# Research prioritisation report: transitions from children’s to adults’ social care

**February 2025**

## Introduction

We’ve led an exercise to develop 10 priority areas for research into transitions from children’s to adults’ social care. You can learn more about this process on our [help set research priorities](https://insightcollective.socialcare.wales/our-work/help-set-research-priorities/what-do-we-mean-by-research-priority-setting) page.

This project involved engagement with social care professionals, parents and carers, young people with experience of using care, and adults with experience of accessing care as young people. The experience of participants covered a variety of needs and service areas, particularly care experience, learning disability, and physical disability.

This report summarises the discussions that took place around each of the top 10 priorities. Some of the priorities were discussed more than others, so some of the summaries are longer to capture everything that was talked about.

The summaries in this report include information from three sources:

* a survey asking people to share what they wanted to know more about in relation to transitions
* a focus group of care-experienced young people, facilitated by Voices from Care Cymru
* a workshop to discuss a shortlist of questions based on responses to the first survey.

## The top 10 research priorities related to transitions between children's and adults' social care

*Hold the Ctrl button on each topic and click on the hand icon that appears to jump to the section with further information.*

1. [How can transitions best meet young people’s needs when adults’ services offer different support, or less support?](#heading_1)
2. [How can young people be supported to make their own choices about transition and what happens after transition?](#heading_2)
3. [How can all agencies and organisations involved in supporting someone work together to support a good transition?](#heading_3)
4. [How can parents and carers be supported with legal matters and decision-making during and after transition?](#heading_4)
5. [How can support for transition planning be coproduced (where people who may use services work together with professionals to create them)?](#heading_5)
6. [How can young people and parents/carers be supported to advocate for themselves/their children in transitions?](#heading_6)
7. [During the transition process, how can young people be supported with understanding what services they can access?](#heading_7)
8. [How is cost and funding of services affecting what support is provided during and after transition, and what can be done to support individuals’ best interests?](#heading_8)
9. [How can age thresholds for support be balanced with individual needs so that needed support does not stop?](#heading_9)
10. [What does a good relationship between children’s and adults’ services look like? How can this be supported in the transition process, and how does it contribute to good transition experiences?](#heading_10)

## #1: How can transitions best meet young people’s needs when adults’ services offer different support, or less support?

Professionals, parents and carers, and young people all agreed that the difference in the support offer between adults’ and children’s services is a serious concern. Multiple participants described the point of transition into adults’ services as a “cliff edge”, after which services just stop. Many also said that they needed more information about what was available and there was not enough advance warning that services would come to an end after transition. Some parents spoke of being given “false hope” when it wasn’t made clear that there was different or less support offered through adults’ services. Being based in rural locations presented additional problems with getting people to needed services. Professionals described the lack of service availability in more rural areas as a surprise and a concern.

Young people said that it was important to them to be able to access support with navigating the differences between children’s and adults’ services. This included help with understanding the different words professionals use in different contexts. Some young people shared that they’d been told initially that they were moving to adults’ services, only to learn later that they did not meet the thresholds for adults’ services support. They shared that their situations would have been better had they not been led to believe that support would be in place.

In general, many participants expressed concern that there was both a lack of available support in adults’ services and a lack of clear communication about what was available and why.

## #2: How can young people be supported to make their own choices about transition and what happens after transition?

Participants raised concerns about the limited choices young people are able to make about transition into adults’ services. They reported that some young people are not offered choices at all about some aspects of what happens after their transition to adults’ services. One parent reported feeling like the local authority had control over everything they could access.

Participants raised concerns about best interest assessments, which are held at 16 but not repeated at 18. This means that young people who have capacity are not always empowered to make decisions for themselves because choices are not available once those young people became legal adults.

In contrast, another participant pointed out that a child, deemed as not having capacity, could be asked to make decisions about the services they needed at transition. Both examples call into question how choice and capacity are handled during the transition process.

There was also discussion of how to make sure that young people are supported to make choices for themselves when they may not communicate in typical ways, such as if they are non-verbal. There were some examples shared of how this can be done well by ensuring that young people are supported by people who know them and understand their ways of communicating.

Young people said that it was important to make sure they are listened to and that professionals “keep them in the loop” about transition planning. For example, by including young people in their own meetings. They also shared that it was important for transition planning to start early and for information about transition to be provided in a way that is “young people friendly”. However, some young people shared that they didn’t want to make decisions about some aspects of support, and they felt forced to make these decisions just because they were legally adults.

The discussions around this question show that it can be complex to make sure that people are supported around decision making in ways that work best for them.

## #3: How can all agencies and organisations involved in supporting someone work together to support a good transition?

Participants implied that there was uncertainty around how organisations involved in transition worked together. Many people shared that they wanted to know more about what good practice looks like and how these relationships should work.

There were examples shared of how multi-agency working was not taking place in expected ways during and after transition. One parent shared that multi-disciplinary team (MDT) meetings for their child stopped happening and that the transition to adults’ services had never included a family handover.

Participants agreed that effective, joined-up working was necessary but that it did not always happen. A professional stated that it was necessary for the whole MDT to be involved, but acknowledged that this was not always the case. They shared experiences with multi-agency referrals going through too late (one example was a referral made just two weeks before a young person’s 18th birthday). Another professional shared positive examples of these relationships working well, which may indicate that there are inconsistencies in how these relationships work in different areas or contexts.

Young people spoke about the importance of joined-up working so that they don’t have to repeat their stories, as this can mean reliving traumatic experiences. At the same time, young people said that it was important that professionals only share information that’s needed. They expressed that sharing private information without good reason was a violation of the young person’s rights.

Young people also shared that it could be difficult for them to understand what support they can access when professionals from different areas don’t “talk the same talk”. They said that they experience a lot of redirection to other services in response to queries. They acknowledged that signposting to other services could be helpful but was also sometimes difficult to navigate.

Participants also shared concerns that person-centred support is difficult to provide when multi-agency relationships don’t work well. Collaboration and good information-sharing practices are necessary to ensure that young people access the individual support they need.

## #4: How can parents and carers be supported with legal matters and decision-making during and after transition?

Parents and carers shared a number of concerns about legal matters and decision making for their children. Many responses expressed that there was a need for more and clearer information about rights, responsibilities, and legal processes. This was particularly true for parents and carers of young people who do not have capacity to make some kinds of decisions. This included issues around mental capacity assessments, deputyship, and supporting young people to make their own decisions when they can. Many participants said that they felt that parents and carers were not being provided with enough information about these processes.

Parents and professionals shared concerns around how these issues were affecting people in the transition process. The lack of clear information and support around legal matters and decision making was highlighted. Participants emphasised that this relates to broader issues of legal entitlement and human rights. One parent highlighted that underpinning the concerns around legal matters and decision making was a lack of equity for disabled people. They felt that things could improve if more information was provided on the relevant legislation and how things changed for young people as they got older. They shared that people have to fight for needed support in this context, but the lack of education about legal entitlements meant that some people did not know what they could fight for.

Professionals shared that these issues impacted the conversations they had with parents, many of whom were not aware of their rights or how a young person’s rights change when they turn 18. They spoke of the legal importance of capacity assessments and Deprivation of Liberty Safeguards and said that parents need more support around understanding how this impacts on rights and decision making. Professionals also shared that these legal processes are often happening later than they should, which causes problems for decision making and accessing support. There was agreement that parents need more support around legal rights, resources, and decision making. Although vitally important, there’s no clear support currently in place.

## #5: How can support for transition planning be coproduced (where people who may use services work together with professionals to create them)?

Many participants said they wanted more information about how coproduction can be “meaningful” and used to make sure effective person-centred support is offered. Many agreed that coproduction could be effective and valuable, especially where clear progress could be seen as a result. Although many said that in practice it did not work.

This research question divided participants. Many ranked it as one of their highest priorities, while others said it was one of their lowest ranked questions.

Parents described coproduction as feeling “tokenistic”. They felt they were not listened to and there was a risk of negative consequences if they challenged things. They said that the term “coproduction” was a “buzzword”, and sometimes professionals said they were doing coproduction when they really weren’t.

Both parents and professionals described coproduction as sometimes being a “tick box exercise” that didn’t lead to “meaningful engagement in support”. Many said that both professionals and families lacked understanding of how coproduction worked.

Young people said that coproduction was important because it was valuable for them to be able to share their point of view, and that this contributed to making sure their transition planning was effective. Several young people shared examples of when coproduction involving them had worked well.

These young people asked why other participants felt that coproduction doesn’t work. In response, parents and professionals shared some of their experiences of where coproduction had not been effective. This included being repeatedly asked to contribute over long periods of time, only for there to be little or no change in response. Professionals shared that there was a lack of understanding of coproduction and that the way social care services worked sometimes made it difficult for true coproduction to happen. For example, an experience was shared relating to a project where a lot of work was done to listen to the voices of people with lived experience. Nothing was then done to incorporate that learning into practice.

## #6: How can young people and parents/carers be supported to advocate for themselves/their children in transitions?

Parents and professionals said they wanted to know more about how self-advocacy and parent/carer advocacy on behalf of a young person can be supported. This prompted a lot of discussion, with many participants highlighting the complexity of what advocacy means and how to make sure young people get the support they need.

Parents shared feeling significantly let down by services, despite having been consulted by service providers and/or having made complaints about services. Although parents said all they wanted was to get the right support in place for their children, they felt they had to fight for everything.

Parents shared that if an unmet need was identified, there was a lack of clarity about how it was recorded and how that information was used. They shared that parents and carers advocate for young people, but that it wasn’t clear if their advocacy had any impact. They spoke of being “passed from pillar to post” in trying to secure needed care for young people.

Parents also talked about the importance of advocacy for young people who need support with decision making. They emphasised that young people’s own individual choices should be taken into account. They also discussed the importance of representatives for young people who are not able to make decisions. Participants also discussed how advocacy may be more complex when people have been assessed as lacking capacity. This can result in questions about whose interest is being advocated for – the parent/carer or the young person.

Young people also felt that advocacy was important and discussed both formal and informal types of advocacy. They pointed out that some young people don’t have an advocate, and that many have concerns about whether they can trust the advocacy service. They shared that there was lack of clarity about what options were available to them. For example, there was uncertainty around whether or not a parent/carer/guardian could advocate for them without accessing the advocacy service. They discussed feeling unsure and lacking in confidence about advocacy and how to challenge decisions made about their lives. While they understood the role of an independent advocate, they said there was a lack of information about how they might challenge things or how they might access legal advice about a situation.

When asked about self advocacy, young people shared mixed feelings. Some young people thought self advocacy was good but emphasised that certain things need to be in place. For example, if a young person uses non-verbal communication to self advocate, it’s important to “make sure the person they’re advocating to can understand them”.

Professionals shared that advocates were always involved in some areas of social services, but this didn’t apply to the transition process. They also shared that they discuss advocacy issues during the transition process, and many parents advocate for their children. They said that an independent voice, such as the advocacy service, is important in transitions. However, the advocate, though independent, should know the young person well enough that they are able to advocate for them effectively.

## #7: During the transition process, how can young people be supported with understanding what services they can access?

Participants asked a lot of questions about service availability after transition. They told us that in the transition process, they were not given clear information about what support would be available to young people from adults’ services.

Young people told us that it was important for them to know what’s available in their community. They also shared that knowing how to access things can be a struggle, and said it was vital to have accessible information and guidance about this.

Professionals agreed better information was needed about what support there is, and how people can access it. They also shared that transition highlights some of the “fault points” in social care, such as siloing (meaning a tendency for teams to work in isolation) and poor information sharing. They discussed how this question could be an opportunity to look into improvements in those areas.

## #8: How is cost and funding of services affecting what support is provided during and after transition, and what can be done to support individuals’ best interests?

Participants agreed that funding issues were a significant problem in transitions from children’s to adults’ services. Some raised concerns about the practical aspects of how funding works. This included concerns about how to ensure effective and timely planning of the transition process when funding is limited. For example, people said not knowing whether funding had been secured for some services until the last minute made it difficult to plan effectively.

Most of the discussion of funding focused on the wider issue of funding restrictions and how they affect the support young people can access. Participants described how “constant cuts” impact on service availability and therefore reduce the choices available to people.

Some parents said they had seen some improvement over the years but felt that they were given “false hope” because reduced funding meant that individual needs were not being met. Parents shared that they’d been told that needed support was “too expensive”, while also being told that individual support was more important than cost. Many parents talked about how funding is prioritised over needed support and quality of life.

Professionals spoke of the need for research to understand how costs are affecting decisions being made about the transition from children’s to adults’ services. Professionals also shared concerns about how some costs involved in service delivery are inefficient. They suggested that putting more preventative funding in place would ultimately lead to cost savings as “families wouldn’t go into crisis”. The costs of transporting people to and from services in rural areas where there are problems with service availability were also raised. Participants also discussed the need for information about how to support young people who are having to deal with the effects of funding problems.

Participants shared that though money was “the biggest issue”, they felt there were “no answers” to these problems. It was suggested that this would need a more complex solution at a higher level. Some said this would need a Wales-wide approach because it’s difficult to get consistency in place at the local level. There was also a suggestion that even broader change is needed because “a business and profit based model doesn’t work for social care”.

Many professionals and parents ranked this question in their initial highest priorities. In contrast, many of the young people (and some parents) ranked this question as one of their lowest priorities. This was because they did not feel that cost should be something that they should have to consider, or even know about.

Young people said they didn’t need to know about cost because it was distressing to hear their support discussed in this way. They talked about not wanting to think about whether their use of a service might mean that the service wouldn’t be able to support someone else: “Talking about the funding is going to make us not want to seek help when we need it”. The young people shared that this could become a mental health concern because these issues are so stressful, and the process of transition is already stressful for them.

Professionals agreed that funding should not be something that young people or parents/carers worried about, saying that it’s “something for professionals to handle”. Some shared that after hearing from the young people, they reflected on the need to be careful in how they speak to young people. They said it was not appropriate for young people to be concerned about the costs of their care, and they should not be aware of funding in this way.

## #9: How can age thresholds for support be balanced with individual needs so that needed support does not stop?

Participants highlighted concerns and lack of clarity about age thresholds. Examples shared included support coming to an abrupt end at 18 even though children’s services support is meant to continue until 25 in some cases. Also mentioned were the different age thresholds that exist in different services, particularly that health services change from children’s to adults’ at 16 while social care’s age threshold is 18.

Professionals discussed how this sometimes resulted in a “gap in services”. They spoke of the need for better planning to mitigate the effects of these inconsistencies in the transition process. They said that an individual’s needs should be what determines the services they can access, rather than their age.

Participants discussed how children’s and adults’ services sometimes have different thresholds for accessing support. This means that a young person might be offered different support after transition, even if their support needs have not changed. The differences in criteria between children’s and adults’ services sometimes mean that young people cannot access ongoing support after transition.

Many participants felt that the needs of young people transitioning were not met with appropriate adults’ services. There were issues raised in the discussion around “crowbarring” young people into inappropriate services because nothing that suited their needs was available. One participant raised the concern that existing research may have focused on the transition process but not on what services are needed for young adults.

Parents shared concerns about the lack of available adults’ services. Young people may be given the impression that they have choices once they reach 18, but that in reality there may not be any adults’ services available to them. They also spoke about existing assessed needs not being included in case records used during and after transition, and questioned why there seems to be an assumption that existing needs disappear when a young person turns 18. It was highlighted that the needs of many young people with disabilities do not change when they reach adulthood. This makes using age thresholds for support and the need for a re-assessment process to access adults’ services difficult to justify for this group.

## #10: What does a good relationship between children’s and adults’ services look like? How can this be supported in the transition process, and how does it contribute to good transition experiences?

Participants agreed that it was important for children’s and adults’ services to work together effectively.

Young people, parents and carers, and professionals all raised concerns about how negative relationships between children’s and adults’ services impacts on transitions. There were lots of questions about how these relationships could work better, and lots of reports of situations where they have not worked well.

Professionals shared experiences of relationships being positive and effective in practice. Multiple professionals said that children’s and adults’ teams worked jointly from when a young person was 14 to 16 years old, and that this ensured that there was good joined-up working during the transition process.

Parents’ views differed significantly from professionals’ views. They shared experiences that highlighted a lack of relationship in practice between children’s and adults’ services and showed they did not always work together. They expressed feeling that “neither one wants to take responsibility” for transition. Some parents shared that sometimes the services engaged in negative talk about each other. For example, one parent shared that they felt there was “scaremongering” about adults’ services from children’s services staff.

Some points also related to the concerns raised in discussion of question nine. Parents spoke of experiences where children’s and adults’ services could not agree about which services young people needed. An example was shared where a young person was supported by an adults’ disability team for a disability they did not have, because adults’ services had nothing available that was appropriate.

Young people said that it was important for them to understand what was going to happen when they transitioned into adults’ services. They also said it was important for this to be communicated to them before they left children’s services. They spoke about the need for relationships between children’s and adults’ services to work well so that they knew what to expect after they turned 18.

## Reflections from the workshop

This section considers what workshop participants told us about the transitions process as a whole.

### Similarities and potential overlaps in priority questions

The prioritisation questions were developed based on the original submissions to the first survey, in consultation with the project’s working group. A number of professionals and parents in the workshop expressed concern that the questions were too similar to one another. Some also felt that the questions in general were too broad and therefore would not be helpful as research questions. Five of the questions from the top 10 were specifically identified as being very similar to one another. These were questions two, four, five, six, and seven. Participants had differing views about which questions overlapped with which.

### How transition works in practice

In the workshop, some professionals expressed surprise that so many people with lived experience shared that the process had not worked as expected. Professionals said that there were clear processes in place, and it was concerning to hear that people’s experiences were not in line with those processes. Young people and parents shared a number of experiences where planning had not happened when it should have, or planned-for services were not in place when needed. Some professionals said that hearing about these experiences had changed how they ranked the importance of the priority questions. This indicates there may be a significant difference in perception of care services between young people and their parents and professionals.

### Questions about the need for transition

The specific question of whether transition should happen is not captured within the priorities. However, some of the parents involved in the workshop were reluctant to rank the priority areas because they did not feel that a focus on transitions was appropriate. The question was raised as to whether transition should happen at all. This was because some young people experienced an interruption or a complete end to support after the transition to adults’ services. Parents felt that the focus of social care should be on supporting the person’s needs and making sure their life can continue as they reach adulthood. Some felt the transition process interferes with this.