



An Evaluation of the Macmillan Learning Disability Clinical Nurse Specialist Project in Wales

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May 2017

Foreword

The population of Wales is currently 3.1 million, accounting for 5% of the total UK population. 30% of the Wales population live in rural areas and this has implications for transport links, travel costs and access to technology. Each year in Wales 19,000 people are diagnosed with cancer and 130,00 people are currently living with or beyond cancer in Wales. Due to improvements in treatment, increasing survival rates for some cancers and an increasing ageing population, the importance of access to care and information has never been more important. It was initially thought that the prevalence of cancer was lower for those with a learning disability, however, more recent studies have shown that rates are comparable.

In 2013, Macmillan Wales appointed a Macmillan Learning Disabilities Clinical Nurse Specialist to lead a three-year project to engage with key staff with a responsibility for cancer services and learning disabilities to highlight the needs of those with a learning disability alongside a cancer diagnosis. The project aimed specifically to enhance the capacity and understanding of those providing cancer care so that the information and support needs of people with a learning disability were better met.

A number of activities were included during the project period including developing a train the trainer programme aiming to train others to deliver the 'check for change' programme. Over 400 health care professionals, people with learning disabilities and carers attended the workshops held across Wales. This work, and other activities, have been formally evaluated and are included in this evaluation report.

Key to the delivery of individualised person-centred cancer care is the consistent use of Holistic Needs Assessments (HNA) and using this assessment to develop a care plan for each person diagnosed with cancer. Macmillan Wales has ensured that this remains a strategic priority for everyone to have access to from diagnosis onwards, through treatment and aftercare and it is committed to in the Welsh Government's refreshed Cancer Delivery Plan.

We can also take some practical steps to support the learning from this project. These include highlighting the need to consider the needs of people affected by cancer with a learning disability and those who care for them through our induction Welcome to Macmillan process for our new professionals and through engagement with existing Macmillan professionals in Wales. This will include making links between the cancer services they provide and learning disability services.

This ongoing work will also include supporting cancer professionals to be aware of and part of reviewing the resources and support available to people affected by cancer with a learning disability and those who care for them. Through Macmillan's cancer information and support services and our mobile information and support services we have considered how we can continue to provide support to people affected by cancer with a learning disability.

I would like to personally thank Tracey Lloyd for her enthusiasm, commitment and professionalism in undertaking the role of Macmillan Learning Disability Clinical Nurse Specialist for the project and leading the developments highlighted in this report, which clearly shows the impact and legacy this work has achieved. I would also like to thank everyone who has supported and participated in this project with the aim of supporting people affected by cancer who have a learning disability in Wales.

Susan Morris
Head of Service (Wales)
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1. Background to the project

In September 2013 a Macmillan Clinical Nurse Specialist (CNS) was appointed in Wales to lead a three year project the overall aim of which was:

‘To improve the experience of and outcomes for people with learning disabilities affected by cancer, their families and carers through the development of timely, coordinated and person centred support’

Based within Hywel Dda University Health Board the post holder was required to work across Wales to create effective ‘bridges’ between learning disability and cancer services. Specific areas of work were identified as being to establish links with both cancer care and learning disability professionals in all health boards, to assess the education and information needs of people with learning disabilities, their families and carers in relation to cancer and to develop educational provision as required. In particular it aimed to enhance the capacity of cancer care services to identify and respond to the additional information and support needs of people with learning disabilities. In addition the post holder was required to promote the sharing of good practice and to develop networks since the aim was for the links developed to ensure sustainability of the project at the end of its three year life span.

From the outset of the project an evaluation was planned to determine the extent to which these aims had been achieved. This report sets out the findings of this evaluation and highlights key learning points to inform future service development. The evaluation was undertaken between June and October 2016 with the project completing in September 2016.

2. Context

Information regarding the nature and pattern of cancer amongst people with learning disabilities is somewhat mixed. Historically it was thought that the prevalence of cancer amongst people with learning disabilities was lower than in the wider population but more recent studies have suggested rates that are comparable (Marriott and Turner, 2015). However, it does appear that the pattern of cancer amongst people with learning disabilities may differ from that of the general population (Marriott and Turner, 2015) in that higher rates of gastrointestinal cancers but lower rates of breast cancer have been reported (Hogg and Tuffrey-Wijne, 2008).

The overall life expectancy of people with learning disabilities is increasing (Coppus, 2013) and thus it might be expected that the prevalence of cancer amongst this group of people would increase given that prevalence rates tend to increase with age (Hanna *et al*, 2011). This may, in part, perhaps account for more recent studies citing rates comparable to the general population (Marriott and Turner, 2015). However, people with learning disabilities still tend to die earlier than their non-disabled peers (Coppus, 2013) and whilst cancer was

the most common cause of death for people with learning disabilities in the recent Confidential Inquiry it was still 20% less common than in the general population and tended to occur at an earlier age particularly amongst women (Heslop *et al*, 2013).

Within the Confidential Inquiry (Heslop *et al*, 2013) delays in diagnosing and treating conditions were viewed as contributing to avoidable and premature deaths. In relation to cancer any such delays mean that the cancer has the opportunity to progress unchecked, the opportunity for timely treatment is missed, and this can be fatal. For this reason within the UK (and within other countries) population screening programmes operate for breast, cervical and bowel cancer. However, lower rates of uptake amongst people with learning disabilities have been noted (for example Marriott *et al*, 2015; Willis *et al*, 2015) and it has been suggested that people with learning disabilities face inequities in relation to cancer screening (Cobigo *et al*, 2013). A range of barriers to accessing screening have been identified including logistical and practical barriers, a lack of knowledge and training amongst health care professionals, consent issues, communication, attitudes, literacy problems and mental and physical health problems (Cobigo *et al*, 2013; Marriott *et al*, 2015; Willis *et al*, 2015). It is thus concluded that health promotion (generally) and cancer prevention (specifically) may be less than optimal in relation to people with learning disabilities (Hanna *et al*, 2011) and that people with learning disabilities may lack accurate information regarding cancer and screening (Wilkinson *et al*, 2011).

Some interventions have been developed to address this deficit such the introduction of screening liaison nurses (Marriott *et al*, 2015), the use of a range of reasonable adjustments (Marriott and Turner, 2015) and educational programmes aimed at increasing the knowledge and confidence of people with learning disabilities (Greenwood *et al*, 2014; Swaine *et al*, 2014). Whilst some success has been noted the need for further work and development in this area is still required.

Cancer screening is, however, only one aspect of providing effective support for people with learning disabilities. For many screening will highlight no problems but for others it will result in a diagnosis of cancer and the sometimes long and complex treatment regimes that follow within which many decisions have to be made. O'Regan and Drummond (2008) note that communication is generally viewed as an important element in helping people to cope with cancer and that it is a prerequisite for making informed decisions regarding care. However, they also note that whilst a lot of information exists this may not meet the needs of people with learning disabilities and hence both cancer and learning disability professionals need to address any knowledge and information deficits they have, to collaborate, and for there to be strategic management and coordination of services. This requires cancer care and learning disability services to work together in order to ensure the best care possible is available for people with learning disabilities who have cancer.

It can thus be seen that cancer and people with learning disabilities is a growing area of interest and concern, that some important developments have occurred, but there remains a need for more knowledge and service development. It is within this context that the three year Clinical Nurse Specialist post for Learning Disabilities was established by Macmillan within Wales.

3. Key Features of the Project

The CNS undertook a range of activities during the course of this project in order to achieve the project aims. Included in these were the following:

3.1 Receiving and Acting Upon Referrals for Clinical Input

The overall aim of the project was to improve the experience and outcomes of people with learning disabilities in relation to the various stages of the cancer journey. To this end the CNS acted as a central point of contact for a number of referrals and inquiries from a range of different sources. It was not intended that the post holder would provide on-going clinical input for individuals however, in some instances, such support was given over a period of time. The nature and extent of these referrals is explored in Section 5 below.

3.2 Development and Delivery of the Check for Change Project

A key aim of the project was to meet the educational needs of people with learning disabilities in relation to cancer. To achieve this aim the CNS worked with a self-advocacy group to develop and deliver the 'Check for Change' project. This project sought to increase awareness amongst people with learning disabilities of the need to access the annual health checks to which they are entitled, the importance of specific screening programmes in relation to cancer (including breast, cervical, testicular and bowel cancer) and strategies to increase health communication such as personal health passports. The workshops utilised a range of interactive delivery methods including discussion, quizzes, and 'body-parts' (such as breasts and testes) that enabled participants to gain 'hands on' experience of checking for the presence of lumps. Throughout the sessions an emphasis was placed on trying to overcome embarrassment that participants may have had in relation to self-examination and talking about what might be thought about as private issues using language that would be familiar to them.

Although aimed primarily at people with learning disabilities many of the sessions also included supporters / carers who worked with those who were attending.

3.3 Delivery of 'Train the Trainers' Sessions for Check for Change

The initial project plan indicated that at the end of the three year period the developments that had taken place should aim to be sustainable. To try to ensure sustainability of the Check for Change Programme a number of 'Train the Trainers' workshops were held towards the end of the project. The aim of these workshops was to train others to deliver the Check for Change programme and to provide them with a resource pack that would support such delivery. The programme was held over one day, utilised a range of interactive teaching approaches and sought to enable those attending to develop the knowledge, skills and confidence to organise and deliver Check for Change workshops in their own area.

3.4 Other activities

In addition to the specific areas of work outlined above the CNS was also involved in a range of other activities that included teaching student nurses, liaising and sharing information

with both learning disability and cancer care services, organising two successful conferences, and disseminating information regarding the project both within Wales and more widely. She also successfully completed an MSc Professional Practice (Learning Disabilities) using the assignments within that course to further extend her knowledge of cancer related issues concerning people with learning disabilities.

The overall progress of the project was overseen by a Project Advisory Group that comprised representatives from Macmillan, from other cancer and palliative care services, from the University, from learning disability services from other health boards, from Public Health Wales and from Learning Disability Wales. Regular reports of progress were provided for group meetings and minutes were kept detailing key project developments.

4. Evaluation Design

The evaluation design was agreed with the CNS and the Project Advisory Group. A range of approaches were used to gather data in order to evaluate key elements of the project and these are set out in Table 1 below:

Element of Project	Method of Evaluation
Referrals for clinical input	<ul style="list-style-type: none"> • Completion of a proforma for each referral received by the CNS
Check for Change Project	<ul style="list-style-type: none"> • Analysis of statistics forwarded by CNS • Three focus groups with people with learning disabilities and supporters
Train the Trainers Sessions	<ul style="list-style-type: none"> • Analysis of statistics forwarded by the CNS • Ten telephone interviews
Other activities	<ul style="list-style-type: none"> • Minutes of Project Advisory Group meetings • A range of other information including external assessments and publicity

Table 1: Methods of data collection used in evaluation

The proformas relating to individual referrals were forwarded to the author by the CNS and data were entered into Excel for analysis. The same process was also used to analyse the

statistical data forwarded in relation to the Check for Change Project and the Train the Trainers Sessions.

Focus group 1 comprised 3 adults with learning disabilities and 2 supporters, focus group 2 comprised 4 adults with learning disabilities and two supporters, and focus group 3 comprised 3 adults with learning disabilities with a further participant forwarding written comments as she was unable to attend the group. All participants except 1 were female. Groups 1 and 3 were digitally recorded and contemporaneous notes were taken. Group 2 was held in a room with difficult acoustics and therefore only contemporaneous notes were taken. One group contained participants who had been involved in the development and delivery of the Check for Change workshops. Each group explored the following areas:

- Previous information received regarding cancer
- Participants views about attending the Check for Change workshops
- What actions (if any) participants had taken as a result of attending the workshops
- What participants felt worked well and what (if anything) they feel needs to be changed
- (For those involved in delivering the workshops) How was the experience of developing and leading workshops?

Following the focus groups the recordings were listened to and the notes reviewed to identify the themes that emerged.

The ten telephone interviews were undertaken with community learning disability nurses (n= 5), learning disability nurse lecturers (n= 2), cancer charity project worker (n=1), volunteer (n=1), and an independent learning disability practitioner (n=1). The following areas were explored with each participant:

- Before attending the Train the Trainers sessions had they undertaken any similar training?
- Did they have previous experience of delivering workshops such as Check for Change?
- What were their expectations of the course and were these met?
- What was good about the course and what, if anything, needs to change?
- Having attended the workshop did they now feel adequately prepared to run a Check for Change workshop?
- Had they led any Check for Change workshops since attending the course?

In each instance contemporaneous notes were taken. These were later reviewed to identify key themes.

Participants in the focus groups and interviews were provided with participant information sheets to inform their decision as to whether or not to take part. The voluntary nature of participation was stressed. They were provided with the opportunity to ask questions regarding the evaluation and signed consent forms if they were willing to participate. All data from participants has been anonymised in this report and reference is made only to the focus group number (for example FG1) or to participant number in the interviews (for

example P1).Data regarding referrals received by the CNS were anonymised before forwarding to the evaluator. Ethical approval for the evaluation was received from the Faculty of Life Sciences and Education Ethics Committee at the University of South Wales and permission to undertake the evaluation was received from Hwyl Dda University Health Board where the CNS was employed and the project was hosted.

5. Findings

5.1 Nature and Extent of Referrals

During the period September 2013 to July 2016 a total of 131 referrals were received by the CNS. The rate of referrals per quarter (excluding September 2013 and July 2016) is set out in Figure 2 below

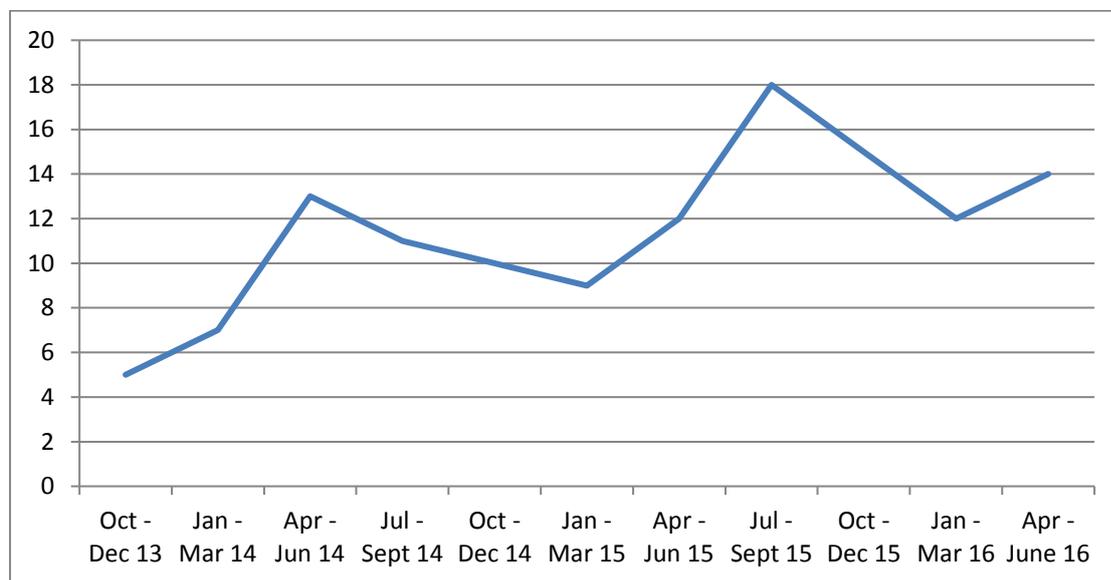


Figure 2: Quarterly rates of referrals received by CNS

Referrals were received from a variety of sources and these are set out in Figure 3 below:

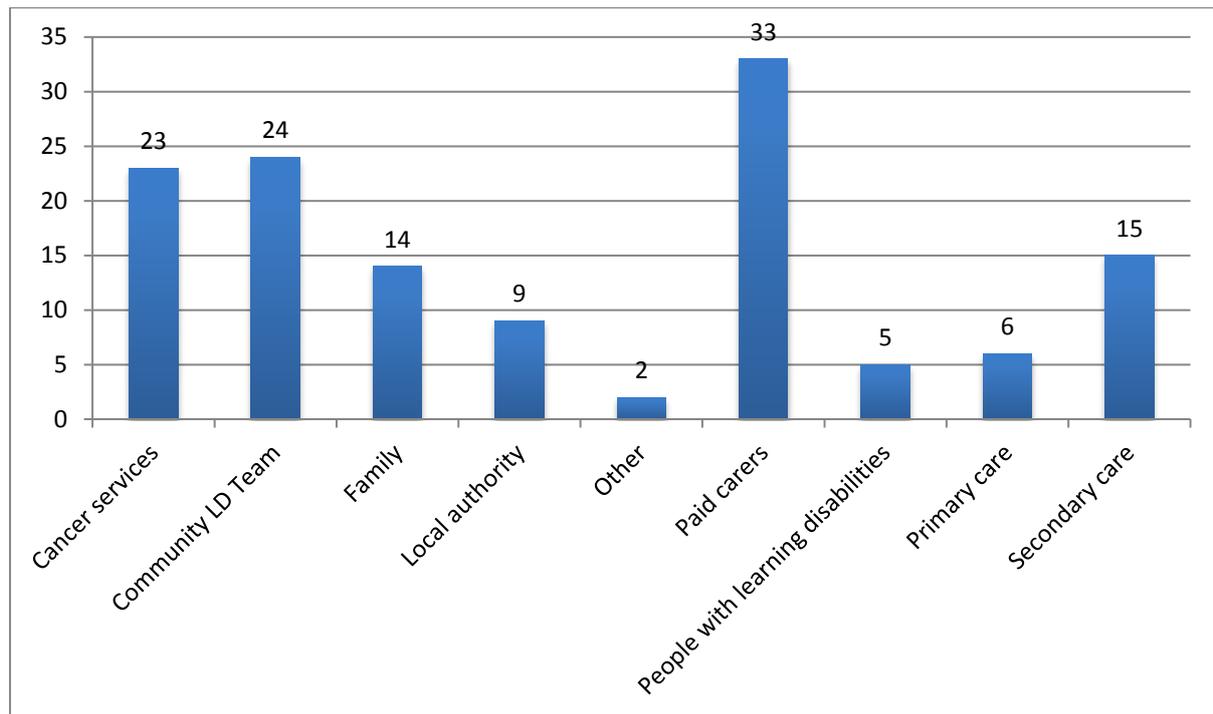


Figure 3: Source of referrals received by the CNS

The focus of the referrals and the actions required varied as can be seen in Figure 4 below:

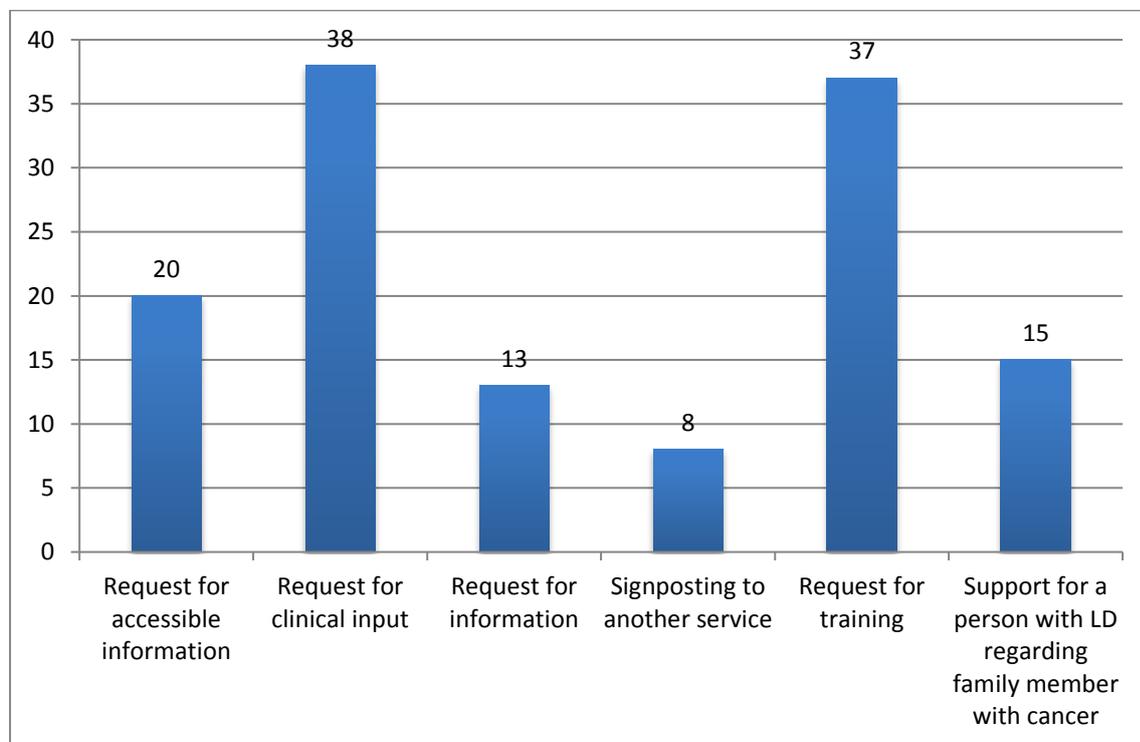


Figure 4: Nature of referrals received

Data were not collected regarding the geographical area from which these referrals originated.

It can be seen that of the 131 referrals 38 led to on-going clinical input. These referrals came from a variety of sources with the most frequent referrers being cancer services and community learning disability teams (see Figure 5 below)

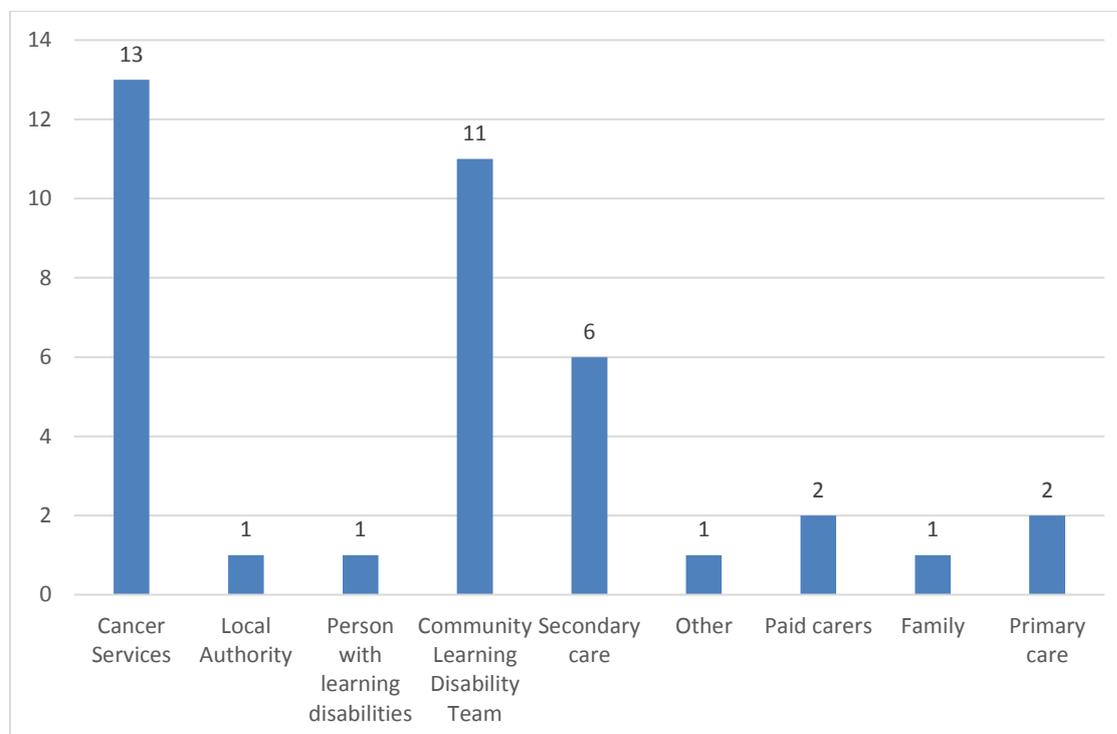


Figure 5: Source of referrals for clinical input

Details of the nature of clinical input were recorded by the CNS as free text. Analysis of these reveals that the most common interventions were the provision of advice (for example regarding treatment options, regarding the nature of learning disability, regarding preparation of individuals for surgery and how best to provide support post diagnosis), support (for example for carers and other residents post diagnosis, to challenge treatment decisions, emotional support and support for interventions), medication (for example in relation to concordance issues), consent and capacity, the provision of easy read materials (or signposting to these), training, and liaison between services. Many referrals required a range of interventions for example 'Out-patient department request for support to investigate causes of symptoms, possible cancer. Education around learning disabilities and reasonable adjustments provided, with support at appointment. Easy read material provided for person and for the department'. In some instances input continued overall several months with one example being of intervention over a period of 8 months.

5.2 Check for Change

The Check for Change programme was planned by the CNS working with members of a self-advocacy group. In total 9 people were involved in the planning process with 6 meetings being held over a period of 6 months (September 2013 – February 2014). The programme and its delivery were reviewed in April 2014 after it had been delivered to one group and

again in July 2014 after it had been delivered on a further two occasions. As a result of this review a decision was made to move from delivery of 6 x 2hr weekly sessions to running the programme over two consecutive days. The rationale for this change was that those delivering the course were finding that the one week gap between sessions meant that a considerable section of subsequent weeks was spent recapping on the previous week's topics as the gap between sessions lead to a loss of recall. Running the sessions over two days meant that recall was not a problem and that there was the opportunity to reinforce learning more readily.

During the project a total of 403 people attended Check for Change workshops. Their background and the location of the workshops (by Health Board area) are detailed in Figure 6 below. It should be noted, however, that people did travel outside of their home health board area to attend workshops on occasions.

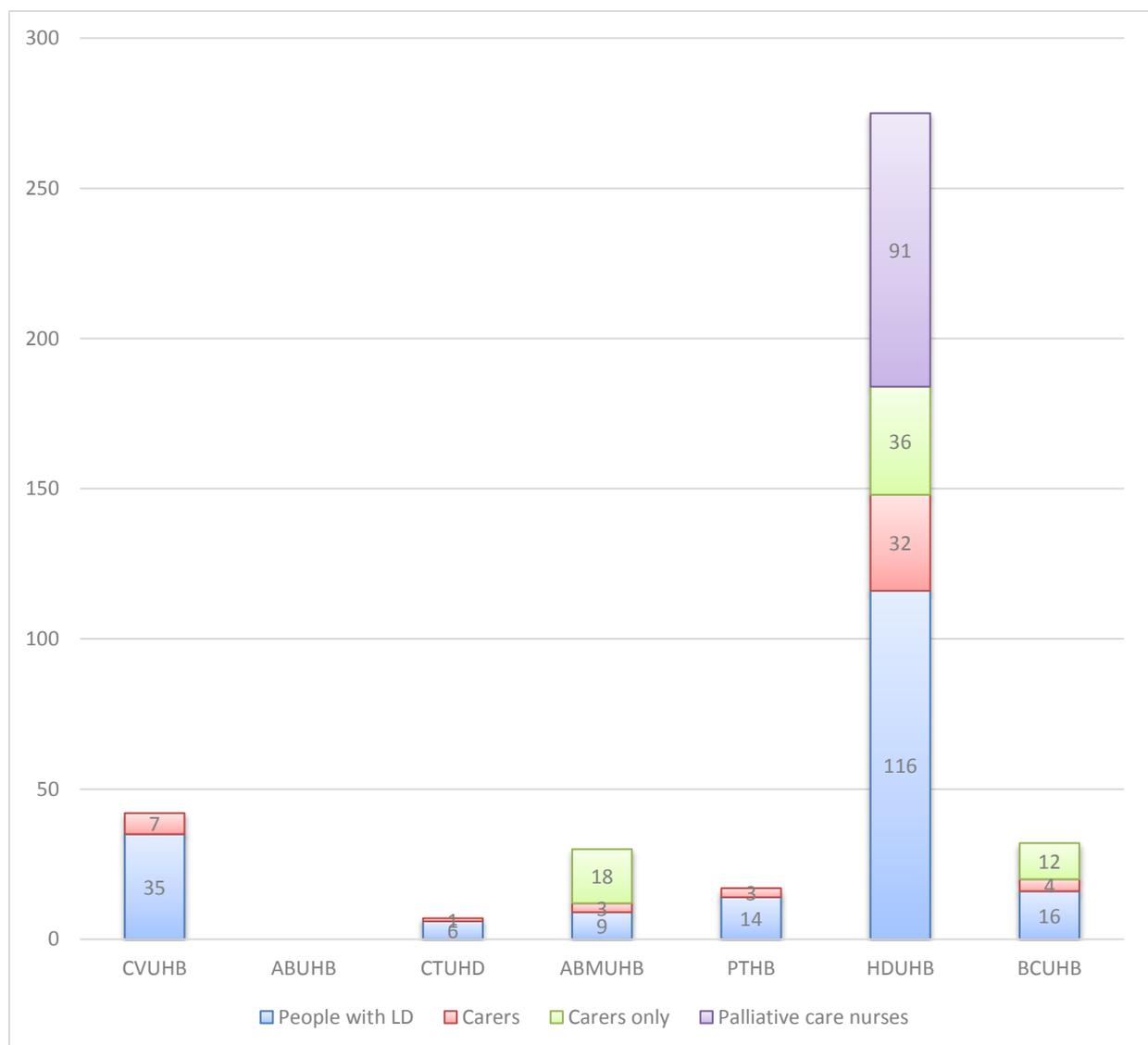


Figure 6: Participants in Check for Change Workshops by Health Board Area and Personal Background

As previously noted the focus groups explored the Check for Change workshops included both those who had delivered the training and those who had attended as participants.

Those who developed and delivered the workshops were already experienced trainers and they felt that this had helped them in delivering this particular programme. In particular they felt that it was important that peer trainers (with learning disabilities) were involved in the delivery of the programme and that it was helpful for both men and women to be involved in the training team. It was noted that a lot of preparation had been necessary as had the review sessions that led to the changing format for delivery. In relation to the actual delivery they reported that groups had varied from about 8 participants to over 30 but that the format had worked well whatever the group size. However, it was important to be flexible in terms of approach as all groups varied and they didn't know who would be in the group until the day of the training. Appropriate use of humour was felt to be important given the potentially upsetting nature of some of the contents and that it was important to be able to offer 1 to 1 support within sessions as some participants were a little nervous. Overall one participant summed it up saying that 'It was a privilege to be part of it' (FG1).

In terms of previous experience of discussing cancer and other health related issues participants generally commented that this had been limited prior to attending Check for change. One person commented that they had lost a friend to cancer because they had not had the right tests and support and that this had motivated them to become involved (FG1). Another indicated that they had previously gone to well woman clinics but nobody had talked to them about cancer (FG2). A participant in FG3 felt that programmes such as Check for Change are important as often people with learning disabilities do not know that they need to check themselves, their families don't explain things to them and some carers don't think that checks are needed. An example of the latter was provided by FG1 participants who recounted how one woman with learning disabilities had attended their workshop and then had subsequently received a letter calling her for cancer screening. Her mother had said that she didn't need to attend the appointment but (due to attending the workshop) the woman concerned argued that she did and went for her screening appointment.

A number of positive aspects to the workshops were reported by participants in the focus groups and these included the interactive approach, the fact that people were able to open up and discuss issues, the structure of the sessions (including breaks and refreshments), the use of pictures and the provision of easy read materials. Those delivering the workshop felt that the use of the body parts to enable participants to learn how to check for lumps was important (FG1) and this was supported by those attending (FG2) although some said that this did cause some embarrassment and that perhaps it would be better for women to focus on women's 'bits' and for men to focus on men's 'bits' (FG3).

As previously noted most workshops also included staff who were supporting people with learning disabilities to attend. This was felt to be positive since it enabled staff and clients to learn together (FG1 and 2). Staff in FG2 indicated that they had enjoyed attending as it had helped them to better understand how they could present the topic to those they support, what they are 'allowed' and able to discuss. They felt this to be important since they observed that service users can ask 'challenging' questions.

Those participating in FG2 had attended the Check for Change workshop within their day service setting and they felt that this had been helpful given the difficult nature of the topic. As one participant commented 'I am at home, safe here'. They also knew some of those delivering the workshop and this was felt to be helpful as they were 'familiar faces' (FG2).

Whilst overall participants in the focus groups provided a positive evaluation of the workshops they did identify some areas that could perhaps be developed / changed. Those delivering the workshops (FG1) noted that in some instances participants with learning disabilities had only met those who would be supporting them immediately before the workshop: given the sensitive nature of some of the material covered it was felt that someone they knew and trusted should provide the support. Those in FG 1 had also thought about how the programme might be developed further for future delivery and are considering including more general information regarding health before focussing on cancer. A suggested title of 'Know your health and check for change' had been suggested.

Those in FG2 indicated that they had enjoyed the workshop but that it would be helpful to have ongoing contact with the trainers following the workshop and also that 'refresher' sessions at 6 or 12 months would be useful. Participants in FG3 commented that while they found the provision of easy read materials to be helpful perhaps the use of jargon could be further reduced and that they would have preferred shorter sessions held over a number of weeks.

One aim of the Check for Change workshops was to encourage people with learning disabilities to recognise and report changes in their bodies as well as to access cancer screening services. It is thus positive to note that participants in the focus groups reported having increased confidence in going to the doctors and having gone for checks (FG2), using the information gained and being more aware of the need to get things checked (FG3) and challenging supporters who expressed the view that screening is not needed (FG1). Those in FG3 indicated that they were currently planning to run the Check for Change workshop for other members in their advocacy group.

Overall it was felt that the workshops had been useful and that the Macmillan project had been a really innovative piece of work with on-going impact (FG1). However, despite acknowledgement that it had been established as a fixed term project, some disappointment was also expressed that it had now ended.

The Check for Change project is listed as an example of reasonable adjustments in health care in the publication (Marriott and Turner, 2015) produced by Improving Health and Lives (IHAL) which is the learning disability public health observatory in England.

5.3 Train the Trainers

In the final months of the project 276 people attended the Train the Trainers workshops. Their background and the location of the workshops is detailed in Figure 7 below. As with the Check for Change workshops, however, it should be noted that individuals did travel outside of their home health board area to attend workshops.

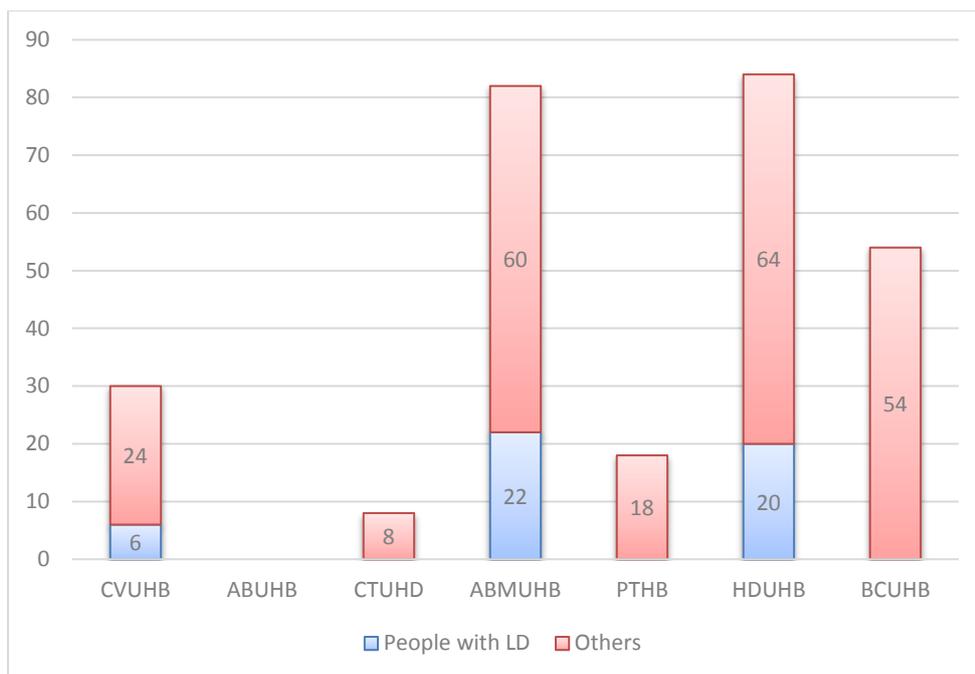


Figure 7: Participants in the Train the Trainers workshops by background and Health Board area

Participants in these workshops came from a variety of backgrounds including people with learning disabilities and their supporters, learning disability nurses, students and lecturers. One session was held specifically for people with learning disabilities.

In the telephone interviews it was evident that people came to the workshops with a range of previous experience. Some had attended previous training or undertaken work in relation to cancer and/ or palliative care with a number having been involved in seeking to increase the uptake of cancer screening. Some had also previously undertaken either individual or group health promotion activities with people with learning disabilities. Groups were therefore quite varied in their composition and generally participants felt that this worked although some suggested that participants with a healthcare background may have found some information easier than others to understand. Nonetheless all those interviewed felt that the groups had been managed effectively by the CNS.

Expectations prior to attending the course also varied but generally participants had anticipated gaining a better understanding of the Check for Change project, of 'where we are at' in relation to people with learning disabilities and cancer, of resources to support people with learning disabilities and to gain access to a ready-made training programme that they could utilise within their own area. Some indicated that they were not sure what to expect whilst others had specific goals in attendance such as increasing their knowledge regarding learning disability and networking with those working in the field of learning disabilities. Generally participants felt that their expectations had been met.

A number of positive aspects of the session were identified which included the style of presentation, the timing of sessions, the activities included (including aspects such as considering the names that might be used for body parts and a quiz), the resources provided

and especially the training resource pack. The opportunity to network with colleagues with different backgrounds and from different geographical areas was also valued. Some participants indicated that they did not feel anything could have been improved in relation to the session itself although others suggested that maybe a longer session or a follow up session would have been helpful. One participant (P4) also commented that although people with learning disabilities were present at the session she attended they did not actively participate and perhaps supporting them to do so would further strengthen the training. It is also important to note that whilst a number of participants felt that the session on 'what do you call your bits?' (in which participants are encouraged to explore the range of terms they use for body parts) had been helpful as had the use of body parts to promote understanding of how to feel for lumps one participant (P9) found this difficult noting that this may be because they recognise they are a 'bit prudish'.

Overall the timings within the workshop were felt to be acceptable and adequate breaks were provided. Two participants (P 3 and P 4) felt that perhaps a longer time was needed to cover the material but P4 queried whether extending it across two days would be justified since participants had a personal responsibility to read around the subject.

The aim of these sessions was to prepare a wide range of people to deliver the Check for Change programme and so to ensure a sustainable legacy of the overall Macmillan Project. Participants in the interviews were, therefore, asked whether having attended this workshop they felt adequately prepared to lead a Check for Change programme. Responses to this question were mixed. Most indicated that they felt confident that they could run such a programme (P1, P2, P3, P4, P5, P6 and P9) although some said that they would prefer to run it with someone else to support them. Participants 7,8 and 10 indicated that they felt less confident in their ability to run Check for Change.

It is interesting to note that the earlier interviews were conducted within a relatively short period of participants having attended the Train the Trainers workshop whereas the latter interviews were conducted sometimes 2 – 3 months later. This time lapse did seem to have an impact on the confidence of participants since in later interviews reference was made to the need for a 'refresher' and to go back over the material before running a course.

At the time of their interviews none of the participants had run a Check for Change programme since attending the course but a number (P1, P2, P3, P8 and P9) all indicated that discussions were taking place locally with a view to running the programme in the near future. Some potential barriers to running courses were identified such as competing demands within their workload (P6) and the views of carers (P7).

This project was always planned to be three years in duration. Nonetheless (and not whilst not being specifically asked about this) some participants commented that it was 'a shame' that it was coming to an end (P3 and 5), that they felt 'sadness' (P4), that they had concerns (P6) and that it would be a 'real loss' (P10). However, some helpful suggestions were also made as to how sustainability of the project might be promoted including the development and circulation of an email contact list of all those who attended the training so that links could be made at a local level to deliver training (P2 and P8), the development of a chat group focused on cancer and people with learning disabilities (P2), the development of a

network or community of practice (P4), the provision of refresher courses (P8 and P9) and the identification of someone to coordinate future developments (P10).

5.4 Other Activities

In addition to the key activities outlined above the CNS was also involved in a number of other areas of work. These included conference presentations (for example Positive Choices and the Learning Disability Wales Conference), information giving sessions (for example to learning disability community support teams, palliative care teams, the South Wales Cancer Network and other cancer charities) and linking with Universities (including Universities of South Wales, Chester and Edinburgh). Two successful conferences were also organised in 2014 and 2015 with the latter attracting over 150 delegates.

The work undertaken by the CNS also gained external recognition as it was shortlisted for the Nursing Times and the BILD Learning Disability and Autism Awards in 2015. It received the Hywel Dda University Health Board Learning Disability and Mental Health Directorate Award for Innovation and Partnership in 2015 and in the same year won the RCN Wales Learning Disability and Mental Health Nurse of the Year Award.

6. Discussion

To discuss the findings of this evaluation it is helpful to consider them in the context of the project aims set out in Section 1 of this document namely – establishing links between services, enhancing the capacity of services, identifying and meeting educational needs, and sustainability.

Over the lifetime of the project the number of referrals received by the CNS increased (Fig 2) and a review of the source of these referrals (Fig 3) indicates that they were received from a wide range of people. Of particular note is that the largest number of referrals came from paid carers, community learning disability teams and cancer services suggesting that the post holder was effective in acting as a ‘bridge’ between learning disability and cancer care services. It is also positive to note that 14 referrals were received from family members and 5 directly from people with learning disabilities themselves suggesting that the service provided had been accessible to non-professionals. The largest number of referrals (n=38) resulted in the provision of on-going clinical input and the majority of these came from cancer services (n=13) and community learning disability teams (n=11). Both these numbers and analysis of the input provided again suggest that effective links between services were established and also that the capacity of services to support people with learning disabilities was enhanced.

During the project 37 referrals were received for training which suggests that meeting educational needs was a key element of the role as per the aims of the project. In addition, early in the project, the need to raise the awareness of both people with learning disabilities and their carers regarding the importance of health monitoring generally and cancer screening specifically (to address the deficits noted in Section 2) was recognised and the Check for Change Programme was developed. It is important to note that this was planned and delivered in partnership with people with learning disabilities and this seems to have been noted as a strength of the programme and something that should be a central feature

of any future developments. Overall 403 people attended these workshops of which approximately 50% were people with learning disabilities. A number of people in the focus groups commented on how important it was to include those who support people with learning disabilities in these sessions so that there can be shared learning. The balance of participants within these groups would, therefore, seem to be appropriate. Generally the sessions were well received and the range of teaching approaches was felt to be appropriate. It is important to note, however, that some participants found the use of 'body parts' and the session regarding naming of body parts to be a little embarrassing and hence sensitivity is needed in terms of delivering the programme. Some participants also commented on the need to be aware of gender issues. Holding the training in a familiar location with people known to participants was felt by some to be important. Consideration is also needed as to the timing of sessions since whilst the facilitators felt that two complete days was the better model some participants suggested that they would have preferred shorter sessions over a longer period to allow for information to be processed more easily.

The outcomes of the Check for Change programme were not formally assessed in terms of whether knowledge and awareness had increased. However, it is positive to note that within the focus groups examples were given regarding actions taken as a result of attending the workshops and of increased confidence in relation to health issues.

This was an All Wales project and hence it is important to consider its geographical 'reach'. In relation to the Check for Change project (as might be expected given the location of the CNS) most sessions were held within Hywel Dda University Health Board (H DUHB). However, sessions were held within all health boards areas with the exception of Aneurin Bevan University Health Board (ABUHB). In relation to the Train the Trainers workshops the largest numbers were again trained in H DUHB and in Abertawe Bro Morgannwg University Health Board (ABMUHB) with none in ABUHB. It should be noted, however, that some people attended courses outside of their home health board area and hence it is likely to some from within ABUHB were included. It can be seen, therefore, that an All Wales approach was achieved although variations were evident in the numbers engaged from each health board.

A key strategy for promoting a sustainable legacy from the Macmillan project was the development of Train the Trainers sessions to enable a wide range of trainers across Wales to develop the knowledge, skills and confidence to deliver the Check for Change programme. A resource pack was also developed to enable them to deliver the programme following their attendance at the Train the Trainers sessions. It is positive to note that 276 people attended these sessions and (given that the importance of people with learning disabilities delivering the programme was noted in feedback) approximately a third of these were people with learning disabilities. Again the sessions evaluated well and most participants reported that they intended to run the programme in the future. However, some indicated that they did not feel confident to do so without further training / refreshing and some that they would like to co-facilitate with others. This raises issues regarding the need for participants to know who else in their area has been trained and for mechanisms to be in place for support and/ or refresher training. Helpfully participants in the interviews put forward a number of suggestions that could be used to inform future developments and these are referred to in the learning points below.

These latter points do, however, lead into discussion regarding sustainability. During the lifetime of the project the CNS has clearly done much to raise awareness of cancer and people with learning disabilities. Furthermore the project was always planned to be of a three year, fixed-term duration. Nonetheless, some participants in this evaluation expressed 'sadness' and 'concern' that the project had ended viewing this as a 'great loss'. The Train the Trainers sessions were intended to address part of this void but from the responses received in the interviews it seems that without some form of coordinated approach there is a danger that further training will not occur as other priorities take over and learning that is not used is lost. The referrals received by the CNS over the life of the project also suggest that there is a need for a point of contact in relation to cancer related issues amongst people with learning disabilities. It may be that the work of the CNS in developing links between learning disability and cancer care services will mean that these links will continue and that coordination of services continues to improve. However, there is also the danger that without an identified point of contact or 'bridge' between services then progress made may be lost.

7. Conclusions and Key Learning Points

From the preceding report it can be concluded that the Macmillan Learning Disability Project in Wales has achieved its aims in relation to the development of links between services, supporting the development of capacity within cancer care services, and identifying and meeting educational needs of a range of stakeholders. Indeed it is important to note that the project received external awards for the work undertaken. Some strategies (such as the Train the Trainers sessions) have been put in place in order to try and ensure that aspects of the project continue now that it has formally ended and the CNS is no longer in post. In addition the advocacy group who co-created and co-facilitated the Check for Change are aiming to secure further funding to continue that element of the project.

It is important to consider how learning from this project can be used to inform the future development of supports for people with learning disabilities who are affected by cancer and in this context the following are identified as key learning points:

- The project revealed that when a point of contact is identified for issues relating to people with learning disabilities who are affected by cancer then this is used by those individuals themselves, their families and carers, and professionals working in both learning disability and cancer care services to access information, advice and support. Discussion as to whether such identified points of contact can be identified within services across Wales may therefore be helpful.
- Peer support for those delivering support and training also emerged from the project as something that was valued by participants and therefore consideration as to how existing networks can be built upon and extended to provide this support would be helpful in the context of future service developments.
- The participation of people with learning disabilities themselves in all aspects of this project (for example in developing and delivering the Check for Change workshops) was viewed as a particularly positive feature and this should be central to the planning and implementation of future service developments.

It is planned that Macmillan Cancer Care Services will share this report with a wide range of key stakeholders and encourage the use of learning from this project to inform the development of better services for people with learning disabilities who are affected by cancer.

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