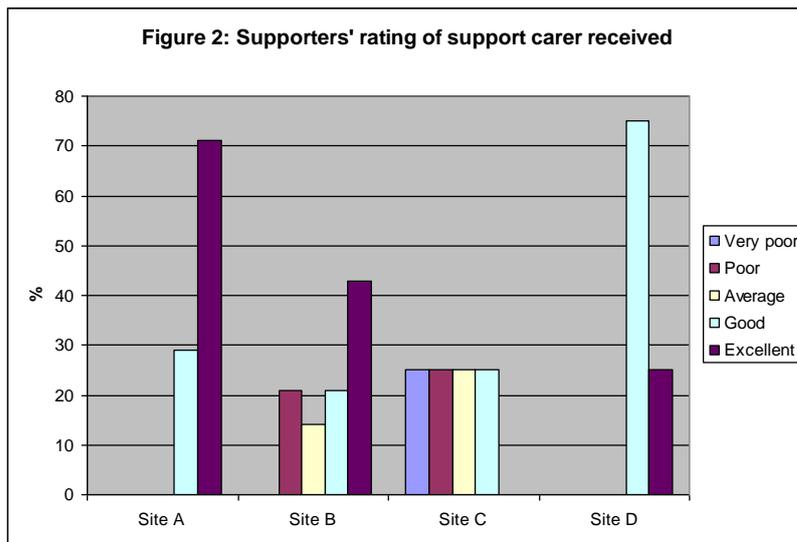
	Site A (N=11) %	Site B (N=16) %	Site C (N=4) %	Site D (N=5) %
How did hospital staff help you understand information?				
Spoke to me in words I understood	91	81	75	100
Used pictures	36	13	0	0
Used DVD or tape	36	0	0	0
Used leaflets	55	6	0	0
Used objects	64	31	0	20
Showed me what would happen	55	38	75	20
Used signs and gestures	27	0	25	0
Did something else	27	6	0	0

Similarly, in Table 2 and Figures 1 and 2 it is possible to see that patterns in overall satisfaction might emerge between sites if there was a larger sample size. In the pilot Site C received lower satisfaction ratings than the other sites (again this finding must be viewed with caution due to the small sample sizes in each site).

Table 2: Supporters' satisfaction ratings (%)

		Site A (N=7)	Site B (N=15)	Site C (N=4)	Site D (N=5)
Supporter's rating of care person received	Very poor	0	0	25	0
	Poor	0	0	25	0
	Average	0	27	0	0
	Good	14	20	50	60
	Excellent	86	53	0	40
Supporter's rating of support carer received	Very poor	0	0	25	0
	Poor	0	21	25	0
	Average	0	14	25	0
	Good	29	21	25	75
	Excellent	71	43	0	25





Conclusions

There is a clear commitment to gathering information about the hospital experiences of people with learning disabilities and carers across the North West Region. With a larger sample size a questionnaire can collect information which may inform future service provision. The questionnaire is being shortened and a separate questionnaire is being developed for outpatients and A&E. It is anticipated that areas across the North West Region will be able to use these questionnaires to inform future Health Self Assessment exercises.

Copies of the questionnaire will be available from Sue Smith, North West Learning Disabilities Project Manager, NHS North West, 3 Piccadilly Place, Manchester M1 3BN Tel: 07825438187 email: susan.smith@northwest.nhs.uk

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Sue Smith and the North West Regional Health Equality Group
Think Quality

Jane Jolliffe (Speech and Language Therapy Practice Advisor) and Moira Donlon (Nursing Practice Advisor), MLDP

Mike Leat and the Clear Communication People

The four hospital trusts who took part in the pilot

Central Manchester Foundation Trust Learning Disabilities Steering Group

The North West Regional Acute Health Network

Lizzie Clatworthy, MLDP

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Case Study Hip replacement

I was contacted by one of the local providers of care concerned that a service user had been declined an operation to replace her hip, Mary was 76 with mild learning disabilities. She lives independently with care input from a provider service, has reduced mobility and has pain on movement thus reducing her social activity and community presence. Mary was low in mood and had a reduced appetite. On assessment Mary told me that she was very active enjoyed socialising and said that the doctor had said that she was too old and because of her learning disability said he wouldn't do any operation, as she might end up with an even more reduced ability to walk. Mary said, "I couldn't be any worse, I want a new hip!".

I contacted the doctor that said the above and asked for a second opinion. A meeting was set and Mary and I attended. After a lengthy discussion about the pro's and cons mainly around post operative care, the doctor agreed to carry out the surgery. A package of care was put into place coordinated by the hospital liaison nurse Mary had her operation and consented to this herself after she had had a discussion with the consultant. Mary made a full recovery and was home and walking within a week. She said it was a struggle for the first few days but after that she was walking with her zimmer frame.

Three years later Mary has moved house. She is well and walks around independently she continues to use her zimmer frame for extra support and continues to have an active involvement within the community and has been happy with her new hip ever since.

The hip gave Mary a better quality of life.

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Palliative Care - Best Practice

A case study on how I best supported a service user through a difficult and challenging time in their life by acting in their best interest at all times.

As part of my case load, I opened a case for a female service user who had recently been diagnosed with bowel cancer and was currently receiving treatment in the form of chemotherapy. For the purpose of this article I will call her Jane.

Jane was a 79 year old lady with a learning disability. She was a very independent lady and although she lived in 24 hour supported accommodation, she performed most of her daily tasks herself with little input from the staff team. Jane had been diagnosed with bowel cancer in the months before and had been receiving a form of chemotherapy called Fluorouracil. Christie Hospital (2011) states that this is one of the mildest forms of chemotherapy and some of the side effects, although still significant, are not seen to be quite as intrusive as other forms of the medication.

During an interval from the treatment, Jane was given a scan to check the progress and it was discovered that the cancer had now spread as a secondary form to her liver. Due to this it was arranged for myself, as her community nurse, her main carer from her supported living home and the manager of the organisation to meet with the consultant at Christie Hospital.

During this meeting, the consultant tried to explain to Jane that her cancer could no longer be cured as it had spread and that she was not going to get better. He explained the options which were available, these included; a more aggressive form of chemotherapy, however, he explained that due to her age, this may not work and if it did, it may only extend her life by 3 months and would make her quite ill during the process. The other option was to treat the symptoms of the cancer rather than the cancer itself and support Jane through to her end of life. Due to Jayne's learning disability, she did not understand this information in the way he presented it to her.

I sat down with Jayne to establish how she was feeling about the situation and what things were most important to her. She repeatedly asked me if she had chemotherapy, would it prevent her from going on her pre-booked holiday as she was really looking forward to it. She said this was very important to her and her close friend and co-tenant and that she would still like to go and enjoy herself with her friend. Other information I gathered on Jane, led me to the conclusion that she was a very independent lady who liked to perform all her personal care herself and had become quite distressed during her last treatment of

chemotherapy due to the constant visits to hospital and the impact it had upon her health and mood towards her friends.

Further to the meeting at Christies and my information gathered from Jane, I referred her to a speech and language therapist for support on trying to explain the options to her so that she could attempt to make an informed decision about her future care and to establish a second opinion before assessing her capacity. NMC (2008) states that everyone should be given all the information available, to empower them to make their own choices and decisions about their care. Following these guidelines, we worked with Jane at a level she could understand, using simple language and pictures and by developing a time line to help demonstrate to Jane how long her life would be for each option and how she would be feeling during this time. We did this over a period of a few weeks to allow her to digest the information and weigh the options up.

The Mental Capacity Act (2005) advises that everyone should be assumed to have capacity unless it is proved otherwise. As Jane has a learning disability, a capacity assessment needed to be done to see if she had the capacity to decide on a treatment and consent to it. Using the evidence gathered during the sessions spent with Jane talking through the options available using all the accessible information mentioned above, I performed a capacity assessment on her. The evidence showed that Jane could not understand the concept of time, either future or past and therefore did not understand how much longer the chemotherapy would extend her life for.

She had stated she wanted to live longer but did not want chemotherapy or her hair to fall out. She was not able to distinguish between the fact that if she wanted to live a little longer, she would need to have chemotherapy which would possibly make her hair fall out. Her understanding of being able to live longer was by eating well and staying healthy. Due to her lack of understanding in these areas, it was felt that Jane was unable to weigh up the information presented to her and therefore not able to make an informed choice. This led to the decision that Jane did not have capacity to consent.

As a result of Jane not having capacity to make the decision about her care herself, I arranged for a best interest meeting to be organised. Invited to the meeting was Jane's main carer, her GP, myself as her nurse, her care manager, speech & language therapist, the consultant oncologist, and as Jane had no living relatives, an independent mental capacity advocate (IMCA) was also invited to advocate for Jane. This meeting was to be as person centred as possible so Jane was also invited to the first part of the meeting so she was aware of what we were discussing. Valuing People Now (2009), advised that a person with a learning disability must be at the centre of all care decisions and involved in all actions possible. I chaired the meeting and allowed Jane to put her point of view across. Again, she stated that she wanted to live longer but did not want to

have chemotherapy. My capacity assessment was put forward for the group to assess. I put the information forward that I had gathered during my sessions spent with Jane about how she liked her independence and was looking forward to her holiday and spending time with her close friend.

If she were to start the treatment this would possibly prevent her from going on holiday or at least enjoying it as it would result in her feeling quite poorly. This in turn would prevent her from spending time with her friend and would have an impact on her dignity as the treatment would require her to be supported in her personal care needs. There was also a good chance that due to her age, the treatment would not have any positive effect on her life span. Due to this, my recommendation for Jane was for her to not have treatment and to enjoy the rest of her time left as much as possible to promote a positive and supportive end of life.

Everyone in the meeting was in agreement with a similar opinion to myself and the consultant, as the final decision maker, agreed that Jane should not have the chemotherapy treatment. This decision was discussed with Jane later who was pleased that she would still be able to go on holiday. I then referred her to Macmillan nurses for support for Jane and for the staff who would be looking after her as her end of life approaches. As a result of this, Jane was able to access some funds provided by Macmillan to use for her holiday and enjoy her final summer with her friends.

It has become apparent, that although this case was never going to have a happy ending as such, Jane has been supported to try to make an informed choice and has received truly person centred and holistic care as all decisions made for her, were done so on a personalised and individual basis holding her best interest at the forefront at all times.

Jane has now returned from her holiday and advised me that she really enjoyed her time away and is still feeling quite well at present. The Macmillan nurse is about to do some training with the staff on how to support someone to their end of life and offer support to the staff in dealing with the emotions and feelings that it will no doubt raise within them. I am meeting with Jane and her carer and currently putting together the 'When I Die' document (MLDS 2007), with all of Jane's requests for death and afterwards to promote a quality death and ensure her decisions and wishes are being respected.

As a newly qualified nurse, this is my first palliative care case and through my own research and guidance from my manager, I feel I have supported Jane to reach the best possible outcome for her, which was to ensure her independence for as long as possible and allow her to live her life to the full, regardless of how long that may be.

This leads me to my conclusion of how death is still a taboo subject and is not commonly discussed or does not play a huge part in the curriculum of nurse training either, however, it may be much more widely accepted if it could be discussed generally before the a person becomes ill and allow them to plan ahead. As a nurse, we can expect death at some point as part of our role, hence the need for further training and understanding on the subject. Each case is individual and what was the right decision for Jane, may not be for the next person but one thing remains the same. If death were a more open topic it may help people to accept their fate in the future, whatever that may be.

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Accessible information resources supporting the patient who is learning disabled through diagnostic and therapeutic procedures: Palliative and Cancer Care treatments.

What was the purpose of the initiative?

To develop accessible resources, in the form of booklets and DVDs on a CT Scan and Chemotherapy treatment, for people with learning disabilities,(and their carers), who have presented with malignant palliative care conditions to take them on the patients' journey enabling them to understand what to expect when attending the Christie in regard to their condition.

50-90% learning disabled people have communication difficulties and 80% of severely learning disabled people fails to acquire effective speech, (BILD 2011). This work contains photos of real people rather than drawn images - as is normally used - and the DVD's will supplement those documents with a visual "step by step" narrative representing the procedures being covered. The script, voice over and all content will be scrutinised by specialist Speech and Language Therapists in this field as well as a core group of learning disabled people.

It is designed to be a pathway journey through an unknown and sometimes daunting process to support the individual and their carers through the difficult times of treatment and is seen as an effective method of disseminating vital health information and guidance in an inclusive and engaging format that is both easy read and appropriate to people with learning disabilities. This format has been found to be useful in explaining complex information to other vulnerable groups. (DOH 2010)

This will improve service provision for people with learning disabilities who have greater health needs but experience inequalities when accessing health care and particularly palliative care services as highlighted by: (Tuffrey-Wijne et al 2005, Healthcare Commission 2005, Alborz et al 2005, DOH 2001)

Is the initiative relevant to nursing practice, education or management elsewhere?

It will make clinicians within Palliative care services more aware of Learning Disabled people, vulnerable adults and support future services to adapt their service delivery in meeting people's communication needs.

The "Death by Indifference" report from Mencap (2007) showed that people with learning disabilities are usually seen as a low priority and that healthcare professionals have had little or no training on the subject of learning disabilities.

It will also serve as a guide for people with learning disabilities and their carers on a wider demographic scale, regionally and nationally due to the cancer care treatments provided by The Christie.

What did the initiative involve

- Research on services accessed within Cancer services by learning disabled people and advice and feedback from carers and parents.
- Identifying key Health and Social Care personnel at The Christie and setting up and attending meetings to discuss the project. Visiting the environments identified for the project, (CT Scan department and Chemotherapy environments)
- Observations of the initiative, (patients journey) by a learning disabled person and myself and acted on their feedback as to the concept of the booklets
- Separate meetings with lead personnel and Information Governance in using current Christie booklets and utilising the Easy Read guidance from DOH (2010) in order to breakdown text into jargon free language.
- Working with this information with our media department in identifying photographs and in design and production of the booklets
- Liaison with The Christie Medical Illustration department, our own Media department, volunteers and nursing staff with the photo shoots and with access to restricted areas.
- Portfolios compiled with information on the initiative, copies of correspondence, contacts of professionals at The Christie in support of the pathway, a chronological history of all meetings that took place booklets.
- Advice and feedback from our Speech and Language Therapists on content, text at draft versions of initiative.

Do you have any advice for others planning similar initiatives?

Research what is currently available. Identify the project you are going to undertake, what is your target audience? What is the purpose of the project? What style/type of images are you going to use?

Essential to collaborate with colleagues in Speech and Language Therapy to ensure an ongoing dialogue is in evidence at every stage in order to receive

constructive feedback and advice. Make your project inclusive and not patronising, helping to remove that "fear of the unknown".

Identifying key people and ensuring they understand their commitment to the project, its importance to vulnerable adults and healthcare staff involved in any form of treatments and/or procedures.

Regular update meetings with professionals and colleagues involved. Collate information around progress of project, liaise with learning disabled groups, involve individuals in visiting areas and professionals that will be included in any project to familiarise themselves with environments and people to relieve any known anxieties, involve carers, advocates, families etc.

Ensure effective communication is used that learning disabled people will be able to understand. Follow guidance in "Making written information easier to understand for people with learning disabilities" - Guidance for people who commission or produce Easy Read Information - Revised Edition (DOH 2010)

What are the benefits of the initiative

It will raise the awareness and build on the existing skills of The Christie to promote quality of care, treatment options, supporting inclusion, rights, independence and choice of learning disabled people (DOH 2001)

To help prevent diagnostic overshadowing and improve awareness around mental health and learning disability issues which have led to people being denied appropriate services and assumptions being made around consent.

Highlighting the effectiveness of the Mental Capacity Act (2005) which supports the need for people with learning disabilities to have accessible information presented in order to ascertain whether they have the capacity to consent or not.

Improvement of collaborative working between Specialist and Palliative Care services to support learning disabled people access the appropriate services with the support they require.

Enabling the learning disabled person and their carers to understand the process of the treatments, relieving anxieties, improvement in communication, inclusion, choice and independence. Helping to increase autonomy and empowerment over treatment choices.

Improvement of the learning disabled patients experience of Palliative and Cancer care services and their involvement in the development of those services (NICE 2004)

Education for all parties in regard to the Disability Discrimination Act and the Equality Act (2010) in making adjustments and special provision for the needs of disabled people.

What are the implications of your work for nursing practice, education and/or management.

Raised awareness of the needs of the learning disabled patient and their right to be treated equally and fairly. The resources are to be used as a tool to explain the treatments and to reassure the learning disabled patient and their carers.

There is a need for improvement of palliative care services as indicated by the Gold Standards Framework for Community Palliative Care (DOH 2005) AND THE National Cancer Plan (DOH 2001) in light of the learning disabled population who have greater health needs but experience inequalities when accessing healthcare as highlighted by: (Tuffrey-Wijne 2005, Healthcare Commission 2005, Alborz et al 2005, DOH 2001)

Development of further accessible resources in Easy Read format for all treatments at The Christie for all vulnerable groups of patients. Improved access to health services designed around the individual's needs.

To improve the skills of The Christie workforce in order to meet the needs of this marginalised group of people through education and training, inter agency and cross boundary working, improved communication on all levels

How do you plan to develop the project or disseminate your findings

My intention is to complete a detailed report on the progress and completion of the project reflecting on the evaluation in conjunction with a conference presentation

The project resources will be made available on line via Manchester Learning Disability Partnership and The Christie website in downloadable PDF formats with additional notes if required and also available within the Christie Information Centre.

Another method will be to attend Palliative Care and Learning Disability Conferences, Regional Cancer network meetings and to present Question and Answer sessions at Health and Social Care Conferences to highlight the efficacy of the project and its resources.

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Dementia and people with Learning Disabilities in the Rochdale Borough

Following a visit to Burnley Psychology in 2005, I took a lead on developing dementia services within Rochdale and a working group was put together. From the group a pilot to look at baseline dementia screening was completed. The assessment tools used were the DMR and a local tool called the Everyday Living Skills Inventory. 17 out of 20 people who were 35yrs plus and had Down's Syndrome took part and 7 people were referred onto psychiatry for further assessments re dementia. As a result of the further investigations 3 people were prescribed Aricept, and their carers received training with support plans put in place.

From the pilot a dementia care pathway was developed. This pathway is now being used by G.P's, LD services and psychiatry in Rochdale.

Dr Sermin (Consultant Psychiatrist for people with Learning Disabilities) developed a dementia clinic following the outcomes of the pilot. These clinics take place once a month and are supported by myself, who works with the person, their carers providing support, and by reviewing assessments. This clinic has been audited and evaluated and new referrals are still coming in.

Pictorial information to support the questions asked have been developed when using the assessment tools (the DMR is now known as the DLD -Dementia Questionnaire for people with Learning Disabilities). The pictorial information has been developed to be person centred with pictures of Dr Who, The Queen, The Bill used as examples. Pictorial pathways for the DLD assessment were also developed.

Following a request from carers an accessible presentation on "What is Dementia" was put together to explain to people with learning disabilities about their friends / peers and how to support them. The presentation has been used on many different occasions with one gentleman talking openly to his carers about his family where previously this subject was never discussed as he found it too distressing.

The dementia service provision for people with learning disabilities in Rochdale has come along way since the baseline pilot in June 2006. The majority of the recommendations in the baseline pilot report have been achieved. Services have since been developed, evaluated and continued to be provided which has proved beneficial from those accessing the services received. Networks within and outside of learning disabilities services across the borough and country have been developed to share good practise. However the service needs to continue to develop to ensure recommendations from reports by Valuing People, Death by Indifference (2007), The White Paper Our Health, Our Say (2006) and Down's

syndrome and dementia- briefing for commissioners (2001) are provided for the people living in the Rochdale Borough.

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