Difference
Changing perceptions of disability

Stockton-on-Tees
BOROUGH COUNCIL

Insight Research for the Health Needs Assessment

Put Me in the Picture

Talking About Healthy Weight & Disability with Disabled People in Stockton

October 2022

Barefoot
Research and Evaluation

Observations on Weight from Disabled People in Stockton

"*I need to lose weight.*

Sometimes I can get too skinny.

As a paraplegic and a full time wheelchair user it is difficult to find ways to increase physical activity.

The hardest things about losing weight are the pain, accessibility of leisure and fitness activity and a lack of accessible toilets in public and green spaces.

Fatigue plays a massive role in my inability to lose weight and I simply tire quicker throughout the day because of treatment so I then don't have energy to sit up, never mind exercise.

There is a multi use game area near me, but I cannot visit as there are no public toilets nearby.

Unless I spend over £70 for a specialist swimsuit then I can't go swimming. I would also be embarrassed to wear more traditional continence swimwear in public swimming sessions.

It's just harder for disabled people, to lose weight and stay healthy because either you can't go to most sessions because they're all inaccessible and food is so expensive now, in the shops locally it's cheaper to eat unhealthily than it is healthy."

Acknowledgements

The research team would like to express their thanks to a number of people who have been involved in this consultation. Firstly, our thanks to those disabled people who responded to our calls and took the time to engage with our consultations. There was an energy and enthusiasm about the responses which demonstrated it was an area which was important to people. Thank you to parents/carers/allies for their contributions which were similarly energetic. Thank you also to those professionals in Stockton on Tees with whom we engaged and who provided us with the information we requested. Finally, thanks to Public Health Stockton for the intentions to engage more profoundly with disabled people in the borough.

About Difference North East www.differencenortheast.org.uk

Difference North East is a charity set up in 2017 by a group of disabled people to work towards equality, reduce discrimination, and change perceptions of disability. They are the first disability rights campaigning and voice organisation since the closure of Disability Arts North East in the 1990s. We work towards change by listening to the voices and concerns of disabled people across the North East and representing these through a mixture of policy and research. Recently, Difference North East has been engaging disabled people in conversations about well being, food and fuel poverty, climate change, human rights, and employment. We take the results of these conversations, which take place via a range of accessible means, and work with local authorities and other legislators for improvements in provision, policy, and practice.

About Barefoot Research and Evaluation www.barefootresearch.org.uk

Barefoot Research and Evaluation is a social research organisation based in Newcastle upon Tyne, working across the North East and Cumbria. They have carried out work on a diverse range of social welfare programmes in the voluntary and public sector, specialising in research with the groups who are underrepresented or who lack a voice. Dr. Christopher Hartworth, who set up Barefoot, has 25 years' experience of research and evaluation, beginning in developing countries in poverty alleviation programmes and continuing in the North East of England in work with disadvantaged communities.

i Summary

This report was conducted on behalf of Public Health Stockton on Tees who are conducting a local health needs assessment. As part of the needs assessment, Public Health wanted to better understand the barriers that disabled people face that may prevent people from easily achieving a healthy weight. Many of these barriers, which relate to access and inclusion, are experienced across all disabilities, irrespective of the impairment. These are the main headlines of the consultation:

- Access is limited to healthy lifestyle services which exist in the community, either in the form of sports facilities or healthy food. The reason access is limited is because there are a range of structural barriers experienced.
- Social and cultural barriers prevent disabled people from engaging in sport, *seeing themselves in the picture* and feeling that sport is not for them. People reported feeling embarrassment, self consciousness and fear of experiencing questions and possible conflict, resulting in non-participation.
- Added to this, are common experiences as many young disabled people have been excluded from universal sport and health activities, in schools for example.
- Publicity and communications about health and fitness rarely picture disabled people, which makes positive reinforcement difficult.
- Transport systems can exclude disabled people, costs make fares prohibitive, and the experience may also discourage attendance.
- Convenience and opportunity are limited in available community resources for disabled people; assistive technology or disabled friendly equipment is often absent.
- Disabled people on fixed incomes said they were unable to buy healthy food because the costs are prohibitive: the cheap products were identified as not being healthy.
- As a result of the barriers in place, many disabled people feel most able to access those projects and services that are exclusively directed at disabled people, like power chair football, visually impaired bowls or other specific sport or health initiatives.

We found that disabled people living in Stockton routinely experience barriers which prevent them from engaging in healthy lifestyle choices. Where services are bespoke and targeted,

such as the work of the life coaches and the local authority’s multisport scheme, the experiences of disabled people within the company of their peers were excellent. However, this contrasts with experiences of more universal services, where as well as the range of social cultural and physical barriers, we also found there appears be a reluctance on the part of some standard groups or clubs in the community to allow disabled people to participate in the activities they deliver.

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1.0 Introduction

This report was conducted on behalf of Public Health Stockton on Tees who are conducting a local health needs assessment. As part of the needs assessment, public health wanted to better understand the barriers that disabled people face that may prevent people from easily achieving a healthy weight. Many of these barriers, which relate to access and inclusion, are experienced across all disabilities, irrespective of the impairment. The following box presents important contextual information for the study, from Activity Alliance, 2022.

Box 1.0 Key Facts

- The most recent census data (2023)[1] indicates approximately 40,000 people disabled people live in Stockton (the North East region has the highest proportion of disabled people at 21.2% or 567,000 people).
- Over three quarters (77%) of disabled people would like to be more active.
- Only 42% of disabled people feel they have the opportunity to be as active as they want to be, compared to 69% of non-disabled people.
- Less than 30% disabled people feel encouraged to return to physical activity after the pandemic.
- The pandemic has resulted in a lack of available support which disabled people need to be active, and an increase in barriers relating to health and finances.
- Only four in 10 disabled people feel they can be as active as they want, in contrast to non-disabled people who are now more likely to say they can be as active as they want (62% to 69%).
- There is a clear sense of disconnection with how disabled people feel, with less than half (47%) thinking that physical activity and exercise is for ‘someone like me’. This is a significant decline from 57% in 2020 and when compared to 72% of non-disabled people believing activity is for them.

[1] https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandwellbeing/bulletins/disabilityenglandandwales/census2021

1.1 The Research Project

This was a farsighted commission from Public Health Stockton on Tees who wanted to ensure a more inclusive health needs assessment. Put simply, the study sought to understand from disabled people in Stockton, the barriers and opportunities they experienced in an effort to achieve and maintain a healthy weight. In particular, the research was interested in the following:

- Challenges and needs relating to healthy eating and physical activity.
- The lived experiences of disabled people in accessing services, support and activities and subsequently identifying gaps and related issues.
- The perceptions of healthy weight and the experiences of weight stigma.
- The knowledge, experience, attitudes, views, and influence of carers and those who support disabled people.

The reason behind the commission was a recognition that disabled people experience a specific set of issues in relation to maintaining and/or achieving a healthy weight. Subsequently, disabled people experience a range of health inequalities resulting in increased incidence of obesity and higher mortality rates. The context to the work is summarised well by Slevin, et al, 2014:

> *'Disabled people are more likely to report poorer general health and acquire a range of obesity-related secondary conditions. Although there are many physical activity and nutrition initiatives aimed at obesity prevention, little is known about whether these options are relevant and accessible for disabled people.' (Page 1).*

This results in many disabled people living insufficiently active lifestyles, being more likely to be inactive and overweight than the non-disabled peers (Smith et al, 2021; Grondhuis & Aman, 2014), as illustrated by the following figure.

Figure 1.0 Physical Activity in 2021: Disabled & Non-Disabled Populations

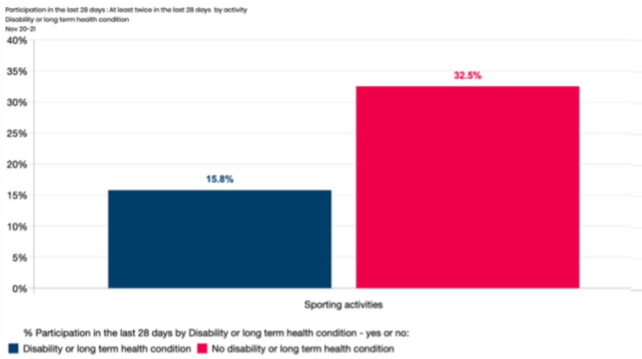
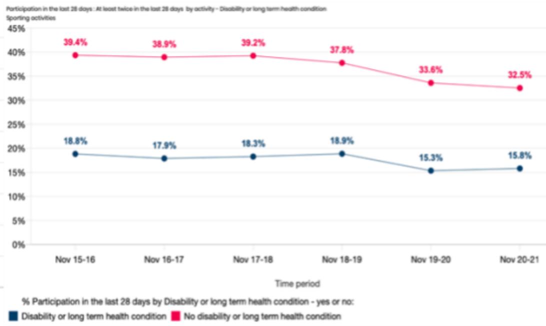


Figure 1.1 Activity Trends, 2015 To 2021: Disabled & Non-Disabled Populations



Source: Sports England, 2022

People with learning disabilities particularly experience worse health outcomes than non-disabled people, which has been made significantly worse by COVID-19. This includes mortality rates that are 18 years shorter for women and 14 years shorter for men, relative to the general population (Naidoo et al, 2022). At the beginning of the most recent NHS England (2019) report which examines the mortality issues in detail, stated:

> *'It is not fair that people with a learning disability die younger than other people.'*

This comment from a learning disabled professional immediately and succinctly located the issue as belonging to both elements of justice and health, which itself is reinforced by the fact that almost 40% of those deaths were avoidable. For example, in 2019, the deaths of 12 people were attributed to constipation (NHS England, 2019; Heslop et al, 2014). Donnie, a self advocate living in the North East, talking about the mortality review report, said:

> *"There is a difference about what should happen and what does happen … when we hear that three out of 10 people receive the best service, it means seven out of 10 people didn't receive the best service … our lives are not valued the same as yours."*

Figure 1.2 Donnie was asked what does it mean that people are dying younger?

The methodology for the research is presented in appendix one, which details how the research team consulted with disabled people from Stockton on Tees making available a range of options to engagement. This included questionnaires, focus groups, consultation events, phone calls, emails and even texts. The disabled people were accessed via both wider stakeholders in Stockton, such as Catalyst and from the networks and contacts of Difference North East. The research also engaged with frontline workers from relevant professional agencies, such as the local authority's Steps team. Throughout the report, text in italics represents verbatim comments from research participants.

1.2 Theoretical Framework

How we understand this thematic area, i.e., healthy weight and disability, depends upon which framework or lens we use to interpret the findings. As the subject matter concerns disabled people, the two dominant narratives surrounding the interpretation of disability are either the social or medical models, or a mixture of the two[2]. Whether we use the social model or medical model influence how we evaluate public health policy (Sherlaw et al, 2014).

[2] We understand that there are several other models which to understand disability, such as Marxist, social relational, and human rights models although here is not the place for an examination of their relative

Difference North East, as a voice and representation organisation, has adopted a flexible mixture which reflects a diverse regional grouping of disabled people, but it is strongly informed by an affirmation model which understands disability as an intrinsic part of an individual's character, which can be recognised and celebrated, and which holds the potential for flourishing. The social model of disability understands that rather than a result of their impairments, it is the social structure and processes that create the sociocultural, economic, and physical barriers which disabled people experience. The medical model sees the impairment or the condition as the disabling factor, something to be cured and if not, to be lived with and managed. Subsequently, medical modelists would stratify disability by condition/impairment type in a reductionist sense, e.g., visually impaired, neurological disease, acquired brain injury. Social modelists would say that an individual's condition/impairment is not important. Rather it is the barriers that apply to all disabled people, not one type to be compared with another, with medical professionals defining the conditions as mild or serious.

However, as Sherlaw et al (2014) points out disability is a spectrum of both limitation of activity and impact on social participation. Difference North East recognise that it is both society and impairments that disable people. For a wheelchair user, steps disable them, preventing an entry into somewhere they want to be. For a person with tremors, it is the shaky hands which disable them and make them spill the tea. Both barriers can be addressed however through a structural intervention, an action: with the solution of a level surface or the use of no spill cup. As agents of change, we can attempt to influence the human response to disability and remove those barriers or at least make them easier to overcome.

The medical model would understand that maintaining or achieving a healthy weight is most strongly influenced by diet and physical activity, calories in versus calories out. The social model of disability would understand that maintaining a healthy lifestyle is dependent on

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advantages and disadvantages. Smith & Bundon (2018) provide such a discussion in how the models are applied to sports disability studies as does Ginis et al (2021). For interested parties, there is a well-stocked free online library hosted by Leeds University, the Centre for Disability Studies: https://disability-studies.leeds.ac.uk/publications/

opportunity, choice, and control: the opportunity to engage in physical activity, the choice of activity or diet and to control when and how to engage. Similarly, the medical model would place most emphasis on calorific value and frequency of consumption, e.g., reduce sugary/fatty drinks and snacks, whereas the social model would place most emphasis on the relationship that exists between those individuals and the people that prepare the meals and their own knowledge, understanding and expectations of food. Often, it can be a combination of impairment related and access issues, as was highlighted by a disabled person from Stockton whom we talked to for this consultation:

> *I can only eat high carb foods, so I gain weight quickly. Added into that medication and steroids which cause weight gain. Then inactivity due to pain and poor mobility. Nearest accessible 'gym' is too far away.*

If we can identify and understand the barriers which prevent opportunity, choice, and control, we will be able to hopefully unblock the process and support disabled people in their healthy lifestyle efforts. As this is a piece of social research, we will place most emphasis on the social model to interpret the barriers which prevent or make it more difficult for disabled people to achieve and maintain a healthy lifestyle. Similarly, we are interested in solutions that have been proposed by disabled people in response to these barriers.

Existing research contributes to this research by providing direction and to a certain extent focus. Local and national research produce two important findings that help to contextualise the consultation: firstly, many disabled people have difficulty finding available physical activity resources which are accessible and/or appropriate (Ginis et al, 2021); secondly, health and well being messages are generally felt not to be inclusive by most disabled people (Smith et al, 2021).

2.0 Consultation Findings

Our consultation found that disabled people experience a number of barriers which can prevent them achieving successful health and well-being (diet and fitness) outcomes. Some of these relate to an individual's impairment, for example energy levels, but many relate to external structural barriers. For example, respondents reported:

> *"If a disabled person wants to get fit, you need the energy to get out of the house, to enable you to deal with all of the shit that you have to deal with, to get to where you want to go … and to be honest I have that energy less and less these days."*

> *"As a paraplegic and a full time wheelchair user it is difficult to increase physical activity because there's nothing really suitable or convenient for me to do – like I'd like to try badminton but don't know if I could."*

The barriers to participation are engrained and can start from a young age for disabled children (Dixon et al, 2021). As a rule, most disabled students report feeling excluded from physical education in school because of poorly trained teachers and disablist attitudes, that do not equate disability with health.

2.1 Social Barriers

There were several reports during our consultation of disabled people feeling excluded from routine services available in the community. There were a number of contributing factors to this, but many could be described as social and cultural in nature cumulatively discouraging disabled people from engaging in sport and/or healthy lifestyles.

This research confirms a widely held belief that for many people, gyms and sports venues can be intimidating places. However, it was also felt that disabled people were more likely to experience psychological issues like ‘gymphobia’[3] (fear of exercising in front of people) or ‘gymtimidation’, embarrassment caused by not being able to operate equipment (Shirlaw, 2014) than non-disabled people when entering such places as a result of feeling they may receive a negative social response, such as being laughed at or refused/discouraged entry (we received reports from disabled people that they had been refused entry to certain activities, groups and venues as a result that was reported as safeguarding and health and safety issues). Comments from participants included:

> *“Body confidence is huge for most disabled people, there’s been fat shaming social media posts and disabled people see that, there's no way they're going to expose their bodies.”*

> *“It’s just a bit embarrassing, walking in and have everybody look at you.”*

> *“When you go out [as a disabled person] it’s generally all eyes on me, that can stop you going out, sometimes it’s okay …. depends how you’re feeling – if you’re feeling strong enough for it, then it’s fine. But if you don’t then, then you just don’t go.”*

> *“I’m not sure I would go [to a sports venue] because I would be too embarrassed, of the looks. Like I like swimming, but I could not use those poolside hoists, really embarrassing.”*

These feelings are increased and amplified through the experience of what has become known as micro aggressions. There are many parallels between disablist microaggressions, and everyday sexism highlighted by the #MeToo movement. These consist of the numerous comments, glances and unkind/unhelpful expressions from non-disabled people, which individually may be considered not serious enough or simply ‘game play’, but cumulatively they have consequences on an individual’s mental health and on their social participation. As

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[3] This is propagated and distributed over social media, for example, people taking videos of over or underweight people in the gym or anyone who does not meet the expected image of a gym user and posting on the social media timelines or personal pages.

a result, disabled people tend to internalise these experiences, keeping them hidden and unseen which can act as much as a disincentive as physical barriers. As one person reported:

> *"You can deal with them when you're on top of your game but if you're feeling a little tired or whatever, they can be really hurtful and can stop you going out."*

And

> *"I've heard it all … from ignorant people saying things like I have a disabled niece, so I know what it's like, you're one of those Paralympians aren't you? Are you alright to go out on your own? I know you like to be so independent. You are so brave."*

These feelings appeared to be mitigated if people participated in disability sport as it was felt they shared common characteristics. For example, respondents said:

> *"You don't feel embarrassed coming to a place where everyone is like you."*

And

> *"We all do bowling together, carers and sighted and non-sighted, we're all comfortable around each other."*

This agrees with other Teesside Research (Dixon at al, 2021) which found that many club settings only fully include disabled people if they can participate in a sport separately to non-disabled people. They also found disabled people can sometimes be forced to adapt to how the club provides a sport, rather than the club adapting the sport to best meet that person's needs.

During our consultation, we received reports from disabled people being sent by their GP to attend physical activity courses, e.g., because of a high BMI or high blood pressure, but when they turned up at the classes, it was explained/ became clear that the club was not really set up for disabled people. For example, one person explained:

> *"When I got to there the instructor told me that they did not have the facilities for people with bad backs or disabilities and he said it in front of the whole class who were not disabled. It was embarrassing."*

Similarly, there were reports of classes being socially inappropriate for some disabled people. For example, one young disabled person from Stockton reported:

> *"Things that I could participate in to help remain fit whilst acknowledging my fatigue and pain, such as chair based exercise, are typically only provided during the day and aimed at over 60s not 30 year olds."*

Our consultation also found that many disabled people often felt that sport or healthy lifestyles were not for them, reporting that general media and community resources did not appeal to disabled people. As one respondent reported:

> *"You just don't see yourself in the picture, you're nowhere, at least on the front pages anyway and when you are in a picture it's to make you feel pity or to get you to give money to a good cause, charity like."*

Furthermore, disabled people in Stockton felt that many sports or physical activities would not be possible because of conditions or impairments. For example, an individual with spinal damage does not take part in a Zumba class as others are commonly able to. Many people are affected by fatigue and describe a 'boom and bust' experience where after engaging in physical activity they are physically exhausted for days after. There are others who said they required specific conditions for different activities, which although could be made available, they are often not. For example, one disabled person said:

> *"The local swimming pool is too cold for me, and I need a heated pool if not my body goes into spasm."*

There were expressions of wishing to increase physical activity because of weight gain but being unable to because all the options available to them were not suitable for their condition. For example, one person reported:

> *"I can't do things that like I used to, like spinning because of my accident, but could do some very slow exercise but there's no classes for that and it is hard to get yourself motivated."*

These were compounded by feelings of embarrassment, self consciousness, and fear of experiencing questions and possible conflict situations. These contribute to non-participation, further reinforcing that the sport/health is not for them. Similarly, individuals who have been disabled since childhood, have experienced general exclusion from sporting activities in school and so as adults, have never felt that sport/health is for them.

On this topic of feeling engaged, we note that publicity and communications about health and fitness rarely picture disabled people, which makes positive reinforcement difficult. As one professional respondent said:

> *"How can you want something, like living a healthy lifestyle, when in your head it's not something that people like you can achieve … marketing generally makes people want things and the adverts and publicity reflects the type of people they want to be interested … if you can't see yourself in the picture, then you are not going to want it."*

They continued:

> *In Stockton, you have got to go and find the pictures of disabled people on the [name of provider] website … there are good things on there like the access guides if you dig a bit deeper.*

The following two figures display marketing material outside sporting venues in Stockton and online.

Figure 2.0 Publicity Outside of a Local Leisure Centre

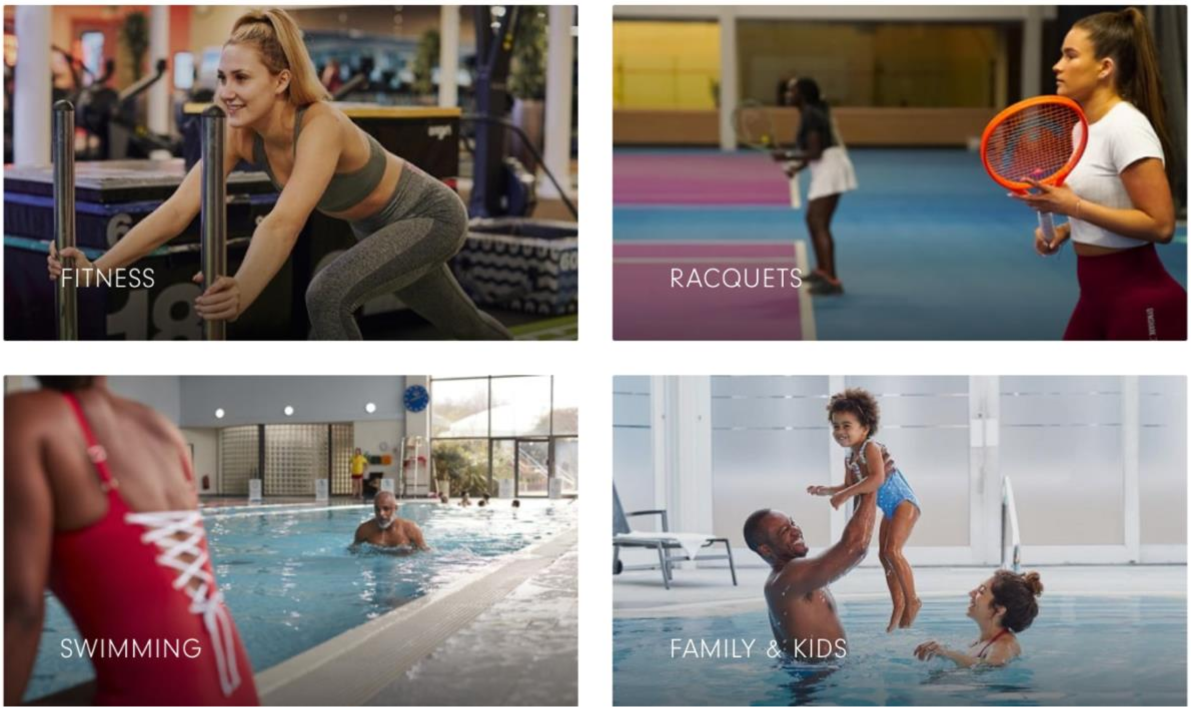
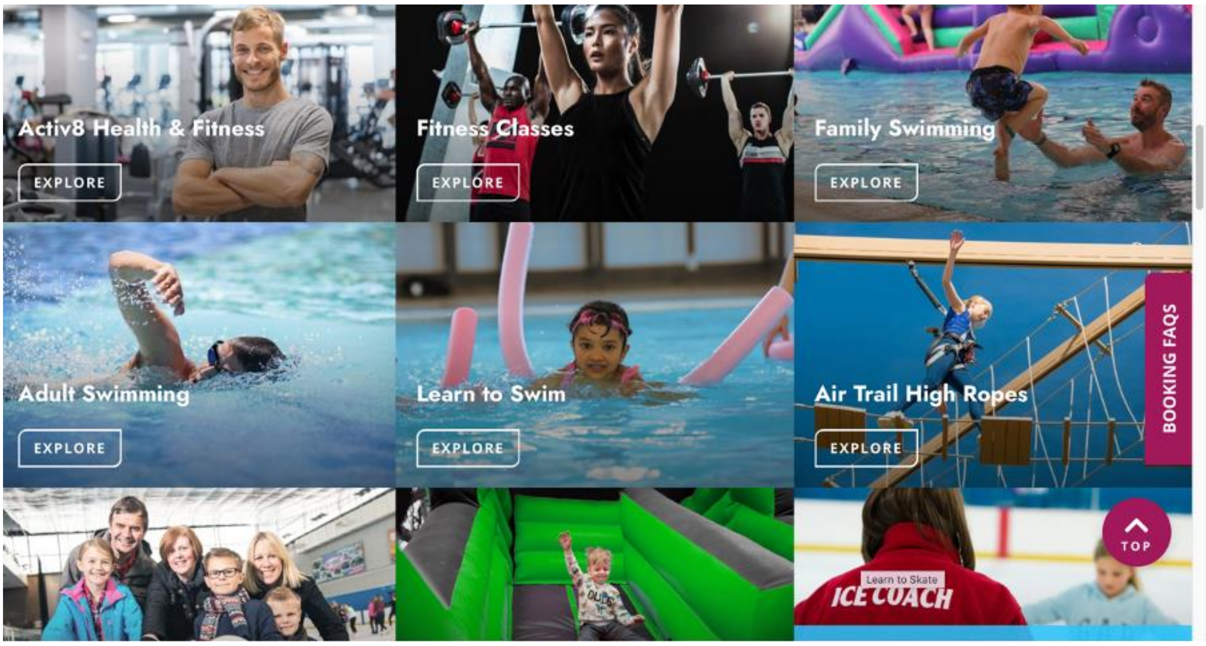


Figure 2.1 Publicity on a Local Sports Provider Webpage



These feelings of exclusion can be contrasted to the reports of participants at local targeted sports activity groups (multi sports and football and visually impaired bowls). Disabled people at these popular sessions reported involvement, friendliness, enjoyment, good venues and staff and an overall positive experience. Their involvement in this was brokered through a local authority community support worker, supporting and assisting a range of vulnerable groups, including disabled people. This team run specialist sessions with an invited group of disabled people providing access for them but nobody else.

This leads into the issue of barriers created by disablist attitudes and biases, unconscious or otherwise, which are experienced by disabled people all over the country every day. This is no different in Stockton on Tees where there were local reports of activity groups being less than enthusiastic with some refusing to take on disabled members without support, despite capable individuals [note: this was reported to non-disabled professionals, who are often given information that would otherwise not be available/known to disabled people]. Support workers found it difficult to find activities in the community from where they could 'bridge' or transition, the disabled people who were involved in their specialist/targeted support and activities. This is reported by young disabled people and carers of children that there are certain groups who refused to take disabled members because of reasons reported as safeguarding and health and safety.

2.2 Physical Barriers

There were a series of physical barriers raised by disabled people in Stockton on Tees, including: blocked entrances; cobbles and generally uneven surfaces; steps; no drop kerb; narrow entrances; noisy/bright environments; lifts which are often out of order; lack of toilets or changing facilities, most of the countryside. These physical barriers can exclude people from engaging in activities, either preventing them entry or exit. For example, one respondent reported:

> *"There is a multi use game area near me, I cannot visit as there are no public toilets nearby."*

Travelling to venues or places is also reported to often be inaccessible, with travel services not having ramps, inability to get Taxis, buses being too full or too nosy. A disabled man who used a wheelchair from Stockton said:

> *"I can't tell you how many times I have been out with people where I have had to turn back, either on my own, or with the people I was with, because of and my disability, lifts constantly out of order, gaps you need to step over, but no ramps."*

During the consultation the lifts at the front entrance of a key community health and sports centre in Thornaby were out of order and had been for one month. The lifts which gave people access at the front of the sports centre on the High Street and brought people near to the reception. The alternative entrance took people to the back of the building, was dimly lit, poorly signed and very steep; inaccessible for many disabled people. Following figure presents the signage.

Figure 2.2 Community Signage for Entrance & Exit [which had been open Sep/Oct 2022]

It was reported during the consultation that an absence of assistive technology prevented some disabled people engaging in sport and activity. For example, a disabled woman felt unable to engage in an activity because of an absence of specialised equipment, and this was reinforced by a social barrier.

> *"I am bowel incontinent. Unless I spend over £70 for a specialist swimsuit then I can't go swimming. I world also be embarrassed to wear more traditional continence swimwear in public swimming sessions."*

There was some mention of a lack of knowledge or access to the correct equipment to engage in sports, for example, wheelchair badminton.

2.3 Cost

When we discussed barriers that presented themselves to maintaining or working towards a healthy diet, a commonly felt issue related to cost and the affordability of healthier food. This raises the issue of the economic position of disabled people in Stockton, which has 13 lower super output areas, which are amongst the most deprived 10% in England (Carling, 2022). This equates to approximately 26,000 people living in those areas, with a minimum of 31% being disabled (Activity Alliance, 2022). Disabled people are twice as likely to live in socio economic disadvantage than non-disabled people and we know that unemployed disabled people are much more likely to be inactive than disabled people who are employed (40% versus 30%) (Activity Alliance, 2022). Disabled people are often on fixed incomes and are especially vulnerable to inflationary price changes and this was raised during the research by respondents. For example, one respondent reported:

> *"I altered my diet, but it was unaffordable and what I could afford it didn't make a difference."*

There were those in the consultation that keenly felt the current economic crisis, with experiences illustrated by the following respondent:

> *"With all the price rises, you can buy less and do less, just sit in the house and feel cold."*

We already know disabled people often require additional electricity and gas because of their condition and because of many being on fixed incomes, this disproportionately impacts upon their household income. A shortage of finance will impact upon an individual's efforts at staying fit and healthy, e.g., as reported in this consultation in relation to the cost of food, and energy required for cooking.

2.4 Diet & Food Preparation

It is clearly unknowable, the prevalence of home cooking amongst disabled people, i.e., how many disabled people cook for themselves. During our research, we found a proportion of disabled people cooked for themselves commonly with another, again commonly someone non-disabled, such as a partner, parent, or carer. With those individuals who prepared food with another, they expressed an experience of control and choice over the food selection and preparation, which varied along standard food choices. For example, one young adult respondent referenced participating in cooking with his mother:

> *"My mam helps me cook … I can make spaghetti Bolognese."*

Another said:

> *"I like to make soup. "*

There were others who relied on ready meals because of their lack of mobility and strength caused by their impairments or chronic condition. For example, one respondent reported:

> *"I can't cut up anything anymore and rely on ready meals, which I know is not the healthiest, but I don't have an option."*

There were others who were unable (either through losing or having never had the ability) to prepare food for themselves and who relied upon others, either a family member, partner, carer, or staff at a residential unit. When we asked participants about levels of control and choice in these situations, there was a variety of responses including some who negotiated the content of the meals with the provider of the food and some who had no control and/or choice. This is bluntly illustrated by one disabled person:

> *"I get what I'm given and I'm happy for that."*

We also encountered disabled people who, as a result of the impairment or condition, have attempted to gain weight through changing their diet. These were not always successful, and information and any specialist input were not unavailable. People we consulted with made the link between healthy weight, eating disorders or underlying mental health problems. One parent of a disabled child said:

> *"Why is everything about losing weight? Why aren't we talking about a healthy weight? Maybe we should also see the issues to health associated with being underweight and seeking to support to minimise the likelihood of an eating disorder."*

Household incomes and the ability to afford transport was raised as an issue which influenced people's purchasing habits. It was felt that fresh fruit and vegetables equate to healthy food but unless you have a car you cannot drive to the supermarket to buy them. As one disabled person commented:

> *The corner shop doesn't sell vegetables which is where lots of people with disabilities go shopping, if they don't have the energy or access to a car."*

2.5 The Experience of Parents/Carers/Allies

The parents, carers and allies of disabled people who took part in our consultation reported thinking about the healthy weight of the people that they parented/cared for either often (n=84%[4]) or sometimes (n=16%). As illustrated by one parent/carer:

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[4] Where n = number.

"I think about the weight of my son a lot."

In addition to this, 100% of respondents said they had attempted to alter the weight of the person they looked after by changing their diet. Respondents reported:

> *"My son is overweight, and I worry about his health, he never feels full. So I have to monitor what he eats and what I buy. [The] family often buy him sweets and crisps."*

Another said:

> *"My son has Downs Syndrome and has gained weight since lockdown. I have tried to offer healthier snacks and meals, but this can be difficult. He snacks on chocolates and cakes all the time."*

In addition, respondents said they had attempted to alter the weight of the person they looked after by increasing physical activity. Several respondents reported difficulties trying to balance impairments with fitness, for example:

> *"We try to balance the eating, but my son has had physical difficulties with feet hips and knees which has caused pain and made exercise difficult."*

Another said:

> *"I try to get my son to be as active as possible to keep his weight under control. However, this is sometimes difficult as he is starting to show signs of scoliosis, so we must be careful. We have always tried to keep him active."*

Our consultation found that number of parent/carer respondents reported feeling disempowered through a lack of knowledge and in need of support and direction. Some said that they felt hamstrung as the critical thresholds are not quite met for intervention, but they develop into critical thresholds from being preventable. For example, one parent reported:

"I've tried to access support for my daughter due to her rapidly losing weight and becoming increasingly rigid about portion size and removing food groups from her diet. Unfortunately, no support was available from the Growing Well, Growing Healthy service as she was not overweight."

Another had the following concerns:

"[We need] free activity sessions, nutritional fun courses as he's likely to listen better if it comes from someone else. What would help most is getting support now as he has just had a growth spurt and slimmed down as a result, but we now can't access any services until his BMI goes up - which it will do as it has done this every occasion before. He finds it almost impossible to lose weight so it will go back on and stay on - at which time we can access support which will be useless as it won't work!"

There were requests for different type of specialist support from the level of information provided to a level of service or intervention.

Parent/carers also felt that public sports venues should be made more accessible. One person said:

"I think more gyms or classes to be disability friendly."

Another said:

"More inclusive fitness programs."

Another respondent said:

"[We need] Support and strategies that are specific to [son's] disabilities and him as a person. Someone listening to our concerns … trust me we have tried lots of things and sometimes it just isn't that simple."

Finally, a group of parents/carers recommended the following:

> *"It needs to be a holistic approach and about wellbeing and health not weight focused... Education and support for the whole family and no punishments or strict plans. Services need to have flexible criteria and listen to concerns."*

> *"Parents don't get listened to when they flag up a weight issue. Services go by narrow criteria, and this isn't adapted to disabled persons."*

2.6 Access Thresholds

It would appear from the consultation that there are access thresholds which affect individuals who are considering engaging in any activities outside of the home, including sport, fitness, and healthy eating. These thresholds are felt differently by non-disabled people, where an intention is often followed by an action using available resources and services, in a seemingly straightforward formula. For example, John wants to go swimming and then goes to the swimming pool to swim. However, if there are barriers in the way of being able to access those available resources or services, then participation may become less likely. Non-disabled people can experience a variety of barriers such as: travel options and distance to venue; times; cost; and childcare. Participation will depend upon the available resources of the individual (e.g., money or transport) and their own capabilities (such as their research abilities, independence, persistence, and emotional fortitude) to access the resources they need. There will also be scales of ease of access, i.e., some things are easier to access than others, which will increase until they become barriers, e.g., somethings are too far away, or too expensive, or require too much equipment: see following figure.

Figure 2.2 Access Thresholds

Low: Easy to access Medium High: Hard to access

Disabled people experience these barriers and a raft of others, including:

1. Insufficient energy levels/psychological fortitude/resilience to negotiate community resources/services in an ablest society (the constant requirement to address questions and comments from members of the public about, concerning and focusing upon the individual's disability or situation, including disabling comments).
2. Inaccessible environments such as heavy doors, uneven paths and surfaces, unsuitable parking, inaccessible toilets. [disabled people negotiate such environments every day, resulting in dispensing considerable effort and requiring either assistance from another person or sufficient energy reserves].
3. Transport systems which may not be accessible, some buses may be full (generally of prams and pushchairs but sometimes another wheelchair user) for wheelchair users, requiring them to wait for the buses to come, bus stops may not be near to people's houses and require travelling to.
4. Amplified existing barriers, for example disabled people may experience increased price pressures and prohibitive costs as they already may have to negotiate higher cost of living prices often on fixed incomes. The experience of weight/disabled shaming, 'gymphobia' and 'gymtimidiation' is likely to be felt much more keenly than the non-disabled population.
5. Absent or insufficient assistive technology, incorporating a wide range of accessible sporting equipment, clothing, hoists, and other assistive technologies

Along with these barriers the consequences of an individual's impairment or condition, can often make exercise too much to consider:

> *"Medication plays a HUGE role in being a consistent healthy weight, it can cause rapid weight gain or fluctuations, so really needs to be taken into consideration. Traditional exercise can be really daunting."*

As a thought experiment we have condensed the relative experiences into a straightforward equation which can help us understand the likelihood of successful outcomes.

Participation and engagement equation: disabled and non-disabled

ND (non-disabled) + I (intention) + R (resources/services) = PE (participation and engagement)

D (disabled) + I (intention) + R (resources/services) + B (Barriers) = NPE (No participation or engagement)

How to remove or neutralise the barriers in the previous equation.

SB (social barriers) – (T (training) + AR (awareness raising) + Pu (publicity) + IP (inclusive practices, policies & strategies) = 0

PB (Physical barriers) – in (investment) + C (consultation) plus + BR (building regulations) + T (training) + AR (awareness raising) + Pu (publicity) + IP (inclusive practices, policies & strategies) = 0

It is progressively being understood that approaches to improving physical functioning are not enough to increase physical activity of disabled people (Glinis et al, 2021). As Sherlaw et al (2014) points out, public health analyses suggest that a population and environmental approach to enablement is more likely to impact positively on disabled people than person-centred action.

2.7 Addressing Barriers & Biases

Biases tend to be most effectively dismantled through familiarity, visibility, voice, and representation; the more time which can be spent together, between disabled and non-disabled people, the better. Improving social participation can be addressed and promoted using many different efforts and angles, from introducing inclusive workplace practices, providing awareness training, and creating inclusive publicity.

Systemic barriers must be removed, and investments made in areas such as active urban design, sport, and recreation to provide more and better physical activity opportunities, regardless of a person's functioning (Glinis et al, 2021). Time and time again from research with disabled people come the calls to address the social and structural barriers that prevent participation.

For example, in a 10 year review of the impact of the 2012 Paralympic games, they concluded:

> *'Systemic and social constraints included provision of sport participation, economic factors, organisations offering unsuitable sport participation opportunities, and access to sport participation opportunities (Brown, 2019, page 3).'*

Indeed, the London Paralympics had little impact on most disabled people's involvement in sport and physical activity. Many disabled people felt that it contributed to a distorted view of disabled people, creating additional barriers of expectation. Portrayals of disabled people as superheroes/superhuman is a strong narrative which exists in society which is used by many sections of society and the media to (unconsciously) categorise disabled people (Ginis et al, 2021).

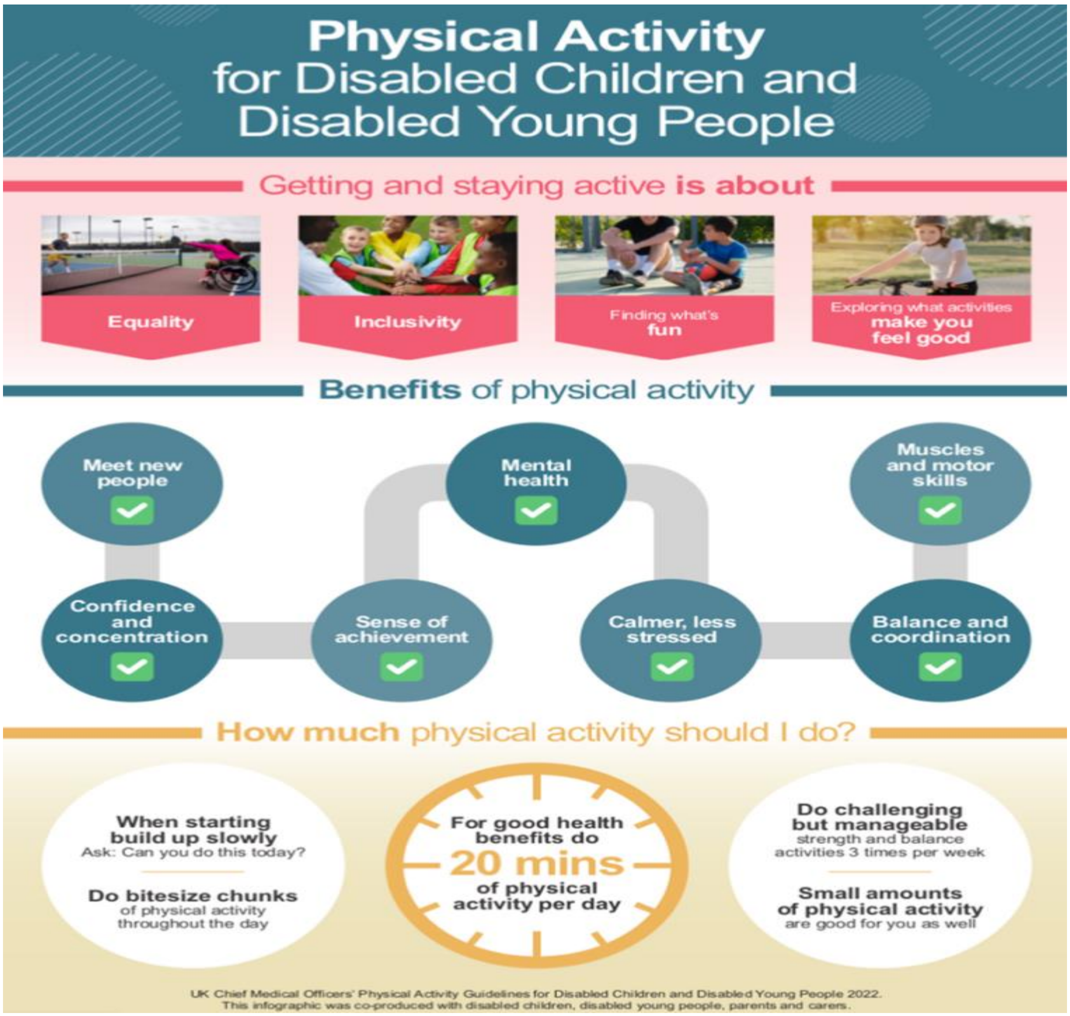
Positive portrayals have been used in campaigns by disability rights organisations recently, such as the Mencap 'Here I Am' campaign showing photos of people with learning difficulties engaged in normal activities, putting disabled people in the frame. Research shows that peer role models, rather than Paralympians, are more likely to inspire physical activity (Brown, 2019).

Figure 2.3 Here I Am Campaign Images

It may be more difficult to engage disabled people in health and sport because of disabled people not feeling part of the picture. As a result of a general historical exclusion of disabled people in sport (except for elite Paralympians), many disabled people do not look/have no contact or information about the services on offer. This means that targeted services if they are to be delivered, require extra marketing, communications, and engagement to reach out and contact those disabled people who may be interested in disability sport or other healthy lifestyle projects. A more sustainable solution is clearly making universal services accessible for disabled people, which implies system change and is a longer term project.

The involvement of disabled people is a pre-requisite for developmental work, which is necessary to improve inclusivity and access. The following infographic is an example of co-produced marketing and communication material. In this example, children and young people were asked to design advertising which was attractive and engaging to other disabled young people, opposed to the routine strap lines of removing high calorie snacks between meals, which only serve to turn young people off.

Figure 2.4 Example of Coproduced Marketing/Publicity Material



The research of Smith (2022) and others, reported the potential in structural change involving public health agencies, beginning with awareness raising and training of frontline service delivery professionals. From this consultation we would agree that first contact is an important factor in the decision of whether to return to the venue or activity.

3.0 Conclusion

We have consulted with disabled people across Stockton on Tees, and we have considered relevant local, regional, and national research. As such, we conclude that there is a strong link between weight and disability, in that having a disability can impact negatively on an individual's weight and furthermore their ability to engage in physical activity. We found that disabled people living in Stockton routinely experience barriers which prevent them from engaging in healthy lifestyle choices. Where services are bespoke and targeted, such as the work of the life coaches and the local authority's multisport scheme, the experiences of disabled people within the company of their peers were excellent. However, this contrasts with experiences of more universal services, where there appears be a reluctance on the part of some standard groups or clubs in the community to allow disabled people to participate in the activities they deliver.

The relationship between diet and healthy weight is complicated in the case of disabled people, as a proportion of the population is not in control of their own diet, either involved in their own food preparation or making decisions about food. There are also those disabled people who are limited to eating ready meals as a result of being unable to prepare food themselves and not having others to prepare it for them. Purchased ready-made processed meals are generally considered to be high in fat, salt and sugar, therefore contributing unhealthy weight. Added to this are the cost of living price increases, which are reported to put healthy food out of reach of many disabled people, and we can see food choices become even more limited for disabled people. These factors constrain the ability of disabled people to exercise high levels of control over the dietary intake.

The parents of children with disabilities raised constant and frequent concerns about maintaining a healthy weight and an active lifestyle. Parents and carers reported spending considerable thinking time about diet and activity and were often at a loss for things to do or options to try. There was a clear service need from these parents who are actively worrying about the health and well-being of their children. In some cases there seemed to be a desperation in their need for support and direction from health and social care agencies.

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Appendix 1: Research Methodology

We have included a presentation of the methodology as an appendix rather than the main body of the report. We do this because it may not be of interest or relevance to certain readers. The research was conducted over the summer of 2022 by a partnership of a social research and a disability rights organisation. Both organisations are disabled person led organisations (DPOs), and as such the organisation can be considered as user led. Requesting a user led group to consult with their members and others in the same groups, represents a strongly participatory approach ensuring a more equal power balance, where subjects of the research are placed at its centre. The social research organisation, Barefoot Research and Evaluation, has been conducting consultations of this nature for 15 years and they specialise in participatory research methods. Difference North East is a relatively new (2017) disability rights voice and representation charity (or collective self advocacy), working for disabled people across the North East and campaigning for equality of access and an end to discrimination.

The research adopted a broad grounded theoretical approach (Glaser & Strauss, 1967) which is well suited to social research topics of this nature, where little is known or expected at the beginning of the research. Grounded theory allows the findings (and the analysis and conclusions) to be led by the data and can incorporate appropriate theoretical frameworks, as we have done here with a social and medical model mix.

Grounded Theory was developed by two American sociologists in the 1960s, called Glaser and Strauss[5]. It is an approach which is well-suited to situations where little is already known, and the stakeholders and situations (or social context) appear complex and possibly confusing. An assumption of Grounded Theory is that there is a logic behind people's actions, even though it may not be first apparent to the outsider[6]. Also, it understands that people with common circumstances, share common characteristics, behaviours, and patterns, which may not always be clearly understood by themselves or others[7]. Grounded Theory means being led by

[5] Glaser & Strauss (1967).
[6] McCann & Clark (2003).
[7] Ibid (2003).

the data; the theory is 'grounded' in what is found. Themes and understandings are derived from the stories constructed by participants to explain and make sense of their lives[8]. Key to the approach is remaining open-minded, having no preconceived ideas and being sensitive to the concerns/problems of the target group[9]. Grounded Theory allows for the data to be matched with relevant theoretical frameworks as we have done here with the social, medical and affirmation models of disability. Grounded Theory is also well suited to participatory research and development, co-production and other situations which require a bottom-up approach.

The principal methodological preoccupation was to make engagement as straightforward and accessible as possible. This resulted in a number of choices for disabled people to choose from. The research team consulted with disabled people from Stockton on Tees making available a range of options to engagement (see following table).

Table A1. Consultation Techniques, Numbers & detail/description

Research Method	No. Of Participants	Detail/Description
Questionnaire: disabled people [online & printed]	23	Distributed via networks of Difference North East, local voluntary sector, sport, health and parent/carer groups.
Questionnaire: parents, carers & allies of disabled people [online & printed]	14	Accessed via Special Needs Activities with Parent Support and the parent carer forum.
Focus groups (disabled people) held at:	35	Focus groups held at Queens Campus Sports Hall with Shape the Play participants (n=12); Stockton Pavilion at the visually impaired bowls club (n=3); Primary Care Network service user/self advocacy group (n=4); online x 2 (n=16))
Focus groups (profs)	14	Online with Steps and the Social Prescribing Team

[8] Corbin & Strauss (2008).

[9] Vishram (2012).

Telephone interviews disabled people	9	Some of these indicated willingness to further engage in the study on the online questionnaires, and others contacted Difference through the call for research participants.
Telephone interviews non disabled people	5	From contacts provided by Public Health Stockton.
Email/texts	33	People indicated willingness to further engage in the study on the online questionnaires, and others contacted Difference through the call for research participants.
Total	107	

The research participants were accessed via both wider stakeholders in Stockton, such as Catalyst, Primary Care Network and Tees Active and from the networks and contacts of Difference North East. The research also engaged with frontline workers from relevant professional agencies, such as Steps and the Social Prescribing Team (see previous table). Research participants who took part in the online focus groups received a £20 Amazon voucher as a thank you for taking part.

Participant information and consent and confidentiality sheets were developed and shared with research participants and other stakeholders. The latter was to enable professionals to explain to their clients as necessary about the study, and information, including information of an accessible version that was placed on the website of Difference North East. We also developed a questionnaire for disabled people themselves and for their parents, carers, or allies. These can be found by following these lines:

https://differencenortheast.org.uk/campaigns/disability-and-weight/

Easy Read Healthy Weight in Stockton (See appendix two)

Disability & Weight Questions for Disabled People

Disability & Weight Questions for Parents, Carers or Allies of Disabled People

The data produced from these engagement and consultation approaches were documented into a narrative format and were thematically analysed, in line with grounded theory (Glaser & Strauss, 1967). This sorted the data into manageable chunks which could be arranged into categories and codes. The research report is arranged by theme as they were raised by research participants.

Although the nature of the study was a detailed qualitative exercise, it is helpful to present monitoring information. Where groups were involved, and where it was not appropriate to ask further details during the consultation, for example, if people were playing sport, we have approximated ages and ethnicities. Except for the professionals interviewed for the study (see previous table), all research participants were disabled people and their parents/carers or allies who worked or lived in Stockton-on-Tees.

Figure A1 Gender of Research Participants

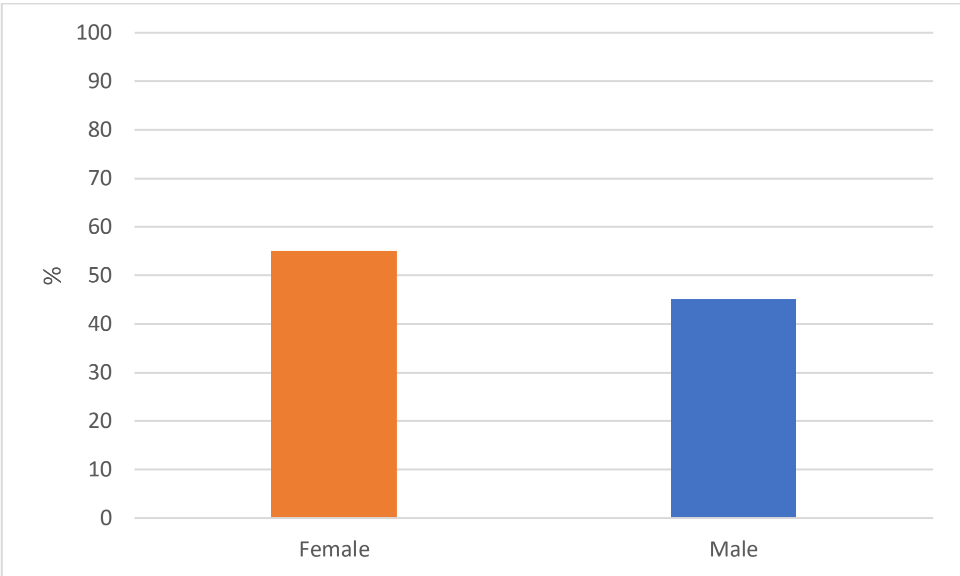


Figure A2 Ethnicity of Research Participants

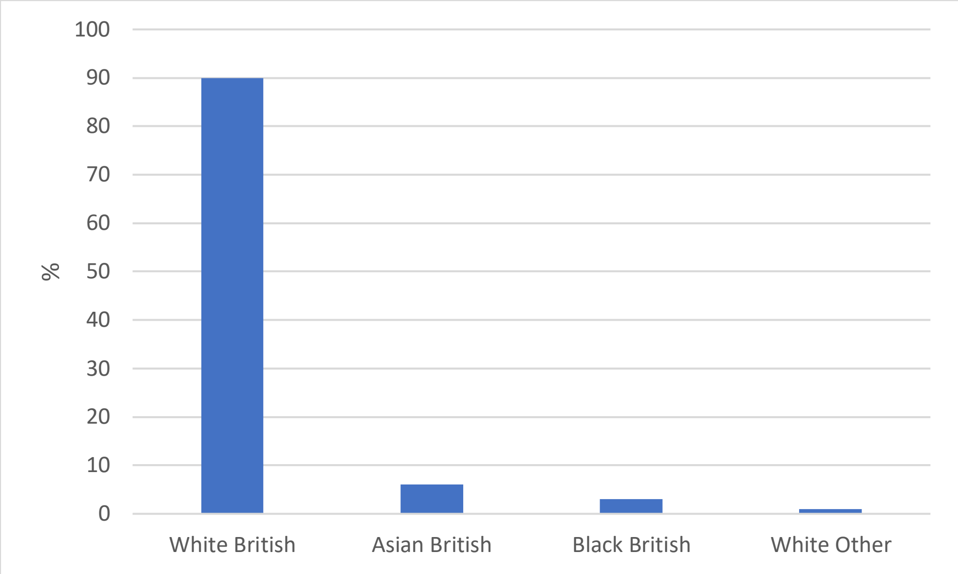
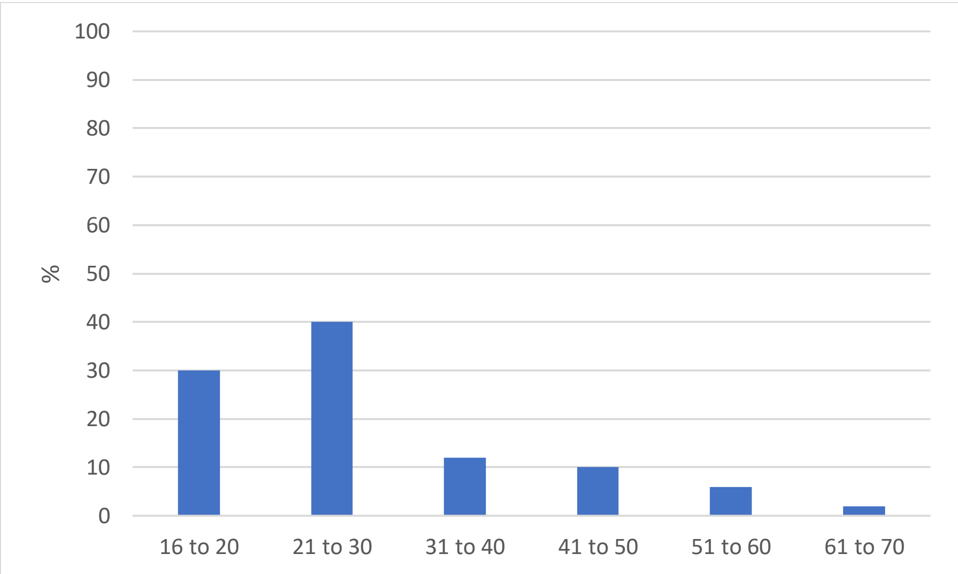


Figure A3 Ages of Research Participants



Peer Review/Face Validity

At the end of the research period, we sent the report to a selection of disabled people who had been involved in the research. This is known as face validity, i.e. checking the robustness and application of the methodology, as well acting as a verification of the findings. All four individuals who reviewed the text were positive and supportive of the results of the study. For example, one peer reviewer said the following:

I've had a good read of the report and I think it accurately represents the different views of disabled people in the area. It was good to see it covered the transport, economic and social barriers that often happen before you even get to take part in physical activity. This is equally important as the activities themselves. I'm keen to see what positive changes and actions may come out of this in the future.

Appendix 2: Accessible Information Sheet

Key information about research into healthy weight and disabled people.

People in Stockton whose jobs is to look after our health, want to know how people manage to keep in shape.

Being healthy means eating well and staying active.

If you have trouble with these things, they want to know so they can help.

If you are disabled and living in Stockton, we would like to ask questions like:

- What food do you like to eat?
- What food don't you like?
- Do you like to eat healthy?
- Can you do exercise if you like?

If you can answer the questions, we would love to hear from you. We will make sure you can take part in a way that works for you. We will make all information accessible.

If you want to take part in this research, click here to fill in a short form and Christopher will contact you.

This is Christopher, a researcher. He will be in touch to let you know what to do.

The views expressed in this report are those of Dr Christopher Hartworth of Barefoot Research and Evaluation and may not necessarily be those of Public Health Stockton on Tees. He can be contacted via:

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