



Innovations
in Dementia



for brian



CITY
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Research report

Experiences of people with dementia

All Ability Cycling Clubs

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Acknowledgements

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The Research Institute for Disabled Consumers

The Research Institute for Disabled Consumers (RiDC) is the leading expert in inclusive research involving disabled and older consumers. We are an independent, national charity with over 50 years of experience in consumer research and insight in this specialist area. We are run by, and for, people with a personal experience of disability.

Innovations in Dementia

Innovations in Dementia (ID) is a social enterprise that works with people with dementia, as partners and volunteers, to develop and test ideas that will enhance the lives of people with dementia. ID facilitates DEEP (Dementia Engagement and Empowerment Project), which brings together over 80 local groups of people with dementia across the UK

For Brian

For Brian aims to empower people living with dementia and their families to design support that meets their individual needs, providing agency in challenging circumstances. A non-for-profit community interest company in Hammersmith and Fulham Borough, For Brian supports individuals with dementia to access exciting activities in the community such as yoga and cycling.

Bikeworks

Bikeworks is a community-evolved social enterprise that provides free-to-access inclusive community cycling initiatives through their All-Ability Hubs, enabling over 3,000 people with disabilities and carers across London to access specialist cycles and a skilled team of instructors.

As an inclusive-cycling organisation their role is to prioritise the engagement of the most excluded, and working together with partners such as For Brian to achieve this. They understand the longer-term impact caused by the pandemic on communities and aim to combat its effect on exacerbating mental ill-health and widening pre-existing inequalities.

Bikeworks also offers a 'side-by-side' Cycle taxi –free of charge to tackle loneliness and isolation by allowing up to three passengers to enjoy gentle exercise and fresh air while carrying out journeys in their neighbourhood.

Introduction

DEEP groups in London all share a desire to change their communities to make them better for people with dementia. In addition to offering support to people with dementia and their carers, many DEEP groups have experience with conducting audits of venues and services to raise awareness of access needs of people with dementia. However, during a meeting with DEEP group leads from across the UK, it became evident that individual groups can struggle to scale their insights.

This partnership project between RiDC, ID and local DEEP groups offers an opportunity to bring together and share insights from local groups in London and document best practices. In doing so, our aim is to contribute to the wide distribution of knowledge and awareness about the needs of people with dementia and the removal of barriers that prevent their meaningful participation in society.

It is important to note that this participatory research was undertaken in a spirit of collaboration with Bikeworks and was not intended to take the role of an inspection. The project aimed to empower and give a voice to members of For Brian in exploring the suitability of various cycling solutions for people with dementia, and supporting Bikeworks in identifying further improvements as well as to celebrate successes.

The research question that guided this project was as follows:

How might cycling initiatives be made more accessible for people with dementia?

Background

For Brian is run by Clare Morris who is well networked in the Hammersmith and Fulham Borough and provides one-to-one support for people with dementia as well as organises activities in the community.

RiDC contacted Clare to learn more about potential challenges that people with dementia experience in undertaking activities in the city of London and within their local communities. Clare noticed that for the people she works with, going out and being active is very important. However, transport can often be a key barrier.

Clare made us aware of a local initiative in the Borough run by Bikeworks, All Ability Cycling Clubs, that enables people with different disabilities to come together and cycle in a local park on a regular basis. We decided to explore how accessible such initiatives are for people with dementia, and how they may contribute to their ability to be active and mobile within their communities.

RiDC had already explored the accessibility of health, wellbeing and arts venues in previous projects and experienced first hand that organising transport from and to such venues could be a key barrier in enabling people with dementia to participate. The idea of a sports venue as a flexible and agile hub that could be taken to a local park on a Friday afternoon resonated.

Following our meeting, Clare reached out to members of For Brian and invited them to join a session at one of their All Ability Cycling Clubs in Wormwood Scrubs Park (see map on next page). Two of the four participants who were scheduled to attend on the day were not able to attend.

When attempting to recruit participants, it became clear that support workers are hesitant to refer participants with dementia due to a concern cycling isn't suitable for their clients as a form of transport (including the ones with recent diagnosis of dementia) and a lack of awareness and knowledge of adaptive cycling solutions. This research hopes to contribute to an increase in awareness, and encourage people to support those living with dementia to access these opportunities.

One of the participants was collected from her house with one of the cycle taxi's ^{slide 7} by a member of staff from Bikeworks trained as a 'pilot' and the other participant arrived independently. Two RiDC researches conducted a risk assessment prior to the event and ensured informed consent was obtained from the participants. On the day, they met with Clare, the participants and the instructors from Bikeworks after which they explored various accessible cycling solutions.

Findings in this report draw from informal interviews and observations, as well as an expert review conducted by the researchers. The report concludes with a set of recommendations designed to further enhance the accessibility of All Ability cycling initiatives for people with dementia.

Map of Wormwood Scrubs Park



https://londonbirders.fandom.com/wiki/Wormwood_Scrubs?file=Scrubs_Now_Map.jpg

All Ability Cycling Clubs

Drop-in All Ability Cycling Clubs are designed for people with learning, physical and/or sensory disabilities to enjoy cycling on a range of adapted cycles

About the bikes

Bikeworks offers a range of bikes for all abilities:

- Single/tandem tricycles
- Side-by-side cycles for two or more people
- Wheelchair platform cycles
- Go-kart style recumbent cycles.

Some of the bikes are part-electric which can be used when needed. Chairs can usually be adjusted and some bikes have chairs that can turn for easy boarding and arm rests. Attending the club can be combined with Bikeworks' side-by-side pick up and drop off cycle taxi service. There are also 'roadshows' in development where people can find out more information about Bikeworks.

After being shown how to use the cycles by friendly volunteers and staff, attendees are free to cycle around the park or green space with their friends, family or carer.

There is no requirement to book – people can simply turn up on the day to take part. The clubs are also a social and friendly place where people can meet the same people time after time.

Where are they?

The Drop-in All Ability Cycling Club's are run in Newham, Tower Hamlets, Kensington and Chelsea, Hounslow, Waltham Forest and Enfield.

Times and days vary and can be found on the Bikeworks' website.

The club we attended at Little Wormwood Scrubs runs every Friday from 9:30am-1:30pm and alternate Saturdays from 9.30am-12.30pm

More info: <https://www.bikeworks.org.uk/all-ability-clubs/>



Findings



What did we find out about the accessibility of All Ability Cycling Club initiatives for people with dementia?

This section details insights gained from a visit to the All Ability Cycle Club and the experiences of participants with dementia. It reflects on topics such as:

- Participation
- Cycles and assistive gear
- Facilities and staff
- Information

This section also shares more general reflections and insights gained from the visit that consider the broader value of accessible cycling initiatives for people with dementia.

What did we find out?

Turn up and go

The fact that no booking is required to take part in an All Ability Cycle Club session makes them very accessible for participants with dementia, whose health or access to carers may vary from day to day. Participants do have to register for a session by filling in a form on a tablet on the day. A profile is created the first time that records access needs and is updated when necessary.

Regularity

Meeting at the same place, at the same time, allows for people with dementia to make attending a cycle hub part of their weekly routine, which is important especially for those who may experience memory loss. It also gives them an opportunity to get familiar with the environment and the people, which can reduce anxiety and help develop relationships.

Tip: It would be fantastic to see this initiative implemented in all London Boroughs and the UK at large!

Variety of cycles

Often, people can experience more than one impairment, and the same is true for people with dementia. The variety of cycles available during an All Ability Club session means that there is a high chance participants can use a bike that suits their needs. Instructors from Bikeworks tend to get to know participants over time and know what bikes have their preference, but are not always able to guarantee they are available. However, there is usually enough time in a session for everyone to have a go.

Assistive gear

During an All Ability Club session helmets are available for those who want to use them, however during the day it was observed this can go unnoticed. In addition, some of the bikes have pedal straps and others don't, which can make some of the bikes more accessible than others.

Tip: Participants who may struggle with communication, such as some people with dementia, may not take the initiative to ask for a helmet but it could help them feel safer, especially if they also struggle with balance. Consider prompting them pro-actively about the use of helmets and straps.

One of the participants who attended the session needed straps for their feet to facilitate their participation when using the pedals, but there were no spare straps (or boards as an alternative to pedals) available for him to use. He eventually managed without them, but straps would have helped facilitate active participation and exercise. In this case, For Brian planned to ensure that additional modification were made available for subsequent visits from individuals.

Tip: It could help to have a few spare straps and boards available during a session. Baskets are also helpful for those who fear they lose or forget their personal items.



Waving at the lorry drivers



When one of the participants arrived at the park in the cycle taxi she was glowing. Not only because of all the attention she received whilst in the cycle taxi from passing cars, but also because it was a personal achievement.

"I had not been on the road since I had an accident years ago."

She even had a chat with a lorry driver while they were waiting at a traffic light.

"I felt like the Queen!"

At the end of the session Dione explains how sometimes she struggles with low mood as a result of her dementia and the importance of being able to engage in activities like these.

"Coming here really lifts me up"



What did we find out?

Pick up and drop off

One of the participants was picked up by a side-by-side cycle taxi – a service provided by Bikeworks that can be booked in advance to take people from A to B in their local neighbourhood by a trained and skilled driver ('pilot'). Without it, she would have struggled to attend. The ride itself furthermore was a fantastic introduction and made her very enthusiastic.

"I felt incredibly safe because the pilot was putting out their hands when they wanted to turn and clearly knew exactly what they were doing" - participant quote.

Tip: Advertise that the side-by-side taxi service can be used to take people to and from All Ability Clubs to local organisations on the website along with locations and timings of the clubs.

Free of charge

The fact that All Ability Clubs don't charge a fee for attending and using the bikes or picking up and dropping off participants with a side-by-side cycle taxi makes them financially very accessible for all. Especially because many of the bikes are unaffordable – with an electric side-by-side tricycle easily costing £15,000 or more. Attending the All Ability Cycle hub can be the only opportunity for some participants to get some exercise.

Local networks

Some of the participants would not have known about the All Ability Initiative had they not been introduced to it through other local community organisations like For Brian, who support people with dementia.

Tip: Continue raising awareness of the Cycle Taxi Service among partner organisations in the voluntary and statutory sectors. Linking with local organisations and establishing relationships with support staff can help introduce new members to all Ability Clubs in their area.



A way to exercise together

The wife and carer of one of the participants explained they used to go out together. Her husband would go on the mobility scooter and she would ride her bike. But since he has been diagnosed with dementia, the couple stopped going out together.

“He speeds up and I am afraid I will lose him.”

The couple travelled all the way from Basingstoke to attend the All Ability Cycling Club and explore if a tandem tricycles might be a solution for them.

“It is not only good opportunity for him to exercise his legs, but also for myself to get some exercise again. But they are very expensive. I wish there were All Ability clubs in my local area.”

Her husband is not able to communicate much as a result of his dementia, but when asked what he enjoyed most, he replied “Vrrrooom....!!”



What did we find out?

Staff training

The presence of trained staff and volunteers was incredibly helpful in making participants feel comfortable and taken care of. It also helped to create a social atmosphere and to carry out adjustments and/or repairs. Staff clearly had developed relationships with members who attended more regularly, which can be really helpful for those who can be a bit more anxious to socialise.



Facilities

There are somewhat accessible toilets near the park, though they could be improved further. For some wheelchair users, the presence of a ridge will cause problems. Researchers understood that there are ongoing discussions with the Royal Borough of Kensington and Chelsea in relation to sanitary facilities and parking. The following tips may be helpful in this regard:

Tip: Perhaps ongoing discussions with the Borough could include improvements to the toilet facilities (a ramp, seat high, a wheelchair accessible sink and a safety cord) and easily visible and accessible drinking fountains.

Tip: Bikeworks could consider providing water for people using their services to ensure participants drink enough when exercising, especially in hot weather.

Tip: Whilst the park is in an accessible location, providing information about parking for wheelchair accessible vehicles (both at the park by the council and on the Bikeworks website) could further enhance access.

“Green spaces

Participants commented how they enjoyed that the cycling session took place in a nice park. For some, it was the only way to enjoy some green space and fresh air.

The air in my area is very polluted, I love coming here for the fresh air and the trees. It helps with my mental health”

Socialising

Especially the cycle taxi which has the ability to transport four people inevitably creates a natural social atmosphere where people can meet new people and have an informal chat while they are cycling together.

This is especially beneficial for participants who attend on their own, but also for those who come with carers or family members. One of the participants used the All Ability Cycling session to meet with her sister in the park and go for a cycle together.

Recommendations



What else did we learn?

This report makes a number of light touch recommendations that could enhance the accessibility of the All Ability Clubs even further for those with dementia:

- Advertise All Ability hubs with local dementia support groups
- Consider increasing spare assistive aid (ie. pedal straps) and baskets
- Increase information on the website about side-by-side Cycle taxi service to and from All Ability hubs
- Encourage the council to improve access facilities in local parks such as disabled toilets, parking and access to drinking fountains

We highly recommend spreading of this initiative across London Boroughs and even UK-wide to further enhance wellbeing, relationships and quality of life for those with dementia and their carers.

Further information

RiDC

- <http://www.ridc.org.uk/news/improving-experiences-people-dementia-london>
- <http://www.ridc.org.uk/>

For Brian

- <https://www.forbrian.co/>

Bikeworks

- <https://www.bikeworks.org.uk/>
- <https://www.bikeworks.org.uk/all-ability-clubs/>

DEEP Network

- DEEP guides to support the involvement of people with dementia <http://dementivoices.org.uk/resources/deep-guides/>

Innovations in Dementia

- <http://www.innovationsindementia.org.uk/resources.htm>

City Bridge Trust

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