



# Carers, Transitions and Co-production

Discussion material



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### How you can use this discussion material

Before our first session, we'd like everyone to read this document which summarises the evidence from research, practice and lived experience about carers, transitions and co-production. The aim of this material is to spark discussions in your groups about your experiences and ideas for change.

This material outlines:

- Some of the policies across the four UK nations regarding transitions in care
- The implications and challenges of transitions for carers
- What co-production is, its benefits and barriers to it being used in practice
- Examples of how to improve carers' experiences of transitions via co-production.

### What is the issue?

Transitions, including across the lifecourse and between services – such as from hospital, from children's to adults' services or into a residential care setting – can be experienced as 'shocks' or as stressful both for the person experiencing them and those who care for them. This Network is focused on carers (unpaid or 'informal' as opposed to care workers) and how they can be better involved during periods of transition. Sometimes carers are 'forgotten' or 'taken for granted' by 'carer-blind' services (Pickard, 2001), processes and decision-making during transitions in care, and the aim of this Network is to explore how they can be more involved in ways that align with the values of 'co-production'.

### What do we mean by 'transitions'?

Care is inherently flexible and fluid: as we age, we experience changes to our health, adjust our personal goals, and in turn the support we need and receive evolves. **Transitions across the life course can significantly impact people's experiences of care** (Pelge and Needham, 2024). However, care transitions are complex and multifaceted. There is no standard definition of 'transition', as it varies depending on whether we discuss it in relation to particular care services or settings (e.g. into or out of residential care), age groups, or a person's health condition. Consequently, over the past three decades, the concept of 'transitions' in social science and care disciplines has been **a work in progress**, with medical and care research contributing to understanding the transition process, as it often relates to **life, wellbeing and health** (Gardiner et al., 2011).

Due to the fluid nature of transitions in care, Kralik et al. (2006) conducted a literature review to answer the questions, "How is the word transition used?" and "What is the concept of transition informing?". The review found that definitions of 'transition' vary according to disciplinary focus, but most agree that they involve **people's responses during a period of change**. Therefore, the crucial elements of transition are that: a) it occurs over time and b) entails change and adaptation.

Care involves **various types of transitions**, often aligning with significant shifts in a person's **life stage** (SCIE, n.d.). For instance, children with learning disabilities, physical disabilities or mental health challenges, who qualify for children's social care support, should continue to receive it until adulthood when they then transition to adult social care services. Research on care transition models have identified **difficulties in maintaining continuity of care** for adolescents and young emerging adults with long-term conditions (Betz et al., 2023), particularly in relation to mental health services (Paul et al., 2015; Clibbens et al., 2019). Similarly, an older person with dementia might transition from living in their own home, with adult social care support, into a residential care home (Sury et al, 2013). Being discharged from hospital is another stressful transition, requiring a shift across health to social care services and from receiving constant care to becoming more independent and/or being supported by informal care networks. These changes also significantly impact family carers, who often face substantial shifts in their personal situations and caregiving responsibilities (SCIE, n.d.). Hence, transitions are **context-dependent** (SCIE, n.d.), and so too are the types of support carers need.

### **Box 1: Transitions to adult care services across the UK nations**

As mentioned earlier, transitions in care are context-sensitive and depend on local services, legislation, and personal circumstances. These differences in the implementation of policies and services to support transitions can be seen in the transition from child to adult care services. Consider the examples below related to transitions from children's to adult social care support:

In **England**, the transition from children's to adult social care services should ideally begin during a child's early teenage years, involving a named worker to plan and review the child's needs comprehensively. This process is governed by the Care Act 2014 and the Children and Families Act 2014, ensuring no gaps in services during the transition. A key aspect is the needs assessment under the Care Act 2014, which must be conducted before the child turns 18. Additionally, an Education, Health and Care Plan (EHCP) is available for those with significant additional support needs up to age 25, focusing on learning, future employment, home and independence, relationships, health and wellbeing. Local Authorities are responsible for ensuring continuous support tailored to the young adult's needs and keeping parents and carers informed about assessments and plans.

In **Wales**, the transition process should also start in early teenage years, with an emphasis on planning and review. Governed by the Social Services and Wellbeing Act 2014, Local Authorities have a duty of care to provide support to young people up to age 25 with special needs. Schools are required to develop additional support plans for children who need extra help with learning. As children approach the age of 16, Local Authorities should prepare pathway plans to assist in the transition to adulthood. These plans build upon the child's existing care and support plan. The process is characterised by collaboration between health and social care teams, ensuring timely information sharing and keeping the child and their carers at the centre of decision-making.

In **Scotland**, the transition process begins between the ages of 12 and 15. During this period, children have the right to have an advocate present during meetings and appointments, challenge decisions formally, and request a coordinated support plan (CSP). The legal framework for this process is governed by the Carers (Scotland) Act 2016, the Additional Support for Learning (ASL) Act, and the Adults with Incapacity (Scotland) Act 2000. At 18, children legally become adults, but this does not mean they must make decisions alone if they are not capable. Parents and carers can be closely involved in helping their child receive ongoing care and support. Local Authorities and schools must collaborate at least 12 months before the child leaves school to prepare for adult life, ensuring a smooth transition.

In **Northern Ireland**, the transition from child to adult services typically occurs around the ages of 16 to 18. Governed by the Carers and Direct Payments Act 2002, this process involves introducing transition plans in the teenage years to focus on future goals and aspirations. Health and social care professionals should work together to ensure thorough assessments for ongoing needs. For children with palliative care needs, a transition plan must be agreed upon at least six months before the transition. Detailed guidance and support are provided by health and social care professionals, who liaise with parents and carers to ensure all needs are thoroughly reviewed and addressed during the transition process.

### Transitions and carers

Transitions affect everyone involved: the person experiencing the transition and those who care for them (Carers UK, 2022). A study by the Centre for Care (Pelge and Needham, 2024) examined how disabled people and their carers define and experience transitions in care. Interviews with eight pairs of participants (disabled people and their unpaid carers or paid care workers) in England revealed that life changes such as becoming disabled, developing diabetes, or experiencing bereavement significantly **impact self-perception and daily life**. These transitions were complex, emotionally charged, and often interconnected. Participants aimed to make significant life changes, such as relocating or accessing education or employment, but faced **societal barriers**. The study found that most participants had limited support networks, often relying on a **single 'anchor' person** during transitions (Pelg and Needham, 2024).

Transitions also affect carers. A scoping review explored unpaid carers experiences during older adults' transitions from hospital to home. It highlighted the complex and often challenging process, which frequently results in poor outcomes such as rehospitalisation, functional decline, and mortality. Unpaid carers play a crucial role in supporting these transitions but often encounter challenges at individual, interpersonal, and systemic levels. However, few interventions target or include carers in efforts to improve discharge education and support (Liebzeit et al., 2023). Carers UK, Carers NI, Carers Scotland and Carers Cymru have outlined the guidance for carers on what to expect and how to manage the discharge of a person from a hospital in the four UK nations. Table 1 outlines the discharge planning process, the rights and responsibilities of carers, and the types of support and assessments available to both patients and carers.

**Table 1: Carers and discharge from hospital across the four UK nations**

	<b>Wales (Carers Cymru, 2024).</b>	<b>Scotland (Carers Scotland, 2024)</b>	<b>Northern Ireland (Carers NI, 2024).</b>	<b>England (Carers UK, 2024b)</b>
<b>Discharge planning</b>	Based on Welsh Government guidance; includes patient and carer involvement.	Governed by the Carers (Scotland) Act 2016; early notification to staff is crucial.	Starts at admission; involvement of both patient and carer is crucial.	Begins at admission; a discharge coordinator manages the process.
<b>Carer involvement</b>	Required if patient consents.	Required if patient consents; Guardianship or Power of Attorney may apply if patient cannot decide.	Required if patient consents; carers' views are considered.	Essential if the patient consents; those with the Lasting Power of Attorney can make decisions if the patient cannot.
<b>Assessments</b>	Confirm medical fitness, support needs, and carer's needs.	Confirm medical fitness, support needs, and carer's needs.	Confirm medical fitness, support needs, and carer's needs.	Confirm medical fitness, support needs, and carer support needs.
<b>Documentation</b>	Written care and support plans; discharge letter to GP within 72 hours.	Written care and support plans; discharge letter to GP within 24 hours.	Written care plans; discharge letter to GP within 24 hours.	Written care and support plans provided; discharge letter to GP within 24 hours.
<b>Post-Discharge Support</b>	Free intermediate care for six weeks; potential NHS Continuing Healthcare for complex needs.	Free reablement care for six weeks; free palliative care available.	Free reablement care for six weeks; free palliative care available.	Includes free reablement care for up to six weeks; potential NHS Continuing Healthcare for significant needs.
<b>Carers Rights</b>	Needs assessment considering their well-being; formal complaints procedures available.	Needs assessment for support; formal complaints procedures available.	Legal right to an assessment; formal complaints procedures available.	Flexible working arrangements and emergency leave; formal complaints procedures available.

**Box 2: Helpful questions to ask during a transition**

- Has the carer/person transitioning been told what will happen before, during and after the transition process?
- What support will be available? How will they manage their care and support needs?
- Have they been informed what advocacy, information and advice services are available?
- Are they aware of all the benefits and financial support they could be entitled to? Have they been given information about organisations or services that can help them? (Carers UK, 2024a)

Similarly, a qualitative study examined the transition outcomes for young people discharged from adolescent medium secure services to adult and community settings in England. It focused on the experiences of these young individuals and their carers, highlighting issues like unsettling environmental factors within adult services, transition management and preparation, and parental experiences of the transition process. The study underscores the importance of well-managed, gradual transitions with consistent support from healthcare professionals and family members, calling for personalised care plans and better coordination between child and adult services (Livanou et al., 2021).

The challenges of transitioning to **become an unpaid carer** are also significant. In the UK, every year 12,000 people become carers (Petrillo et al., 2022). The evidence indicates mental health deteriorates for both men and women during the first year of becoming a caregiver, particularly for women under 50. Physical health also deteriorates for carers under 30. Transitioning to increased caregiving (10+ hours/week) is associated with a deterioration in both mental and physical health across all age groups (McMunn et al., 2023). Similar findings were highlighted by a study by Lacey et al. (2023), investigating how transitioning into unpaid caregiving in the UK affects mental and physical health, with a focus on variations by gender, age, and caregiving intensity. Using data from the UK Household Longitudinal Study (2009-2020), the research assessed psychological distress and physical and mental functioning. The results showed increased psychological distress during the caregiving transition across all age groups, particularly for those under 64, providing over 20 hours of care weekly, or caring for household members. **Mental health wellbeing declined notably for carers aged 30-64 and those providing intensive care.**

Another study, by Allen et al. (2022), explored the support needs of informal carers during the transition of older adults from inpatient care to the community. Using a qualitative exploratory design, the study involved semi-structured interviews and focus groups with carers and healthcare practitioners. The findings highlighted the importance of **including carers as partners in care planning**, the need for streamlined **multidisciplinary care**, and providing carers with education to support

them to care. Carers often had to advocate for discharge planning and reported mixed experiences with follow-up care. **Current care planning around transitions often excludes carers, leading to negative outcomes.** The study recommended developing and implementing models of care that integrate informal carers as essential members of the care team, and suggested further research to support carers from diverse backgrounds, and those with different health conditions. Healthcare practitioners emphasised the necessity of engaging carers in the care transition process and identified barriers such as high bed demand and communication challenges (Allen et al., 2022).

### **Box 3: The numbers regarding transitions**

Transitions, particularly those involving care responsibilities and life changes, have been the subject of various studies. These transitions, whether related to unpaid care, leaving formal care systems, or navigating healthcare services, carry significant implications for the individuals involved. Statistics from various studies shed light on the numerical nature of the complexities and challenges faced by different groups during these transitions. For example:

- In 2020, in the UK, 6.7% of women and 6.2% of men **transitioned into unpaid care**, which translates to approximately 2 million men and 2.3 million women (Petrillo et al., 2022).
- When it comes to transitions such as **leaving care**, only under a quarter of 123 surveyed care leavers – individuals who leave care, usually between the ages of 15-26 – thought they were “well” or “very well” prepared for independent life, while nearly half thought they were “badly” or “very badly” prepared. Half felt they had been prepared “badly” or “very badly” for independent life (Baker, 2017).
- Another study included in a review conducted by Baker (2017) suggested that over 50% of care leavers felt it had been their choice to leave care when they did, while 32% felt they had no choice.
- Regarding **hospital and transitions**, a meta-analysis showed a 19% reduction in the probability of hospitalisation for patients receiving integrated (health and social) care compared to those receiving usual care (Hudon et al., 2022).

### **Getting key stakeholders and community members involved in transitions**

The existing body of literature highlights that improving transitions in care involves more than just the person transitioning and their carers. **Community involvement** is essential; educating community members, professionals, and staff about the nature of transitions and engaging them in facilitating smooth transitions can enhance the process. For instance, as hospital stays decrease and complex care needs increase, people and their informal carers often need to manage care in the community post-discharge (Meulenbroeks et al., 2021).

Involving key stakeholders is critical in transitions of care. A review which focused on transitions for older adults (60+) within long-term care systems emphasised that effective communication among professional groups, coordination of resources, information transfer, staff training, and patient and family education were vital for smooth care transitions. Financial aspects, such as financial incentives, also impact care transitions by promoting better care coordination (Wieczorek et al., 2022).

### Co-production, lived experience and their benefits

Poorly managed transitions can lead to **adverse health and social care outcomes and increased costs**; therefore, there are calls for research exploring strategies to enhance care transitions (Wieczorek et al., 2022). Early planning and preparation can help make transitions smoother (Carers UK, 2022). However, existing research highlights that policies need to adopt a fluid understanding of transitions and care, **acknowledging their diverse meanings and emotional impacts** (Pelge and Needham, 2024). This is particularly important regarding early identification and support for caregivers, especially younger ones, to prevent long-term negative health effects, urging care service providers to actively engage in supporting carers (Lacey et al., 2023).

Recent research-oriented concerns align with the growing **demand to transform social care delivery**. A report from the House of Lords Adult Social Care Committee highlights the need for a significant shift in attitudes, advocating for a departure from hierarchical methods with power imbalances. Central to this transformation is the concept of “**co-production**”. While definitions of co-production vary, it generally involves:

*making care decisions collaboratively and equally, recognising individuals as experts and active participants in their care rather than mere recipients.*

Despite its importance, there is a notable lack of research on co-producing social care (Peat, 2023). The involvement in decision-making is crucial for individuals with lived experiences who desire to be integral to the entire process, **not just passive listeners and recipients**. This inclusive approach ensures that care delivery is more effective and responsive to the needs of those it serves (Peat, 2023).



**Box 4: An example of co-production in social care**

The increasing population of older people living outside residential care facilities shows the importance of significant support from family and unpaid carers. However, caregiving impacts carers' wellbeing and poses challenges to the sustainability of such care. Therefore, there is a critical need for accessible, flexible, and responsive interventions to enhance carers' coping and resilience; supporting the health, wellbeing and independence of those they care for.

To address this need, a study was conducted to develop a digital programme aimed at promoting carers' resilience and coping by supporting effective use of information and web-based resources. This study followed a co-production approach, involving carers and stakeholders to understand how web-based interventions can address carers' challenges, identify target behaviours, intervention components, and develop a prototype.

The methodology was guided by person-based theories of co-production and included extensive patient and public involvement. Using the Behavior Change Wheel framework, the study focused on behavioural issues related to caregiving through scoping literature reviews, interviews, focus groups, and an agile approach to IT development.

Four key behavioural challenges were identified: the burden of care, lack of knowledge, self-efficacy, and lack of time. It was found that local health and social care services were under-used by carers, who acknowledged the potential value of web-based resources but faced difficulties in identifying reliable information when needed. To address these challenges, the programme focused on education (enhancing knowledge and understanding), enablement (reducing barriers and increasing means for caregiving), and persuasion (encouraging active use of the intervention). A resources library was developed, linking to various websites, guidance, videos, and materials classified into over 30 subcategories under Care Needs, General Information and Advice, and Sustaining the Carer. Additionally, features like a journal and mood monitor were included to address enablement challenges, and proactive, personalised prompts were also employed to encourage carers to update their profiles and receive relevant notifications (Dale et al., 2018).

The benefits of involving people in decision-making are substantial across various levels. On an individual level, participation fosters a sense of being valued and empowered, improves confidence, and provides a sense of purpose. It enhances **ownership of services**, and strengthens social connections and peer support. Moreover, it contributes to better health and wellbeing, increased engagement and trust, and higher levels of satisfaction and awareness regarding the services they use.

Encouraging participation from individuals with lived experiences also positively impacts the wider community. It promotes inclusiveness and diversity by giving a voice to underrepresented groups and improving quality of life outcomes for both citizens and public service commissioners. It supports the better use of resources and fosters a sense of ownership of the final product, making individuals more likely to advocate for/promote the activity or resource within their local community. This, in turn, may increase **uptake, effectiveness, and sustainability**. Additionally, it helps grow social networks to support resilience, contributing to **community development** and democratic participation (Ayiwe et al., 2022; Burns et al., 2023; Loeffler and Bovaird, 2019).

However there are some barriers to co-production, as highlighted in Box 5.

#### **Box 5: Barriers to co-production**

Successful co-production requires addressing barriers related to individual capabilities, structural and systemic constraints, and power dynamics between service providers and users. Key barriers identified by Holland-Hart et al. (2019) in the Prudent Healthcare initiative in **Wales**:

- Lack of awareness of the term "co-production"
- Inadequate communication between clinicians and citizens
- Variability in each citizen's capability to participate influenced by:
  - Overall physical health
  - Mental health
  - Psychological factors such as knowledge, health literacy, empowerment, self-efficacy, and communication skills
- Poor health, especially mental health
- Socio-economic inequalities and preconceptions about patients' limitations to co-produce

#### **Jakobsson et al. (2023) identified similar barriers in mental health research:**

- Challenges with safeguarding
- Power imbalances and mental health stigma
- High turnover among mental health professionals
- Power differentials with researchers maintaining control

- Preconceptions of user involvement and mental health stigma
- Social and economic constraints limiting effective participation
- Structural barriers faced by vulnerable populations in co-production activities include:
  - Language barriers and understanding of cultural codes
  - Familiarity with public services, especially for newly arrived refugees
  - Traumatic experiences, and mental and physical health problems
  - Bureaucratic 'language games' obstructing the effectiveness of support tools

**These structural vulnerabilities prevent direct and indirect involvement in co-production at higher levels (Mulvale & Robert, 2021).**

### Co-Production and Transitions in Care

Although the literature on co-production demonstrates its benefits and the literature on transitions highlights their multifaceted and often challenging nature, these two topics are rarely combined in research. There is a significant gap in research that integrates co-production and transitions in care. However, existing studies that do explore this integration focus on **empowering individuals undergoing transitions**. For instance, Mulvale and Robert (2021) examine various aspects of care transitions, particularly for vulnerable populations, through empirical and theoretical studies. They emphasise the need for **inclusive approaches to co-designing public services** that engage and empower marginalised communities, such as in palliative care transitions. Their work underscores the importance of involving diverse participants in designing future care scenarios, especially through visual tools.

In the context of transitional-aged young people with mental health issues, Mulvale and Robert (2021) highlight the necessity of a planned approach to address structural vulnerabilities and relational challenges in co-production processes. They explored Experience-Based Co-Design processes with transitional-aged youth in Ontario, Canada, stressing the importance of early engagement of managers, participant preparation, relationship building, and maintaining relational safety to shift vulnerability towards collective empowerment.

To address barriers in co-production and bridge it with transitional care, Dixon et al. (2019) investigated methods for **involving young people in the care system in England, focusing on those transitioning out of it**. Their study emphasised participation, consultation, peer research, and co-production to ensure the voices of young people are heard. The research highlighted the importance of moving from passive involvement to active participation in creating and evaluating care services, addressing past vulnerabilities, and ensuring authentic representation of young people's voices.

Similar findings were highlighted by Liabo et al. (2017) who explored the experiences of young people transitioning out of foster or residential care, focusing on their interactions with

health and social care services. Their study involved 24 young people aged 16-24, 11 professionals, and used participatory meetings, individual interviews, and visual tools. The findings suggested that health was not a top priority for care leavers compared to housing, financial support, and education. Social care support was inconsistent, with frequent changes in social workers affecting transitions, while professionals struggled with substantial workloads.

The study concluded that transitions should be gradual and supported, emphasising early preparation and consistent support. Effective transitions should be viewed as a long-term process rather than a single event, **requiring coordination among various services and collaboration with young people**. It was highlighted that policy and practice need to focus on **encouraging active participation** of care leavers in their care.

Dixon et al. (2019) provide several case examples illustrating effective approaches. The [New Belongings \(NB\) programme](#) required local authorities to **consult care leavers**, resulting in substantial input from young people that shaped service improvement plans. The [National House Project](#) **involved care-experienced young people in co-designing and managing a supported housing project**, enhancing their transition to independence. These examples demonstrate that involving young people in decision-making empowers them and improves service outcomes. Peer research projects, like the [Staying Put initiative evaluation](#), revealed that young people felt more comfortable being interviewed by peers, fostering openness and trust.

The study emphasised that **meaningful engagement requires thoughtful, planned, and responsive approaches** to address power imbalances and relational challenges. Successful co-production depends on early and sustained engagement of all stakeholders, preparation and empowerment of participants, and **creating a safe space for genuine dialogue**. Dixon et al. (2019) concluded that while participatory methods hold promise for improving care services, they must be carefully implemented to avoid tokenism and ensure all young voices, including those from harder-to-reach groups, are heard and valued.

Similarly, as hospital stays decrease and complex care needs increase, people and their carers often need to manage care in the community post-hospital discharge. Meulenbroeks et al. (2021) conducted a review examining caregiver-inclusive transitional care offering better value than routine care, assessed through patient/caregiver satisfaction, population health, and cost. While the evidence is not definitive in proving that carer inclusive transitional care provides better value, there are positive trends in patient and carer satisfaction (Meulenbroeks et al., 2021).

Another study employing co-production principles was conducted by Davies et al. (2019). The study aimed to develop an online support system for family caregivers of people with dementia at the end of life. The development process involved the following stages:

- synthesising data from interviews
- a systematic review and theoretical frameworks
- identifying intervention targets and components with a research development group
- developing a prototype website based on these targets
- conducting user testing through interviews with carers to refine the website.

The core targets identified for the intervention included **feeling prepared and equipped, feeling connected and supported, valuing themselves as caregivers and individuals**, and maintaining control of the caring situation and being the coordinator of care. Carers reported needing **more information** about end-of-life care to feel confident in managing medical decline, and expressed a desire for connection and support from both other caregivers and professionals. The **prototype website** that emerged from the project included written information on expectations at the end of life, support with day-to-day caring, care planning, and communication. It featured videos from other caregivers to provide relatable peer support and shared experiences, and sections for peer and professional support, including an integrated telephone support service (Davies et al., 2019).

### **Box 6: Case study- Homes from Hospital and North East Lincolnshire**

The "Home from Hospital Service" as part of the [ADASS Carers Challenge 2024](#) created a support system facilitating safe and effective hospital discharges for individuals in North East Lincolnshire. The service is designed to help patients transitioning from hospital or step-down care to their homes through a **multi-faceted approach that includes transportation, home safety checks, medication collection, and emotional support**. It adopts a "home first" approach, ensuring that the majority of patients return to their usual residence promptly, **using community and voluntary sector resources**. The initiative also identifies and supports informal carers, aiming to improve patient outcomes, prevent readmissions, and reduce reliance on formal health and care services. In many ways, it adopts a co-production element, with a strong focus on local collaboration and the involvement of trained staff and volunteers. The service is monitored regularly to improve its delivery based on user feedback and performance data (North East Lincolnshire, 2024a).

Similarly, the ["Carers Guide to the Hospital"](#) created by the Carers' Voice NEL for the ADASS Carers Challenge 2024, provides essential information and practical tips for carers supporting someone admitted to the hospital. For example, it advises obtaining the ward's direct phone number, sharing important documents and communication needs, and clarifying the support the carer can offer. The guide emphasises the carer's right to be involved in care discussions if they have consent or a Lasting Power of Attorney. It highlights the importance of discharge planning from admission and outlines the steps to ensure a safe and supported return home. Carers are encouraged to ask for resources such as yellow carers' lanyards and freshen-up packs, and to use the Carers Hospital Liaison for support. The guide also includes a jargon buster to help carers understand hospital terminology and reassures carers that it is okay to decline the caring role if it becomes too overwhelming (Carers' Voice NEL, 2024).

### **Practice examples of co production in transition**

Practise to support co-production during transitions is emerging, there have been a number of initiatives focusing on specific transitional phases of care. Consider the examples below:

- A project called "[Redesigning Support for Care Leavers](#)" took place in Argyle and Bute, Scotland. The initiative discovered that a review was beneficial for all participants, enabling them to gain insights from the project's activities. This included learning from concepts that weren't implemented. Providing feedback to everyone involved was crucial, ensuring that all participants were included in the learning process (Iriss, 2012).
- [Think Local Act Personal \(TLAP\)](#) is a national leadership partnership across various sectors, improving **personalised, community-based social care**. Their strength lies in bringing together service users and carers with central and local governments, as well as major providers from the private, third, and voluntary sectors, along with other key stakeholders (TLAP, 2024). In the past, they collaborated closely with the National Co-production Advisory Group, a network of over 20 individuals with personal care and support experiences (SCIE, 2013). TLAP have also disseminated the promising potential of **Individual Service Fund implementations**, for example in [Bexley](#) where people can exercise choice and control over their care and support without the complexities of managing money and employment-related matters (Johnson, 2021). The Adults' Services Directorate of Birmingham City Council is one of the test sites for TLAP's Making it Real initiative. They have established various frameworks to facilitate the co-production of their work. These efforts include:
  - Creating methods to involve service users as early as possible in specific projects.
  - Allocating resources and dedicating staff time to support co-production efforts.
  - Implementing a communication strategy that uses multiple channels to inform everyone about co-production and share updates on ongoing work and projects.
- Discussions and collaborative design sessions with carers in [Pembrokeshire](#) revealed the need for **support** for unpaid or family carers at the early stages of the dementia journey, especially during initial visits to the GP regarding their loved one's memory or behaviour issues, **before any diagnosis is made**. Carers suggested providing an A6 card at the GP practice, accompanied by a brief explanation that the service is specifically for them, not the patient. This card would include the contact information for the Pembrokeshire Carers Information & Support Service (PCISS), where carers can find support and information (Carers Trust, 2024).

## Summary

Based on the evidence regarding transitions and co-production in care, effective transitions in social care are multifaceted and context-dependent, varying across different life stages and regions within the UK. Successful transitions require **early planning, robust support systems, and active involvement from all stakeholders, including care recipients, their carers/their families, and community members**. Co-production plays a crucial role in improving care transitions, as engaging individuals with lived

experiences in decision-making makes care more personalised and effective. Despite its benefits, barriers such as power imbalances and inadequate communication must be addressed. Integrating **lived experiences** into care planning empowers individuals and enhances the overall quality of care, ensuring support systems are adaptable and resilient to meet evolving needs.

**Having read the material above, in the first Local Network Meeting, we'd like you to discuss:**

**Your experiences and perspectives...**

- What do you think “transition in social care” means?
- Would anyone like to share their experiences of transitions in care either as a person who receives support, a carer, a care or service provider?
- During a transition, has anyone been involved in co-production?

**Thinking about this discussion document...**

- 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 identified? Any that were missed? What do you think would help to address these challenges?
- Anything in the document 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? Anything you'd like to discuss?
- Do you think there is anyone else who should be involved in your meeting?
- Is there anything you need from the IMPACT team?

**References**

- Allen, J., Lobchuk, M., Livingston, P. M., Layton, N., & Hutchinson, A. M. (2022). Informal carers' support needs, facilitators and barriers in the transitional care of older adults: A qualitative study. *Health Expectations*, 25(6), 2876-2892.
- Arrieta Hernandez, T. (2021). The consequences of the austerity policies for public services in the UK. *Studies in Social Justice*, 15(3), 518-537.
- Ayiwe, E., Colom, A., Cook, A., Murray, A., & Parry, L. (2022). *Engaging people with lived experience: Best practice, challenges, and opportunities*. The Democratic Society Ltd. [https://www.alliance-scotland.org.uk/wp-content/uploads/2022/10/Lived\\_Experience\\_Report\\_2022\\_WEB.pdf](https://www.alliance-scotland.org.uk/wp-content/uploads/2022/10/Lived_Experience_Report_2022_WEB.pdf)
- Baker, C. (2017). *Care leavers' views on their transition to adulthood: A rapid review of the evidence*. Coram Voice.
- Betz, C. L., Coyne, I., & Hudson, S. M. (2023). Health care transition: The struggle to define itself. *Comprehensive Child and Adolescent Nursing*, 46(3), 162-176.

- Burns, P., McGinn, T., & Fitzsimons, L. (2023). Coproduction with service users in adult social work: A study of service users' and social workers' experiences in Northern Ireland. *The British Journal of Social Work*, 53(8), 3566-3583. <https://doi.org/10.1093/bjsw/bcad15>
- Carers Trust (2024, July). Pembrokeshire Dementia Support Carers Card. <https://carers.org/downloads/bil-2.1.-case-study---pembrokeshire-dementia-support-carers-card---bilingual.pdf>
- Carers' Voice NEL (2024). *A Carers Guide to the Hospital: Written by Carers for Carers*. Carers' Voice NEL.
- Carers UK. (2022). *Cycles of caring: Transitions in and out of unpaid care*. Carers UK. [https://www.carersuk.org/media/heklewjb/cuk\\_carers\\_rights\\_day\\_research\\_report\\_2022.pdf](https://www.carersuk.org/media/heklewjb/cuk_carers_rights_day_research_report_2022.pdf)
- Carers UK (2024a). *Moving from child to adult care services*. Carers UK. <https://www.carersuk.org/media/1sfdqwzm/carers-uk-moving-from-child-to-adult-care-services-web.pdf>
- Carers UK (2024b). *Coming out of Hospital*. Carers UK. <https://www.carersuk.org/media/jnvbxhfs/coming-1.pdf>
- Carers Wales (2024). *Coming out of hospital: A guide for carers*. Carers Wales. <https://www.carersuk.org/media/cmocaxyk/2023-2024-eng-coming-out-of-hospital.pdf>
- Carers Scotland (2024). *Coming out of Hospital*. Carers Scotland. <https://www.carersuk.org/media/ebsa4lbm/coming-1.pdf>
- Carers NI (2024). *Coming out of Hospital*. Carers NI. [https://www.carersuk.org/media/fkabh53l/coming-out-of-hospital-ni\\_april-2024-25.pdf](https://www.carersuk.org/media/fkabh53l/coming-out-of-hospital-ni_april-2024-25.pdf)
- Clibbens, N., Berzins, K., & Baker, J. (2019). Caregivers' experiences of service transitions in adult mental health: An integrative qualitative synthesis. *Health & social care in the community*, 27(5), e535-e548.
- Dagdeviren, H., Donoghue, M., & Wearmouth, A. (2018). When rhetoric does not translate to reality: Hardship, empowerment, and the third sector in austerity localism. *The Sociological Review*, 67(1), 143–160. <https://doi.org/10.1177/0038026118807631>
- Dale, J., Loew, J., Nanton, V., & Smith, G. G. (2018). Coproduction of a theory-based digital resource for unpaid carers (the care companion): Mixed-methods study. *JMIR Aging*, 1(1), e9025.
- Davies, N., Hopwood, J., Walker, N., Ross, J., Iliffe, S., Walters, K., & Rait, G. (2019). Designing and developing a co-produced theoretical and evidence-based online support for family caregivers of people with dementia at the end of life. *BMC Palliative Care*, 18, 1-16.
- Dixon, J., Ward, J., & Blower, S. (2019). "They sat and actually listened to what we think about the care system": The use of participation, consultation, peer research and co-production to raise the voices of young people in and leaving care in England. *Child Care in Practice*, 25(1), 6-21.
- Hansen, T. K., Jensen, A. L., Damsgaard, E. M., Rubak, T. M. M., Jensen, M. E. J., & Gregersen, M. (2021). Involving frail older patients in identifying outcome measures for transitional care—a feasibility study. *Research Involvement and Engagement*, 7(1), 36.
- Holland-Hart, D. M., Addis, S. M., Edwards, A., Kenkre, J. E., & Wood, F. (2019). Coproduction and health: Public and clinicians' perceptions of the barriers and facilitators. *Health Expectations*, 22(1), 93-101.
- Hudon, C., Aubrey-Bassler, K., Chouinard, M. C., Doucet, S., Dubois, M. F., Karam, M., Luke, A., Moullec, G., Pluye, P., Tzenov, A., Ouadfel, S., Lambert, M., Angrignon-Girouard, E.,



Schwarz, C., Howse, D., Kehoe MacLeod, K., Gaudreau, A., & Sabourin, V. (2022). Better understanding care transitions of adults with complex health and social care needs: A study protocol. *BMC Health Services Research*, 22(206). <https://doi.org/10.1186/s12913-022-07588-0>

- Jakobsson, C. E., Genovesi, E., Afolayan, A., Bella-Awusah, T., Omobowale, O., Buyanga, M., ... & Ryan, G. K. (2023). Co-producing research on psychosis: A scoping review on barriers, facilitators and outcomes. *International Journal of Mental Health Systems*, 17(1), 25.
- Johnson D. (2021). Purpose, trust, and flexible commissioning. Think Local Act Personal Blog. <https://www.thinklocalactpersonal.org.uk/Blog/Purpose-trust-and-flexible-commissioning/>
- Johnson, L. (2020). *The influence of intermediary systems on public sector transitions during a period of austerity* (Doctoral dissertation, University of Warwick). University of Warwick Publications. <http://wrap.warwick.ac.uk/147851/>
- Gardiner, C., Ingleton, C., Gott, M., & Ryan, T. (2011). Exploring the transition from curative care to palliative care: A systematic review of the literature. *BMJ Supportive & Palliative Care*, 1(1), 56-63.
- Holland-Hart, D. M., Addis, S. M., Edwards, A., Kenkre, J. E., & Wood, F. (2019). Coproduction and health: Public and clinicians' perceptions of the barriers and facilitators. *Health Expectations*, 22(1), 93-101.
- Kralik, D., Visentin, K., & Van Loon, A. (2006). Transition: A literature review. *Journal of Advanced Nursing*, 55(3), 320-329.
- Lacey, R. E., Xue, B., Di Gessa, G., Lu, W., & McMunn, A. (2024). Mental and physical health changes around transitions into unpaid caregiving in the UK: A longitudinal, propensity score analysis. *The Lancet Public Health*, 9(1), e16-e25.
- Liabo, K., McKenna, C., Ingold, A., & Roberts, H. (2017). Leaving foster or residential care: a participatory study of care leavers' experiences of health and social care transitions. *Child: care, health and development*, 43(2), 182-191.
- Liebzeit, D., Jaboob, S., Bjornson, S., Geiger, O., Buck, H., Arbaje, A. I., ... & Werner, N. E. (2023). A scoping review of unpaid caregivers' experiences during older adults' hospital-to-home transitions. *Geriatric Nursing*, 53, 218-226.
- Livanou, M. I., Bull, M., Lane, R., D'Souza, S., El Asam, A., & Singh, S. P. (2021). Transition outcomes for young people discharged from adolescent medium secure services in England: A qualitative study exploring adolescents' and carers' experiences. *Clinical Child Psychology and Psychiatry*, 26(4), 1227-1242.
- Loeffler, E., & Bovaird, T. (2019). Co-commissioning of public services and outcomes in the UK: Bringing co-production into the strategic commissioning cycle. *Public Money & Management*, 39(4), 241-252. <https://doi.org/10.1080/09540962.2019.1592905>
- McMunn, A., Xue, B., Di Gessa, G., Lu, W., & Lacey, R. (2023). P137 The mental and physical health effects of transitions into unpaid caregiving: A longitudinal, propensity score analysis in the UK Household Longitudinal Study.
- Meulenbroeks, I., Epp, J., & Schroeder, L. (2021). The value of caregiver inclusive practices in geriatric transitions of care: A systematic review. *Health Policy*, 125(7), 888-898.
- Mulvale, G., & Robert, G. (2021). Engaging vulnerable populations in the co-production of public services. *International Journal of Public Administration*, 44(9), 711-714.
- North East Lincolnshire. (2024). Supporting Carers in North East Lincolnshire. <https://www.adass.org.uk/wp-content/uploads/2024/04/KEY-PROJECT-DOCUMENTS-North-East-Lincolnshire-ADASS-Carers-Challenge-2024-1.pdf>

- Paul, M., Street, C., Wheeler, N., & Singh, S. P. (2015). Transition to adult services for young people with mental health needs: a systematic review. *Clinical child psychology and psychiatry*, 20(3), 436-457.
- Peat, G. (2023) Co-production: defining the future of social care, NIHR School for Social Care Research Blog, 14 February 2023.
- Pelge, H. and Needham, C. (2024). *Transitions that matter*. Centre for Care. <https://centreforcure.ac.uk/commentary/2024/05/summary-report-transitions-that-matter/>
- Petrillo, M., Bennett, M.R., and Pryce, G. (2022) Cycles of caring: transitions in and out of unpaid care. Carers UK.
- Pickard, L. (2001). Carer Break or Carer-blind? Policies for Informal Carers in the UK. *Social Policy & Administration*, 35(4): p. 441-458.
- Power, L., & Raphael, D. (2018). Care leavers: A British affair. *Child & Family Social Work*, 23(3), 346-353.
- SCIE n. d. *Transitions of care – Activities to achieve integrated care*. Social Care Institute for Excellence. <https://www.scie.org.uk/integrated-care/research-practice/activities/transitions-care/>
- SCIE. (2013). Co-production in social care: what it is and how to do it. [https://www.thinklocalactpersonal.org.uk/assets/COPRODUCTION/Co\\_production\\_what\\_it\\_is\\_and\\_how\\_to\\_do\\_it.pdf](https://www.thinklocalactpersonal.org.uk/assets/COPRODUCTION/Co_production_what_it_is_and_how_to_do_it.pdf)
- Stranges, P. M., Jackevicius, C. A., Anderson, S. L., Bondi, D. S., Danelich, I., Emmons, R. P., ... & Smithgall, S. (2020). Role of clinical pharmacists and pharmacy support personnel in transitions of care. *Journal of the American College of Clinical Pharmacy*, 3(2), 532-545.
- Tarrant, A. (2018). Care in an age of austerity: Men's care responsibilities in low-income families. *Ethics and Social Welfare*, 12(1), 34-48.
- Think Local Act Personal (2024, July). Think Local Act Personal. <https://www.thinklocalactpersonal.org.uk/About-us/>
- Ward, J., & Blower, S. (2019). "They sat and actually listened to what we think about the care system": The use of participation, consultation, peer research and co-production to raise the voices of young people in and leaving care in England. *Child Care in Practice*, 25(1), 6-21. <https://doi.org/10.1080/13575279.2018.1521380>
- Wiczorek, E., Kocot, E., Evers, S., Sowada, C., & Pavlova, M. (2022). Key care provision aspects that affect care transition in the long-term care systems: preliminary review findings. *International Journal of Environmental Research and Public Health*, 19(11), 6402.

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