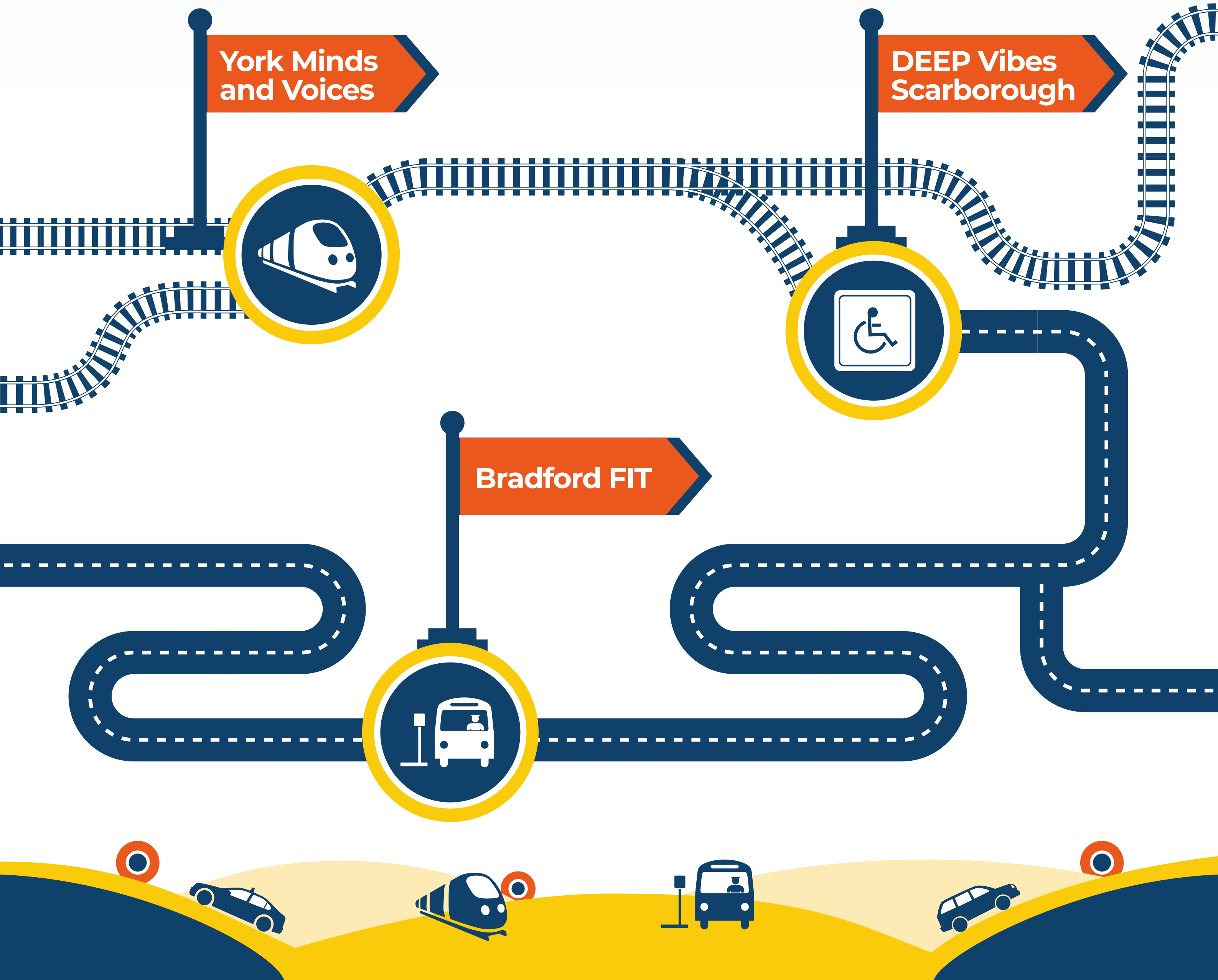
The Right to a Grand Day Out

a story of co-production



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deep
The UK Network of Dementia Voices

Dementia Enquirers

iD
Innovations in Dementia

COMMUNITY FUND

Working together

Influencing services

Transformational

Introduction

Once upon a time in the ancient county of Yorkshire…

A story is the telling of an event. A story needs a listener. And the listener needs to experience or learn something because they have heard the story.

A story is a way of sharing information, experiences, attitudes or points of view. The reading and telling of stories can help us to make sense of our world.

This is our story of co-production. **Co-production – a word most of us aren't familiar with**…

We are a collective of groups in the DEEP network from Yorkshire. DEEP is the UK network of Dementia Voices – which connects over 100 involvement groups of people with dementia to provide mutual support and to amplify our voices.

Throughout 2017 and early 2018 we worked together on different transport issues that bothered us.

- **DEEP Vibes** in Scarborough campaigned on the availability of Blue Badge parking permits for people with dementia.
- **Bradford FIT** investigated how helpful bus information was to get people to their destination.
- **York Minds and Voices** explored train accessibility and train travel.

Chapter 1

What is this thing called co-production?

Co-production means different things to different people. It is quite hard to define. It is a term that is used a lot in research, and also in health and social care, especially when new services or policies are being developed. It is about:

- getting involved as equals.
- being recognised for the experience you bring.
- making something happen together.

It is not just about participating in other people's work or ideas. But helping to shape new ideas from the beginning.

The New Economics Foundation describes co-production as:

> Where professionals and citizens **share power** to design, plan, assess and deliver support together. It recognises that **everyone has a vital contribution** to make in order to improve quality of life for people and communities.

The Care Act (2014) says this about co-production:

> Co-production is when an individual influences the support and services received, or when groups of people get together to influence the way that services are designed, commissioned and delivered.

But what does co-production **really** mean? It isn't a word that we feel very warm towards! This is how we think of co-production:

It sounds technical

Don't know

Working together

Boring

Management speak

Producing something

But we do know that when we are fully involved, all the way through a process- this can be **transformational**.

> It made us realise we can make change happen if we get together. Our voices became louder.

Chapter 2

Making an idea meaningful

Let's start at the beginning of our story. With support from Innovations in Dementia, we came together to talk about dementia rights.

We were asked what we thought about dementia rights. There was a resounding silence!

The idea of dementia rights wasn't something we were familiar with.

We found out that:

- people with dementia have the same civil and legal rights as everyone else.
- lots of Alzheimer's organisations have committed to a human-rights based policy.
- some people with dementia have written a report about their rights for a United Nations Committee, and presented it in Geneva.
- the All Party Parliamentary Group on Dementia has carried out an inquiry about dementia and disability.

But dementia rights still felt so far removed from our day to day lives.

> Where, after all, do human rights begin? In small places, close to home – so close and so small that they cannot be seen on any map of the world. Yet they are the world of the individual person. Eleanor Roosevelt, 1958

But we had no problem thinking about an issue that causes difficulty for us, **close to home**. The world of transport – that enables or disables us from getting out and about.

We learnt that the United Nations Convention on the Rights of Persons with Disabilities is an international agreement about protecting and promoting the human rights of disabled people throughout the world. People with dementia are recognised in the definition of disability. This Convention contains a commitment to **'ensure personal mobility in the manner and time of choice and at affordable cost'** (Article 20).

Thinking about **our right to get out and about** made rights suddenly feel real. We were off!

Chapter 3

Sharing our stories and becoming equal

We knew we wanted to look at the importance of transport to keep connected to our lives and communities.

We wanted all members of our groups to be able to get fully involved.

So we started at the beginning, with some help from Andy at Go Upstream – talking about our journeys to our meeting. We found we could all get involved in this discussion.

We used lots of different transport to get to York:

car

walking

police van

bike

train

taxi

bus

It was a varied experience, some high and lows:

enjoyable

quiet

high profile

cold

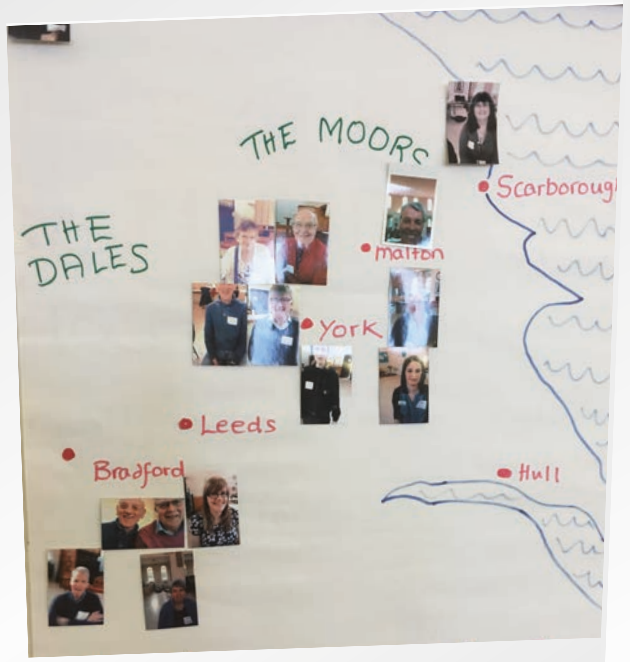
quick

good

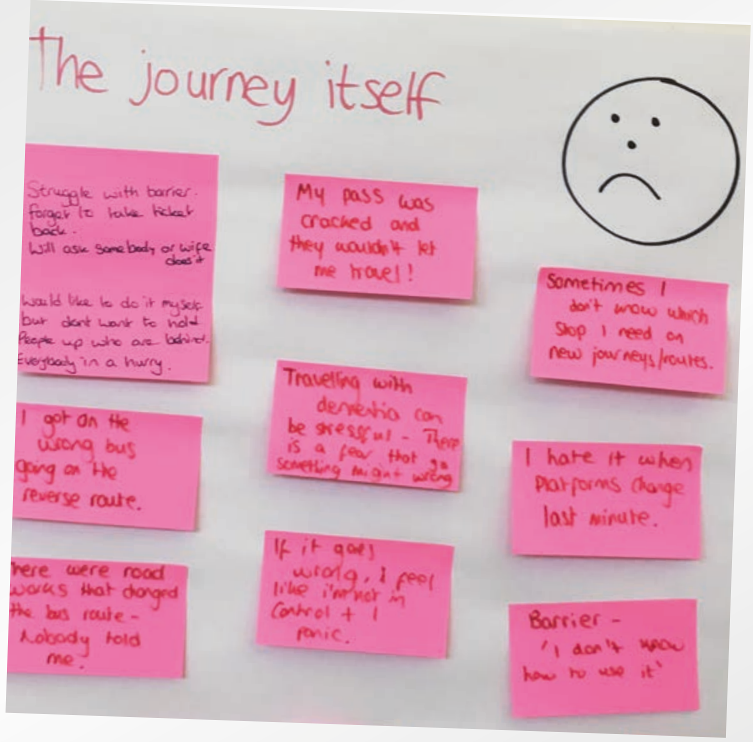
windswept

short

got lost!



Where we have come from


The journey itself

Struggle with barrier. forget to take ticket back.
Will ask somebody or wife does it

would like to do it myself but dont want to hold people up who are behind. Everybody in a hurry.

My pass was cracked and they wouldn't let me travel!

Sometimes I don't know which stop I need on new journeys/routes.

I got on the wrong bus going on the reverse route.

Travelling with dementia can be stressful - There is a fear that something might go wrong

I hate it when platforms change last minute.

here were road works that changed the bus route - Nobody told me.

If it goes wrong, I feel like i'm not in control + I panic.

Barrier - 'I don't know how to use it'

Our journeys

We might not have had much to say about rights. But we had a lot to say about our daily experiences when using transport.

- Transport websites can be difficult to use.
- Timetables are often complicated and different e.g. a bus timetable will be presented differently by different bus companies.
- It can be difficult to decide between the array of transport options.
- Tickets are often cheaper online but some people prefer face to face interaction.
- People make a difference – small things like a smiling driver.
- It could be good to have a pass that shows you might need assistance (but not everyone likes this idea).
- Information boards change too quickly in stations. The main destination is displayed in large print, but others en route are very small.

Planning a journey

Positive ideas:

- Writing down the start and end point helps.
- Using familiar routes e.g. driving to park and ride.

Challenges:

- Buses changing number on the way.
- Worries about how the journey will turn out.
- Worries about toilets.
- No visual display of the route on buses or at bus stops.

The journey itself

Positive ideas:

- Sitting at the front so we can see where we're going.
- Familiar places for getting off.
- Counting the stops.
- Parking spaces available for people with dementia.

Challenges:

- Bus setting off too soon.
- Not sure whether we want to be identified as having dementia.
- Ticket barriers.
- Last minute platform changes.
- Bad customer service.
- Length of walk at train station.

The people we meet

Positives:

- One person got lost on the way back from shops, but a lady stopped and helped.
- It would be good to feel we could ask someone who would put us right if we get lost. It would raise our confidence in getting out and about.

We also talked about Blue Badges and disabled parking:

- Some people are able to apply for Blue Badges, and others are not. Some find it hard to apply in the way required.
- Even if you have a badge, there are different rules in different places – sometimes you can park anywhere (e.g. in metered carparks), other times you can only park in allocated spaces.
- There are often not enough disabled spaces.
- Spaces are not wide enough.

> "It's up to us to spread the word about dementia and living with it. I think we should have a stall in Parliament Street."

And there was our light bulb moment! By talking about issues that were important to us, we began to think about our rights.

> "We are the voice for future generations. Nothing changes if nothing changes."

A reminder of our story

People with dementia have a **right** to get out and about. Transport is an important part of being able to get out – to the shops, to the cinema, to the doctors, to visit friends, to attend a DEEP group.

There are some changes that could be made to transport to make it **easier** for people with dementia to use. We have talked about some of these ideas during our workshop.

So now we want to take action!

Here are some ideas about how you can collect **evidence** that will help you to take action, and get your message heard.

Chapter 4

Time to take action – in our different ways

We all wanted to take some action – to make change happen to help us to carry on getting out and about. Each group had different priorities. It was very personal to local circumstances and how these affected people with dementia.

Group	Action topic	Reasons for choosing topic
DEEP Vibes Scarborough	Blue Badges	Expensive, fee & photos. Complicated to apply. You may not even be awarded the badge. Medical tests are measures of physical ability rather than mental ability or need for supervision.

Group	Action topic	Reasons for choosing topic
York Minds & Voices	Trains (disabled access)	Problem journey on train from York to Manchester – ramp only available at front carriage, seats booked much further down train. Meant a member of Minds and Voices had to walk through several carriages and across uneven joints to sit with friends.

Group	Action topic	Reasons for choosing topic
Bradford FIT	Bus timetables	Different providers and route changes make it very confusing. Some display information screens and some don't. Buses changing number en route. Worries about how the journey will turn out. Worries about toilets. No display of the route on buses.

Innovations in Dementia have used a variety of accessible methods to empower people with dementia to get involved and capture their views. These ideas helped us to plan the best approach to achieve our different actions. This felt like good collaboration – ideas and support that could help us to get on with the changes we wanted to see.

These were our plans:

DEEP Vibes Scarborough

- We will use our links with people in the council and write **personal stories** and use video diaries.
- We aim to **increase** the number of people living with dementia who have Blue Badges.
- We will create an **on-line** campaign.

Bradford FIT

- We will make an iPhone **film** of members trying to understand timetables in Shipley market place.
- We will propose **personalised** bus timetables; and colour coding for buses, bus stops and bus information.

York Minds and Voices

- We will encourage the train company to have a **ramp** at every carriage entrance. This will be beneficial to all (including people with walking aids and those who do not like the gap).
- We will do this by using **Twitter, video diaries and inviting the train company to meet Minds and Voices**.

We worked with Innovations in Dementia, using this template, to help us come up with our plan.

The worksheet on the next page helped Bradford FIT to plan their action.

Making Bus Information Accessible to People with Dementia

The current problem	**The current risks**
• Different providers have different systems – very confusing. • Some display information screens (e.g. with next stop) and some don't. • Route changes can be very confusing. • Difficult to understand timetables.	• Person with dementia gets off at wrong stop, then lost. • Confusion and demoralisation about info. • People stop going out and get isolated. • Difficulties getting to appointments. • Loss of social and family contacts if unable to use buses.
The opportunities	**Our actions**
• Existing links with some bus providers.	• Video diaries to illustrate problems. • Photo stories to illustrate problems. • Ask all bus providers to meet with group? • Request simplified and perhaps personalised timetables.

You can read more about how to use the different methods to collect evidence at the back of this book (Appendix 1).

Chapter 5

What happened? Some stories

DEEP Vibes Scarborough

Our project started when we wrote to our local MP – Robert Goodwill. There are no Blue Badges available to you if you live with dementia in Scarborough. But in Wales you can get a Blue Badge if you live with dementia. Why can't we learn from their system?

There could be dementia spaces in car parks, a simple symbol would indicate where. The criteria applied to blue badge applications are too strict.

6 of us started a 38 degrees petition **https://bit.ly/2M4Jfms**

38degrees is an on-line place where you can start a petition on any issue that is close to your heart. We used the Twitter hashtag **#BlueBadges4Dementia** to get interest. Photos of key messages went out on Twitter. The petition got over 1300 signatures.

We had local victory! You can now apply for a Blue Badge over the phone – and answer **"cognitive questions"** such as **"How will a Blue Badge help you?"**, **"Do you want to give up and go home if things go wrong when you are out?"**. These changes came about because they wrote to the Council and they told us that they couldn't change the forms, but could take our application over the phone. Their letter prompted a phone-based resource.

We also took part in a national consultation about Blue Badges (maybe this even came about because of the noise we were making?) The criteria for Blue Badges have now changed. People are eligible who:

- cannot undertake a journey without there being a risk of serious harm to their health or safety or that of any other person.
- cannot undertake a journey without it causing them very considerable psychological distress.
- have very considerable difficulty when walking (both the physical act and experience of walking).

We feel really proud to have been a stimulus of this process.

Bradford FIT

We shared lots of stressful stories of travelling by bus. Most of us can no longer drive, and buses are a lifeline. Bradford is well served by buses – there are 14,000 bus stops in West Yorkshire alone.

When information is presented well it can really help us to feel confident. As soon as something goes wrong, it knocks us down. We are reluctant to try again.

A friendly bus driver makes all the difference. But it's accessible bus information that helps us to plan our journeys and feel in control:

- easy to understand maps and timetable displays (showing up-to-date and accurate information).
- cards that work at all station machines.
- announcements about "the next stop' are really helpful. Knowing an announcement was going to be made reduced anxiety and gave confidence.
- personalised bus timetables could really help (that you could plan in advance and print out; or could be turned into an App).
- there could be colour coding on timetables which are consistent across transport (e.g. blue OUT red RETURN).

We made a film to show us in action, trying to understand bus timetables and information. You can watch our film here:
https://bit.ly/2IDzDwU

In the film we asked for 3 things: comprehensive colour-coding; clear route maps at bus stops; personalised timetables.

Minds and Voices York

Train travel was our annoyance! We had travelled as a group on the train from York. It was very traumatic for our members as those who needed a wheelchair or walking frame to get on the train could only do so through one door – completely at the opposite end of the train to where our seats were booked. We all wanted to be able to travel together more positively.

We had a good conversation with Charlie from the train company – who wanted to find out how trains could be improved for people with dementia. He listened to our concerns and suggested that he organise a supported journey for our group – with the right assistance being put into place.

He would travel with us, and 'witness' our journey. We decided to go on a grand day out by train to Scarborough. DEEP Vibes and Bradford FIT met up with the group for an open top bus tour. We took a photographer and a cartoonist for good measure!

Our journey was rubbish! Rita still could only get on via ramp on one set of doors two carriages away from us and had to wobble and shake along the wobbly and shaky train to get to her seat. Why can't the train wait before setting off for all people to be seated? Why can't the train make all doors accessible by a ramp? This can be very scary crossing from one carriage to the next with the floor moving underneath you. Different train companies have different accessibility policies and practices. This can make travelling very difficult. There are really complex accessibility issues when trying to book online. There was a maximum of 9 tickets one could buy online (there were about 15 or more of us). To sit all together near the only accessible door would mean paying for first class seats as the accessible door was just next to first class...

The design of new trains should involve us and other passengers. It takes IMAGINATION. Everything happens so quickly, we need to take more time to get things right.

Let's keep the pressure on!

Chapter 6

Involving a range of experts in our issues

All too often we are consulted about other people's ideas. This is not true co-production. In this project, we asked transport providers to come to us, to discuss our ideas on our terms.

Throughout the day, they listened to our experiences and the practical steps we had been taking.

We then consulted them!

Q What do you think having listened to our work?

A

> Your groups have really taken the bull by the horns, what you are doing is really important – keep doing it.

> Providers need to hear your words.

> The stories I have heard are very powerful, they make a difference.

> I feel euphoric hearing you all speak, it is inspiring and heart-warming.

> Linking human rights to everyday concerns is positive for all of us, including people who live with dementia.

Q What will you go away and do?

A

> We will be removing advertising space on Bus Timetables in West Yorkshire so that we can make better use of the space for maps.

> We will respond to the great suggestion of colour coding timetables.

> I will include dementia rights in University courses I am involved in.

> I will ask what the Alzheimer's Society can do to take forward a rights-based approach.

The experts reciprocated by giving some advice on continuing to build our campaigns:

- Ask providers about THEIR rights, make it personal to them as people.
- Develop dementia awareness for Service Providers.
- Build a business case, talk £££s, for example preventing accidents saves money.
- Remember the applicability of the Equality Act.
- Emphasise the right to a community and family life and the responsibility of providers and authorities.
- Rights is not just a language issue, it is real practice.
- EU regulations came into force in 2018 include dementia training for all bus drivers.

It was a great day and we felt we were working together on a common issue.

Chapter 7

What has changed because of our work?

So, there is still work to do. But the best thing that happened was that we began to believe in our rights to a grand day out.

Remember, the artist, photographer and cartoonist that we took to Scarborough with us on our ill-fated train journey?

Ian Beesley, Tony Husband and Ian McMIllan created a beautiful book of our transport highs and lows; and captured our collective energy to want to make changes to transport for people with dementia.

THE UNFURLING

Let us celebrate the gradual opening
Of a banner taking its place in the world;
A long unravelling and a fine unwinding,
Like a flower unwrapping itself from itself,
A parcel of thinking softly untying
Or an origami of ideas hugely unfolding
As, caught by the breeze, image and language
Spread their twin messages into the air.

The book was published as part of “A Life More Ordinary Project”. You can read the book here: **https://bit.ly/2LS21Lx**

By sharing our experiences and ideas, we developed collective strength to want to make changes happen for all people with dementia. We began to understand the language of rights – on our terms and in our own personal ways.

What better way to take social action to achieve your rights – than creating a trade union banner and organizing a protest! For hundreds of years, organisations have made banners to identify themselves.

We created our own DEEP Yorkshire banner. The banner has two sides. The black side is ‘**negative**’ – the consequences of not being able to get out and about. The red side is ‘**positive**’ – “a grand day out.”

We then unfurled the banners in the foyer of York train station. We handed out leaflets and talked to commuters about our campaigns to create better transport for people with dementia. Local newspapers and TV news captured our protest.

Negative
The consequences of not being able to get out and about.

Positive
A grand day out.

This is what Wendy Mitchell, a member of Minds and Voices said after the unfurling:

> “We were all on a high as it had been such a success. As Ian said: “we are unfurling the banner because we are unfurling the future.”
>
> And what a wonderful booklet to come out of this amazing experience for us all – full of cartoons, photos, poems and stories – superstars. Travel is so important to me, yet is so stressful. Yet small changes can make it possible. I’m so glad I changed my plan today because all our words of the past 18 months, today became an ACTION of our own...”

Chapter 8

Conclusions to make co-production a good experience

We are near the end of this phase of our co-production story. Protesting with banners at a public train station was not what we had anticipated at the beginning of our story!

These are our recommendations for positive co-production:

- Have a belief that keeps you focused on what you are doing. Ours was “everyone has a right to accessible transport.”
- Keep it simple! Don’t use jargon. Explain ideas.
- It’s good to have some encouragement – to keep us on track and give us ideas.
- Find someone you trust to help you with the practicalities. But don’t let them take over.
- Don’t feel you have to accept what others say. Keep challenging each other.
- Payment to our group has enabled us to keep involved in this project. It also acknowledges our work and contributions to the learning around co-production.

We’ve been involved as equals, recognized for our expertise and together we made something happen. Co-production is a powerful process when we are in the driving seat!

Appendix 1

Accessible methods to collect evidence.

Idea: take photographs of transport difficulties

What do I need?

☐ A camera.

☐ Or a mobile phone with a built in camera.

Take photos of the issues you encounter. This might be a car park bay a long way from the building. Or a sign in a train station that is difficult to understand. It might even be a photograph of you feeling cross. Or a friendly guide at the train station (don’t forget to ask permission to take a photo!).

Think about how you present your photos to ‘tell a story’. A slide show on a computer? Or printing them out and creating a ‘storyboard’?

It is probably helpful to include some writing to explain the photos.

Idea: make voice recordings of our opinions

What do I need?

☐ A dictaphone.

☐ Or a mobile phone with a built in sound recorder.

☐ Or another type of sound recorder.

As you encounter issues, voice record your views about it. It would be useful to:

○ Explain what the difficulty is.

○ Say how it makes you feel.

○ Talk about what improvements can be made.

You could either do this at the time, or go home and record later.

Idea: create a short film

What do I need?

☐ A Go-Pro Camera (the advantage is that you wear this rather than having to carry it).

☐ Or a video recorder.

☐ Or a mobile phone with a built-in video recorder.

☐ Or an iPad.

You would wear or use this camera during a travel situation. It will record continuously once you hit the ‘record’ button. It will probably be helpful for someone else to film you as you take your journey. Make sure you hold the camera horizontally not vertically.

As this is amateur film footage, you may want to voice record your opinions afterwards (it may not be picked up at the same time). Why don’t you watch your film again, and record your comments whilst watching?

You may also need to edit the film so that it is interesting to watch. There may be particular points you wish to highlight. You can put your clips together into a short film using a simple App such as iMovie?

Idea: walking the patch

What do I need?

☐ A friend with a pen and paper or a voice recorder.

Attempt a journey or a transport activity e.g. catching a bus to a new location, trying to book a train ticket. All the time you are doing this, explain what your thought processes are. Your friend may help by asking you prompt questions:

○ What are you looking at?

○ How did you choose between this way and that?

○ Can you see that notice? What do you think it means?

○ Is it easy to find the entrance to the building?

It is recommended that a ‘walking the patch’ exercise doesn’t take any longer than 45 minutes.

Idea: write a regular diary

What do I need?

☐ A pen and paper.

☐ A voice recorder (for an audio diary).

Keep a diary about all the journeys you make.

○ What helped?

○ What made it difficult.

○ How did the situation make you feel?

Idea: creating an on-line petition

What do I need?

☐ Access to the internet.

Create your on-line petition by

1. Deciding which petition platform to sign up to.
2. There are many e.g. **38degrees.org.uk**; **change.org**. and **avaaz.org**.
3. You can also create a petition targeted at the UK government, who will respond if you get 10,000 signatures or more. Use this link to create a petition **https://bit.ly/28RCAdx**.
4. Collect some evidence to support your cause. Use this to write about:
   ○ What your cause is.
   ○ Why it is important.
   ○ What difference you hope to make.

5. Think carefully about what you call your petition. You will want other people to understand quickly what your petition is about.
6. You will need to promote your petition if people are going to know about it, and sign. Twitter and Facebook can be good places to raise awareness of your petition.

Appendix 2: National Rail – a helping hand

All train companies offer a helping hand for any trip through Passenger Assist. You can book assistance 24-hours a day by contacting Passenger Assist on freephone **0800 0223720**. You need to arrange this at least 24 hours before your journey.

The train company you're travelling with will organise assistance for your entire journey, even if you travel with someone else to complete the trip.

They can arrange for:

- Someone to meet you at the station entrance or meeting point.
- Help you navigate around the station and accompany you to your train.
- Help you on and off the service.
- Provide a ramp on and off your train.
- Meet you from your train and take you to your next train or the exit.
- Carry your bag (up to three items of luggage).

More information is here: **https://bit.ly/2ORIVLA**

This includes telephone numbers of the different train companies.

Appendix 3: How can taking a rights-based approach help you?

Taken from "The United Nations Convention on the Rights of Persons with Disabilities": What does it mean for you? (2010) Equality and Human Rights Commission.

Why is the Convention important for disabled people in Britain?

1. **The government will be held to account** by means of reports on its performance in promoting disabled people's rights by the UN Disability Committee.
2. **It should give disabled people a stronger say in the policies that affect their lives**. Government is expected to involve disabled people in the plans to implement the Convention when it is making new laws and policies which affect disabled people, and when it is writing reports for the UN on how the UK is meeting its obligations under the Convention.
3. **It sets new standards on how government and public bodies should ensure that disabled people's human rights should be protected and promoted**. This is the first human rights agreement that talks in detail about things like an inclusive education or the right to live where you want to.
4. **It puts wide-ranging responsibilities on government to take practical action to strengthen disabled people's control over their own lives and full participation in society**.
5. **It could lead to stronger and fuller protection against disability discrimination**. Government may need to take action to close gaps in UK law on disability discrimination.
6. **It can be used to interpret the Human Rights Act and, alongside the Equality Duty, to challenge failure to respect human rights and to work towards disability equality**.

7. **It can be used by disabled people and their organisations as a framework to negotiate and influence national and local matters** – for example when a local authority is proposing to withdraw essential social support services which will affect disabled people’s rights to live independently.
8. **It should help promote positive attitudes towards disabled people** as the government has an obligation to raise awareness and foster respect for the rights and dignity of disabled persons, to tackle prejudice and abuse against disabled people, and to promote awareness of what disabled people can contribute to society.

Notes

With thanks to **Exeter University** for permission to include the cartoons, photographs and poems from 'A life More Ordinary' project, funded by the ESRC (ES/M50046X/1) and linked with the 'Improving the Experience of Dementia and Enhancing Active Life' (IDEAL) study' at the University of Exeter; investigators: L. Clare, I.R. Jones, C.Victor, J.V. Hindle, R.W.Jones, M.Knapp, M.Kopelman, R.Litherland, A.Martyr, F.Matthews, R.G.Morris, S.M.Nelis, J.Pickett, C.Quinn, J.Rusted, J.Thom. For more information see **http://www.idealproject.org.uk**.
Follow IDEAL on Twitter: **@IDEALstudytweet**.

Give us the right to a grand day out

Give us the right to a grand day out,
Give us a seat on a nice clean train;
Give us a view of the shining sea
As the sun breaks through the Yorkshire rain.

Give us a trip we can all go on
Give us a day that'll make us grin;
Give us a toilet close to hand
Not a mile down the train by a smelly bin.

Give us some signs that are crystal clear
Give us a guard who knows their stuff
Give us a trip we can file away
When the world seems harsh and life gets rough.

Yes, give us the right to a grand day out,
Give us a seat on a nice clean train;
Give us a view of the shining sea
As the sun breaks through the Yorkshire rain.

by Ian McMillan

deep
The UK Network
of Dementia Voices

Dementia
Enquirers

iD
Innovations
in Dementia

COMMUNITY
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