



Actioning Health in Struell Lodge for People with Learning Disabilities

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Summary of the project

This project has applied a model of health facilitation and health action planning as outlined by Valuing People (Department of Health, 2002) for adults with a learning disability who live and work within a statutory residential and resource centre. The impact of this model has been evaluated and the implications for replicating this approach throughout Down Lisburn Trust are considered.

Background

People with a learning disability are at increased risk of early death when compared to the general population. They are three times more likely to die from respiratory disease (Mencap, 2004); have higher rates of gastrointestinal cancer and stomach disorder (Hogg et al., 2000); are three times more likely to develop schizophrenia (IASSID, 2001); are more likely to have sight, hearing and dental problems (Hatton et al., 2003) and are more likely to be either underweight or overweight (Mencap, 2004).

It is also well evidenced that people with a learning disability are less likely to lead healthy lifestyles; are more sedentary than the general population; take part less in physical/sport/leisure activities and less than 10% of adults with a learning disability eat a balanced diet (Mencap, 2004).

As well as actual health status, it is also recognised that people with learning disabilities have inadequate access to primary healthcare services (Giraud-Saunders et al., 2003) and that primary care professionals feel poorly equipped to adequately care for people who have a learning disability (McConkey et al., 2002). Even when people with a learning disability are visiting primary care services as often as that of the general population, they are likely to receive less health screening and preventative care (Hatton et al., 2003).

Other studies have found that many GP practices have no means to identify those patients with a learning disability (Giraud-Saunders et al., 2003) and that GP's also feel inadequately trained to work with people who have a learning disability. They also have minimal links with, and knowledge of, local community learning disability professionals who can provide specialised help and facilitation in the pursuit of better health care for this population (McConkey et al., 2002).

An audit of learning disability in Northern Ireland (McConkey et al., 2004) suggests that a limitation of some of the health screening research in Northern Ireland is that although it reports on the number of unmet needs identified, and referrals made to other services, there is no clear indication of the action that these other services subsequently take, and the outcomes achieved for the person with a disability.

Previous ground breaking work carried out by Down Lisburn Trust (Healthcheck, 2000) recognised the above point and made several recommendations around the need for ongoing health promotion and health development programmes targeted at people with a learning disability (Marshall et al., 2000).

Although a number of local health promoting initiatives have taken place, particularly around exercise, it is also evident that a number of recommendations targeted at enhancing the role of primary care and other mainstream services in health surveillance and health promotion have made little impact.

In recognition that greater attention needs to be given to "actioning health" rather than simply screening for health needs, the project team decided to develop and test out the concepts of health facilitation and health action planning as endorsed by Valuing People (Department of Health, 2001) within one of the Trust's statutory residential units for adults with a learning disability.

Aims of the project

The project had the following primary and secondary aims:

Primary aims

- To develop and apply a person centred holistic, robust and sustainable health action planning format for each resident living or working within Struell Lodge. This document would serve the purpose of helping to identify important health issues in participants lives and to enhance and clarify personal and professional accountability in achieving health gain
- To improve access to primary health care services by facilitating appropriate and timely uptake of local mainstream services, e.g. GP, dental, ophthalmic, podiatry, audiology, in conjunction with the individual Health Action Plan (HAP)

Secondary aims

- To consider and advise upon the concept of health facilitation in the context of this project, and the impact of this role upon community learning disability nursing (CLDN) staff
- To explore and support new opportunities for promoting health e.g. physical activity programmes, dietary awareness programmes, targeted and appropriate health promotion strategies (e.g. cervical screening)
- To consider the replicability of the HAP format and process throughout Down Lisburn Trust

Health facilitation

The White Paper, Valuing People (Department of Health, 2001) suggests that health facilitation can take place at two different levels. Health facilitation at level 1 centres around more strategic and service development work, such as working with other services (e.g. GP practices or acute hospitals) to develop policies and protocols that aim to improve access to and the quality of health care for people with a learning disability.

Health facilitation at level 2 is more about person to person case work with individuals with a learning disability to help ensure that health needs are appropriately identified and regularly reviewed; that access to mainstream services is improved; and that good health care is delivered as far as possible, by mainstream services, with the support of specialist learning disability services, where appropriate.

Health action planning

Valuing People (Department of Health, 2001) states that health facilitators will be available for all people with a learning disability by 2003 and that each individual should have a HAP by 2005. The process of health facilitation at the individual level (level 2) is guided and informed by HAPs, which are tools that should detail the actions needed to maintain and improve the health of a person and any help that is required to action this (Department of Health, 2001).

HAPs are individualised to the needs of the person. There is no set format and a variety of different tools have been developed. For the purposes of this project, the project team reviewed several HAPs that have been developed in other parts of the UK and decided to develop their own tool, which was adapted from the HAP developed by Wokingham NHS Primary Care Trust, who gave their approval for the amendments made.

The Northern Ireland Review of Policy and Service Provision for people with a learning disability, (Equal Lives, DHSSPS, 2005) has also recommended the adoption of HAPs by 2008 and health facilitation by 2009.

Method

19 residents from the Struell Lodge Unit (a statutory residential and resource centre that is currently registered to provide residential, respite and day support services for adults) were included in this project. This included the 8 permanent residents, 7 permanent residents living in the attached supported living accommodation and 4 day care residents. The day care residents were included in order to provide the project team with a flavour of the usefulness and impact of the health action planning process for people not actually supported by the residential facility, and who lived in other settings within the community.

An outline of the project and its aims was presented to the residents who were being asked to participate, and to

the staff of Struell Lodge who would be central to the level 2 health facilitation role and subsequent achievement of the stated aims. Following the presentation, all residents were asked to indicate their consent by signing or marking a consent form. The project team then worked on developing and producing a Health Action Planning Booklet that was person centred, simple to complete and facilitated thorough analysis of bio-psycho-social health issues.

Once the HAP format was constructed and agreed by all relevant parties, the "Health Booklet" was left with the key worker of each participant to complete with them over a period of two weeks. Members of the project team then met with each individual participant and their key worker on an appointment basis to discuss the issues arising from completion of the "Health Booklet". This was to give the individual participant an opportunity to highlight and prioritise those health issues that were particularly important to them, and to ensure that they were incorporated into the specific Health Action Care Plan. Whilst the project team were very eager to ensure that this was not simply another health screening project, some baseline screening did take place in relation to routine observations. These included blood pressure, weight, height, BMI, urinalysis and blood glucose testing if felt appropriate. Physical, psychological and social health issues emerged (see under health findings) from this interview, and were documented by the project team member for inclusion on the specific individualised HAP.

Following this interview the project team developed the final care plan component of the HAP identifying clear, understandable health care objectives, which were time-scaled, and outlined who had core responsibilities for ensuring that each issue was addressed. A further meeting with the individual residents and key workers was arranged to discuss the fully completed HAP.

The final component of this project involved a focus/evaluation group meeting (including participants and key worker staff) three months following completion of the HAP to obtain views, comments and perceptions about the process, and what needs to be changed or adapted to facilitate sustainability and replicability.

Key health findings

As this project was primarily centred on developing and testing out health facilitation and health action planning processes, limited information is provided about health findings. Specific actions were identified within the Health Action Care Plan for each individual participant. However, analysis of the data identified several shared health issues that could be potential areas for group based health promotion work. These included:

- Healthy eating and help to lose weight
- Men's/women's health issues
- Mental health issues
- Dental hygiene
- Medicines management

Discussion

Although the work in Struell Lodge was time limited for the purpose of this project, it is only the beginning of a longer term objective to help Down Lisburn Trust establish workable systems and processes that can achieve:

- Improved physical and mental health status for people with a learning disability wherever they may live
- Improved access to and utilisation of mainstream health services where appropriate
- Increased time and effort given to "downstream" health promotion strategies

- The recommendations laid down by Equal Lives in relation to health facilitation and health action planning (DHSSPS, 2005)

Although Equal Lives (DHSSPS, 2005) recommends the introduction of health facilitators and HAPs by 2009, it was felt by the project team that we should utilise this project to explore the impact and workability of these concepts to achieve the stated objectives.

This project has also become part of a larger initiative, whereby the same project team members are considering how best to replicate the work done within Struell Lodge in other learning disability settings, and to consider the impact of this work on the future role of community learning disability nursing staff working within the Trust. As a result, the project has resulted in a considerable number of issues that need to be further explored, if replication into other settings is to happen.

A primary aim of this project was to construct and test out a client centred health action planning format. At the focus group, a number of recommendations were suggested in relation to improving the "Health Booklet" including the need for it to be smaller, more space for additional information within the document and the need for it to be in ring-bind format in order that pages can be easily added and removed as necessary.

The issue of who holds the booklet has also been raised on a number of occasions, and this is a question that has not yet been fully resolved. Whilst staff did have concerns about confidential and important information such as this being mislaid or lost, it could be argued that if professionals hold these booklets, this would detract from a central purpose of doing HAPs, that is, to stimulate an interest in personal health issues and encourage some personal responsibility for meeting health action plan objectives by the individual themselves. If the health action plan is not with the individual, this becomes much more difficult to achieve.

The focus group felt that the booklet and methodology adopted a person centred approach. The following positive attributes were identified:

- The information gathering process is clear and straightforward and considers health from the individual's point of view and from a bio-psycho-social perspective
- Key workers and clients were supported and guided by CNLD staff
- The HAP considers actions to improve and to learn about health
- Priorities are agreed with the individual based on their lifestyle and their choices
- The HAP sets out clear responsibilities for the completion of identified actions, timescales and review dates

One of the most important changes we need to make to the current format is to enable the HAP to reflect changing needs, otherwise the HAP cannot be regarded as dynamic, living and growing. For the purpose of this project the CNLD staff involved have agreed to review that the HAP objectives and responsibilities have been met for the 19 individuals involved, but in terms of replicating this process to all people with a learning disability within the Trust, particularly those living in the community, the issue has significant implications for practice and needs to be carefully considered and thought through.

It is well known that one of the most significant barriers to people with a learning disability accessing health services centres around their lack of awareness and understanding of health, particularly from a preventative point of view, as well as the services that are available to them. One of the most positive outcomes of this project was therefore an increased awareness of health by both carers and the participants:

"It's something you just don't take time out to think about. So many health issues are not obvious and if the health problem is not obvious, you don't pick it up". (Carer)

"Yes, I agree. I know that now I will be more vigilant about health. This has been very useful for me in learning about mental health issues and problems." (Carer)

"I loved taking part in this. I enjoyed it because it was good to talk to someone about my health." (Resident)

"I now watch TV programmes about health things." (Resident)

It is also evident that more energy has been directed towards health gain, and health promoting practices. Staff indicated at the focus group that this project has emphasised the need to think more around such issues as nutrition, the need to advocate for better health screening, and to give more thought to how they can prevent/reduce mental health problems arising.

The project has also had a significant impact on the work patterns of CNLD staff. As well as facilitating breast screening (via Action Cancer) they have also taken a closer look at their role and function to determine what to change in order that they can make more impact in terms of achieving better health outcomes for clients.

Central to the success of health facilitation or health action planning processes is that mainstream providers of primary and secondary care can become more familiar with the health needs of people with a learning disability. As a result of this project, a small number of local GP's have contacted project team members, expressing an interest in knowing more about health issues and how practices can be supported to improve the services they deliver to people with a learning disability. More work needs to be done to consider how the booklet can also be useful for mainstream providers. For example, there is a need to tease out those elements of the HAP which have relevance for GP's and those which do not, as it is likely to be unhelpful and create problems, if every item on the HAP is taken to them.

Key opportunities, challenges and recommendations

Undertaking this project has stimulated a review the role and responsibility of community nursing throughout the Trust around health facilitation, health action planning and the impact on local and multi-disciplinary working arrangements. The tentative and preliminary view is that the health facilitation role of nursing is more of a co-ordinating and facilitating role, (i.e. at level 1) encouraging others to adopt this process, helping to get it established within settings, linking with, supporting and educating mainstream providers, with a key role in reviewing and monitoring impact. It is believed that the day to day health facilitation responsibilities for progressing the HAP lies

best with front line workers and carers/relatives, otherwise its introduction will be simply tokenistic and result in little health gain or development for this population.

Consequently, it is recommended that health facilitation should be regarded primarily as a process rather than a dedicated post, and that a central responsibility for CNLD staff should lie in co-ordinating and driving its implementation. It is acknowledged that issues around training will undoubtedly arise from the adoption of such an approach.

This project took place in one small residential unit with the Trust, and it is the view of the project team that the process outlined does work and has already had a positive impact on the health status of those involved. As a result we will also be recommending to the Trust that this process be introduced formally to all other residential units falling within the boundaries of Down Lisburn Trust.

However, it is already apparent that moving forward the HAP for the small number of individuals who did not live in Struell Lodge (rather, attended for day care) is much more difficult and resource intensive. It is acknowledged that to try and introduce this process to all people with a learning disability living in the community, at this stage, would be destined to failure, due to the resource issues involved, and so, the tentative view is that we should aim initially to establish the health action planning process at those young people at transition stage. Follow on work being undertaken via the RCN and University of Ulster Practice Development Initiative will explore this issue further.

Although a small number of mainstream service providers have expressed interest in learning more about the health needs of people with a learning disability, it is the view of the project team that nursing staff within the Trust need to become much more proactive in, and seek out opportunities to, develop stronger links with key staff within primary and acute care settings if real and lasting differences to culture and practice are to be achieved.

Conclusion

The project team believe that the introduction of a structured and supported process of health action planning does make a positive difference in addressing the health needs of people with a learning disability.

As a result of this project, Down Lisburn Trust now has a health action planning format, and a process, that if adopted, can make significant inroads to improving and maintaining the health status of people with a learning disability.

We have shown that there has been an increased awareness and understanding of health issues by staff and more importantly by those involved in the process. Local GPs have also expressed an interest in linking with learning disability specialists to improve the primary care services they deliver.

With the improvements made in accessing mainstream primary care services, it is hoped that professionals such as GPs, practice nurses, dentists etc. will become more aware of the health needs of people with a learning disability, and of their responsibilities in actively addressing these needs.

Whilst we will have to wait and see whether or not "health gain" is actually achieved, the project has resulted in several health improvement approaches being planned

or taking place for those involved, both on an individual and group basis. Overall, it is felt that the project has engendered a dynamic, positive and optimistic approach to addressing health need as opposed to therapeutic pessimism which the literature would say is all too common in the lives of people with learning disability.

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Further reading

A full report can be downloaded from the FoNS website: www.fons.org/ahcp/grants2004/healthfacilitation.asp

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