

# The ‘So what, what next?’ project

Supporting people with a learning disability, autism or both to use their skills and interests to play a part in their community

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# Background

## About the Transforming Care empowerment steering group

The 'So what, what next?' project is part of the Transforming Care programme of work, which aims to improve services and support for people with a learning disability, autism or both who may display behaviour that challenges. A key aim is to support people to move out of specialist hospitals and into the community.

This project was designed by the Transforming Care empowerment steering group. Members of the steering group are people with a learning disability or autism, or family carers, with lived experience of long stays in hospital settings. The steering group is a part of the national Transforming Care programme and is supported by the Local Government Association (LGA), one of the national delivery partners for the Transforming Care programme.

The empowerment steering group said:

**“Everyone agrees that getting people out of hospital is important but making sure people have good lives out of hospital is important too. This can make sure people don’t go back to hospital.”**

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## 4 THE 'SO WHAT, WHAT NEXT?' PROJECT

### About the 'So what, what next?' project

The empowerment steering group wanted everyone involved in the project to think differently and creatively about people's support. They wanted the focus of the project to be on supporting individuals to establish links within their communities, to increase independence and enable people to be active citizens, contributing their skills and passions.

The group called the project 'So what, what next?' because they wanted to emphasise that the Transforming Care work does not stop at the point of someone moving out of hospital; it is about the 'what next' that is the key to growing people's independence and improving their quality of life.

The group said:

**“It can take time and a lot of effort to make good links in the community and do all these things. This project is about working in ways that really value people and focus on what people CAN do. Not what they can't do.”**

The group felt that this way of working with people can help lead to positive outcomes.

They said that it can help people to:

**BECOME  
MORE  
INDEPENDENT**

**HAVE  
DREAMS  
AND REALLY  
SHINE!**

**FEEL MORE  
CONFIDENT**

**DEVELOP RELATIONSHIPS WITH OTHER PEOPLE  
IN THEIR COMMUNITIES – NOT JUST WITH STAFF  
AND THE PEOPLE THEY LIVE WITH**

The empowerment steering group designed the project, co-produced the project brief and interviewed the organisations which bid for the work. They wanted to try a different approach. They wanted the project to work with a small number of people with a learning disability or autism who have recently moved out of hospital, alongside the people who support them in the community. Therefore, they asked organisations who wanted to lead the work to get sign up from one of the Transforming Care Partnerships to work with them, and help them identify individuals who might want to be a part of the project.

This report shares the learning from the ‘So what, what next?’ project for other local areas to use and learn from. It will be shared by the empowerment steering group and the LGA.

## Community Catalysts

Community Catalysts was the organisation which successfully bid for the work. They are a social enterprise based in Yorkshire. Community Catalysts work with people and communities, local and national government and public and third sector organisations all over the UK. They help people and organisations to be creative.

Community Catalysts know that health and care services don't always work well for people and that there are other ways for people to get the support they need. They know that:

**OLDER AND  
DISABLED  
PEOPLE HAVE  
TALENTS  
THAT ARE  
NOT ALWAYS  
SEEN**

**PEOPLE  
SHOULD GET  
THE SUPPORT  
THEY NEED  
TO LIVE THE  
LIFE THEY  
WANT**

**COMMUNITIES  
CAN HELP**

Community Catalysts appointed Cathy Dale to lead the project and Angela Catley to manage and support it. They wrote this report.

### The Black Country Transforming Care Partnership

To deliver the 'So what, what next?' project, Community Catalysts needed a local partner, and the Black Country Transforming Care Partnership (TCP) really wanted to get involved.

1.4 million people live in the Black Country in the West Midlands. The area is very diverse, with people from lots of different backgrounds living there.

The Black Country TCP is made up of:

- four clinical commissioning groups (CCGs)
- four local authorities

In March 2017, 101 people with a learning disability or autism from the Black Country were in specialist hospitals. The TCP had a plan to reduce this to 43 people in two years. In the year leading up to the project, 66 people had been discharged from hospital settings.

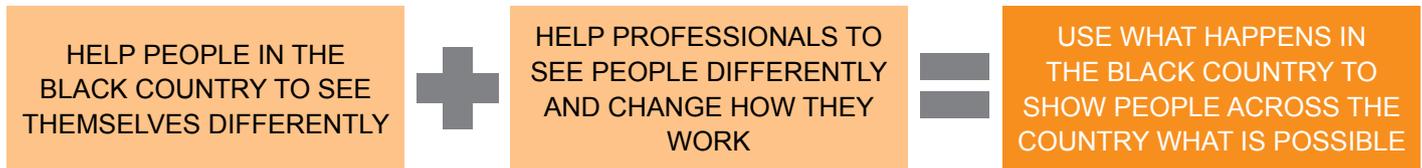
The Black Country TCP has four case managers, with each case manager working for one of the four CCGs. The case managers supported the 66 people to move out of hospital and know them well.

Claire Parker, Senior Responsible Officer for the Black Country TCP, said:

**“This is a real opportunity to make a lasting and profound difference in the lives of people with a learning disability or autism and I am delighted that the Transforming Care Partnership in the Black Country is supporting this project.”**

# What Community Catalysts did

Community Catalysts, working with the Black Country Transforming Care Partnership, wanted to use the 'So what, what next?' project to:



## What Community Catalysts did

Told people about the project.

Made connections with all the people we thought might help. This included:

- people with lived experience and peer support groups
- commissioners
- social workers
- care and support providers.

Found out what was already happening in the Black Country.

Wrote lots of easy read forms and tools.

Identified 14 people who had recently moved out of hospital and into the community. Found out if they wanted to talk to us.

Found out about lots of the good things that are happening in the Black Country that might help people use their strengths.

Met 10 people and some of their families and support providers. Found out what they are good at and what they care about.

Came up with ideas for them, their families and support providers. Found opportunities for people in their local community. Made introductions.

Helped people and their supporters to make a plan for the future.

Wrote down the stories of some the people, who they are, what they are good at, what they did and what they are planning to do next.

See Appendix A for more detail about what Community Catalysts did.

# The people

10 people with experience of life in hospital helped us with this project. They had all moved out of hospital within the last 12 months and some people had only moved out very recently. They told us their stories, shared their hopes and dreams and helped us keep the project real.

People like:

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## Sharon

Who is working hard to keep the good life she has achieved for herself.

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## Chris

Who knows everything about trains and could be such a strong member for the local trainspotters forum.

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## Jack

Who likes wildlife and photography and has a lot to offer his local RSPB

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## Jamie

Who loves walking and the outdoors and could make a great conversation volunteer.

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## Jackie

Who loves being in water and would like to get out more. Trying hard to find a relaxing place where she feels welcome and safe.

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## Simpson

A considerate woman who wants to make something of her life. Has a strong message to share about how to get Transforming Care right for her and others

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## Eunice

Who knows the way down memory lane and loves her garden. Looking to get involved with a local 'user led' organisation.

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## Philip

An active young man with a lot of dreams. Would love to get a job and find a girlfriend.

**See Appendix B for the detailed stories of some of the people that helped us.**

Each person, with support from their provider and/or family, worked with us to think 'so what, what next?'. They let us find out about opportunities in their local community, think about how they might use what they are good at and write a plan of action. Their supporters agreed to help them do the things in the plan once the project was finished.

# What we learned

## Helping people to use what they are good at

### **Everyone has strengths**

Everyone has things that they are good at and things that they care about. It usually isn't very hard to find out what these are. People want to talk about what they are good at and are proud of the things they can do.

### **Family and friends are really important**

Not everyone gets on well with their family, but most people do. People told us their relationships with family and friends are very important. Making friends and maintaining friendships is something that needs to be worked at. Family members told us it can be difficult to stay in touch with their loved one, especially when they live in places like specialist or secure hospitals or are a long way from home.

### **People often have lots of resources they can use**

We found out that many people have a lot of staff to support them. Some people have their own car.

### **There are lots of things happening in local communities**

There are lots of opportunities in every area for people to connect with their community. Often people and their supporters do not know about all of the things that are available in their area.

Sometimes people don't know how to find out about and connect to the opportunities. Most councils have things going on to help people connect to their community and use community resources. Sometimes these things are not linked with people who are part of the Transforming Care work.

*“Linking people to families, universal services and the local community is critical, so they have a sense of belonging and resilience to manage.”*

**Commissioner**

### **It can cost a lot to get out and about**

Costs can be high for people who want to get out and about, connected and contributing to their communities. If someone has two or three staff with them everywhere they go, they have to pay the cost of travel or entry of those staff as well as themselves. Many places let one carer go free but not two or three carers.

### **People need time to settle in their new home**

Some people have spent many years in and out of hospital and other places that they have not liked very much. People said it takes time for them to feel comfortable once they have left hospital.

## “People need some time to orientate themselves to their new home on discharge.”

### Provider

#### **People need supporters who know them well**

A big part of settling in and getting a good life is having supporters who know you well. If supporters keep changing, people are always having to 'start again' and are never able to think about their future.

#### **Choice isn't always an easy thing for everyone**

Some people find choice really hard. They might have made the wrong choices in the past, for example getting into debt or making friends with people who weren't very nice. They may have had very bad life experiences as a result of the choices they made. Some of the people we met told us they have learned from these experiences and know what they need to get their good life in the future. They want the people around them now to support them to not make the wrong choices in the future.

#### **Some opportunities don't quite fit**

Lots of activities and opportunities that are available to people don't quite fit them and their interests. Some things are designed for people who have a particular 'label' – for example cooking classes for people with a learning disability or gardening for people with mental ill health.

Lots of the people we met find themselves with many different labels. This means people never really fit into the options and opportunities available and find themselves having to do things that don't really suit them.

“I really think there is a strong need to continue work such as this, as I know people really do need a lot of support and are not just merely 'looked after' in the community..

This takes some thinking and sometimes 'out of the box' but that should be a norm, not an exception, which in my experience is not the case yet. People who may display behaviour that challenges others are complex but should be treated with dignity, respect and given the same opportunities as other fellow citizens.”

Social worker

### **Some people don't get the support they need to live their good life and keep well**

People we spoke to talked about moving out of hospital without enough support. They were clear that this led to them becoming unwell and going back into hospital. This is not good for the person and is a false economy because it often costs more to help people in hospital than it does to help them at home. Providers said that they found it hard to support people to get their good life if the funding available wasn't enough to provide the help and support that was needed.

## **Managing a project like this one**

### **People, families, professionals and providers all want to make things better**

All the people we connected and worked with understood the challenges people face. Everyone said they wanted to work together to make things better.

### **Finding people takes time**

It took a long time to find and get introduced to people. Professionals and supporters are careful who they share personal information with. People coming through Transforming Care can be 'invisible', with few friends and limited contacts in their community.

### **Contacting people can be hard**

Once we found people it was hard to keep in touch with them. Very few people have phone numbers and emails. Working through staff can be difficult for anyone who is not already part of the person's life. Meeting new people and making new connections is important for most people. A key part of this is having ways to contact people once a connection is made.

### **Getting to know people takes time**

We learned that it takes a long time to meet people and get to know them. Some people find it very hard to meet and connect with new people. Sometimes people aren't well enough to meet and make positive plans. Sometimes people are having a bad day and don't want to meet and make positive plans. Sometimes staff are very busy and may find it hard to make plans or help people to stick to them.

### **Talking to a new person about positive things is good**

People and their supporters said they really liked talking to someone new. They liked that Cathy, the project lead, was not a clinician or someone whose job it was to 'assess' them. Meeting someone who has time to talk helps people and their supporters think about different things and to learn more about each other.

### **Most people need help to make changes in their life**

Nearly all the people we met need a lot of support to live their lives. Most people can only make changes in their lives if professionals and staff help and support them to do so. This makes things more difficult for the people we worked with than for others.

### **Transforming Care and this project**

#### **People wanted to get involved but were still in hospital**

Some people stay in hospital for many years. We met people who were planning to move from hospital. They wanted to get involved in the project but did not get out of hospital in time.

We met a man at the start of the project whose discharge from hospital was imminent. He was very excited about being part of the project and how we could help him reconnect with his old life. He has autism but no recognised learning disability. This, and additional discussions about finance, have delayed his discharge from hospital. There have been lots of discussions about the organisations responsible for his future support and funding. We kept in touch with him and his mum and helped him contribute to a local consultation on heart disease being run by NHS England. He is still in hospital and this is stopping him from getting his good life.

**A focus on positives is needed and welcomed**

The Transforming Care work has a strong national focus on numbers and targets. People we met said they were sad that there is much less focus on people and possibilities. This work to tell positive stories was welcomed by almost everyone we talked to.

**Some people have had very bad experiences of health and care services**

Many people told us about bad experiences they had had using health and care services in the past.

“Being called back to hospital over and over again has a deep impact on people. Some people have a deep fear which they have learned from the system. They say things like ‘if I don’t behave they will put me back in hospital.’”

Provider

“We should be pulling out all the stops to avoid readmission.”

Provider

**It is hard for some people to think what might be possible**

Many of the people we met have spent a long time in hospital or prison. This means they might not have much experience of a good life in their community. It might also mean they find it hard to know what might be possible.

“For people who have lived in long-stay hospitals for some time, it can be difficult to find out about their interests and what they like to do, as [their] opportunities have been so limited.”

Provider

**Legal rules can make it difficult**

People who may have broken the law in the past often have rules about what they can do and where they can live and go when they come out of hospital or prison. It can be hard to find ways for people to do things in their community without breaking these rules.

“People with forensic histories face huge barriers in finding work and meaningful activities. Finding organisations willing to take a chance with this can be hard.”

Provider

## Transforming Care in the Black Country

**Everyone we connected with is putting people at the centre**

Most of the commissioners and providers we met are working really hard to put people at the centre.

“It was a pleasure to see the change in the individual and how their self-esteem has grown and they are motivated to try out new activities and take pride in what they are doing.”

Provider

**Having a medical approach can stop professionals focussing on the person**

Lots of people we spoke to talked about the need to focus on people, their strengths and hopes and dreams. Sometimes this gets forgotten and the person's challenges become the main thing that everyone is thinking about.

“There is a clear steer towards the medical model, which leaves you sifting through information and opinion until you find the real person underneath.”

Provider

### **Commissioning the right kind of support is very important**

Commissioners are key to the person getting their good life with the right support in place.

*“The support that is commissioned needs to be fluid so that rotas can adapt when things get tough.”*

**Provider**

### **Helping people to dream and make dreams happen is sometimes missing**

Most of the professionals and supporters in people’s lives were very good at putting the person first. They were working hard to support people in the best possible way even though this was sometimes difficult. Although commissioning and support for people is very person-centred, sometimes it is not as aspirational as it could be. The system does not always help people to live their whole life with a past, present and future. It does not always help people to dream and plan to make those dreams come true.

### **Fear of what might go wrong can get in the way**

Some people may present risks. They might hurt themselves, or potentially members of the public or the people around them. Working with people to keep them and other people safe can be challenging. This is especially true if time and resources are tight. Sometimes supporters can get too worried about the risks and what might go wrong. This can mean they find it hard to help people to try new things and chase their dreams.

*“I find often organisations say they offer so much but in reality don’t always provide the quality they should, focussing on managing and containing behaviour rather than on building on strengths of the unique and different person.”*

**Commissioner**

### **Issues around health and medication need to be addressed**

Some people have health conditions that need regular checks and treatment. Some people might find these checks and treatment difficult to understand or consent to. Professionals need to find ways to get people the checks and treatment they need, even if this is difficult.

# Top tips for decision makers, professionals and supporters

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1. **Start early**

Don't wait for me to move into my new place. Start while I am in hospital.

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2. **Remember my history**

Understand the impact the health and care system has had on my life. Don't forget you are playing a part in how my life looks in the future.

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3. **Work with all the people in my life**

You can't do this on your own. Partnership is very important, and everyone must work together. My family and friends might be the people who know me best. If they are, bend over backwards to learn from their experience.

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4. **Focus on the positives**

Start by thinking about my strengths, what I am good at and all the things I care about. Don't focus on the challenges I face.

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5. **Find out about my dreams**

Use what I am good at and what I care about to learn about my dreams and aspirations.

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6. **Stretch further than person-centred**

Think about the kind of creative and consistent support I will need to reach my dreams. Not just 'what shall we do today'.

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7. **Don't let the risks take over**

Think about my ideas before considering the risk. Then explore how to make things happen in a positive way that takes account of the risk and manages it carefully, without allowing it to mask everything else.

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8. **Understand what my community can offer**

Find out about local opportunities and resources. Discover who might be able to help me get involved.

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**9. Understand what I might offer my community**

Discover what is needed locally. Help me think about ways I might be able to use my skills and strengths.

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**10. Help me meet new people and make new connections**

We all need people in our lives – and not just people who are paid to spend time with us. Help me to make new connections and develop friendships and relationships. Having new people in my life could open up all sorts of opportunities for me.

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**11. Plan for my good days and bad days**

Don't let the possibility of a bad day stop positive, creative planning. Don't let a good day go to waste.

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**12. Recognise and celebrate all achievements**

I might have had a difficult life. I might face lots of things I find challenging right now. Success looks very different for different people. Make sure you spot and celebrate all my achievements – even if they look tiny to people who don't know me very well.

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**13. Hold my dreams through good times and bad**

My circumstances might change for the worse but I am still good at things and still have my dreams. If I have to go back into hospital don't forget all that. Make sure your systems help me remember all the good stuff and reconnect with it once I am well enough.

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# Appendix A

## What Community Catalysts did

What Community Catalysts said they would do	What Community Catalysts did
1. Tell people about the project	<ul style="list-style-type: none"><li>• worked with the LGA to write project information; put it on the LGA and Community Catalysts websites</li><li>• told people about the project using blogs, social media, articles, and presentations at lots of events</li><li>• reported to the empowerment steering group.</li></ul>
2. Make connections	<ul style="list-style-type: none"><li>• talked to commissioners from all four areas of the Black Country and asked them to connect Community Catalysts to people, families, social workers and providers</li><li>• talked to Dudley Voices for Choice who represent people on the local Transforming Care board and engagement group</li><li>• met the autism drop-in group who said they would help</li><li>• met nine different care providers who are working with people</li><li>• met the NHSE right care pathways lead, brokered local introductions.</li></ul>
3. Understand what else is happening	<ul style="list-style-type: none"><li>• asked commissioners about what is happening in the Black Country with Transforming Care</li><li>• read information on Transforming Care in the Black Country</li><li>• talked to people in Wolverhampton and asked why they have found no people to be part of the project.</li></ul>
4. Write tools	<ul style="list-style-type: none"><li>• decided who should be involved in the project</li><li>• wrote easy read tools including:<ul style="list-style-type: none"><li>◦ information about the project for people and their families and supporters</li><li>◦ forms to write down what people do and what changes when they do it</li><li>◦ consent forms for people who wanted to be involved</li><li>◦ a process map so that people, families and professionals could see how we would work.</li></ul></li></ul>

What Community Catalysts said they would do	What Community Catalysts did
5. Connect with people who have been discharged from hospital	<ul style="list-style-type: none"> <li>• met people from the Black Country Transforming Care Partnership, local commissioners and key stakeholders</li> <li>• gained an introduction to 14 people across three areas: Dudley, Walsall, and Sandwell &amp; West Birmingham.</li> </ul>
6. Understand the good things locally	<ul style="list-style-type: none"> <li>• explored the good things that are happening in the four local areas; worked with Dudley Voices for Choice and other local people to capture their knowledge</li> <li>• talked to people who run community organisations and asked them to help</li> <li>• visited a local lifestyle centre, the only centre of its kind in the UK: it has excellent facilities for people with disabilities.</li> </ul>
7. Meet people and help them get their good life	<ul style="list-style-type: none"> <li>• 14 people were put forward to be part of the project: six people from Sandwell &amp; West Birmingham, six from Dudley and two from Walsall</li> <li>• three people decided not to get involved and one became unwell before Community Catalysts had a chance to meet her</li> <li>• met 10 people: five from Dudley, one from Walsall and four from Sandwell &amp; West Birmingham</li> <li>• nine people had been discharged from hospital in the last 12 months and one person was planned to be discharged soon after the start of project</li> <li>• the discharge plan for the person in hospital did not go as expected and they are still there</li> <li>• one person didn't need help from Community Catalysts but was proud of their achievements and wanted to share their story as part of this report</li> <li>• worked with 10 people to find out what they are good at and what they care about and to explore their community connections and aspirations</li> <li>• gained commitment from the people who support them to take forward activity once the project has ended.</li> </ul>

### What Community Catalysts said they would do

#### 8. Write down stories and learning

- listened to people's stories
- captured them in a format that can be shared
- worked with people to get their permission to share their story
- did a survey of all the commissioners and providers Community Catalysts met as part of the project
- ran an event for providers and learned about the experiences they have had and the challenges they face.

#### 9. Use stories to influence people

- shared stories and lessons with the Black Country Transforming Care Partnership board
- shared learning at national Transforming Care events
- shared stories and lessons with people, families, providers and commissioners.

# Appendix B

People's stories: Jack (page 21), Jamie (page 23), Sharon (page 25), Eunice (page 27), Simpson (page 29), Jackie (page 31), Philip (page 35) and Chris (page 37)

All the stories were written using information shared by the people themselves and/or by people who care about them. People have chosen their own pseudonyms (the names used here are not their real names).

## Jack's story

Jack is a quiet man and is a very considerate and caring person. Jack likes to go shopping for clothes – Adidas is his favourite label. Jack also likes to collect bird ornaments, displayed in his bedroom alongside a range of family photos including a cushion with his mum's picture on it. This is very important to him. Jack is a West Bromwich Albion football fan. He has been to watch them but he found the atmosphere at the ground difficult, with people shouting a bit too much at times. Jack enjoys working outdoors with wood and has recently rediscovered his talents as a photographer.

### What Jack is good at and cares about

Jack cares about his family. His brothers and sisters are important to him. Jack has recently reconnected with his sisters after nearly 30 years and is relishing being able to communicate with them on Facebook, meeting with them whenever possible. His sisters live in another area of the Black Country which is not easy for Jack to reach on public transport. Jack is also enjoying being able to meet friends that he had lost touch with.

Jack has recently rediscovered his enjoyment of and skill in photography. He has taken a great photograph of a sunset and has had this printed onto a fabric frame. It is displayed on the wall in the lounge. He hopes he might be able to enter local photography competitions.

Jack loves to take care of animals, particularly horses, which is something he did in the past. Jack would like to work with animals and in outdoor activities again. He has taken some amazing photographs of horses in nearby stables. Jack has recently started a programme at a craft centre where he has focused on woodcraft, making a sign for his house and a bird box. His next plan is to make shelves for his bedroom.

Jack is enjoying the flexibility and increased choice he has since he left hospital. He has recently helped interview for new staff, something that he would not have done a short time ago.

### Jack's experience

Jack has a learning difficulty. His mental health has had the biggest impact on him and his life. Jack has self-harmed since he was 13. He says this was the only way he felt he could release the pain when he was feeling anxious. Jack's past life experiences have impacted on his mental health.

When Jack was a child he was placed in a children's home in another part of the country. As an adult Jack has spent many years living in secure institutions, many out of his local area. This included six years in prison.

Before Jack moved to his current home he was in hospital. A transition plan was made for Jack to move out of hospital and into a new place. He had decorated his new room and made arrangements to move.

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This transition lasted 18 months, after which a decision was made that it wasn't the right place for Jack. Jack believes it was due to a lack of staffing. This was a huge disappointment to him and the setback really knocked his confidence. When the transition to his current home was taking place, he says that he 'misbehaved', partly because he felt the same thing would happen again and they would not want him.

Jack struggles with low self-esteem and the belief that he deserves the opportunity to have a good life – a second chance. Jack would hate to go back to hospital or to prison and he worries about this. Jack also worries about his sisters and he is fearful something will happen to them. He worries that one sister, who is unsteady on her feet, might fall down the stairs.

### **The support Jack gets to live his life**

Jack currently lives in a residential home with one-to-one support when he goes out. Jack is building his independence skills, including cooking for himself. Jack has a long-term goal of moving into supported living accommodation.

Jack's care and support provider has identified a 12-week, three-day-a-week training programme for Jack working with pigs and owls, woodcraft and horticulture. The craft centre is 40 minutes in the car from where Jack lives. Jack will have the support and transport he needs to travel to the centre and get involved.

Jack is being supported to talk about his worries and to have more confidence and belief that he deserves the opportunity to have a good life. As Jack builds up trust in his new staff team, he is trying to talk more when he is upset and not harm himself. As Jack's confidence increases he sets himself new challenges, with help from his support team.

### **Jack and 'So what, what next?'**

We met with Jack three times and talked to the staff that support him. We learned a lot about Jack: what he is good at, what is important to him and the things he finds difficult. Together we felt that it would be good for Jack to have a way to use his skills when his current training programme ends. We were worried he might get unwell if there was not something else in place. We talked to the registered manager of Jack's support, the local community development team and the commissioner of Jack's support.

We did some research to find local places where Jack might be able to try something new and contribute his skills to his community. We found out that the RSPB might have an opportunity for Jack to become a volunteer ranger – to help out, enjoy the outdoors and have opportunities to take photographs. We found and visited a local voluntary organisation with large gardens and animals where people can go and help.

We worked with Jack's care and support provider to develop a plan for him. The plan was written to make sure these opportunities are not lost once the project has ended. The registered manager has committed to pursuing the links and information and make arrangements with Jack to take up the opportunities we found out about. They have also connected with another provider to think about how Jack could use his skills and help at their gardens. Jack has also said he is going to do more to develop his photography skills, and his care and support provider has agreed to help him do that.

## Jamie's story

Jamie is described by everyone as a happy person with a good sense of humour. Jamie uses limited speech to communicate but has a personalised Makaton vocabulary of more than 100 words. Jamie loves to go out in his car and enjoys long country walks. Jamie is close to his parents and goes to visit them every Sunday for dinner.

### **What Jamie is good at and cares about**

Jamie is a very sociable young man and likes the interaction and banter with the people who support him, his family and others. Jamie understands and responds to what people say to him most of the time. Jamie's family are very important to him, he goes home each weekend and they also visit him in the week. Jamie has a mobile phone and likes to speak to his mum each evening before going to sleep.

Jamie loves being out in the fresh air. Jamie has enjoyed horse riding and swimming in the past. Jamie likes sensory experiences and the people who support Jamie are creating a sensory area for him.

### **Jamie's experience**

Jamie has a learning difficulty and autism spectrum disorder. He has been looked after by other people since he was 11, when his parents felt they could no longer support Jamie at home.

As an adult Jamie has lived in different types of secure accommodation locally and further away. Jamie has previously lived out of hospital for four years, but this did not work out for him and he went back into hospital. Jamie's social worker says it took a long time to find the right support organisation in the community for him this time.

Jamie likes things to be done in a certain way and has to complete routines. He finds change from this very difficult and can spend long periods of time repeating certain actions if his routine is broken. People supporting Jamie need to make sure they understand Jamie's routines and responses.

Finding the right opportunities and activities in the community that Jamie can enjoy safely is something that needs to be thought about carefully. People who know Jamie say that keeping him safe is the priority. He is a very smart young man and his sense of humour and adventure means that sometimes he can put himself at risk.

### **The support Jamie gets to live his life**

Jamie lives on his own in a detached bungalow that has no immediate neighbours. He moved there in summer 2017 and has had the same care and support provider since then. Jamie has 3:1 support during the day and 2:1 at night.

Following a routine, knowing what is happening now and next, is really important to Jamie. Jamie also gets support from other people who help him and his support staff think about some of the behaviours that may put

him or other people at risk. They try and help Jamie by making sure that all of his support team follow the same routine, making life less stressful for Jamie.

Jamie is getting a new car. The care and support provider who supports Jamie tries to employ staff who can drive his car so that he can get out and about. They look for staff who are patient and can connect with Jamie and his sense of humour; it is important that the people who support Jamie are quiet in their approach with him and respect and understand his need for routine and reassurance.

### **Jamie and 'So what, what next?'**

We met with Jamie twice and talked to the staff that support him. We spoke to Jamie's social worker on the phone several times and also arranged to go to a meeting with her and some of Jamie's support team.

We learned a lot about Jamie, what he is good at and what is important to him. We learned about Jamie's interests and some of the activities he enjoyed in the past.

We found out that Jamie loves to take long walks and might like to help look after the places he likes to walk in. We thought Jamie might also like to contribute to his community in a way that linked to his routines. We thought it might be good for Jamie to try and spend time in a different sensory space.

We contacted a nearby country park to see if Jamie could get involved in some conservation as a volunteer. We also found and visited a local wellbeing centre to talk about Jamie using their hydrotherapy room and sensory room. We thought that the wellbeing centre was good because the people who worked there could help plan visits for Jamie in a safe way that worked for him.

We worked with Jamie's care and support provider and social worker to develop a plan. The plan was written to make sure these opportunities are not lost once the project has ended. Jamie has a senior member of staff who has overall responsibility for his care and support planning. They will work with Jamie to help him test the idea of becoming a conservation volunteer. They will also make contact with the wellbeing centre on Jamie's behalf. Jamie's social worker sees him regularly and has committed to monitoring how things are progressing and the impact these steps are having on Jamie's life.

## Sharon's story

Sharon is a young woman from the Black Country who lives in her own flat. Sharon always makes you feel very welcome when you visit. Sharon is a very kind, thoughtful person who loves animals. As well as being really creative, Sharon is hardworking. Since we first met Sharon she has been unwell. In the past this would most probably have resulted in a hospital admission, but this time it did not. Sharon's story is a celebration of her successes.

### **What Sharon is good at and cares about**

Sharon is a sociable person who likes people and making friends. Sharon loves her own home and has lived in her current flat for about a year. She is conscientious, hardworking and has a passion for keeping things tidy. She really likes music and having the chance to sing and dance. Sharon enjoys shopping and going to the local shopping complex. Sharon also enjoys craftwork and is very good at it. She has a cat at home. Sharon likes to get a good balance between keeping busy and having time to herself to chill.

### **Sharon's experience**

Sharon has a learning difficulty. The thing she finds hardest is her anxiety. Sharon has a good understanding of what causes her anxiety. In the past she has spent frequent periods of time in hospital. Sharon left hospital 12 months ago.

Sharon says she prefers to meet people at organised events and activities. In the past she befriended people, and this didn't work out well for her, so she prefers her social life to be organised with others. Sharon says that her money is managed for her by an appointee because she got into debt in the past.

Sharon recently became unwell. She recognised the main reason for her anxiety on this occasion was a noisy neighbour. The neighbour had always been noisy, but over time Sharon found this very difficult and her anxiety became overwhelming. In the past, a period of anxiety like the one Sharon has recently experienced would have resulted in Sharon being readmitted into hospital.

### **The support Sharon gets to live her life**

When we first met Sharon, she had 26 hours of support a week from a care and support provider. Sharon has several staff who support her with different interests and activities. This means she knows a number of people really well and is not dependent on one or two people.

The manager of the care and support provider, along with the home treatment team, have supported Sharon through the difficult period of being unwell. The manager believes that because the team had built up a trusting relationship with Sharon, this was key in her not requiring a hospital admission. Sharon's support team work with her to recognise and solve problems in her life. They do this by exploring the issue and the pros and cons of different actions before supporting Sharon to make her

own decisions. Recognising that the noisy neighbour was the root cause of Sharon's anxiety, they supported her to find a new flat. Sharon is now well on the road to recovery and has been discharged by the home treatment team. Sharon is focusing on organising things for her new home and making a fresh start. She recently attended an 'X factor' audition.

Sharon attends zumba and mindfulness classes once a week at a local social space. The organisation that runs the space recognised that people often become unwell because there is not enough opportunity for them to connect with other people. They invested in the resource for people to connect, offering a range of activities and opportunities to improve mental and physical well-being.

Sharon is happy to share her story, she is proud of what she has achieved and wants to celebrate this with everyone.

### **Sharon and 'So what, what next?'**

We met Sharon twice at home and at the launch of the social space where she showed us around. We kept in touch with the manager when Sharon was unwell and went to see Sharon at the social space when she was feeling a bit better.

We learned that Sharon has a lot of skills and needs the right support from people she trusts. The support she gets must be flexible and offer what she needs, both when she is well and unwell.

The trust Sharon has with her support team helped her when she was unwell. The other thing that helps Sharon is having a safe space to go, when she is both well and unwell, to meet other people she trusts and spend time out of her flat.

Sharon and the people she trusts are working together to put things in place to support Sharon to have a good life.

## Eunice's story

Eunice has a great memory for television programmes, advertisements and recording artists from the past. You can spend a lovely afternoon with Eunice walking down memory lane. She has a lovely flat which she keeps really tidy. She also loves her garden, watching the birds and going out locally. Eunice loves her tabby cat. Eunice enjoys getting visits from her sisters.

### **What Eunice is good at and cares about**

Eunice cares about her sisters, who visit her regularly. She was the youngest of eight children. Eunice's connection to her early family life is important to her and she has furniture and accessories from her family home, where she lived until she went into hospital the last time. Eunice also has her cat back – he was taken care of while she was in hospital.

Eunice cares about her garden. She loves flowers, birds and is very observant about changes in the environment around her. She has recently started to feed the ducks in a nearby park.

She likes to go to the shops but doesn't like it if it is too busy. Eunice told me that when she was in hospital she used to visit a local country park. Eunice likes nice things. She cares about her appearance and likes to make an effort to dress up when she is having visitors or going out. Eunice also says she used to like swimming when she was younger.

### **Eunice's experience**

Eunice has a learning difficulty. Her fluctuating mental health, including psychosis and depression, can be difficult for her. Eunice has spent time in hospital at different times in her life.

Some of Eunice's early life memories are not positive and these will often be reflected when she is having a bad day. If she is having a bad day Eunice will be very vocal and will sometimes break things if she is distressed. Eunice lives in a quiet but community-spirited suburb in the Black Country. The people who care for and support Eunice are sometimes concerned about the impact her shouting might have on the neighbours, and their response to this.

Eunice was upset that she could not return to her previous home when she left hospital, but having some of her possessions and her cat has helped ease some of the distress. Eunice has diabetes. As she is getting older she has had different treatments to make sure she does not develop any conditions that can be associated with diabetes. She has had laser eye treatment and is having scans to check her blood vessels.

### **The support Eunice gets to live her life**

Eunice had a two-month transition from hospital to her new flat. She moved in September last year. Eunice lives in a downstairs flat; another lady supported by the same organisation lives upstairs. They live in a suburb close to shops with good community links.

Eunice has 2:1 support from support workers during the day. At night she has waking and sleep-in night staff. Eunice is supported to go out locally. Support staff ensure that Eunice attends any medical appointments that she has. Sometimes she cannot attend if she is not having a good day. Eunice's money is managed by a local authority appointee, but there is cash available for Eunice to use to do the things she needs to do like getting a taxi or buying her cigarettes or other items she needs.

### **Eunice and 'So what, what next?'**

We visited Eunice at home five times, but on three occasions she was not feeling great, so we couldn't spend time with her. We talked to Eunice and the staff that support her and found out about her interests and the things that she enjoyed in the past.

We learned that Eunice has a lot of skills, including a great memory. We also found out that Eunice can have times during the day when she feels better than at other times. We thought that it would be good to find opportunities for Eunice in places that interest her but are not too busy and can offer flexibility based on how she is feeling.

We found and visited a local wellbeing centre, where there is a large hydrotherapy pool that Eunice could relax in and practice her swimming. Eunice could use the facilities there for free. We also contacted a user-led charity which offer opportunities for people interested in gardening and growing fruit and vegetables.

The wellbeing centre is managed by a team who are experienced in working with lots of different people. They would understand if Eunice was having a bad day. The user-led organisation works with people with a learning difficulty and people who have poor mental health, and the gardening activities have been designed to be inclusive of people who have difficult days with their mental health.

We worked with Eunice's care and support provider to develop a plan. The plan was written to make sure these opportunities are not lost once the project has ended. Eunice's support team will talk to her about these opportunities. The general manager who oversees Eunice's support will ensure that Eunice's support workers make plans to call into the wellbeing centre on a day that they are out with Eunice. The care coordinator will contact the user-led organisation to arrange a visit.

## Simpson's story

Simpson is a young woman who is very considerate of others – for example, she always asks her neighbour if she needs anything when she is going out. Simpson likes to be active. She loves to walk, shop and visit places that interest her. Simpson says she would like to do something meaningful with her life. She has a message that she wants to share with others. This message is that you need more support for things to get better. Simpson says that before she went into hospital, the support she had was not enough.

### **What Simpson is good at and cares about**

Simpson gets on well with most people. She is proud of her flat and keeps it very tidy. When she first moved she had a lot of belongings and it took a while for her to get her flat looking as she wanted it to. She also likes gardening.

Simpson loves to walk. She also has a bike that she would like to ride more often. She loves shopping and finding a bargain. She also enjoys bowling and visiting the Black Country Museum – she now has an annual pass, so she can visit whenever she wants to. Simpson likes to set herself goals – for example with cooking. She cooked a full breakfast and also helped do the food for her birthday party. Simpson would like to get a job and she has applied to do work experience through her local council, which is promoting this opportunity.

She would like to go on organised trips with a local company now that the weather is improving. Simpson has booked a holiday – she is staying in a log cabin in Derbyshire. Some other people she knows are there at the same time and they may be able to do some things together.

### **Simpson's experience**

Simpson has a learning difficulty. She also has depression. In the past, Simpson lived in her own flat with four hours of support a week and used to attend a day centre. This was not enough support for Simpson and life got very difficult for her. She attempted to hurt herself and was admitted to hospital for two months. This is why she wanted to share her message about the importance of people getting the level of support they need in order to be able to get a good life.

Simpson is a very trusting person, and this has been taken advantage of in the past. She has had experience of financial abuse on the internet as well as people applying for credit cards in her name. She finds it difficult to understand that people would take advantage of her.

### **The support Simpson gets to live her life**

Simpson lives in a flat in a suburb in the Black Country, she moved there in July last year after transition from hospital. She visited her flat three times and liked it. She moved in quickly. Simpson made an agreement with her care and support provider before she moved in. The agreement meant that arrangements were put in place

to protect her from experiencing financial or other types of abuse again. These include putting her phone and laptop away at night.

Simpson has one-to-one support during the daytime and a staff member sleeps in the spare bedroom in her flat overnight. Simpson's support worker goes with her to appointments and meetings and supports her at all times. Simpson's support staff provide encouragement if she is having a difficult day.

Simpson is working with a woman at the job centre who is helping her find a part-time job. She is also looking for training courses that would be of interest and helpful.

Simpson is being supported to build a new life, she is encouraged by staff to do things that will benefit her. Her support team hope that with enough good things in her life, life will move in a positive direction for Simpson – very different to the life she had before.

### **Simpson and 'So what, what next?'**

We visited Simpson three times and also met her care and support provider and the commissioner of the services she uses. We found out about Simpson's skills and interests and the things that she is good at. She told us about some of the activities she enjoyed in the past. We learned that she likes to set personal goals and she told us about her aspirations for the future. We found out about the support that Simpson needs to live her life, her way.

We found out that Simpson likes to keep fit and found and visited a local centre where she could access a gym for free. We also heard how she would love to get a job. We contacted a user-led organisation which offers activities across the Black Country. We thought it was a good contact because it offers opportunities to engage, learn and contribute that fit well with Simpson's interests. It also provides social opportunities to meet new people. The organisation can also help people to develop their employment skills and provides opportunities to practice these. This might help Simpson realise her goal of getting a job.

We worked with Simpson's care and support provider to develop a plan. The plan was written to make sure these opportunities are not lost once the project has ended. In the plan, Simpson's support team have said they will support Simpson to visit the centre with the gym and apply for a pass while they are there. Simpson and her support team will contact the person at the user-led organisation and arrange to have a look around to find out what they offer that Simpson might be interested in. The care coordinator who oversees Simpson's support has committed to ensure that this happens.

## Jackie's story

Jackie is someone who loves a bit of pampering – having a hand massage or going to the hairdressers to get her hair done. Jackie lives in her own bungalow. She has a great view from her bedroom over a large park – this is perfect for Jackie as she loves people-watching.

### **What Jackie is good at and cares about**

Jackie cares about her mum and dad, they come and visit her each week.

The people who are working with Jackie are still finding out what she likes, is good at and what she cares about. Jackie finds her own way of interacting with people when she chooses to. She loves paper – one of the things she likes to do is to take a folded newspaper, unfold it and give it back so it can be folded again and repeat the process. At other times Jackie will choose to spend time on her own.

Jackie came to live in her current home in May 2017. She appears to like it and her mum says she can see a difference in Jackie since she has moved there. It is a bright property, and Jackie has her own private accessible garden. Jackie's mum and dad have helped Jackie and her support staff to choose and buy new things for her home. Jackie has curtains hanging up in her bedroom and lounge, she has rugs and some cushions. Since moving to her new home, Jackie is taking less medication than she did in the past.

Jackie has recently started to sit and watch the television for short periods of time. One of her favourite programmes appears to be 'Little house on the prairie'. She is able to relax, sitting with her support staff. Jackie also really likes water, enjoying long soaks in a bath full to the top with water. Jackie sleeps well at night, which was a problem for her in the past.

In the past, her mum says that Jackie used to like to walk, go out for a drink and enjoyed going out for a drive.

### **Jackie's experience**

Jackie has been looked after by others for most of her life. As a child she did not have much opportunity to go to school and learn different ways to communicate. Jackie does not use speech but can let other people know if she is hungry, thirsty or unhappy about something.

Jackie has a heart condition. When she was in the assessment unit she became short of breath and was admitted to a general hospital. At the time they prescribed medication for her to take. People who care about Jackie worry about the amount of medication she takes, even though it is less than in the past. Jackie has taken medication to help keep her blood healthy for many years. Every Sunday morning, she has to have a small prick in her finger to test her blood. She has a good routine and copes well with this.

The doctors have not wanted to make any more changes to Jackie's medication because she couldn't agree to having a blood test. This has caused a lot of worry for her parents and staff, as they do not really know how well Jackie's heart is working and if she needs all the medication. Since we first met Jackie there have been what are called 'best interests' meetings to discuss how to support Jackie to have a blood test. The doctor came to Jackie's house to take a sample of blood for testing. She has now had the blood test and is waiting for the results.

Sometimes Jackie looks like she may not want to go out for a walk or out in her car. Her way of expressing this is by sitting on the floor or pulling away from staff. It is not clear if she is objecting to going out or if she is uncertain about where she is going and what she is going to do. Jackie's support staff are fearful of her physical health; because she is on medication which makes her blood thinner, they worry about taking her out in case she hurts herself.

Jackie's mum says that Jackie lived out of hospital for 10 years prior to her last hospital admission. Although Jackie did some interesting things with her previous support team, the amount of care and support she received was not enough. Her mum says this was very disappointing because Jackie had a person-centred plan that involved lots of people. Mum says that what people said would be good for Jackie did not seem to happen when she moved. There was a lot of good information gathered that now seems to be lost.

If Jackie is going to be able to try new experiences, building trust and ways to communicate will be really important for her and her staff team. Jackie's parents would like her to go out more regularly to improve her wellbeing. This is one of the reasons they like her new home, as it is opposite a large park.

### **The support Jackie gets to live her life**

Jackie now lives on her own and has 2:1 staff support during the day. Jackie's parents have been a constant support to her all her life.

Jackie's parents found her current home, which is one of six bungalows in a small cul-de-sac. It is close to her parents, so they can pop in regularly. Her dad has put her curtains up and he and mum have helped Jackie to make things nice for her. Her parents don't stay long if Jackie is not in the mood for visitors, but being close by means that this is easy to do. Jackie's parents manage her money for her, and she now has her own car which means she can go out somewhere if she wants to.

Jackie's support staff say that she has changed a lot since they first met her in the hospital unit. The information they had about Jackie gave them quite a negative impression of her. They believe having her own space and support in her bungalow has made the biggest difference to Jackie. Jackie's team have limited information about Jackie's likes and dislikes and this can be a challenge as they try to support her to try new things.

Jackie's parents do know about her likes and dislikes and they share this information and their ideas. Staff have said they would like to take Jackie away for a couple of nights, maybe to a Centre Parcs. This is something they will explore later in the year or next year.

Jackie has fewer professionals involved in her life now than she did when she first moved to her new place.

### **Jackie and 'So what, what next?'**

We met Jackie at her home and also met Jackie's parents and talked to Jackie's mum on the phone several times. We also met with Jackie's support staff on two occasions and spoke to them on the phone. We learned what has happened to Jackie in the past and what her parents would like for her future. We found out about some of the activities that Jackie used to enjoy in the past. We realised that the support staff worry about Jackie, and in particular about taking Jackie out, because of her heart condition.

We looked for somewhere nearby with a hydrotherapy pool where Jackie would feel safe and could relax. We found and visited a local wellbeing centre and learned more about what they offer. We found out that lots of different people spend time at the centre and that the staff at the centre can support people if someone gets upset or is finding things difficult. We thought the wellbeing centre would be ideal for Jackie because it had lots of activities that Jackie would enjoy and isn't too far from her home if she used her car.

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We thought it was somewhere Jackie could go on a regular basis to give some structure and familiarity to her week. It offers a very relaxed environment and people would understand if Jackie changed her mind about doing an activity. There were lots of rooms that Jackie could relax in if she wanted a quiet space, and lovely grounds outside with an accessible path which would be safe for Jackie.

We met with the area community development team because we thought they could help find local activities that are happening in Jackie's area that might work for her.

We sent Jackie's staff team information about a consultation workshop on heart disease being run locally by NHS England. We thought that it would be good for Jackie's staff to attend the workshop on her behalf to learn about how heart disease affects other people. We also thought Jackie's experience could help NHS England by sharing the experience of someone who has a heart condition and does not have the capacity to consent to treatment or tests.

We worked with Jackie's care and support provider and family to develop a plan. The plan was written to make sure these opportunities are not lost once the project has ended. Jackie's team have visited the wellbeing centre but their plans to take Jackie were altered by her having an unsettled period. The plan shows that they will help Jackie go to the centre and try and make this a regular day.

They plan to book the hydrotherapy pool. Jackie's parents say that she has plenty of money to pay for the sessions. No one attended the NHS England workshop on Jackie's behalf.

## Philip's story

Philip is a young man with lots of aspirations and ideas about his future. Philip has many interests, similar to other young people of his age. He loves music, gadgets, his phone, shopping, dancing and visiting theme parks. Philip also enjoys swimming and going to college. He likes to be busy and active. Philip is very sociable and likes to talk to you about his interests, as well as finding out from other people about their interests. Philip likes to hear other people's opinions. Philip's biggest wish is to have a girlfriend, he has very specific ideas about the type of person he would like to meet.

### **What Philip is good at and cares about**

Philip's family are very important to him, he visits his mum every Sunday. Philip loves to be busy and know what is happening next.

Philip enjoys cooking but is not enjoying his current cookery course. He prefers food that has more spice, specific to his cultural heritage. Philip's Mum says that when he was younger he would help with preparing and cooking food at home such as dumplings, fried chicken and salt fish. Philip says the course is too simple and that everyone takes a turn at preparing one shared item. Philip has many skills in cookery, so he finds this boring.

Philip would really like to do a computer course at college in September. He says he would like to get a job somewhere like a cinema, where he can use the

computer to book people in.

A cinema would be a good place to work, he says, because he could also watch the films. Before he went into hospital Philip was doing a painting and decorating course. Philip says he enjoyed the course because it was in-depth and structured, and he felt it would help him to get a job. Philip's mum would also like him to do something for two or three days per week; something that is practical and can help Philip with employment in the future.

Philip was happy to share his story, he says he likes attention and would like to be an actor on television one day. He loves watching films. He has a big TV in his lounge and a media package so that he can watch his favourite films when he wants to.

Philip also likes music, dancing and the opportunity to meet other people. He goes to a disco organised for people who have a learning disability twice a month. He says he would really like to go to a nightclub.

Philip loves his phone and uses it to take photos. He also uses the internet to find what is happening locally and will look for things he is interested in. Philip likes his bungalow and has helped to choose and put together furniture for it. Philip has a bicycle and rides along the enclosed driveway outside of his bungalow. His staff do not have bikes, so he cannot go riding with them. He has talked about buying bikes for his staff.

Philip also enjoys swimming and has it on his planner to go weekly, although this is dependent on certain staff being on duty who will go swimming, and whether there is access to the car and a driver.

### **Philip's experience**

Philip wants to be doing things all the time and he often thinks and talks about what is happening next, before he has finished what he is doing. Philip does not always see the danger or risk of some of the things that he does or wants to do. This is a particular issue with the internet, where he will share his personal details with people.

Philip is very focused on having a girlfriend. That is his biggest ambition.

Philip has 2:1 staff during the day and because of this using public transport is expensive. Philip has to pay for his staff to travel which means he does not use public transport often. This can be isolating for him.

### **The support Philip gets to live his life**

Philip lives in a bungalow in a suburb in the Black Country. He has lived here since he left hospital in October last year. Philip has 2:1 support during the day and one-to-one support at night. The manager of the care and support organisation says that all staff like to work with Philip because he is very active and enjoys doing lots of different things. The people who support Philip try to help him stay focused on a task or activity and help him to refocus when he becomes distracted.

As Philip's support staff are getting to know him they are trying to create a more structured plan for Philip.

Philip has restricted access to the internet at night and supervised access with staff during the day. This arrangement is designed to keep Philip safe and is part of the agreement that Philip made when he left hospital.

Philip has a plan on his wall of what he is going to do that week. He can change it each day. Certain staff take him swimming but not all staff can drive the company car.

### **Philip and 'So what, what next?'**

We met with Philip four times and also talked to his mum and members of his care and support team. We learned that Philip has a lot of skills but needs support to find the right opportunities. He has a lot of ideas about what he would like to do and is very active. He told us that he is often signposted to activities for people with more complex disabilities than he has. He finds this boring and it is not helping him to develop his skills. We did some research and found a cycle pathway at a local country park where Philip could take his bike and hire bikes for his staff. We thought that hiring bikes initially would help Philip find out which staff enjoyed riding a bike. We also thought that going to the country park would be safe place to ride the bikes, as the roads can be very busy and not a good place to practice.

We also found some information about local volunteering opportunities that might work well for Philip. We thought it would be helpful for Philip to talk to an organisation about volunteering, to help him build up experience whilst making a community contribution. He could put it on his CV to help him get a job in the future.

We looked at the local college and what courses they had. We knew it was important for Philip to talk to someone at the college quite quickly, so he doesn't have to wait another academic year. We thought it was really important for Philip to enrol on a course that would give him the structure he is looking for and also help him achieve his aspiration to get a job.

We worked with Philip's care and support provider to develop a plan. The plan was written to make sure these opportunities are not lost once the project has ended. Philip and his support staff said they would discuss the information we sent about opportunities. They said they would share it with the other support staff. Philip said he would think about the voluntary work, but he really wanted to be paid to work.

We shared the college contact details with the operations manager. In the plan, she says she will make sure that Philip is supported to make an appointment about future college courses. Philip, his support staff, team leader and registered manager have agreed to work together to make these changes to Philip's life.

## Chris's story

Chris likes a quiet life and his own space most of the time. Chris has many interests which include trains, buses, plane spotting, gardening and doing jigsaw puzzles – often of steam trains. Chris likes to talk to people if he knows they are interested in his hobbies. Chris loves to go to the shop to buy scratch cards and do the lottery. Chris has a good sense of humour and enjoys banter with people. Chris likes to have control over when he sees people. He makes it clear when he doesn't like someone.

### **What Chris is good at and cares about**

Chris often talks about his childhood, parents and grandparents and likes to look at photos of when he was younger. Chris has a good relationship with his sister, who visits every week and phones every Sunday.

Chris spends a lot of his time thinking about and 'spotting' trains, buses and, to a lesser extent these days, planes. Chris often visits his local train and bus station. He keeps a log of each vehicle he has seen and is very organised. Recently, Chris went to a new train station with his support staff. It is busier with more tracks and trains and provides more opportunity to collect train tickets, which Chris likes to do. Chris also loves steam trains and steam train models and he has several on display in his bungalow.

Chris likes gardening and has two raised beds in his shared garden. He has planted a small tree in each, is sowing seeds and has more plans and ideas for his garden. Chris likes to look at photos. He has lots of photos of the things he has done, as well as photos of his family.

More recently Chris has developed an interest in big trucks. He has lots of magazines about them that he collects.

### **Chris's experience**

Chris has a learning disability, complex epilepsy and anxiety. Chris has spent many years in different hospitals, far away and nearer to home. Chris was very unhappy in hospital and found it a very difficult place to be. It has made Chris worry about things and means it is hard for Chris to trust other people and make friends. It has made it hard for Chris to think about his good life and future.

When Chris is anxious he will scratch his legs until they bleed, sometimes very badly. Chris also has complex epilepsy and sometimes needs emergency medication to stop his seizures. Chris needs people around all the time to make sure he is safe if he has a seizure.

Chris likes to be on his own, so having people around all of the time is something that he doesn't always like. It was recommended that Chris have a sensory pad under the mattress of his bed. The pad would detect if Chris had a seizure at night and would raise an alarm that would let staff know.

This upset Chris and he removed the pad. Chris understands why the pad is needed and is being given time to think about his decision. It has been agreed that if Chris is still unhappy, all the people who support him will respect his wish not to use it.

Chris can get upset about other men who live nearby using the garden. He also worries about what they think of him. Chris can get angry sometimes but will usually feel sorry about that once he has calmed down.

### **The support Chris gets to live his life**

Chris lives in his own bungalow, with a lounge/diner/ kitchen area, bedroom and wet room. Chris's bungalow is in the garden of a house where four other men live. Chris moved into his new home at Christmas so is still getting used to it and getting to know the people around him. Chris's supporters are still learning when he wants his own company and when he wants people around him.

Chris is supported by a staff team that work for an experienced care and support provider. Chris has two support staff with him when he goes out. Chris decides where he wants to go and what he wants to do. Staff also help Chris to think about doing new things and going to new places. Chris goes shopping most days and there is a car that his staff can use if this is needed. Chris has used public transport but finds it expensive to pay for a ticket for himself as well as two support staff.

Chris is supported by the district nurses when his legs need dressing due to the scratching. At home, staff need to be around in case Chris has an epileptic seizure. They also need to give Chris time on his own when he wants it. To do both things, they visit Chris's bungalow often but only stay for a few minutes. Chris does not like staff to stay in his bungalow all night, so they pop and see him every 10-15 minutes. Chris is happy with this way of doing things.

### **Chris and 'So what, what next?'**

We met Chris several times and also talked to his support staff. We learned a lot about Chris, what he is good at and what is important to him. We found out about his interests and train spotting in particular.

We thought it would be helpful if the people who support Chris learnt more about his interests. We felt that this would help them to build a good relationship with him. We also recognised that, through his passion for trains, Chris could connect to a wider community of people who share his interests. Through this connection Chris could meet more people, widen his social network, develop his hobby and get an even better life.

We researched trainspotting and found some local connections. We also researched a trainspotting forum where people from around the country engage, share news about events, share information about trains and share their preference for different models of trains.

We worked with Chris's care and support provider and social workers to develop a plan. The plan was written to make sure these opportunities are not lost once the project has ended. We shared all the links and explored opportunities with Chris and his support team. The deputy manager has a very good relationship with Chris, as does his key worker. We talked about including the information in staff induction, to help new staff get to know Chris. We thought about how Chris could help with this. The plan said that Chris's key worker would help Chris to join a forum to connect with people and find out what is happening locally.



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