Moving the West Midlands Forward

Improving Physical Activity for Disabled People

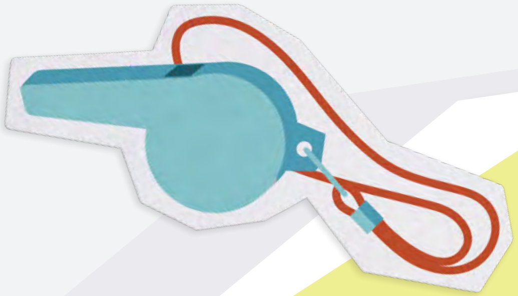
April 2020

Get Yourself Active
@GetYrselfActive

West Midlands Combined Authority

Disability Rights UK

Contents



Introduction

In 2019/20 Disability Rights UK (DR UK) was commissioned by the West Midlands Combined Authority (WMCA) to find out how disabled people in the West Midlands feel about access to physical activity. This was with a view to discover disabled people's ideas about how these opportunities could be improved and to create a mechanism by which the Include Me West Midlands (IMWM) programme could be led and supported by disabled people. IMWM aims to improve access to physical activity for disabled people through a number of approaches including; improving access to transport, creating a network of supporter organisations and through the development of a 'Citizens Network'. DR UK was asked to engage with disabled people and community organisations in the West Midlands to scope out the interest and appetite in Citizens Network amongst disabled people, as well as provide a potential plan to make it happen.

Disability Rights UK is a disabled persons user led organisation, led by people with diverse experience of disability and health conditions. We are disabled people leading change, working for equal participation for all. We work with many organisations to support them to put disabled people's priorities at the heart of their policies and practices. Since 2015 we have developed and delivered the Get Yourself Active (GYA) programme, in partnership with Disabled Peoples User Led Organisations (DPULOs), funded by Sport England. Together, we aim to lead change in improving the experience disabled people have of accessing physical activity through taking a social model approach. Through running this programme, we know far more needs to be done to understand the day-to-day challenges disabled people face. These include living independently, gaining access to the right to social security and being active members of the workforce. We use this as a backdrop to work with partners in the disability, social care and sport sectors to improve access to physical activity and the many benefits and outcomes this brings.

This document comes from the voice of disabled people within the West Midlands and takes a social model approach. We were interested in their experiences of physical activity in their local areas, capturing real examples of barriers they are facing, and finding out about their suggestions of how things can be improved. In this document we will start by setting the scene and exploring what we already know about disability and physical activity in the UK. We will then go onto discuss what we mean by co-production in an evidence review exploring co-production ideologies and approaches in the UK. The next section of the document outlines our approach to engagement with disabled people and community groups in the West Midlands. This will be followed by setting out what people told us through sharing the main findings from a series of Knowledge Café's and survey results. We will also highlight the emerging themes coming from Knowledge Café discussions about a potential Citizen's Network. We will bring all the above together to outline what we believe should be the Building Blocks for engaging disabled people and co-producing solutions to inactivity in the West Midlands.

In terms of the target audience, this document is for disabled people, groups and community organisations in the West Midlands, colleagues working on IMWM and sport sector providers.

There is also a summary version and illustrated document available for viewing key findings and recommendations from this work.

What we already know about disability and physical activity

There has been a wide variety of research around disabled people and their experiences with physical activity through various projects, programmes and research papers.

When considering recommendations for physical activity it is essential to take into account the physical activity for disabled adults infographic, which was co-produced with disabled adults to communicate evidence based physical activity recommendations (Smith & Wightman, 2019). The review recommended that disabled people should do at least 150 minutes of moderate intensity activity per week. It also established various health and wellbeing benefits of physical activity for disabled adults, such as improved quality of life. The review informed the UK Chief Medical Officers' Physical Activity Guidelines, published in 2019.

The benefits of physical activity were supported by Disability Research on Independent Living and Learning (DRILL) (2019), who funded physical activity intervention based in Northern Ireland for people with severe and enduring mental health problems. Findings included in the 'Empowering People through Physical Activity' report showed multiple physical and mental health benefits from the 12-week exercise programme, including improved energy, better decision making, and lower levels of stress. The participants also valued the social aspect of the programme and helped to create a sense of belonging for those that were socially isolated, providing new opportunities to meet people and increase their social network.

Despite health benefits, disabled people are often physical inactive. For example, in the Annual Disability and Activity Survey, Activity Alliance (2020) stated high levels of inactivity. This is not however to say there is no appetite to be active. The Annual Disability and Activity Survey reported that there is a strong desire for activity among disabled people. Four in five (81%) want to do more activity than they currently do, and nine in ten (90%) disabled adults aged under 40 want to be more active. However, just four in ten (40%) of disabled people feel like they are given the opportunity to be as active as they would like. This was more the case for respondents with mental health problems or memory impairments. Disabled people were also found to have a less positive perception of sport and

physical activity, and were half as likely to agree that sport was for someone like them (32% vs 63%).

Activity Alliance (2019) also published the report named 'Delivering Activity to Disabled People', which investigated perceptions among people who deliver sport and active recreation sessions and their experiences of delivering inclusive activity to disabled people. They found the level of awareness and experience of delivering to disabled people is low among the general population of activity deliverers. Many use their experiences, media stories or stereotypes of disabled people to create a picture of a disabled audience. This then leads to low levels of confidence and interest in delivering physical activity to disabled people. Lack of knowledge is the biggest challenge among those without experience, and the lack of experience can create a sense of fear around interactions. Other concerns included fear of a negative impact on non-disabled participants, and concerns around health and safety. The study highlighted the need for further training for deliverers to make sure that they are more confident and therefore interested in providing inclusive opportunities for disabled people. The DRILL (2019) funded physical activity intervention echoed this. Having supported work on the health benefits of physical activity, the study recommended that physical activity should be a core responsibility of health and social care and community-based provision, and that the social aspect of participation should be at the forefront when planning and delivering programmes.

It is also essential to consider the Get Yourself Active evaluation (2019) which evaluated the Get Yourself Active programme between 2015 and 2019 to test certain assumptions about the value of grassroots disabled people led organisations as legitimate partners in a local system to tackle inactivity. Findings from the evaluation showed the main barrier that disabled people face was a lack of knowledge about accessible opportunities. Seventy-five percent of disabled people reported 'not knowing what was available' as the main barrier to participating in physical activity, while eighty-six percent of social workers felt that they knew 'nothing at all' or 'only a little' about accessible opportunities available in their local area.

Local co-ordinators were placed within Disabled Peoples User Led Organisation's (DPULOs) to improve physical activity among disabled people. Support that worked included providing one-to-one conversations with disabled people to improve their knowledge about accessible physical activity opportunities and encouragement to participate.

What we mean by co-production

Disability Rights UK is a disabled people led organisation and exists to create leadership and power amongst individuals and organisations to build a movement for change. Co-production is embedded in our approach and practice and this inspires us to work with others to create understanding and commitment to co-production. We believe that co-production is the key to unlock opportunities to tackle the inequalities that disabled people face when it comes to being active. This section is a review of ideologies and approaches around co-production.

What is Co-production?

There are many definitions of co-production. We have chosen one definition which we believe supports the purpose of the proposed Citizens Network. Think Local Act Personal (TLAP) explains co-production in this way:

Co-production is not just a word and it's not just a concept, it is a meeting of minds coming together to find a shared solution. In practice, it involves people who use services being consulted, included and working together from the start to the end of any project that affects them.

Co-production is linked closely to the Social Model of Disability, which says that society disables people through barriers in the environment, in organisations and through other people's attitudes.

Disabled people are the best people to make decisions about their own lives, and when disabled people work together, they can make changes in a society that currently disables them. Removing these barriers creates equality and offers disabled people more independence, choice and control.

The Social Care Institute for Excellence (SCIE) asserts that it may be helpful for organisations and groups to assign a set of principles to co-producing outcomes rather than try to define it. The below principles are seen by SCIE and others as critical for making co-production happen positively and constructively.

Equality– everyone has assets

Diversity

Accessibility

Reciprocity

Coproduction – what is it and how to do it (SCIE)

Develop the services that people really want

Working alongside disabled people around the planning, design and delivering of a project is an essential way of including their voice and can also provide multiple benefits. For example, it can help to ensure that resources are used to develop the services that people really want, help to develop stronger communities, and help to build better outcomes for people who use services. Co-producing solutions and outcomes make it more likely that you will get things right for people the first-time round, preventing expensive repeat visits or underused services. It may also lead to savings in the longer-term because it can help to ensure that people get services that they really need to begin with. Working with people can lead to the identification of new resources or existing resources being better used (Warwickshire County Council, 2020). Simply, when co-production is embedded in work, the impact of it is more likely to be greater.

Therefore, when creating a Citizen's Network where the aim is to improve physical activity for disabled people, it is essential that disabled people are involved at every opportunity. To make the most of every opportunity, co-production needs to be considered at every stage: from Analysing, throughout Planning and Delivering, all the way to Reviewing (Warwickshire County Council, 2020). Sustainable co-production also requires long-term lock-in to a particular programme. A discussion by Pestoff (2014) suggests that size of a network is an important aspect of long-term sustainability. However, he suggests that purpose and focus is more important than size. For example, a smaller group with a clearly defined purpose would be more effective than a large collection of people with broad needs.

In order to achieve meaningful outcomes, everyone involved must also have the same vision, and everyone involved should be clear about what their expectations are and be fully engaged in the process (TLAP, 2014). Competing agendas can make it more difficult to achieve positive outcomes. TLAP (2014) also recommend starting small and building up to bigger projects, which may be a better way of achieving co-production in the longer term.

Be aware of the risks

Care must be taken to ensure co-production is carried out correctly. Co-production has many competing definitions, depending on the circumstances and the perspectives taken (Osborne et al., 2016) and can often be simply a fashionable term to use in policy documents (Voorberg et al, 2015). There is always the danger that co-production can thus be ‘tokenistic’. That is to say, people often have the best intentions to embed co-production in work, but because it can be a lengthy and challenging process, it becomes heavily watered down.

There are a number of risks when carrying out co-production that are important to take into account. The Disabled People’s Commission (2017) found that often co-production networks can lose enthusiasm and co-ordination if there is not an engine for co-produced change or hub, that can help to improve the support and resources different parts of the network have.

Brandsen and Helderman (2012) describe how co-produced systems and services can exclude outsiders and respond only to the needs of those involved directly in co-production. Co-production can also undermine accountability and is sometimes used by risk averse service providers to absolve themselves in the case of failure but take undue credit in the case of a successful initiative (Verschuere et al., 2012).

Co-production also carries risks when one or more parties enters a co-production process in bad faith or does so without due consideration. In summarising the potential downsides of co-production, Williams et al. discuss how: “Imbalanced power and unresolved stereotypes between service providers and citizens can lead to co-contamination. The service provider has the burden of working towards an equitable partnership to protect citizens from these consequences.” (Williams et al., 2016, p. 17).

However, when done correctly and with the right purpose, co-production can give individuals a greater say over services and involve them in the operation of those services in various ways (Pestoff, 2006). This can lead citizens to feel a greater sense of ownership over a set of services (Vamstad, 2012). It is vital then that co-production practices are reflected on throughout any work and every effort made to support high-quality co-production. When this happens, significant change can be made.

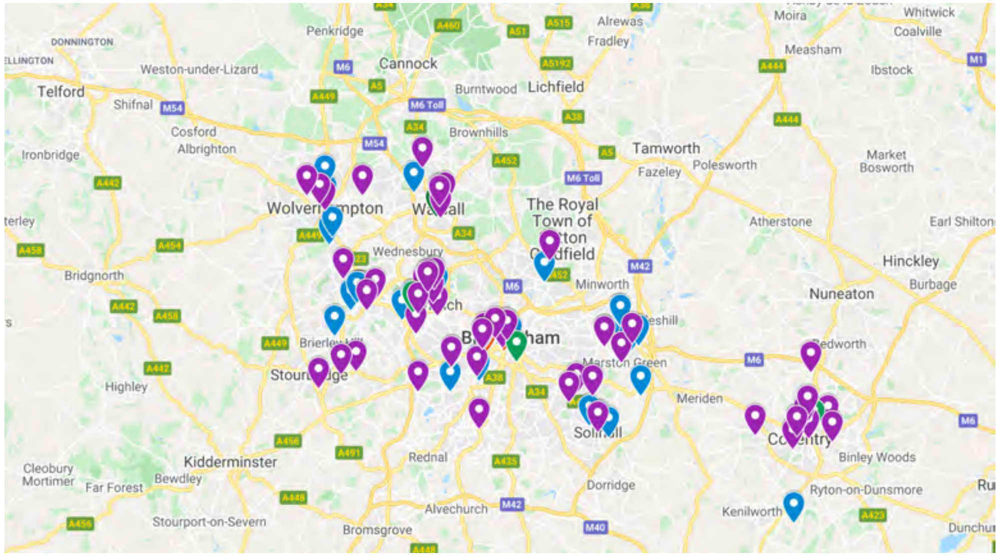
How do we imbed co-production?

Our Approach

Features of co-production and the social model of disability fed into the approach DR UK decided to take to gather views from disabled people in the West Midlands. We wanted to talk directly to local disabled people and community organisations so that they could share their ideas. This would then feed directly into the plan for the development of the Citizen's Network or share alternative suggestions for reciprocal feedback. Our aim was to talk to people who lived in different areas, had different experiences and engage with those who may not currently be active. We believed this would give us the best feedback around barriers that people currently face.

Community groups and organisation mapping

To begin our engagement work, we created an organisational mapping tool to enable us to visualise where different organisations, groups and networks for disabled people existed within the West Midlands. This enabled us to understand what already existed for disabled people in specific areas of the West Midlands and to start to form a plan as to the most useful and efficient way to engage with people. We found a range of non-sport sector groups and organisations working with local disabled people and therefore decided to direct our engagement activity through these links. To do this we initially contacted a range of services to explain our engagement work and ask if they would like to be involved.



Knowledge Café’s and online survey

We visited five different organisations working with disabled people in the West Midlands and engaged with a total of 60 people. These organisations were based within Walsall, Dudley and Birmingham, and provided good insight into the range of experiences in different parts of the West Midlands. We called the engagement events ‘Knowledge Cafés’, and they were in the style of interactive workshops with a range of different activities created to explore views and experiences.

As well as our face to face work, we created a survey so that we could expand our findings of experiences around the West Midlands. This gave us the chance to gather information from other areas, from individuals who do not access services, and from groups and organisations that we had not been able to gain feedback from as part of our face to face engagement.

Within the knowledge cafés and the survey, we planned activities and questions around a topic guide that helped to ensure we collected essential information. We aligned this topic guide with the Activity Alliance (2014) ‘Talk to Me’ principles. For example, one of the principles is to find out what is important to people and what they value in life. This can help in the longer term as providers can frame sport in a way that appeals to individuals. It was also essential to find out the experiences of disabled people in the West Midlands around accessing physical activity, and any barriers they may face.

The main topics in the guide included:

- **What’s important to me?**
- **Activities I take part in and the benefits of these.**
- **Activities I haven’t taken part in but would like to – what is stopping me?**
- **Where can I get information from to get active, and who can help me?**
- **How can physical activity be improved in the West Midlands.**

What We Found

Creating engaging activities that linked in with the topic guide helped us to create a structured session in the knowledge cafés in order to collect information. The information gathered from all the workshops was then synthesised and summarised into the separate topics, which enabled us to see the main responses and feedback to include in this document.

Living a good life

When thinking about physical activity it is important to look at a person’s wider life and what they value. For example, emphasising an activity to achieve goals helps people to see how it is relevant to their lives. This was found in the Get Yourself Active evaluation (2019) where participants set goals in relation to getting active around aspects that were important to them, such as increased social contact. Disabled people should be able to make choices in their lives without undue pressure or restrictions and focus on what is important to them. We therefore began all our knowledge cafés with the aim of finding out what participants value in their lives. Like identified in the review (Public Health England, 2018; Smith et al., 2019) that informed the updated Chief Medical Officers’ Physical Activity Guidelines, there were several different responses and these centred around a few different areas:

- **Spending time with loved ones** this included spending time with family, friends, and pets. This response came out frequently in all five knowledge cafes. Physical activity was viewed as a positive way of being able to spend time with people you are close to and having fun together.
- **Being part of the community** – participants commented on how getting out and about was important for them; this included being able to meet new people and socialise within their local area. Certain organisations were essential to enable them to be part of the wider community; for example participants spoke about the support they received at Queen's Cross Network. Participants often described a strong sense of community in the area they lived, and that their local area was important to them.
- **Being independent** – Participants spoke about wanting to stay as independent as possible and doing things that promote independence, for example, going to college or working. Some participants said they may need support in some parts of their daily life, but this does not take away from wanting to be as independent as possible.
- **Pursuing hobbies or interests** – participants enjoyed taking part in activities that were in line with their interests, for example, art, going on sailing trips, dancing, or going bowling.

Reasons to be active

Getting active has many benefits for disabled people and those with long term health conditions. The 2019 UK Chief Medical Officers' Physical Activity Guidelines for disabled people name just a few benefits – improving mental health, improving fitness and helping people to feel part of a community (Department of Health and Social Care, 2019). These were mentioned in our knowledge cafés, where participants spoke about being able to lose weight and keep healthy.

Participants also spoke about other benefits. These included being able to try new things and learn new skills, being part of a competition, and physical activities as a great way of having fun and gaining pleasure. One of the main benefits of taking part in physical activity that came out of knowledge cafés, rather than keeping healthy, was being part of the community and spending time with others. Participants described being part of groups and clubs that meant they had the opportunity to meet new people and make lifelong friends.

There were a range of activities described by disabled people in the West Midlands, from going to the gym, taking part in local sports or everyday activities that help people stay active, such as walking the dog. Some people found it easier than others to access their local gym. For example, one student at the Walsall Disability Hub described accessing his local gym and spending time running on the treadmill. He found this easy as he started going with a friend who is also disabled, and so they felt more comfortable to go together. He accessed the gym so that he could live a healthy, balanced lifestyle, as he knew by exercising he would not feel guilty for rewarding himself with a treat.

> **I like going to the gym with my friend. Being competitive makes it more fun! "**

Many participants did take part in some sports, either in the community or at the organisation where we held the knowledge cafés. These ranged from running, swimming, to playing football. One student at The Hive College in Birmingham described taking part in archery and how this was positive for his mental health, as it is such a calm sport to take part in.

It helps me to focus my mind

Others said they used sports and activities as a way of relaxing. It helped people to forget about worries or stresses they may have in life. One participant at Focus Birmingham said she is tired after taking part in activity, but in a positive way.

It makes me a good type of tired!

Some participants were part of groups in the community. For example, one participant described being part of a running club where he was able to meet new people and spend time with friends. He also described it as a great way to keep healthy, and he likes the feeling he gets after running.

There were some local services that made accessing sport easier. For example, participants at Walsall Disability Hub spoke about the Oak park Active Living Centre which had a range of activities that are accessible to disabled people, such as walking football. Importantly, and also key to promoting physical activity, the staff were friendly and helpful, which helped make people feel more comfortable when attending. Sense College also had a good relationship with their local gym, developed through the Sense Sport Programme, which has accessible facilities for people attending and helpful staff who help to arrange activities for students.

Other participants may not have taken part in sporting activities but kept active in other ways. For example, a participant at one event said he visited the local working men's club once a week. He described it as a great way to socialise, enjoy the music and being able to dance in rhythm. He said having the opportunity to go to this event helped to prevent isolation and made him feel part of the local community.

I can lose myself in the music

Others took part in activities such as gardening, which is a way of getting them outside and active in other ways. Sense College have a sensory garden, which students can access. A participant at The Hive College described going to her Grandad's house at the weekend and walking the dog, which was not only a great way to keep active but also meant she could spend quality time with her Grandad. This, in turn, can foster better intergenerational relationships, leading to people having more positive views about ageing and older people.

Reasons for not taking up physical activity

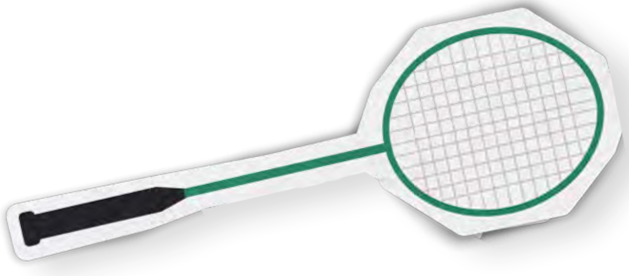
It is essential to consider what barriers people in the West Midlands face when taking part in physical activity. Despite the many benefits of getting active, many disabled people find the barriers they face mean taking part in activity is sometimes not possible for them.

The DRUK (2019) evaluation of the ‘Get out Get Active’ peer support programme found key barriers were often rooted in stereotypes and accessibility. This chimes with feedback from the knowledge cafés, for example, disabled people are often told they cannot take part in an activity and it can be difficult for them to overcome certain stereotypes.

Many knowledge café participants expressed a concern about whether the sport or activity would be welcoming to disabled people, as well as concerns around the attitudes of staff and other customers.

Staff at Sense also described difficulties with supporting people into the community for activities, particularly when the people they support often communicate and express themselves differently to others. However, they adapt this depending on an individual’s needs. For example, if someone is not able to access the gym because the environment causes them anxiety, they will think of other activities to promote wellbeing, such as going for a walk. This observation raises a question about how facilities can be made more accessible to people with sensory impairments.

Staff talk to our support workers instead of us! ”



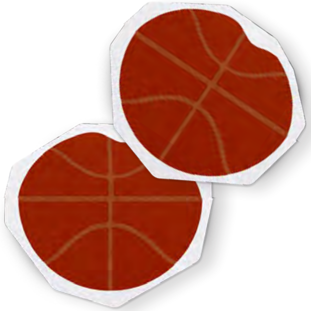
Case Study

Negative perceptions from the public were described during a visit to Sense College, where students have a range of complex needs. A staff member described negative communication from members of the public, which was the main barrier for people taking part in activities in the community. She described how staff are not trained to communicate with people with complex disabilities. For example, they speak to the member of staff instead of the person they are supporting.

Levels of confidence

Because disabled people can often feel unwelcome when taking part in physical activities, this can also mean they feel less confident to pursue their interests. One participant at Hive College said they had always wanted to try gymnastics, but the fear of injuring himself put him off giving it a go. Someone said they need initial support of being shown how to do an activity, as this means they then feel more confident when doing it alone. However, they did not always know how to get this support in the first place or felt concerned that they would be looked down on.

> I'm worried I will hurt myself "



Accessibility of the activity

Many individuals took part in activities at school but no longer take part, usually due to not knowing where to find out about an activity or if it would be accessible for them. Someone mentioned horse riding, but he had to stop as he was always falling off the horse, and the stables did not have the equipment to help prevent this. This was also the case for swimming, participants mentioned that there were no hoists in their local swimming pools which made it more difficult to enjoy this physical activity.

One participant, with autism who suffers with anxiety, mentioned a disabled swimming group. However, this was not always accessible, as often the group is cancelled or changes time which makes it difficult to access for people who rely on following a routine. Our survey also gave us an insight into the experience of working adults and the fact that many activities are difficult for them to attend due to employment and rigid timings of physical activity provision. For example, one person mentioned the fact that they can only get support to take part in activities in the afternoon, but they cannot attend due to being at work. Therefore, timings of activities can be a barrier.

Some organisations do not have access to some physical activities that would provide benefits for the people that access their services. For example, Focus Birmingham have no access to hydrotherapy in the local area. This was an activity that people who use their service attended in the past but have since not been able to access due to a change of provider. Hydrotherapy helped participants to get active and was adaptable for those with more complex disabilities. However, staff verbalised their frustration that they could not access this activity in their local area.

Case Study

One member of staff and a service user described how she started rock climbing but this was not manageable for her condition as it made her sick. So instead of this they started going for walks in the community, where she met a man who was fishing. This chance interaction led to the woman trying out fishing and sustaining that activity in the longer term.

Lack of information

One of the main barriers that came up multiple times in all knowledge cafés was people not knowing where to go to access physical activity. There were particular sports that people were willing to try, and wanted to take part in, but did not even know where to begin in looking for these activities. These included activities such as horse riding, tennis, and water polo. Participants were unsure about where to get this information from and felt there was a lack of information provided.

> I don't know where to go

Getting there

Transport was another barrier that people faced. This came up frequently when visiting Focus Birmingham. Participants described how they were unable to leave the house without 'dial a ride' taxi which is currently changing providers and leaving people anxious. Many people also explained how they were highly reliant on transport to support them to get out of the house and into the community. Some participants, especially those in Walsall and Dudley, described getting out to activities on public transport difficult. Both Activity Alliance (2014), and research by Phoenix et al (2015) with visually impaired people in the Midlands, discussed how it can be harder for participants to make physical activity into a habit if the travel is too taxing, especially if their motivation is already limited.

> There are no staff to take me

Funding

Another barrier is funding. Participants described taking part in activities at some point, but often these activities became unavailable due to funding issues. This was also something that was found in the Get Yourself Active evaluation (2019), where it was found that disabled people were reluctant to consider physical activity due to funding difficulties, as well as social workers being unsure if they could secure funding for physical activities through personal budgets. One woman we spoke to in Walsall Disability Hub mentioned she loves going out on boats, but due to funding issues these trips only take place once a year. Funding issues were a major barrier for people with complex disabilities.

At Sense College, students are able to access many activities and are supported in the community. However, one woman only had social care funding (personal budget) to access the centre two or three days a week. She loves taking part in activities and is always keen to try a new sport she is introduced to. However, on the day she is at home, she does not have the support she needs to access activities. This lack of funding support results in her being inactive on these days. If she had funding for all five days, her activity levels would be greatly increased.

There were also concerns around cuts to local funding impacting on wellbeing outcomes of disabled people. Local authorities are under continuous pressure to cut budgets across all departments which often impacts adversely on communities. Many grassroots voluntary and community sector organisations struggle to cover core costs of their activities which has an impact on their ability to deliver or support wellbeing initiatives. There is also concern about whether resources are directed towards local communities in the West Midlands. For example, one participant raised concerns about the amount of money going into commonwealth games and whether this would filter down to local, accessible activities. There may also be further issues that have since arisen with the economic impact of Covid-19, and therefore a long-term view to health and wellbeing initiatives for disabled people is essential.

Where do I find info on activities?

Boat trips only once a year

No staff to take me

Support Networks

Participants spoke about a variety of help to get active, however this was dependent on the area the person lives. For example, those in Birmingham found it easier to find out information relating to physical activity than those in smaller areas such as Dudley. This said, the ongoing theme running through all the knowledge cafés was that it is difficult to get this information. Participants spoke about not taking part in as many activities as they would like to simply because they don't know where the groups are in the first place. When they do try to find the information this can be difficult, which was also found by support workers who attended the events. Many individuals said that the only way they find out about information is through word of mouth. Targeted physical activity communication is vital.

> **I don't know where to look!**

Suggestions for places that could help included the disability organisations the individuals were already attending, which were a combination of day centres, drop-in centres and a school. Participants felt confident that they could be provided with information in these settings or that staff could help them to find information if they were unsure. For example, at Walsall Disability Hub participants said the centre was the main source of information. Staff are helpful, find things out and give out information when possible.

> **My support worker helps me to find information**

There are also other local organisations that some people are connected to that can help them to become active. For example, one participant in Walsall that cares for her daughter said her local carer's centre sends out newsletters and gives information around local activities.

Other suggestions were places such as the local library, which provides a variety of leaflets, youth clubs, speaking to a GP and the job centre. One participant said they had a disability advisor at the Jobcentre who is always happy to pass information on to them about local activities.

Participants commented that it used to be easier when there were more leaflets and posters around their local area, but that does not seem to be the case anymore. Newspapers were a good way of finding information, but participants don’t recall seeing activity sections within these. One person mentioned that there is a noticeboard in their local supermarket and they find it really helpful for finding information.

Other suggestions were looking on the internet, although there were mixed responses. Some individuals found it helpful to look on TripAdvisor or sign up to emails or newsletters. There were also suggestions of social media and specific websites, for example, local authority e-market places or directories. One participant mentioned the Walsall Community Living Directory, however, it is not always apparent if activities are suitable for disabled people. There was also some concern around using the internet. For example, it was not always seen as being up to date or reliable. It may not be accessible for everyone, for example, those with sight loss. It is also vital to keep in mind the ‘digital divide’. This divide was highlighted by participants when they reminded us that not everyone has the internet, not everyone can pay for the internet, and not everyone can use it easily. However, where the internet was not an option, individuals were happy to pick up the phone to gain information about activities and services they could access.

> **I sign up to newsletters on websites, these can be useful for sending over information straight to my email**

> **My GP can help me, and there’s also a notice board at my GP surgery**

Suggestions for engagement

There are a variety of ways that people like to be engaged with, and it is important to consider various forms of contact.

Most individuals spoke about valuing personal contact, meeting face to face and building relationships. Attending different organisations for knowledge Cafés was a positive way to engage with and meet a variety of disabled people in the West Midlands. However, it is essential this face to face contact is continued in the longer term in order to build and maintain trust. Some participants spoke about their frustration around being asked their views by different people, but this is usually a one-off engagement to feedback and these views are never taken on board. Therefore, when seeking views and opinions it is crucial for people are kept informed about how this information is being used.

Participants spoke about the importance of engaging not only with disabled people, but also taking on board views of others that are close to them. Family, carers and support staff have important and valuable insights to share and can offer a well-rounded view of how disabled people experience physical activity.

It is essential to investigate a variety of ways to engage with disabled people and to gain feedback from diverse communities. For example, older people may have different experiences, or may face different barriers compared to younger people, and it is essential that this is not forgotten. This is also the case for different nationalities, cultures, genders and sexuality. As well as this, it is important to consider hidden disabilities. For example, during one knowledge café there was discussion around the fact that those with a mental health diagnosis are often not involved, or if they are, they feel that their feedback is not listened to or valued.

Co-producing Include Me West Midlands

A Citizen's Network – Emerging Themes in the West Midlands

There was a consensus in the knowledge cafés that having a Citizen's Network would bring about benefits for disabled people in the West Midlands. Talking through the variety of topics helped participants to see what may prevent them from being active and what changes can be made. This in turn helped participants to start to develop ideas around what the Citizen's Network could look like in practice.

Below we highlight the key themes arising from these discussions.

Flow of information

The purpose of the network for most participants was to receive information and to feedback about physical activity. For example, there were suggestions of creating an online website similar to TripAdvisor, which would focus on providing information around physical activities in the local area and be a way of rating what is available. Having a system like this could also be a way of making suggestions or comments, as well to feedback what changes are necessary to make activities more accessible for disabled people. Working together with local sports organisations, venues and groups alongside disability organisations can also ensure that information is being better communicated to all members of the local community.

Sharing lived experience

As well as a significant focus on sharing information, the network is also seen as a way to provide training to different organisations and venues around the West Midlands. For example, local gyms. Many participants found they were not welcome to take part in physical activity, whether that is due to accessibility or lack of awareness. The Activity Alliance (2019) report 'Delivering Activity to Disabled People' found that

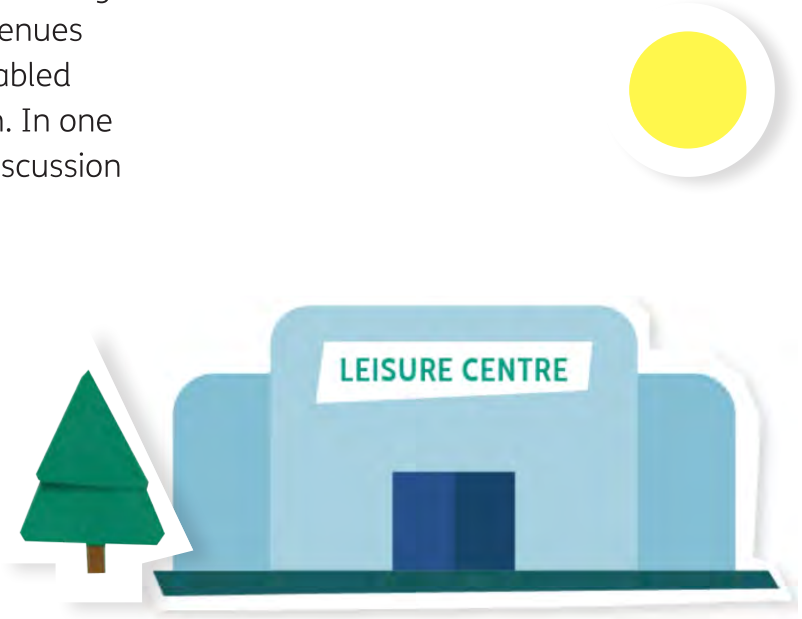
sports providers can lack the confidence or understanding to deliver physical activity to disabled people. Participants felt that providing co-production or disability awareness training would raise awareness and offer the opportunity to build positive and collaborative relationships between the sports sector. Training could also help sports providers to better communicate with people in their local areas, ensuring information is shared.

A stronger, combined voice

Participants spoke about the fact that, when it comes to physical activity, there is currently no mechanism enabling people to feedback and be involved in. Participants spoke about wanting to have a stronger combined voice, and to change the way physical activity is run in local areas. They spoke about the network as a way to join together existing groups that are already in place but might not have a voice. Engaging a diverse range of community and grassroots organisations could be a way to engage with decision-makers and commissioners, for example, local councils. Disability organisations can act as local partners supporting the agenda to increase levels of activity amongst disabled people. This echoes conclusions about the value of DPULOs set out in the Get Yourself Active evaluation in 2019.

Accessibility

Improving accessibility was also seen as a main aim of the network, and a way of creating a larger variety of accessible options for getting active. The network could be a way of feeding into the development of new venues and activities and ensuring disabled people are able to access them. In one knowledge café, there was a discussion around the development of new leisure centres in Dudley but that these are not accessible for disabled people. Participants felt that they could support the development of more accessible venues if they were involved in the early stages of design. Another barrier to accessibility was also the timing of activities and available support, which can mean activities being inaccessible to people who are working. The network would support the sport sector in the West Midlands to consider these issues at the early stages of development.



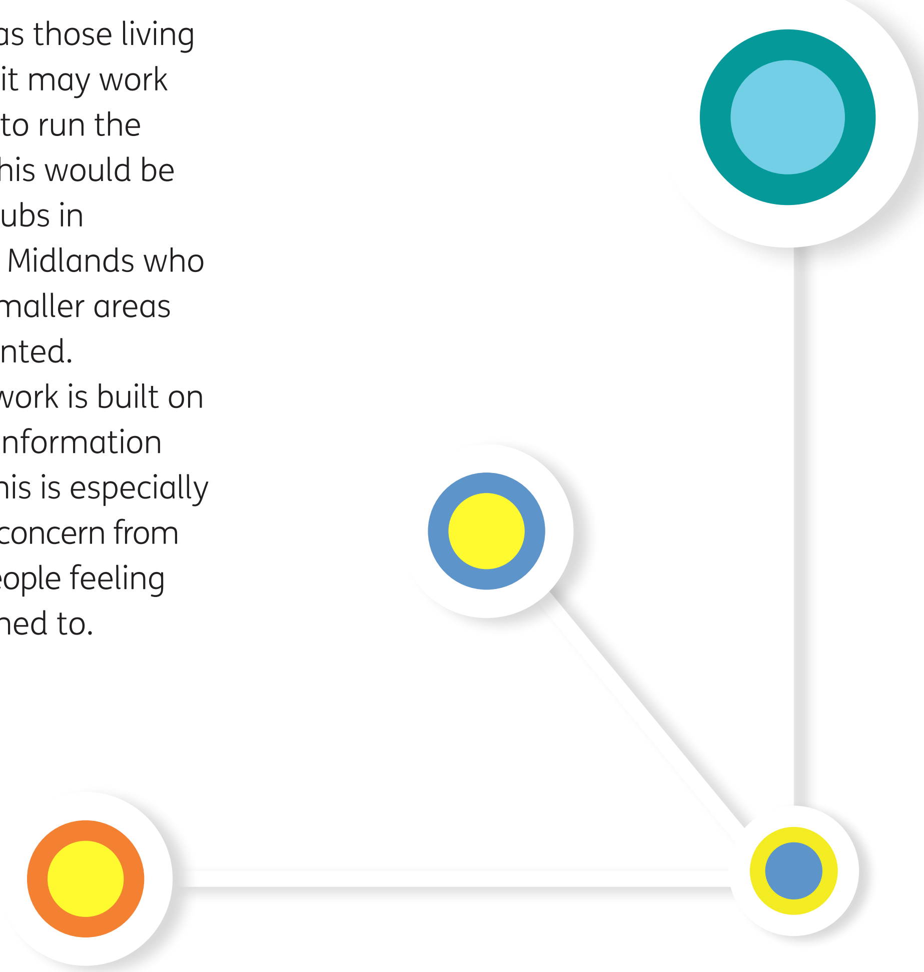
Utilising existing networks

It is important to acknowledge that not all participants were on board with the idea of a Citizen's Network. For example, at both Focus Birmingham and Queen's Cross Network some participants said they are already linked into networks that help them and that they would not engage with a new one. They also thought the development of a new network may cause confusion. For example, one participant said he attends regular meetings with the Royal National Institute of Blind People. He saw this existing network as useful for sharing his views and that the network held a lot of trust amongst its members. There were concerns that there have been groups in the past with a similar aim, but these often disappear. Therefore, there needs to be a lot of thought and consideration around ensuring that the Citizen's Network be a constant and consistent mechanism for co-production.

Management of the network

Participants also spoke about the West Midlands being a large area and that it would be difficult for the Citizen's Network to cater for each borough. Participants in smaller boroughs felt they were not involved or did not have as many resources available as those living in Birmingham. Therefore, it may work well to have a central hub to run the network and keep focus. This would be accompanied by smaller hubs in different parts of the West Midlands who would ensure that these smaller areas were included and represented.

It is essential that the network is built on reciprocity and also feeds information back to disabled people. This is especially important as a significant concern from engagement events was people feeling they were not always listened to.



Citizens Network - Purpose and outcomes

Here we set out what we believe disabled people in the West Midlands would like out of the Citizen's Network. This is based on the above feedback as well as our knowledge and experience of models of co-production. Disability Rights UK is experienced with this way of working, and our work is based around supporting organisations to put disabled people's priorities at the heart of their policies and practices.

The outcomes also link to the Social Model of Disability in relation to overcoming both physical and attitudinal barriers. See below our working statement of purpose.

The Include Me West Midlands Citizen's Network exists to improve the flow of information and knowledge about physical activity between disabled citizens, their communities, support networks and the sports sector.

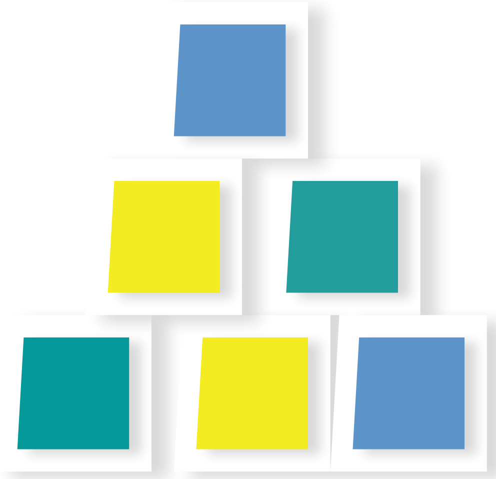
The outcomes of the network should be as follows.

- **Disabled people receive information about physical activity through trusted channels.**
- **The sports sector workforce builds capacity to create inclusive opportunities for physical activity.**
- **Disabled people see an improvement in access to physical activity.**
- **The WMCA utilise existing networks and build strong links with community organisations.**

Citizen’s Network – The Building Blocks

Based on the above statement of purpose and outcomes, DR UK has developed a set of recommendations or ‘building blocks’ for the Include Me West Midlands programme manager and advisory group to consider. These are all about how to create the environment needed to develop the Include Me West Midlands Citizen’s Network.

- Create a hub for communication between disabled people, community organisations and the sport sector. This will ideally be delivered by an independent organisation.
- Agree a set of principles that underpin the work of the Citizen’s Network and review these regularly.
- Build flexibility into the Citizens Network and be open to ideas and plans changing.
- Build trust and connections with the community sector, who are already a trusted source of information for disabled people.
- Be open to working in different and creative ways as a result of working alongside the community sector.
- Build awareness of the social model of disability and the principles of co-production.
- Create opportunities for the Sports Sector to learn from the lived experience of disabled people.
- Be aware that not all disabled people access community organisations and therefore create ways to communicate with diverse disabled people.



Disability Rights UK

Moving the West Midlands Forward

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References

- Activity Alliance (2019). Delivering activity to disabled people: The workforce perception gap. Retrieved from: http://www.activityalliance.org.uk/assets/000/002/641/Activity_Alliance_Deliverer_Perceptions_Research_Report_Final_Accessible_PDF_report_original.pdf?1548778930
- Activity Alliance (2020). Annual Disability and Activity Survey 2019/20. Retrieved from: http://www.activityalliance.org.uk/assets/000/003/311/Annual_Disability_and_Activity_Survey_%E2%80%93_full_research_report_original.pdf?1579684345
- Activity Alliance. (2014). Active together: Evidence-based report on how to provide sport or physical activity opportunities for disabled and non-disabled people to take part together. Retrieved from: http://www.activesussex.org/wp-content/uploads/2014/06/Active_Together_Report_V6.pdf
- Activity Alliance. (2014). Talk to me: Understanding how to increase participation in sport and physical activity amongst disabled people in the UK. Retrieved from: http://www.activityalliance.org.uk/assets/000/000/271/Talk_to_me_FINAL_original.doc?1462896025
- Brandsen, T., & Helderman, J.-K. (2012). The Trade-Off Between Capital and Community: The Conditions for Successful Co-production in Housing. VOLUNTAS: International Journal of Voluntary and Nonprofit Organizations, 23(4), 1139–1155. https://doi.org/10.1007/s11266-012-9310-0
- Department of Health and Social Care. (2019). UK Chief Medical Officers' Physical Activity Guidelines. Retrieved from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/832868/uk-chief-medical-officers-physical-activity-guidelines.pdf
- Disability Research on Independent Living & Learning (DRILL). (2019). Empowering people through physical activity: A co-produced research project studying how to improve physical activity for people with severe and enduring mental health problems. Retrieved from: http://www.getyourselfactive.org/wp-content/uploads/2019/12/drill-empowering-people-through-physical-activity_0-1.pdf
- Disability Rights UK (2019). Increasing participation in physical activity and sport: Evaluation of Get Yourself Active. Retrieved from: http://www.getyourselfactive.org/wp-content/uploads/2019/06/GYA-final-report_FINAL_29.03.19.pdf
- Disability Rights UK. (2019). Peer Support Programme: GOGA Evaluation. Retrieved from: http://www.getyourselfactive.org/wp-content/uploads/2019/12/GOGA-Peer-Support-Report-Final-191119.pdf
- Disabled People's Commission. (2017). Nothing About Us Without Us: Working together to transform public services in Hammersmith and Fulham. Retrieved from: https://www.lbhf.gov.uk/sites/default/files/section_attachments/nothing_about_us_without_us_hf_disabled_peoples_comission_report.pdf
- Osborne, S. P., Radnor, Z., & Strokosch, K. (2016). Co-Production and the Co-Creation of Value in Public Services:

A suitable case for treatment? Public Management Review, 18(5), 639–653. https://doi.org/10.1080/14719037.2015.1111927

- Pestoff, V. (2014). Collective Action and the Sustainability of Co-Production. Public Management Review, 16(3), 383–401. https://doi.org/10.1080/14719037.2013.841460
- Phoenix, C., & Griffin, M., & Smith, B. (2015). Physical activity among older people with sight loss: A qualitative research study to inform policy and practice. Public Health. 129, 124–130.
- Public Health England. (2018). Physical activity for general health benefits in disabled adults: Summary of a rapid evidence review for the UK Chief Medical Officers' update of the physical activity guidelines. Retrieved from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/748126/Physical_activity_for_general_health_benefits_in_disabled_adults.pdf
- Smith B, Kirby N, Skinner B, et al. (2018). Infographic. Physical activity for disabled adults. Br J Sports Med Epub. doi:10.1136/bjsports-2018-100158
- Smith B, & Wightman L. (2019). Promoting physical activity to disabled people: Messengers, messages, guidelines and communication formats. Disability and Rehabilitation. doi:10.1080/09638288.2019.1679896
- Sport England (2019). Active Lives Adult Survey - May 18/19 Report. Retrieved from: https://www.sportengland.org/know-your-audience/data/active-lives
- Think Local Act Personal. (2014). Top Ten Tips for Co-production. Retrieved from: https://www.thinklocalactpersonal.org.uk/Latest/Top-Ten-Tips-for-Co-production-One-page-profile-and-Easy-Read-version
- Vamstad, J. (2012). Co-production and Service Quality: The Case of Cooperative Childcare in Sweden. VOLUNTAS: International Journal of Voluntary and Nonprofit Organizations, 23(4), 1173–1188. https://doi.org/10.1007/s11266-012-9312-y
- Verschuere, B., Brandsen, T., & Pestoff, V. (2012). Co-production: The State of the Art in Research and the Future Agenda. VOLUNTAS: International Journal of Voluntary and Nonprofit Organizations, 23(4), 1083–1101. https://doi.org/10.1007/s11266-012-9307-8
- Voorberg, W. H., Bekkers, V. J. J. M., & Tummers, L. G. (2015). A Systematic Review of Co-Creation and Co-Production: Embarking on the social innovation journey. Public Management Review, 17(9), 1333–1357. https://doi.org/10.1080/14719037.2014.930505
- Warwickshire County Council (2020). A guide to Co-production. Retrieved from: https://apps.warwickshire.gov.uk/api/documents/WCCC-859-394
- West Midlands Combined Authority. (2019). Improving the life chances of disabled citizens in the West Midlands by being active. Retrieved from: https://www.wmca.org.uk/media/3099/include-me-wm-report.pdf
- Williams, B. N., Kang, S.-C., & Johnson, J. (2016). (Co)-Contamination as the Dark Side of Co-Production: Public value failures in co-production processes. Public Management Review, 18(5), 692–717. https://doi.org/10.1080/14719037.2015.1111660

Appendix 1: Community Organisations

Below is a summary of information about the organisations where we were able to host Knowledge Cafes.

Queen's Cross Network

Queens Cross Network is a local support centre for adults with physical and/or sensory disabilities. Located in Dudley, they offer person centred, tailored support programmes within a relaxed and friendly environment. The network is home to Disability in Action, Dudley Carers Hub, vision support services and services for people who are deaf, hearing impaired or have dual sensory loss.

Walsall Disability Hub

The Walsall Disability Hub is run by Mencap and aims to enable easy access to support, guidance and information. It provides an environment which enables individuals to access a range of support and creates opportunities for individuals to engage in leisure and learning. Individuals can access information to a range of preventative services and activities, including health promotion, signposting to services, advice, retraining, employment opportunities and social and fitness activities to maintain or regain as much of their independence as possible.

Focus Birmingham

Focus Birmingham is a registered, specialist charity providing support, advice and information to anyone in the Birmingham area affected by sight loss or other disabilities. Focus Birmingham provides community services, a large specialist day service and a Low Vision centre that's unique to the West Midlands, as well as a helpline which is run entirely by volunteers. Their aim is to help people come to terms with sight loss and also stay independent. Each year, they work with 7,000 people across all ages and cultural backgrounds to support them in living independent and fulfilling lives.

Hive College

The Hive College is located in north Birmingham. The college provides education and training for young people with special educational needs and/or disabilities who are over the age of 18. Most students aspire to move into employment or to contribute to their communities through voluntary work. A minority of students have complex learning needs and aim to improve their personal skills and independence.

Sense College

Based in TouchBase Pears, Birmingham, Sense College offer personalised learning for young people with complex disabilities, aged between 16 and 25. They provide accessible day opportunities to learn, develop communication and living skills, connect with other people, get creative, and enjoy fun activities. The college supports people to achieve chosen outcomes through formal study programmes, employment, and sport and leisure activities within the local community.

Appendix 2: Knowledge Café Plan

- (10 minutes) **Short introduction around the purpose of workshop. The group are split into smaller groups for the purpose of the workshop.**
- (10-15 minutes) **What matters to you? – Pass an object around and say three things that matter to them in their lives.**
- (15 minutes) **'What do you think of when you hear the phrase 'Physical Activity' - Have a mixture of words with different emotions on the table and they have to pick 3 each and tell group what they chose.**
- (20 minutes) **Pictures of different sports/activities on the table with people with and without disabilities – pick one activity they have taken part in and talk about what went well/ what they enjoyed.**
- (20 minutes) **Select a photo of an activity they have never tried but might want to – what has prevented them/might prevent them from taking part?**
- (20 minutes) **Case study about a person that wants to be active in the community. Where would they find out about this information? Talk about personal experiences.**
- (20 minutes) **Group discussion around the Citizen's Network – how it could work in practice, pro's and cons, and other ways physical activity could be improved.**

Appendix 3: Survey Questions

1. Where do you live in the West Midlands?

2. Do you take part in any physical activities?

3. What sport or physical activity do you currently take part in?

4. How confident do you feel about accessing physical activity in your local area? 1 is “I have no idea how to find physical activities to do”, 10 is “I can take part in whatever physical activity I want to without any difficulty”

5. What sports or physical activities would you like to do, but don’t currently do?

6. Why have you not been able to take part in these sports or activities?

7. Is there anything else that prevents you from taking part in physical activities or sports? Can you give examples?

8. Where would you go, or who could you ask, to find information about physical activity in your area?

9. Are there any organisations in your area who can provide information or support to take part in sports or physical activities?

10. Have you been part of any kind of network before? By these we mean a group of people who work together to do something or change something in the world around them. If yes, what worked well?

11. What didn’t work so well?

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