

Background

The Department of Health white paper 'Valuing People' (DoH 2001) and the Disability Rights Commission Independent Inquiry into the health care experiences of people with Learning Disabilities and mental health problems have both identified key targets for improving the health care and access to services for people with Learning Disabilities. A key area of concern is the inequalities that were highlighted.

The Michael enquiry stated that there was "convincing evidence that people with learning disabilities have higher levels of unmet need and receive less effective treatment". It found that they had more difficulty accessing assessment and treatment for general health problems unrelated to their disability and in getting reasonable adjustments to support equitable treatment, particularly in the area of communication, which enables understanding and provides support for personal preferences. People with Learning Disabilities and their family carers also found it hard to be accepted as equal partners in care.

To enable the PCT to identify and support the health needs of people with learning disabilities, the Merseyside & Cheshire Cancer Network have developed the Anticipatory Care Calendar to assist care providers with monitoring people's health.

Month/Year:		Key for actions  Needs immediate action  Requires action  No further action required	
Surname			
Forenames			
DOB			
Health Screening Information			
Cervical screening (25 years to 49 years of age every three years) (50 to 64 years of age every 5 years)			
Date of last screening	Next screening date:	If not attending screening programme(s) Please state why. If not applicable please indicate with N/A.	
Results:			
Breast Screening (50 to 70 years of age every three years) self referral 71 years and older			
Date of last screening	Next screening date:		
Results:			
Bowel Screening (60 to 69 years of age every two years) self referral over 70 years of age			
Date of last screening	Next screening date:		
Results:			
Dental screening (as directed by dentist)	Last Test date:	Next test date:	
	Outcome:		
Eye testing (Every 2 years or as directed by optician)	Last Test date:	Next test date:	
	Outcome:		
Managers signature to acknowledge screening information completed:		Date:	

The aims of the calendar will be to provide anticipatory care rather than crisis management i.e. tracking health care and noting changes in people's health and to be able to act on these changes before symptoms become worse. When health screening does take place, it often reveals high levels of unmet physical and mental health needs, poor deferential diagnoses and significant diagnostic overshadowing.

Month/Year:																																
Please detail any medication changes (drug changes NOT dosages):																																
Pain hurting																																
Date	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	
Severe Pain																																
Severe Chest Pain																																
Moderate Severe																																
Moderate																																
Mild																																
No Pain																																
Bowels/pooing																																
Date	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	
Blood/ mucous																																
Diarrhoea																																
Loose																																
Hard/Soft																																
Constipation																																
Normal																																
Self Caring /Unobserved																																
Urine/weeing																																
Date	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	
Not passing urine																																
Blood in urine																																
Urgency																																
Frequency/ Incontinence																																
Normal																																
Self Caring /Unobserved																																

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ACC/LD – V7 November 2008

The new early detection and prevention strategy advocates new service models which focus on all eligible people access Cancer Screening including people with Learning Disabilities: Merseyside and Cheshire Cancer Network assert that the Anticipatory Care Calendar assists with achieving this and have established a small Project Team to support Cheshire and Merseyside PCTs in implementing the programme.

Why was the Anticipatory Care Calendar developed?

Within our local area, clinical experience demonstrated that social care staff wanted to provide a high standard of care for the people they support; however, training and existing systems of accessing health care provided multiple barriers, which included;

- **Physical barriers – e.g. wheelchair accessibility**
- **Administrative procedures – e.g. appointment time, waiting rooms**
- **Communication difficulties – e.g. an inability to describe symptoms clearly**
- **Attitudes of health professionals – e.g. lack of confidence, limited experience, negative attitudes and assumptions**
- **‘Problematic’ symptoms (such as aggression) may be brought to the attention of services earlier, others that are equally significant (such as withdrawal, loss of interest) may not**
- **‘Diagnostic Overshadowing’ – the inability to see beyond the disability**
- **Perceived difficulty obtaining consent**
- **Assumptions and negative predictions about how patients might react or co-operate**
- **Family members/carers may not have the skills & knowledge to support individuals with learning disabilities to obtain health care or to maintain health related behaviour**
- **Recognition of ill health may be difficult or delayed because symptoms may not be easily identified**

Many social care providers in the area had little or no standard approach to health record keeping and large gaps were thought to exist in particular relation to health improvement, well person health checks and access to NHS cancer screening programmes. With the varying standards of documentation within care homes, screening information is rarely documented or acted upon. Symptoms for major illness or potential harm are not necessarily recorded on a day-to-day basis. Added to these concerns were patients with learning disabilities entering services in crisis due to poor early diagnosis, or signs of impending health crisis going missed or improperly addressed.

How did we address this?

In consultation with the local joint commissioning team for learning disability services, it was identified that a simple tool aimed at improving the general daily surveillance of health would be useful in helping adults with learning disabilities overcome some of the barriers known to exist to their health. Of particular interest was developing a tool that would identify early changes in a person's health which might signify a serious underlying condition or an impending health crisis and the development of a care pathway approach for social care staff to follow in these circumstances. The calendar outlines if patterns in patient's health and behaviour are changing on a daily basis. The anticipatory care calendar prompts care providers to assess and follow care pathways for clients with Learning Disabilities. The Anticipatory Care Calendar allows experienced professionals to assess complex symptoms on an ongoing monthly basis. The ability to evaluate patterns and themes can be determined easily through a visual picture of the client's health. Patterns and symptoms can be linked to identify the potential causal effects of ill health.

The aims of the anticipatory care calendar include:

- **To reduce health inequalities.**
- **Provide a sound clinical governance and critical care review mechanism.**
- **Provide care pathways that lead to action.**
- **Improve communication with the multidisciplinary team.**
- **Standardise information/documentation.**
- **Ensure that the legal requirements for documentation are met.**
- **Record patterns in behaviour and symptoms, which can be visualised more easily, using the monthly chart so that alterations in the client conditions can be viewed on more than one health variable.**
- **Assist in identifying underlying health issues, which may be considered a behavioural problem.**
- **Record the accurate screening of Cervical, Breast and Bowel Cancer.**
- **Provide learning opportunities between teams caring for clients.**

Pilot & Implementation Process

The following domains are assessed daily, pain, bowels, urine, eating and drinking, sleeping, mobility, behaviour, health observations such as lumps or lesions, breast or testicular abnormalities, mouth or sensory problems, difficulty swallowing and the final category include other symptoms for example photophobia, fever, breathing problems or seizures. A baseline assessment for each client is to be completed by the team supporting the clients at the outset. This is used to demonstrate what is "normal" status for each client under each of the sections included in the calendar.

When completing the following assessment, please refer to the description sheets for .

**Anticipatory Care Calendar For Clients with Learning Disabilities –
Baseline Assessment Sheet**

Name of Client:		Date of assessment:
Pain hurting	How does the client display pain(i.e. pinching, withdrawal, screaming etc)	
Bowels/ pooing	Record the usual bowel pattern/problem for the client	
Urine/ weeing	Record the usual urine pattern for the client	
Health Observations	Describe the normal menstruation cycle for the client	
Baseline weight		
Eating and Drinking	Describe the clients normal eating habits	
Sleeping	Record the clients usual pattern of sleep	
Mobility	Record normal mobility/activity for the client	
Behaviour	Record normal behaviour for the client	

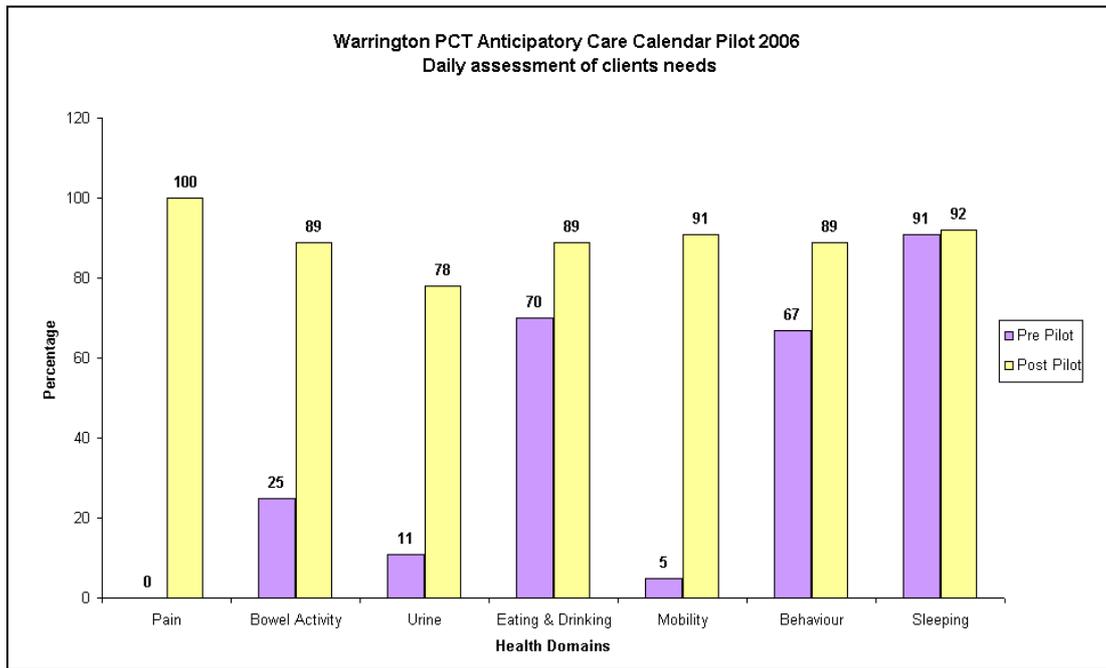
Results/Impacts

To ensure effectiveness, the Anticipatory Health Care Calendar was initially piloted across two social care providers with Warrington Primary Care Trust over a three-month period. Sixty client records were benchmarked against set criteria prior to implementation of the calendar to ensure we were able to measure improvements. A second pilot in Wirral Primary Care Trust included one hundred clients over nine months.

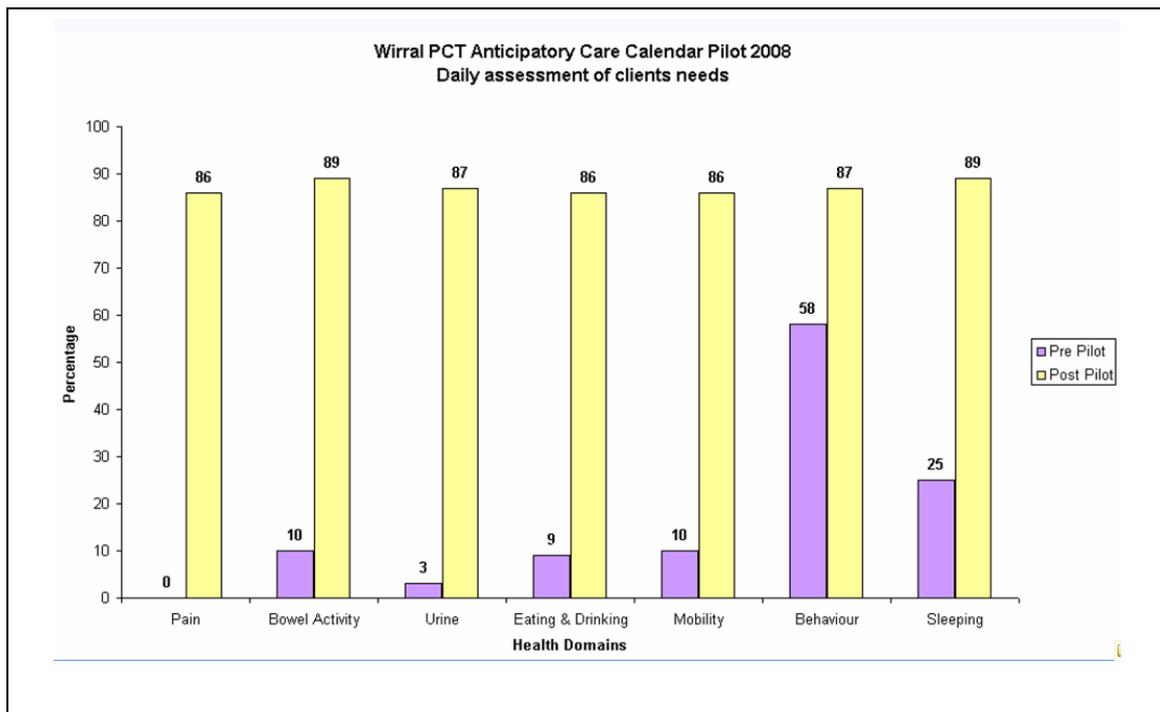
Care homes and all community day care facilities were visited and questionnaires were used to ascertain staff perception of their service. All staff and managers using the calendar received a briefing and education session prior to the pilot. In Warrington, two Community Matrons were on call during the pilot period to answer any health related queries and ensure rapid access to clinical care were required. Calendars were reviewed by the Community Matrons or the project lead at the end of each month and any identified patterns or health needs addressed. The Wirral and Cheshire pilot however, used local primary care services and the specialist Learning Disability Team with two health facilitators reviewing the calendars on a monthly basis.

There were large improvements in the daily recording of client’s health which assisted with picking up early symptoms of health issues as demonstrated in graph 1,2 & 3.

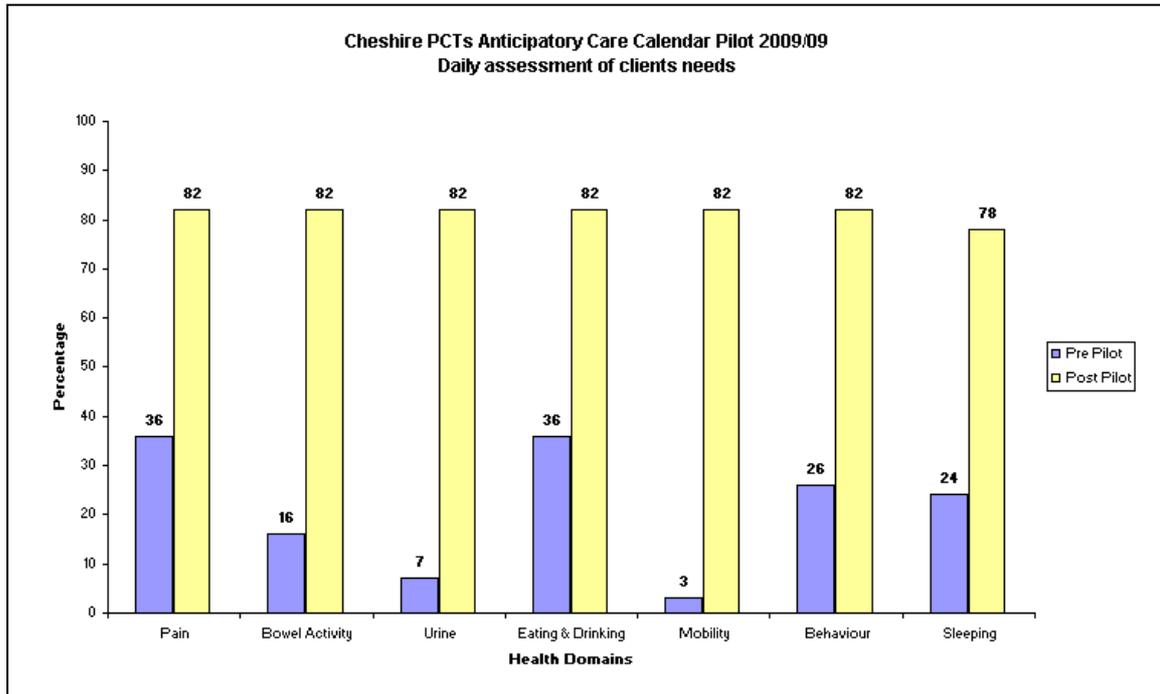
Graph 1



Graph 2



Graph 3

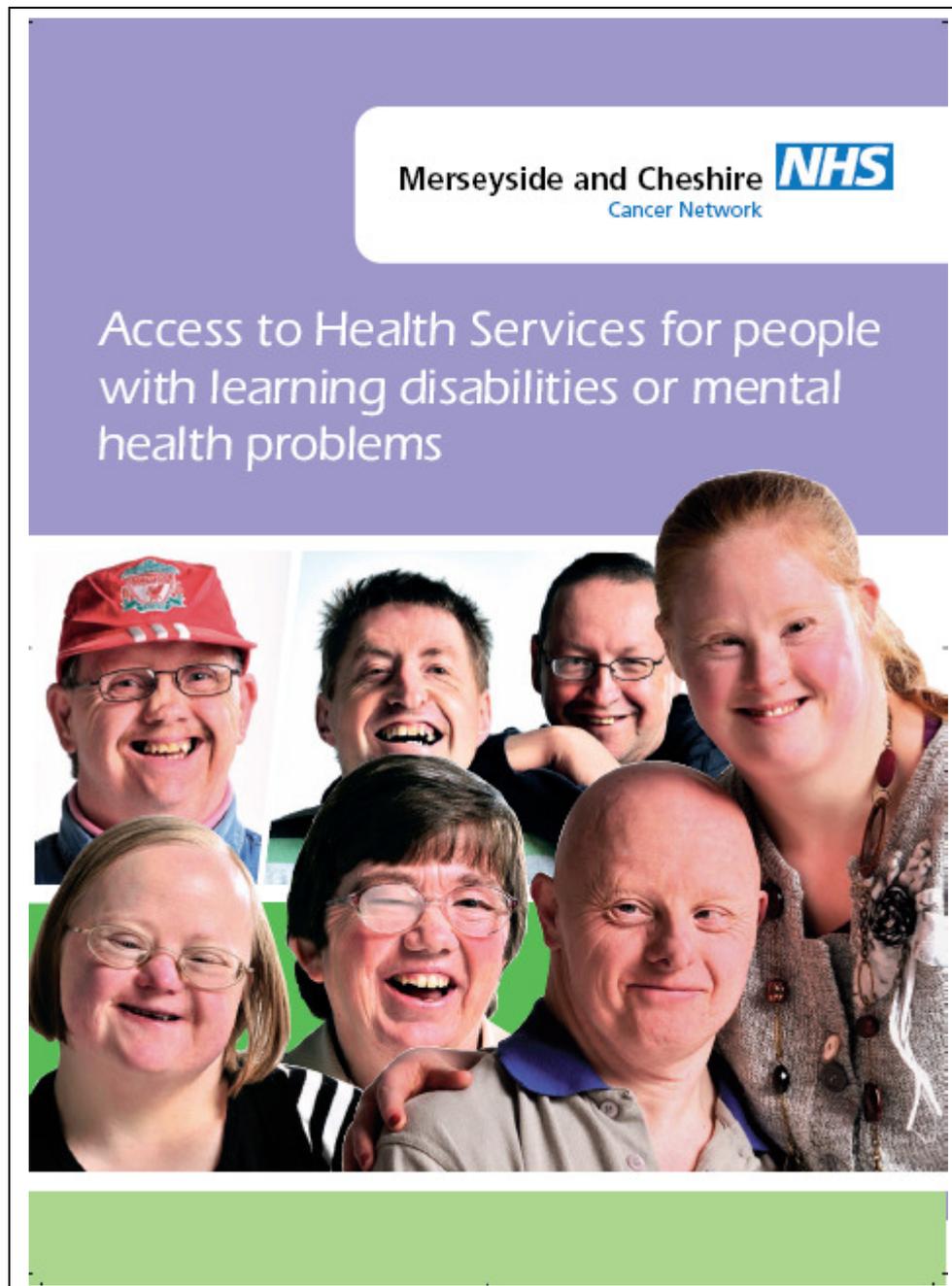


Other significant benefits of the pilot include:

- 23 ladies back on the screening programmes
- Oesophageal Cancer diagnosed following dysphagia pathways
- Severe changes in Cysts observed on testicles
- Drug interaction identified for a client with frequent falls
- Referrals to specialist team for swallowing problems
- Lumps observed in testicles
- Fractures identified due to mobility change
- Pneumonia diagnosed with GP intervention
- Hernias identified and reported
- Dental treatment initiated
- GP Completing records
- Fast track breast referral following observation of changes
- An increase in staff awareness to the early signs and symptoms of impending health issues

As a result and to support the training package that is available, a DVD has been created to help social care staff and other organisations understand how the Anticipatory Care Calendar works in practice and how it will benefit carers to give support to clients. Within the DVD is an introduction to the project and why the calendar was developed, it also gives detailed explanations of how to use the

Anticipatory Care Calendar and includes some short films showing the calendar in use within care settings. Help was received from a local drama group, the Eastham Players, who put a lot of effort in to acting for the DVD, putting their own plans on hold to be able to give time and dedication to this project. The Eastham Players all have learning disabilities and taking part in this project has helped them to gain recognition whilst learning from the work.



Conclusion

The development of the Anticipatory Health Care Calendar enables a streamlined pathway for the client. People with Learning Disabilities are less likely to undergo inappropriate tests and be transported to accident and emergency unnecessarily. GPs are able to assess client's health status over a calendar month and it can improve communication between day care and care provider leaders. Clients are now receiving appropriate care and early monitoring so that cancers can be detected earlier along with other long-term conditions such as diabetes and asthma. Client's behaviour will no longer be an excuse for missing clinical health problems.

What do Social Care Staff think?

" We have service users with profound levels of LD and ACC has proved to be a very effective tool in highlighting our awareness of health needs whilst reducing the levels of paperwork"

Jenny - Macclesfield

"The ACC has helped to identify changes in both behaviour and health whilst increasing awareness"

Julia – Macclesfield

"Works really well in helping staff show doctors their concerns about the service user"

Sue - Wirral

" You can instantly see if there is a problem, the info is instant so you're not having to look at reams of diary entries"

Alan - Wirral

This work has a potential to impact on services other than Learning Disabilities and is currently being piloted within Dementia and could be used within other vulnerable groups.

For further information or a copy of the DVD, contact:

Tracie Keats, Project Manager

Tracie.keats@mccn.nhs.uk