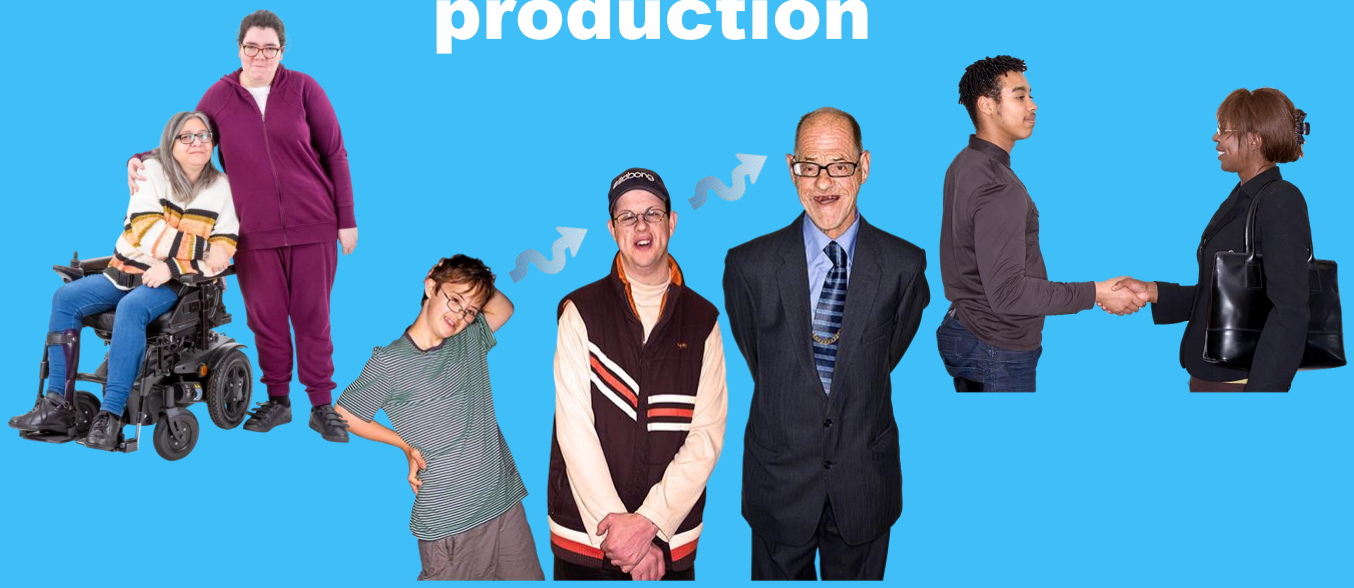
IMPACT
Improving Adult Care Together

Economic and Social Research Council

The Health Foundation

IMPACT Network – Carers, transitions and co-production



This leaflet is in Easy Read

What is the issue?
Why are care transitions difficult for both people in transitions and their carers?

How is co-production being used?
Can we improve how people in transition and their carers are supported through working together?

What do you think?
Questions for your network to think about before our meeting.

Introduction

IMPACT
Improving Adult Care Together
Economic and Social Research Council
The Health Foundation

This leaflet has been made for the **IMPACT local network meetings.**

It is to discuss the difficulties facing people and their support networks going **through transitions in care**.

To do this we look different research about **carers, transitions and co-production**.

We talk about people's lived experiences and look at case studies to see **how people are tackling issues.**

This leaflet is in **Easy Read**. Easy Read makes information accessible for people with Learning disabilities. We do this by using **Plain English and pictures.**

Introduction

We will go into **different examples across the UK** and talk about **how services are supporting people in transition.**

We will **discuss what coproduction is**. We will look at the barriers to co-production and **why it's important.**

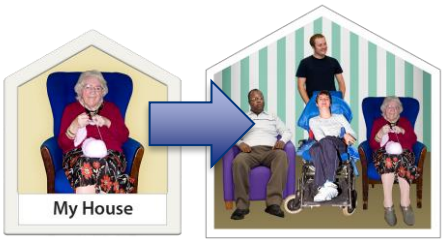
We also look at how services are improving carers experiences **of transitions by using co-production.**

We would like everyone to **read this leaflet before our session**. At the end of the leaflet, there are questions you may want to make notes on.

What’s the issue?

Transitions means to move from one thing to another. Transitions in care means that **someone's care needs are changing or** they now need care when they didn't before.

When we hear people talk about **transitions in care, or transition age,** they usually mean someone who is moving into adulthood**.**



This isn’t always the case though. Transitions can also be about someone’s **care needs changing at any age.** This could be moving to somewhere with more support.

It could also mean someone’s condition has changed**, meaning they now need different support.**

The important thing to remember is **transitions are different for everyone.** Transitions can affect **people's experiences of care.**

What's the issue?

Children with disabilities should continue to receive **social care support until adulthood.** They should transition to **adult social care services.**

But this transition into adult services **doesn't always go smoothly**. Lots of people saying the care they receive **after transitioning is very different.**

These transitions also bring big **changes to family carers.**

Family and unpaid carers face big changes in their lives if they need to **give someone more care and support**. The same is true if someone they care for **transitions into living independently.**

People have said that **big changes and transitions** can be quite a shock when they are unprepared.

What's the issue?

Research show that **transitions are stressful** for both the person going through the changes and the people who care for them.

This is especially true for informal or unpaid carers, which our network focuses on. For **example, family, friends or guardians.**

We want to look at how carers can be **better supported in transition times.**

Sometimes carers feel **forgotten or taken for granted by services. Austerity** in the UK cut funding for social care. Families and unpaid carers are expected to do more, putting extra pressure on them.

This Network aims to explore how carers and people in transition can be more **involved through coproduction**. We will go into coproduction in detail in a later sections.

Find out how different parts of the UK help people through transitions in the next section.

What are people around the UK doing?

In this next section we are focusing specifically on transitions from **children's to adult's services in social care.**

England

Transitions from children's to adult social care services should begin when someone is in their early teens

The aim is to make sure that someone has a worker to help with their changing needs and making sure there are no gaps in services.

Guidelines say someone must have a needs assessment before they turn 18.

These guidelines come from the Care act in England.

England also offers **an Education, Health and Care Plan** for people with additional support needs up to age 25.

Local authorities, **like the council, are responsible for this support**. They must also tell parents and carers about assessments and plans.

What are people around the UK doing?

Wales

Transitions should start in early teenage years. There is a big focus on planning and reviewing care to make sure people are looked after and happy.

The Social Services and Wellbeing Act says that local authorities must support young people with special needs up to 25 years old.

Schools have to give additional support plans for children who need extra help with learning.

When children **turn 16 they should have a plan to help them transition**. These plans build upon the child's existing care and support plan.

Health and social care teams **should work together** to make sure that the person and their carers are **involved in making decisions.**

What are people around the UK doing?

Scotland

In Scotland, the transition process begins when someone is between 12 and 15 years old.

Children have the right to an advocate at their meetings and appointments.

They can also question decisions and ask for a coordinated support plan.

The Carers Act, the Additional Support for Learning Act, and the Adults with Incapacity Act all have guidelines on transitions.

At 18, children legally become adults, but this **does not mean** they must make decisions alone. Parents and carers can be closely involved in helping their **child receive ongoing care and support.**

Local authorities and schools must work together at least 12 months before somone leaves school to prepare them for adulthood.

What are people around the UK doing?

Northern Ireland

In Northern Ireland, the transition from child to adult services happens around the ages of 16 to 18.

The Carers and Direct Payments Act has guidelines on this. The process involves talking about transition plans in the teenage years to focus on future goals and aspirations.

Health and social care professionals should work together to make sure assessments are done for someone's ongoing needs.

For children who need **end of life care,** there needs to be a plan in place six months before a transition happens.

Guidance and support is provided by health and social care professionals. They work with parents and carers to make sure the **young person's needs are met.**

Transitions are difficult for people going through them, but what about their family and carers?

Transitions and carers

Something that is often missed is how much **Transitions affect everyone involved.** This includes the person experiencing the transition and **those who care for them.**

What needs to be looked at is **how disabled people and their carers** experience transitions in care.

There was a study done in 2024 which interviewed **eight pairs of people about their experiences.**

Each pair involved a **disabled person** and someone who supported them as **a paid or unpaid carer.**

This study showed that a transition, such as **becoming disabled or when someone dies**, has a big impact on everyone's daily life

Transitions and carers

People say that **transitions are complex,** emotional, and often more than one happened at once.

People said that transitions came with other life changes, like **moving house or getting a job**, but there were many barriers.

This study also found that people **had small support networks** after a big change or transition, often relying **on one main person for support.**

Another study looked at **unpaid carers** who supported an older adult transition from being in hospital to **being looked after at home.**

It showed how complicated and challenging this process can be. There were examples of older people often getting worse and **needing to go back to hospital.**

Transitions and carers

There was also another study around **young people's transitions.** This was around young people who lived in secure services, like a hospital, who were **moving into the community**.

It focused on young people and **their carers or families.** It showed how difficult it could be for transition to adult services that are very different to an in-patient child setting.

This study found that well-managed and step by step transitions had the best feedback. It was also found both the **young person and their carers** want **support from healthcare** professionals over a long period of time.

Unpaid carers are very important **in transition times.** But they often find a lot of barriers to supporting people. Despite this, not enough is being done to help **support unpaid carers.**

Unpaid carer group suggestions

Unpaid carers have **written guidelines** on how to help improve this system. It has been made with the experience from **Carers groups around the UK.**

Making plans to discharge people from hospital.

Wales: Plan includes patient and carer involvement based on government guides.

Scotland: Must let staff know about plans early, based on Carers Act 2016.

Northern Ireland: Plans start when someone goes into hospital and must involve both the patient and carers.

England: Plans start when someone goes into the hospital, there is someone called a discharge coordinator who manages the plan.

How involved are carers?

Wales: have to be involved if the patient consents.

Scotland: have to be involved if the patient consents. Something called a Guardianship or Power of Attorney applies if patient is not able to consent.

Northern Ireland: have to be involved if the patient consents. Carers' views about what is best are considered.

England: must be involved if the patient consents. Something called Power of Attorney applies if patient is not able to consent.

Unpaid carer group suggestions

Discharge Paperwork

Wales: There must be written care and support plans and a discharge letter to their doctor within 72 hours.

Scotland: There must be written care and support plans and a discharge letter to their doctor within 24 hours.

Northern Ireland: There must be written care plans and a discharge letter to their GP within 24 hours.

England: There must be written care and support plans and a discharge letter to their doctor within 24 hours.

Carers rights

Wales: Wellbeing assessments for carers. Ways for carers to complain.

Scotland: Support assessments for carers. Ways for carers to complain

Northern Ireland: Legal right to a carers assessment. Ways for carers to complain.

England: Workplaces provide flexible working and emergency leave if someone is a carer. Ways for carers to complain.

Support after leaving hospital

Wales: Free care after hospital for six weeks. Longer if someone has complex needs.

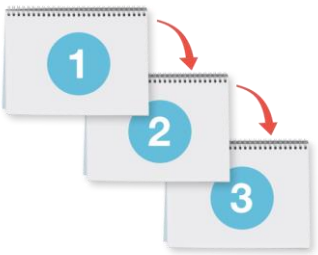
Scotland: Free care and support for six weeks. End of life care is also free

Northern Ireland: Free care and support for six weeks. End of life care is also free.

England: Free care and support for six weeks. Longer if someone has complex needs**.**

Helpful questions to ask during a transition

Another study was done with Carers UK on how to check if a **transition is being managed properly**. They suggest asking different questions to **make sure things aren't missed.** The questions are:



Has everyone involved been told what will happen **before, during, and after** the transition process?

What support will be available? Does someone know how they will **manage their care and support?**

Has everyone been told what **advocacy, information and advice** services are available?

Are people aware of **all the benefits and support with money** they could be given?

Have they been given information **about organisations or services** that can help them?

Transitioning to being a carer

Some studies have been done about the **challenges facing** people when they become an unpaid carer.

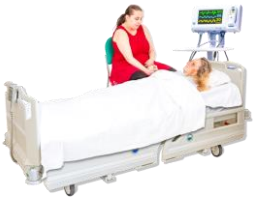
Examples of unpaid carers are **often friends, family, and partners** of people who become unwell or disabled and now need care and support.

Every year **12,000 people** become carers in the UK.

Studies show that when people become carers their mental health is often affected. This is particularly the case for **women under 50**.

A lot of people under 30 reported their **Physical health** got worse too.

Transitioning to being a carer



Several studies found that people's well-being was most affected for carers aged **30-64 and carers helping with intensive care.**

Another study looked at the support needs of unpaid carers for **older adults coming out of hospital.**

The carers in this study said how important it was to **include them in care planning.**

Current care planning around transitions often **doesn't include carers.** This can often mean things **don't go as well as they could.**

Carers also said that different teams working on helping someone **don't always work together well.** Involving the carers as a key part of the team **would help this.**

Getting professionals and communities involved in transitions

Improving transitions in care involves more than just the **person transitioning and their carers.**

Community involvement is important. Everyone should know how transitions work, and what **extra support** might be needed.

If we want to help people **stay out of hospital** and be looked after at home, we need to make sure people and their carers **are supported in the community.**

A review that focused on **transitions for older adults.** It showed that good communication among professional groups made a difference.

This included making sure different teams had access to the right information, **staff were trained on transition support**, and people and their families had resources and support.

Co-production, lived experience and the benefits

Badly managed transitions can make people's health get worse and add extra costs to health and social care.

Early planning and **making detailed plans** can help make transitions smoother.

But research also shows that **current policies around transitions** are not as person-centered as they could be.

Transitions planning **needs to be flexible**. It needs to know that transitions put a lot of strain on people, and it **is not a one size fits all process.**

Services need to make sure caregivers have support. This is very true **for younger carers,** who often need more support to make sure their **health and wellbeing doesn't get worse**

Co-production, lived experience and the benefits

Lots of different people and professionals want **social care to change**.

A report from the House of Lords showed there needs to be a move away **from social care doing things for people,** not with them.

For this change to work, we need to look at **co-production.**

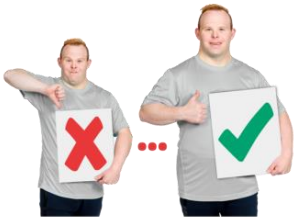
Co-production **means working together**. It is a way of working that sees people as **experts by experience** and involves them in decisions about their care.

Co-production **tries to make this process equal.** This can be hard to do but it helps people have ownership of their care and their lives.

Co-production, lived experience and the benefits

People with lived experience want there to be more research done into **coproducing social care.**

On an individual level, people say that being involved **makes them feel valued.** It can help with rebuilding confidence and being happier with their care



People have said that their **health and well-being** has improved when they are involved in services.

Co-production also has a positive effect on the **whole community.** It promotes diversity and gives a voice to often underrepresented groups.

Public service workers say it also supports better use of their resources and makes it easier to get **feedback from people.**

An example of co-production used in social care

A study was done to develop **digital support for carers** to access for support. It was made because people wanted to **support carers of older people** living in their own homes.

As unpaid carers are often friends and family, there was a need for **accessible and flexible support** for their own wellbeing.

This study **used co-production.** It involved carers and services to look at how web-based support can **help carers' challenges.**

Four big challenges were found in this study:

how difficult care can be for carers

Not knowing what to do, or what support is available

Being able to look after people without a support network

Not enough time for other responsibilities.

An example of co-production used in social care

It was also found that **local health and social care services** were under-used by carers.

The study found that carers could see the **web-based resources helping**, but said they wouldn't always know where to start.

To tackle these challenges, the study focused on **educating people on how to use it** and looking at the barriers carers face.

A resources online library was developed. It included links to things like **websites, guidance, and videos.**

It also had a **journal and mood monitor** to help people manage what they were doing and how they felt.

Barriers to co-production

Doing good co-production means looking at what could stop people taking part. Here are some of the barriers:

- Bad communication and information
- Not being well enough, mentally or physically, to take part.
- Thinking someone isn't able enough to take part
- Challenges with safeguarding
- Knowing how to get involved.

- High turnover of staff
- Bad past experiences with services.
- Language barriers, including too much jargon.
- Lack of money and support to go to meetings
- Researchers have control, not an equal partnership

These things stop people getting involved in co-production. They need to be considered when planning projects.

Case study- Homes from Hospital and North East Lincolnshire

The **Home from Hospital Service** created a support system for people in North Lincolnshire. The service is designed to help patients **transition from hospital to their homes.**

It thought about different things that affect this. Like **transportation, home safety checks, medication collection, and emotional support.**

It also included using **community and voluntary sector resources**. The service supports informal carers as well.

Its aim is to **keep people out of hospital.** It also wants to improve people's health overall and **reduce use of health and care services.**

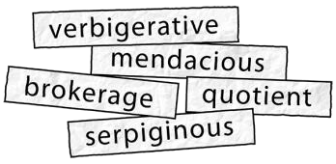
This service uses **co-production.** There is a big focus on **working together locally** and involving trained staff and volunteers.

Case study- Carers Guide to the hospital

The **Carers Guide to the Hospital** was created by the Carers' Voice group. It provides information and practical tips for carers supporting someone in hospital.

For example, it has advice about obtaining the **ward's direct phone number**, sharing important **documents and communication needs.**

The guide reminds people of the **carer's right to be involved** in care discussions if they have consent or **Power of Attorney.**

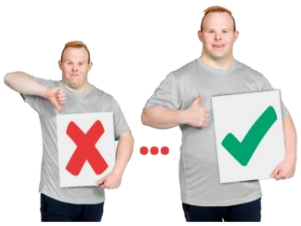


The guide also includes a **jargon buster** to help carers understand hospital language.

It also reassures carers that it is okay to **say no to the role if it becomes too overwhelming.**

Problems with Co-production in transitions

While **research on co-production** shows there are positives to working this way, there isn't enough **research into co-production and care transitions**.



The research available combining these subjects mainly focuses **on making people feel more confident about their transition.**

Other studies show the need for inclusively co-producing public services. Work needs to be done to **engage marginalised communities too**.

There was a study that looked at barriers in co-production for **young people in the care system in England.**

The research showed how important it is to make sure **young people take part** in creating and reviewing care services, **rather than having things done for them.**

Problems with Co-production in transitions

Another study about young people in **the foster care system** looked at how bad experiences could impact their overall health.

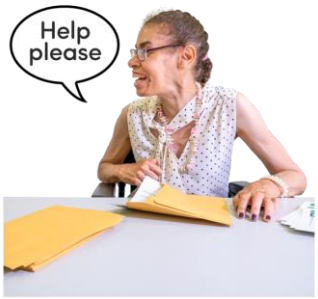
The findings showed that **health was not a top priority** for young people leaving foster care.

They also said social care support was inconsistent, with **frequent changes** in social workers **affecting their transition.**

The study concluded that transitions should be **gradual and supported,** with early preparation and consistent support.

Good transitions should be viewed as a **long-term process rather than a single event.** There needs to be services that work with young people and each other, **or people will have a bad experience.**

Problems with Co-production in transitions



There have also been studies about **peer-to-peer** support for young people. Young people said they felt they could be more open and willing to take part when people **understood what things were like for them.**

Good co-production must be **carefully managed** to make sure all young voices, including those **from harder-to-reach groups,** are heard and valued.

Another study using co-production looked at an **online support system for family carers.**

This went through lots of stages when it was being made. At each stage**, carers were involved in making sure it would work for them.**

From this study, there were lots of **things that carers had in common.** This would have been harder to find without co production. But there were voices that were missed from hard to reach groups.

Problems with Co-production in transitions

A website was made in response to this, including the information **people said they needed most.**

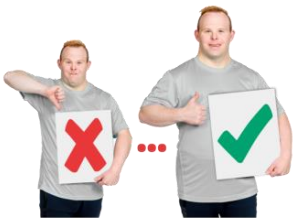
It also had videos from other caregivers to **provide relatable peer support.**

Peer support was seen as really helpful, especially when **services were confusing.**

There was also an option for further professional support, **including a telephone support service.**

Overall, there is not enough research done into **co-production with transition ages.** But there some examples of what work there is on the next pages.

Examples of co production in transitions going well.



Projects about co-production during transitions are starting to **become more common.**

There have been several recent projects focusing on specific transitions. **Here are two examples:**

Redesigning Support for Care Leavers

This project found that **reviewing support** made improvements for both staff and care leavers.

It also gave them **more information about how the system worked**, which helped them in their own care journey.

Providing feedback to everyone involved was important. It made sure that all participants were included in the learning process.

Examples of co production in transitions going well.

Think Local, Act Personal

This is a project focused on improving **personalised, community-based social care**.

It also involved people who work in **voluntary sectors and providing care services.**

This project looked at **individual service Funds**. This is a way of **managing a care budget**. It gives people control of their care without handling money and **employing people directly.**

One part of this project made **guidelines to help put co-production in place**. These guidelines include:

- Creating ways to involve people as early as possible in for **specific projects.**

- Making sure there is **staff time** to support co-production efforts.

- Using different ways to tell people about co-production and **share updates on ongoing work and projects.**

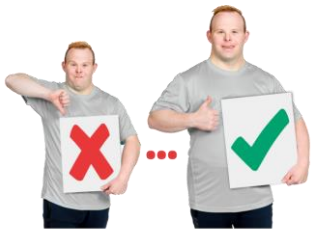
Transitions in care summary

Transitions in social care **need to be seen as complex and personal.** They will vary across different life stages and regions within the UK.

Successful transitions **require early planning,** and good support systems. It also involves everyone, From people who have care, carers, and services.

Co-production plays an important role in improving care transitions. Engaging people with lived experiences in **decision-making** makes care more **personalised and effective.**

Despite the **benefits of co-production**, barriers to taking part must be **thought about for it to work.**



Putting lived experiences into care planning makes the **quality of care and support better.** It also helps people to know what they want and need.

Questions

Having read the material above, in the first Local Network Meeting, we'd like you to **talk about these points in your groups**. You may like to take notes before the next meeting.

Your experiences…

- Would anyone like to share their experiences of transitions in care?
- During a transition, has anyone been involved in co-production?

Thinking about this Leaflet

- Were there any ideas in this document that you thought were interesting and could support improvement of transitions through co-production?
- Are there other things that help during transitions?

- What did you think about the challenges we talked about?
- Are there Any that were missed?

Questions

Thinking about this Leaflet

- What do you think would help to solve these challenges?

- Anything that you didn't agree with, or didn't match your experience?

Next steps

Are there any **next steps** you'd like to agree as a group?

Do you think there is anyone else who should be **involved in your meeting?**

Is there anything you need from **our team at Impact?**

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Extra information and Contact details

There are some details from the strategy not in this **Easy Read booklet to keep it accessible.**

A full version of this leaflet, **including a source list**, is available on request.

Labels are for Jars, not People!
SHEFFIELD VOICES

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