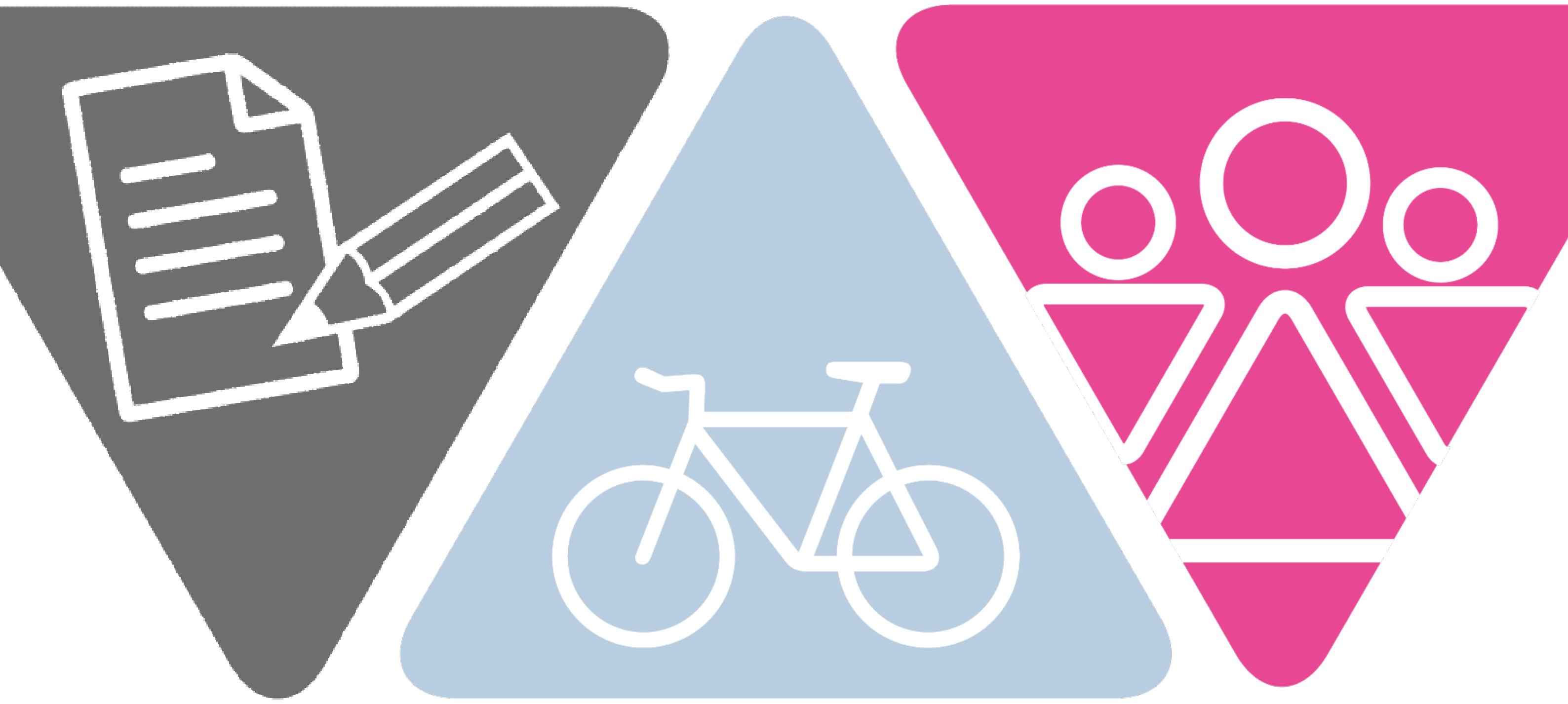
Healthier Scotland Conversation



SCLD

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Introduction

The Scottish Commission for Learning Disability (SCLD) is an independent charitable organisation for the learning disability sector. We are ambitious for change - our vision is for a Scotland where people with learning disabilities are included and respected as equal citizens.

We are a strategic partner to our principal funders, the Scottish Government and work with them to support and evaluate interventions and delivery projects and drive improvement.

We are committed to ensuring that people with learning disabilities have an opportunity to express their views and share their experiences on issues that have an effect on their lives.

The Scottish Government wants to hear what people in Scotland think a healthier Scotland should be like in the next 10 to 15 years and what steps could be taken to make it happen.

SCLD wanted to ensure that people with learning disabilities had an opportunity to share their views and experiences. This report details the findings of SCLD's consultation with people with learning disabilities on the Healthier Scotland Conversation.

What we did

SCLD facilitated three engagement events for people with learning disabilities. These were held in Glasgow, Falkirk and Annan in Dumfries and Galloway. In total, we spoke to 49 individuals, of whom 25 were people with learning disabilities (14 were male and 11 female).The locations were chosen in order to ensure a range of experiences were heard from different geographies. We made sure we spoke to people from one rural area, a large city and a smaller urban area.

- In Glasgow 19 people attended, 10 people who have learning disabilities (5 male and 5 female) 8 support staff and 1 family carer.
- In Falkirk 23 people attended, 12 people with learning disabilities (8 male and 4 female).
- In Annan 7 people attended 3 people with learning disabilities (2 female, 1 male) 3 support staff and 1 person who has a physical disability and works for a disability rights organisation.

At each event, we presented event participants with three key questions in the Conversation:

- **What support do we need in Scotland to live healthier lives?**
- **What areas of health and social care matter most to you?**
- **Thinking about the future of health and social care services, where should our focus be?**

To enable participants to consider their responses and articulate their views, activities were outlined on the theme of health and wellbeing. The first activity involved people selecting a picture relating to health and wellbeing at random and talking about what the image meant to them. Images available to select for this activity have been included in Appendix 1.

This was followed by a group discussion where all participants were asked to reach a consensus on the importance of the concept depicted by the pictures selected. The pictures were then placed on a 'barometer' to indicate the order of importance. This resulted in an overall chart of health and wellbeing topics ranked in order of importance to participants. Comments made during the conversations were recorded on flipchart paper to ensure all input was captured.

The second activity involved participants splitting into smaller groups; three groups in Glasgow and Falkirk and two in Annan. Groups were asked to make a poster (using writing, drawing and craft) which showed what they need now to be healthy and well and what they would need in the future in order to remain healthy or to become healthy. They were also given paper shapes on which they were to write or draw who helps them to keep healthy.

The poster was designed as a focal point and functioned as an activity which allowed people some freedom to say what they wanted on the topic. Facilitators moved amongst the groups during discussion to find out more about the topics being depicted and the reasons why.

The comments made during these discussions were recorded, either on the posters themselves or on flip charts along with other notes from the event. Groups made their own decisions about the content and design of their poster. Some groups chose to include all individual input whereas others opted to reach a consensus on content before depicting it. The eventual output (the poster) was less important to the findings of this consultation than the conversation that went on during its creation.

In addition to the consultation events, SCLD also promoted the Conversation across networks and at a number of events. Specifically, SCLD staff hosted an information stand at the launch event for the Scottish Learning Disabilities Observatory. There were 182 people in attendance at the event.

Information and Conversation materials were handed out and attention was drawn to the stand during plenary presentations. A 'Graffiti Wall' was hung and participants were invited to record their views on health and wellbeing. This input was structured around the three key questions presented at the consultation events:

- **"What do we need to live a healthy life?"**
- **"What areas of health and social care matter most to you?"**
- **"What do we need for the future to live healthy, happy lives?"**

People with learning disabilities were specifically targeted but professionals who were in attendance also took part. SCLD staff were in attendance at the event in order to facilitate the conversation and support people to contribute to the Graffiti Wall.

Information and Conversation materials were also distributed at the Learning Disability Evidence Event hosted by SCLD. Over 60 professionals from health, social care and policy were in attendance across the public and voluntary sector and all were given clear information on how to engage with the Conversation.

In addition to these specific activities, SCLD also promoted the Conversation at various other meetings and across professional networks. People likely went on to engage with the Conversation themselves however we did receive a small number of responses from other organisations and individuals who wished to engage with the conversation but were unable to attend the organised events.

The results of all these methods of engagement, including the additional responses received, have been incorporated into the findings as detailed below.

What we found out

The Barometer activity served as both a discussion point and as an opportunity to gauge how important each of the items and concepts was to the people who came to the consultation events.

Across all three events the positioning of the items on the barometer was relatively similar. Primary health care and doctors were the most obvious thing people talked of initially when asked about "health". General Practitioners were quickly identified as important by all groups because they offer a primary care service; to quote a participant:

> **"(The GP is) the person I go to see if I am not well."**

Interestingly however, all groups went on to place images representing things they considered to be important for keeping them well, above the doctor on the barometer. Broadly speaking, the discussion at this point shifted from a focus on crisis response health care services to concepts around wellbeing and preventative measures to ill health.

> **"...if you are able to keep well then you don't need to see the doctor."**

People spoke about feeling depressed and the physical health problems which can arise from this. All participants were clear that spending time with people, doing activities that are enjoyable and getting out for fresh air and exercise are all important for preventing a person from experiencing poor mental and physical health.

The positioning of the pictures on the barometer indicated the things that were most important to people. Clear themes emerged from this across all methods of engagement and input is most usefully considered under these. Specifically, the predominant themes were:

Social Connectedness

Diet

Accessibility

Professionals’ Attitudes

Comments and discussion points are detailed in this report under these four headings.

Social Connectedness

In all consultation events, socialisation and 'getting out and about' were valued very highly. Discussion centred on the benefits of these to their physical and mental health with a number of participants stating they were more likely to feel down and depressed when they are not supported to get out and access communities and networks. The Graffiti Wall used at the launch of the Scottish Learning Disabilities Observatory included a number of short answers in response to "What support do we need in Scotland to live healthier lives?" which relate to the concept of social connectedness;

Friends

Laughter

Being involved

Good relationships

Family

Fun things to do

To be connected

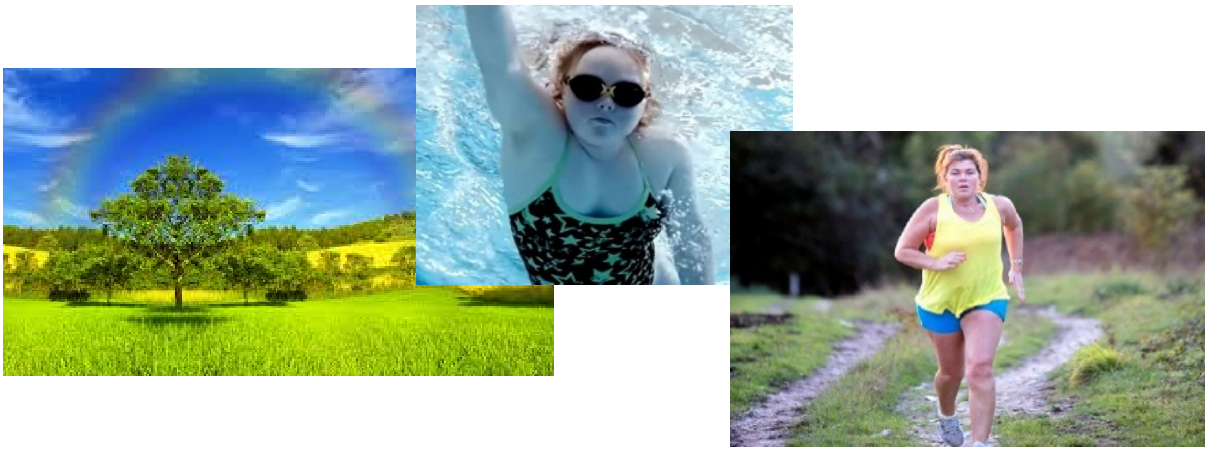
When talking about exercise, few participants reported that they participate in any kind of physical activity for the sole purpose of exercising. Rather, exercise was discussed for the social benefits it brought to participants. One participant further developed this concept of personal gain from physical activity and spoke of the positive feelings associated with winning medals in the Special Olympics:

> **“(Winning) feels good, powerful”.**

People talked specifically about walking with company and identified it as an enjoyable activity that made them feel better and gave them an opportunity to exercise. The majority of participants made the link between exercising and weight loss and keeping fit but weren’t able to explain the tangible physical health benefits of this. More often, people expressed that doing an activity they enjoy, in particular when it involved an element of social interaction, improved their mood and feelings of wellbeing. Walking, especially in a place of natural beauty or a park, was often mentioned as being a favoured activity.

It was noted by participants that they found it difficult to motivate themselves to exercise and that being told to do it for health reasons didn’t change this. Participants instead focused on what makes physical activity enjoyable and cited the inclusion of an element of social interaction as making exercise something they would then want to take part in. Participants also talked of the need to feel the benefit of taking part immediately and were less motivated by longer term benefits.

Furthermore, staff who were present spoke about the challenges in finding meaningful and accessible physical activity for people with more complex support needs to enable them to achieve the same benefits.



In all consultation groups, the picture of the countryside above was ranked higher in importance than either of the pictures of people taking part in physical activity. Discussion of the reasoning behind this revealed participants felt this was representative of the part that exercise plays in ensuring their health and wellbeing. Being outside, and in a pleasant and attractive environment was cited as important and people reported that this simply made them feel better. The countryside picture was identified by many participants as a place they would like to spend time and by far the most reported reason for this was it being seen as an opportunity to socialise while exercising and enjoying an outdoors experience. Participants were clear that the other images depicted activities which they viewed as solitary and as such were not seen as desirable.

On the whole, participants were clear that they are unlikely to participate in these kinds of activities on their own. However, support to take part in such activities was identified as being essential for many; when this wasn't in place or wasn't sufficient, people reported missing out.

Disability sport was mentioned as being a good opportunity to engage in sport for fitness purposes as well as providing an opportunity to socialise. A number of participants we spoke to reported having made friends through their involvement with disability sports initiatives. Participants were positive about such initiatives as they organised sports activities which enabled people to take part independently without reliance on a support worker.

Some people we spoke to said they are able to get out most days but others said they only have support on a small number of days per week. One participant said they have support two days a week and the rest of the time was spent alone:

"I just have to play on my computer games, it's boring"

Comments from the Graffiti Wall in response to the question "What do we need to live a healthy life?" further supported the idea that people with learning disabilities need to be supported to be able to get out and about into their communities.

“Support to be more active - walking, rambling.”

“To be able to get out and about –meetings, groups, shopping and to meet friends.”

“Fun things to do”

“The right support at the right time”

Socialising and seeing friends was reported as being very important for people to maintain good mental health. One participant commented that socialisation **“stops you feeling bad and lonely”** there was some discussion within the consultation events about how important this is. It was also noted that when people need support to meet friends **“sometimes their support workers don’t realise how important it is”**.

Interestingly, the images chosen by participants were often seen as depicting social activity rather than for their health impacts. For example, this image of a man drinking from a bottle represented going to the pub rather than simply ‘alcohol’ to the participants who discussed it.

Participants said that even though they do not drink alcohol they like to go to the pub as a leisure activity; they enjoyed playing bar games and the pub is where they go for social interaction.

This image was ranked as being of high importance to health and wellbeing on the barometer activity when seen as depicting visiting a pub. When asked to consider it as simply representing alcohol, the group chose to place this as being of very low importance on the barometer.

Lack of social contact was also mentioned by one participant as a factor in eating healthily:

> **“I don’t like eating alone so I just have a cup a soup”**

For this person eating is viewed as a social activity and without the social contact cooking and eating well isn’t viewed as a pleasure and is therefore not treated as a priority.

Diet

There was a high level of awareness about the need to eat a healthy diet amongst participants in the consultation events. When asked about what a healthy diet involves, levels of understanding varied.

Many participants said they need help to shop, cook and plan meals. Most said they need to have more support in order to cook and eat better.

One participant spoke about how they like to eat fry ups, pizzas, energy drinks and other **"unhealthy"** foods but they **"know they shouldn't**". Their support worker helps them to plan meals but tends to eat unhealthily themselves so they eat this type of food together. Twice a week this person eats a ready meal, on the days when they don't have a support worker, and they consider this to be their **"healthy eating days**".

Comments from the Graffiti Wall reiterated that people know that diet is important for health:

"Less fry ups, more vegetables."

"More affordable healthy food."

"Better information on healthy eating."

However, there are some barriers for people with learning disabilities to be able to do this. One participant said they had been told by their doctor not to eat fatty foods and their doctor did clearly explain what kinds of foods they shouldn't eat. They would prefer to eat home cooked food but can only do so on days when they have support staff available to cook with them.

They can cook ready meals themselves but had been advised to use branded diet ready meals which they have said are not satisfying meals and they have since learned that these are full of sugar.

It became clear through participant input that good, healthy food isn't always an affordable or accessible option and some skill is needed to be able to cook. One participant said they went on a course to learn how to cook and this has made a big difference to their diet and their enjoyment of food; prior to the course they only ate ready meals.

Many people mentioned that there was a need for more information on healthy eating and that this needed to be in accessible formats. It was unclear from the discussions whether support staff were provided training and information to enable them to support people to eat healthily and affordably. The need for information and training may apply more to support staff than it does to people with learning disabilities.

Access

Accessibility was an issue for people in a variety of different ways. Physical access to facilities, accessible information and affordability were all mentioned as barriers to participating in social and leisure activities.

The need to have support workers to enable people to take part in activities can be a barrier in terms of the availability of workers. One person clarified this by saying:

> **"...having the ability to do what you want to do and the support to do it"**

There was some discussion that charging entrance fees for both the person and their support worker makes the cost of taking part in activities prohibitive and restricts people's access. Getting to take part in activities and visits to places of interest gives people a **"feel good factor"** that they identify as having great benefits for their wellbeing.

Participants identified GPs as being really important in their role as gate keepers to make referrals on to other services. Participants also noted that GP appointment times are very short and it can be difficult to explain yourself and all of the things that you would like to say in that time.

> **"Sometimes they listen to you, sometimes they don't"**

Participants were clear that it is important that doctors listen to people and understand what they need in order to make referrals to specialists or other services appropriately.

Making themselves understood can be difficult for people with learning disabilities and many participants said it is also difficult to understand doctors:

> **“Don’t understand what they say, need someone with you, it’s difficult if you’ve not got someone with you”**

Participants reported issues with being given access to a doctor in their local surgery. It became apparent that many had experienced being given an appointment with a nurse when they want to see a GP. Participants believed this was because they had a learning disability and felt less important than other patients as this process suggests they have to be ‘approved’ in order to see their doctor.

Hospital appointments were another area where it was noted that communication and information is not always easy for people to understand. One person spoke of a hospital appointment involving several cancellations on the part of the hospital with the result it was difficult to understand all of the changes. When the appointment was finally rearranged it was in an unfamiliar hospital; resulting in appointment non-attendance because the patient felt anxious about how to get there and how to find the correct department.

All participants agreed this wasn't acceptable and could have a significant health impact but be avoided if information and communication was clearer and more accommodating of need.

Participants agreed that home visits from health professionals are preferable to attending a surgery or hospital and they reported a more positive overall experience in which they felt comfortable and confident:

"It's easier to talk in your own house."

Other things noted as being important for people with learning disabilities to maximise health service experience were recorded as;

- **"information that is provided in ways that can be understood"**
- **"information that is meaningful for people"**
- **"longer appointment times so that there is enough time to communicate clearly and to understand what is being said"**

Participants recorded a number of other comments on the Graffiti Wall relating to the theme of access:

- **“Easy Read Information / Longer Appointment Times with information that’s accessible so conditions anyone has are understood and diagnosed.”**
- **“Information in ways it can be understood and meaningful.”**
- **“Simple signage”**
- **“Easy Read ’Data”’ – if this isn’t accessible to people with learning disabilities it makes me feel depressed”**

Professionals' Attitudes

Extensive discussion took place on the difference the attitudes of professionals can make to the experience a person has. If the staff seem happy, are pleasant and **"ask you how you are and know your name"** this makes a really big difference to people. People said they feel down if the staff do not treat them in this way. One person noted:

> **"it is important to be treated like a 'normal' human being, not a number"**

The phrase 'being treated like a person' came up in some way across all consultation groups and on the Graffiti Wall at the Scottish Learning Disability Observatory event launch.

Some people had experienced particular difficulties with doctors who come from different countries. There were problems with communication, when English was not the first language of the doctor, which participants believed served to exaggerate any communication difficulties they had. In addition people had experienced negative treatment which they felt was partially due to the fact that other cultures view people with learning disabilities differently and they are rarely seen in their community.

In addition to this there were times when the attitudes of the people who work in leisure facilities can prevent people from feeling like they are welcome. One participant spoke about their efforts to use a local sports centre, noting that it is important to feel that staff are “interested in you”. It can be difficult for people who need support to use leisure facilities and equipment if they don’t feel they can ask for help.

Additional Points

During the barometer activity in all groups, having enough money, feeling safe and access to transport (e.g. bus passes) were all viewed as important but there was little further discussion about them. It is difficult to ascertain whether these concepts would have been raised by group participants if they had not been the pictures selected during the barometer activity.

The facilitator had to explain the meaning of these images whereas the ones discussed in more detail were interpreted by participants themselves.

Who helps people to stay healthy?

During the group activity, participants were asked to use paper templates of people to represent the people who help them to be healthy. Not every group chose to do this but of those that did, support workers were identified as the people most important in helping people with learning disabilities to keep healthy. Those who lived with their family also cited their parents as having an important role in keeping them healthy and well.

Some people voiced concerns that they might lose their support workers within the context of welfare reform and the reported cuts to services:

"Keep my support staff so I still feel safe and can take part in things"

Other feedback indicated that some individuals are not currently getting the kind of support they want: One person's comment about what they needed for the future was;

"Support workers who want to be there to help and join in and encourage my choice".

This was indicative of the fact that at present they do not always feel that their support workers do seem like they want to be there.

More detailed information was recorded during the poster activity in response to "Who keeps you healthy”:

My Friend:

- Can talk about problems
- keeps me safe
- keeps me out of mischief
- kind
- wonderful
- powerful

Worker:

- keeps me safe
- helps with tablets
- keeps me warm
- help if not well
- help to get out and about and do things
- support plans

Ideas for the future

People were asked to think about what they would need and want in the future in order to be able to remain healthy. It was often mentioned that good planning was important, for example to enable people to be able to live where they want in the future. Participants were clear they wanted to feel prepared for the aging process and need to be able to make informed decisions about where they want to live and the kind of support they need in order to be able to live in the place they choose.

A number of participants expressed some concerns about the future and fears about the impact of changes that might happen. This was particularly focused on 'assets' and the belief that, in order to be able to keep healthy and well into the future, people had to be able to keep what they have now. Most participants were concerned that cuts to benefits and social work budgets might leave them without the support and standard of living that they are currently used to and that, without this, they would struggle to cope and their health would suffer:

> **"(I would like to) keep my support staff so I still feel safe and can take part in things"**

Choice and control was a common theme across all areas of engagement with the Conversation. Participants in consultation events were focused on their worries that the future would change and they would lose what they have now.

In contrast, Graffiti Wall contributions indicated more of a desire for change and to be more in control than they are now:

"In control of my own life and to be listened to"

"To feel in control"

A need for more information to be provided in easier to understand formats was expressed by all of the groups we spoke to. Some participants from the consultation event in Annan (Dumfries and Galloway) had been involved in supporting their local NHS to develop Easy Read leaflets. This had been viewed as being beneficial and something they would like to see extended to cover more information and to other areas.

Participants in Annan also talked of a scheme where hospital staff are being trained in learning disability awareness and are being encouraged to become Learning Disability Champions. This was felt to be beneficial since there had been a number of times when people with learning disabilities had felt that staff had constituted part of the problem when it came to accessing health and social care services.

In some areas, participants reported the use of health passports and were clear they found these to be very useful, particularly as they support people who may be unable to clearly communicate their health needs. It was thought that more people should have these.

The use of telecare equipment was noted to be beneficial in terms of supporting people to live independently in their own homes.

Other Comments

In addition to the people we spoke to directly we received a statement from the Royal National Institute for the Blind who commented on the specific needs of people with learning disabilities and sight loss. Their comments centred around the need for people with learning disabilities to be supported to have their eyes tested regularly as they may not be aware that they are having trouble with their sight or may have difficulty expressing the difficulties they are having. Their sight loss may therefore be overlooked.

Sight loss can have a negative effect on a person's ability to communicate and on their mobility; this can affect their ability to have choice and control over their own lives:

> **"If sight loss is not recognised, the ability to learn, develop and to enjoy social, learning and leisure activities is greatly reduced"**

Summary

The conversations SCLD had across all consultation events indicates there are similar issues for people with learning disabilities across the country when it comes to being healthy.

People need good, clear information about health and ways to keep healthy including information about diet and exercise. Information that is provided by professionals needs to be presented clearly so that people with learning disabilities can understand it.

A great many people with learning disabilities we spoke to reported experiencing negative attitudes from medical professionals. People want to be given time to speak and to feel that they are being listened to.

Participants felt that learning disability awareness training should be provided for medical staff and people who have public facing roles in sports and leisure venues. It was believed that this would improve these types of service provision and the understanding of staff working in them.

People's motivation for exercise and activity tended to be higher when there is a social element and when the benefits of exercise can be felt immediately. Long term physical health benefits didn't seem to factor into people's decision to take part in exercise. People did understand that exercise can be useful for weight management and for improving fitness but this did not serve as a motivating factor in itself.

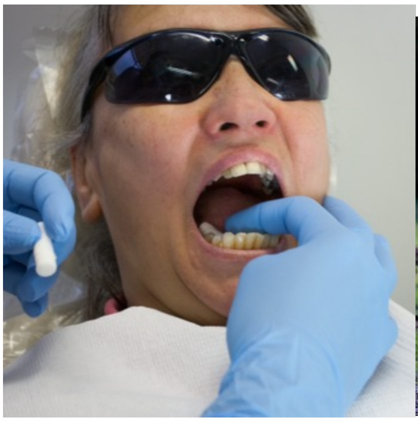
Most people we spoke to said they enjoyed physical activity, such as going out for a walk in a park or the countryside, over activity such as attending a gym. It was noted that activity in pleasant environmental surroundings has a ‘feel good factor’. People said that this kind of activity made them feel better but it wouldn't be something they would engage in if they were alone. Owing to the prevailing social isolation, this often results in people feeling unable to participate on days when they did not have support.

A number of people we spoke to reported requiring their support workers or families to help them to shop and cook healthy food for meals. Where this support is not available, people reported eating 'ready meals' and other convenience foods instead. There is a need for support workers to be able to support people with meal planning and preparation.

In general, people valued social connectedness very highly and every consultation group considered this as having an equal or higher importance than GPs and other health professionals. People identified social isolation as a major factor in producing negative feelings and associated physical health impairments. In the groups we spoke to, depression and feeling ‘down’ were identified as factors in attendance at the GP practice. If people have opportunities to get out and socialise, they experience better mood and better health. Many people rely on their paid support to be able to get out and socialise and when this support is not readily available people find it difficult to take part in activities.

Appendix 1

Images used in the barometer activity

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107


Pain Relief Clinics
Clinic 4
Clinic 5
special clinic today
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Podiatry
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Now
Who?
1 Month
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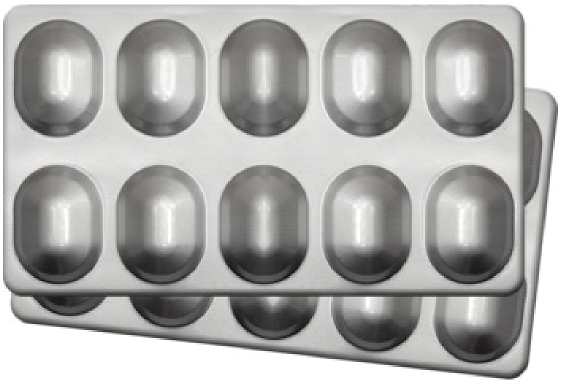


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