

Steps To Health



Learning Disability, Health Promotion, Health Inequalities

Duration: 14 weeks

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Project Summary

Steps To Health is a project funded by the Queens Nursing Institute For Scotland in their Catalysts For Change programme for 2016/17. The Community Learning Disability Team in West Lothian recognised that , while there were a number of health promotion initiatives in the area, none were specifically aimed at people with a learning disability and, therefore, when Community Nurses recommended these take-up was very low. People with a learning disability reported that they found written information aimed at the general population difficult to understand and that they lacked the confidence, even with support, to attend a “mainstream “ group. Furthermore, the existing health promotion groups tended to be single issue whereas people with a learning disability were frequently dealing with multiple health issues.

This project was aimed at people with a learning disability and intended to have the following outcomes;

People are better informed about a range of health issues

People are more confident in taking part in health screening and having control over their health and wellbeing

People have made use of peer support to better understand their own health and wellbeing

People with a learning disability in Scotland generally have poorer health outcomes than their peers. The national learning disability strategy 2015-2018, The Keys To Life (1), identified health inequalities in terms of diet and exercise and a higher incidence of preventable illnesses among people who have a learning disability. People with a learning disability are also living with more long-term and chronic conditions than their peers.

A partnership approach between the Community Learning Disability Team in West Lothian and New Directions, a third sector support organisation, enabled us to identify people who were at risk because of their lifestyle and underlying conditions and were motivated to take control of their own health .

Nine weekly group sessions were attended by an average of twelve people. Health professionals provided advice and information on a range of topics and made sessions informal and interactive.

At the end of the nine weeks we held an awards ceremony where everyone who had taken part was given a certificate of completion. It was attended by the families and friends of the people who took part.

At the end of the life of the project we also organised a session at an indoor climbing centre as a way for participants to have fun, try something new and celebrate the relationships that they had formed with each other.

Over the ten weeks of the project participants told us;

“ I know more about what healthy eating is” Fiona

“ I was glad that it was just women when we were talking about smear tests” Charlene

“ I told people about exercise and how I like running” Mark

The success of the project very much depended on collaborative working between NHS practitioners and the third sector. We were able to combine the skills and knowledge of practitioners from both teams with specialist input from other professionals to deliver a tailored programme

Steps To Health- Final Report

Background

The Community Learning Disability Team in West Lothian provides advice, treatment and support to people and their families as well as training and advice for social care staff. New Directions West Lothian is a third sector organisation providing practical, social and emotional support to people with a range of reasons for needing support including learning disability. Work with individual people led practitioners from both teams to identify a need for informal and welcoming groups which presented information in ways which were accessible. The predominant health issues encountered by both teams were;

Diet and obesity

Mental health, anxiety and depression

Barriers to accessing health screening

Physical activity

In 2013 West Lothian Council's Single Outcome Agreement identified priorities for the next ten years

"We live longer, healthier lives and have reduced health inequalities.

People are able to look after and improve their own health and wellbeing and live in good health for longer Inequalities in health outcomes between the most affluent and disadvantaged members of society are longstanding, deep-seated and difficult to change." 3

From our work with the people we support we know that people with learning disabilities have experienced a lack of choice and opportunity as well as experiencing significant barriers to accessing information about health promotion. People with learning disabilities are also more likely to be exposed to common causes of poor health such as poverty, poor housing, and lack of employment, social isolation and discrimination. The uptake of health screening among people with a learning disability is considerably lower with one study finding that only 16% of women with a learning disability having had a cervical smear test within the preceding three years. 4

The Keys To Life Strategy states that "To be truly accepted in society means being treated equally and fairly in other ways. It means having a health service that recognises and redresses the stark fact that people with learning disabilities still die 20 years earlier than the general population." 1

The Project

The project set out to deliver nine weekly health promotion workshops led by an experienced Support Worker from New Directions and practitioners from a range of health and health promotion services.

The Project Planning Group met several times to identify priority topics and outcomes and agree referral methods . The outcomes were agreed as;

People are better informed about a range of health issues and have been given information in a way that is right for them

People are more confident in taking part in health screening and having control over their health and wellbeing

People have made use of peer support to better understand their own health and wellbeing

We agreed that the building used by New Directions was the most suitable venue for the group to meet as it would be familiar to most of the prospective participants and had good access for people with a physical disability. However, we also built into the project plan the need for people to become familiar with community settings and, therefore, set aside some of the budget for transport.

Early in the project planning phase we anticipated the need to make the referral process simple, streamlined and informal in order to encourage participation without creating more demand than we could meet. This meant that referrals came from New Directions or the Community Learning Disability Team. We also agreed that we would not ask people for information about their health, other than for basic risk assessment purposes, as the project was aimed at people who were motivated to make changes to their health and wellbeing and not necessarily those with the greatest assessed health needs.

Week	Topic	Facilitator
1	Personal Health Plans Ground rules and expectations	New Directions Support Worker
2	Mental Health and Wellbeing	Support Worker Mental Health Team practitioner
3	Physical Activity and gym visit	Support Worker and West Lothian Council
4	Healthy Eating	Support Worker and Dietician

5	Health Screening	Support Worker and Community Learning Disability Nurse
6	Admission to hospital	Support Worker and Hospital Liason Nurse
7	Epilepsy	Epilepsy Nurse Specialist
8	Dental Health	Community Dentist
9	Evaluation and Awards Ceremony	

Impact

The eight group sessions, each attended by an average of fifteen people, meant that 120 individual opportunities were created for people with a learning disability to take more control over their own health and wellbeing. Group participants were each given an information pack of easy-read health information which was added to at each group signposting them to further services. The key health messages in the pack meant that support staff and families could reinforce the steps that people planned to take to manage their health.

Bringing a group of people together meant that people had the support of their peers, could share experiences and felt confident to ask questions and be open about their worries without feeling that they were being judged or evaluated.

Exploring a range of topics meant that there was less pressure on individuals than if they had attended a "single issue" group where, possibly, participants would have found it difficult to absorb information. We used a Talking Wall which enabled people to talk about the positive impact that the project had had on them. We used prompt statements to get people started

" I was interested in coming to the group because...."

" I feel that I have learned more about....."

"The time of the group was right for me because....."

" I am going to more....."

" I liked the topics we covered because....."

" I am thinking about"

Common themes were that;

Some people were going to attend health screening appointments and ask if a Support Worker could go with them

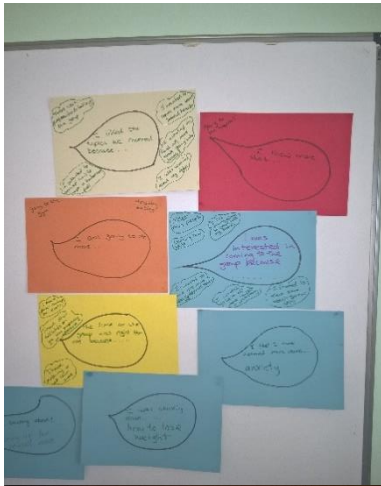
Some people liked that fact that information was delivered by health professionals

Some people had specific worries about their health

Almost everyone valued the opportunity to be with other people who have a learning disability

The majority of people said that they could talk openly and informally about how they could make changes to their health and wellbeing

All the participants thought that other people they knew would benefit from any future projects.



The Challenges

There were some initial challenges for the project in the planning and start-up phase. As referrals could be made by any member of the Community Learning Disability it took more time than we expected for each of them to identify potential group members, discuss the project with people and their families and wait for confirmation that the person wished to attend the group. We should have anticipated that people with a learning disability might need more time than their peers to absorb information, process their anxieties about meeting new people, adapt to a change in routine and commit to attending the sessions. However, we were able to delay the start of the project by a week in order to gather referrals.

Although we had made allowances in the budget for meeting reasonable travel expenses we had not anticipated that, as the project was across all of West Lothian, people would experience difficulties with public transport and with learning new bus routes. In order that people were not reliant on family members providing transport we made use of taxis which undoubtedly contributed to the high level of participation.

It was also difficult to free up those planning and delivering the project from their existing workloads which meant that communication was more fragmented than we would have liked. We also discovered after the first session that one Support Worker would not be able to manage such a large group, particularly if anyone in the group needed to take time out or needed individual support with communication. We were, however, able to use the budget flexibly, so that a second Support Worker was made available.

What worked well

Fifteen people consistently attended the group each week with only one person dropping out after week three.

Closer links were established between members of the Community Learning Disability Team and New Directions.

Participants took pride in attending the groups and valued the awards ceremony. Family and friends were able to come along and share in their achievement. Holding the event in local hotel demonstrated to participants that we valued their learning and commitment. The climbing session enabled people to try something new that tested their confidence.

There has been a legacy effect as practitioners from both teams have been able to continue the health conversations with their clients and enable them to take forward plans to have more control over their health and wellbeing.

By having an experienced Support worker co-facilitate sessions we were able to use her knowledge and insight to identify people who were uncomfortable with particular topics, people who were dominating the group and those with communication differences who needed assistance to contribute. This would have been much more difficult to manage in a health promotion group aimed at an average population.

Case Studies

Alan is a man in his fifties who has a mild learning disability and some issues with his mental health including anxiety and some degree of paranoia. His diet is mixed and he is over a healthy weight. He

had played sport as a younger man but not in recent years. He had consistently told us that he wanted to join a gym but felt them to be intimidating and "only for young, thin folk"

By organising a visit to the most central gym in the area and giving people the opportunity to meet gym staff and hear about tailored exercise programmes Alan was able to see that all abilities were catered for, that changing areas were not communal and that gym staff were on hand for ongoing advice. This encouraged him to start using the gym during their taster sessions so that he could find out which exercises worked best for him.

Cathy is a woman in her late twenties with a learning disability and some long-term health conditions which meant that she had a number of surgical procedures carried out when she was a child. This had led her to become very anxious about her health and she had regular panic attacks and need sedative medication to attend appointments and have blood tests taken. She had initially said that she could not take part in the visit to the local hospital which was intended to help people familiarise themselves with the building and explain what happens during a planned admission to hospital. However, as Cathy had built up a trust with other women in the group, she felt able to change her mind. She said "I felt quite panicky during the visit but had made a promise to see it through and that's what I did"

Natalie is a woman who has a learning disability and epilepsy. Until a few years ago she was unable to attend any social or group events as she was anxious about having a seizure in public. This made her very dependent on her family and affected her mood which, in turn, increased her seizure activity. Now she has a part-time job, travels independently and has a good group of friends. She was able to talk to others in the group about her experience of epilepsy and how it no longer prevents her from enjoying life.

Next Steps

An application has been to West Lothian Council's Third Sector Ambition Fund to run the project again with a new group of participants. We will continue to pursue other funding opportunities should this not be successful. We also have the option of future participants using their personal budget from West Lothian Health and Social Care Partnership to purchase a place on the programme as already happens with other groups delivered by New Directions.

The project has been publicised on the New Directions website and a copy of this report has been sent to the lead for Learning Disability Services in the West Lothian Health and Social Care partnership.

References

1 Keys To Life- Improving Quality Of Life For People With Learning Disabilities. Scottish Government 2013

2 Improving the Health and Wellbeing of People with Learning Disabilities: An Evidence-Based Commissioning Guide for Clinical Commissioning Groups, Royal College Of General Practitioners, Royal College of Psychiatrists 2012

3 West Lothian Council Community Planning Partnership, Single Outcome Agreement 2013=2023

4 Journal of Public Health, Volume 27, Issue 4, 1 December 2005

Photographs have been used with permission and names have been changed

Financial Report

Budget Catalyst For Change

New Directions West Lothian-Steps To Health 2016/2017

Income

5,000

Expenditure

	budget	actual	
Management Costs	540	540	
Support Worker	1800	1800	£25 per hour, 3 hours per session, 9 sessions
2nd Support Worker	200	324	
QNIS workshop travel	32	32	
Room Hire	675	675	
Materials	335	160	
Travel	300	196	
Refreshments	50	47	
Stationery	120	257	
printing and copying	180	180	
Hire of room for award presentation	180	307	
Catering for award presentation	120		
Awards	140	140	
Outdoor Activity	400	356	Ratho Climbing Centre
total	5072	5014	