Preparing for adulthood

Understanding rights and choices, planning and staying in control

May 2025

Think Local Act Personal

Contents

Acknowledgements

Introduction

Everything starts with the young person. When a young person turns 18, their life does not change overnight. Their support needs, preferences and wishes do not suddenly stop. They don't start using different words and phrases to describe their everyday ordinary lives. So why do we expect services to do that?

The word 'transition' has been used in education, health and social care to describe the time when a young person who draws on care and support reaches adulthood and starts accessing adult social care. It is a significant period in the life of a young person and the support, information, and advice they are offered can greatly impact the direction of their life into adulthood, as well as their wellbeing. The time and the age at which the 'transition' happens is variable from young person to young person, depending on where they live, what specific needs they have, and what local government policy dictates. Therefore, it is important to use consistent language which makes sense to the young person and the people who care and support them.

A lot of good work has already been undertaken by other organisations to understand and elevate the voices of young people. In other programmes of work, the preferred terminology expressed by young people and the people who care and support them, is 'preparing for adulthood'. We will be using the term 'preparing for adulthood' in this report instead of 'transitioning' to move away from language that suggests pathways, processes, or people being passed between systems. There are plentiful resources and guidance available to professionals and practitioners. We did not want to rewrite the same information in this report, but we have included some examples for reference.

In our research and exploration for this project, we spoke to people in organisations who have completed similar work. We found that there was little information on the experiences of family and friend cares. Family and friend advocacy and involvement are significant elements which support choice, control, and self-direction for the young person as they are supported and guided into adulthood, so we wanted to listen and learn from these narratives.

We also wanted to hear about the clarity and accessibility of information available to family and friend carers, and young people about their right and opportunity to self-direct their support alongside good person-centred plans which go beyond moving into adulthood and help to embed a holistic 'good life' approach to planning and implementing support.

"'Moving out of care' and 'leaving care' were the terms used for me. It was all 'closure' language. There was nothing positive, constructive, strengths-based or person-centred. It was all about leaving a process. The descriptions were derived from the terminology of the Children's Act legislation at the time…."

Project aims:

- Develop a broad understanding of what work has already been undertaken to improve the experience for young people and the people who care and support them.

- Understand some of the key elements which support a good experience for young people and the people who care and support them.

- Understand the extent to which parents, carers and young people can self-direct their support at this stage in their lives.

- Find examples of best practice, to share what works well.

- Understand where there are gaps in information and resources, and process issues.

- Co-produce a set of recommendations to help improve the experience for young people and the people who care and support them.

Project stages:

1. Researching and identifying other aligned work focusing on preparation for adulthood.

2. Gathering insights from other organisations and practitioners exploring the same issues.

3. Holding a series of online workshops to listen to the lived experiences of family and friend carers.

4. Co-producing a survey using parent and carer narratives as a framework to gather wider data from family and friend carers across England.

5. Presenting data from the survey to support key themes, with a set of recommendations.

"Our language needs to purely centre around the person making the journey, not the journey itself"

Context

'Aiming High for Disabled Children' (2007) identified a number of key issues for improving the lives of disabled children and their families. 'Learning from the Aiming High for Disabled Children (AHDC) programme,' Council for Disabled Children (2011), reviewed the implementation and impact of the AHDC programme to date.

Key issues highlighted in the 2011 report were the need for:

- better information for families
- simplifying access to services and planning with families
- supporting families through the system: key workers and lead professionals

The Children and Families Act and Care Act (2014) began to be implemented in 2015. The Children and Families Act and corresponding Special Educational Needs and Disabilities (SEND) code of practice introduced Education, Health and Care plans (EHCPs).

The National Development Team for Inclusion (NDTi) were commissioned by the Department of Education to support the implementation and embedding of the Children and Families Act policies and guidance, under the programme 'Preparing for Adulthood'. This work focused on four key areas: Employment; Independent Living; Good health; Friends, Family and Community.

Both legal frameworks were designed to overlap, with a common 'strengths-based' focus and a holistic approach to assessment, planning, and reviewing, and a right within law to receive a personal budget for the arrangement and payment of services. A decade later, anecdotal evidence from those with lived experience and professionals who work in this area of support, suggests that the system is broken. The two legal frameworks do not interface with each other in practice, and professionals who have a role in facilitating the transitional process either in the early or later stages are not speaking the same language. Parents, carers, and practitioners we have listened to have expressed many of the same frustrations and issues which were identified back in the learning from the Aiming High for Disabled Children (AHDC) (2011) programme report.

> "Information, there is a lack of it – what should happen and when. Too much pressure and presumption that family and friend carers go out and find this information"

Current guidance and recent examples

There is a vast amount of information and supporting resources available to support and inform practice and decision-making relating to preparation for adulthood. We have shared some examples below. This is not an exhaustive list.

Example	Description
SEND code of practice 2015	Chapter eight provides guidance for preparing for adulthood from early years. There is a focus on the link between raising aspirations and supporting positive outcomes, promoting a strengths-based approach which works with the young person's interests and skills as a basis for planning future opportunities and support.
Care Act 2014: Transition for children to adult care and support	The Care Act introduced a new duty on local authorities to carry out Child's Needs Assessments (CNA) for young people who are likely to have needs for care and support after they reach the age of 18. The purpose of the assessment is to determine eligibility for adult social care after the young person's eighteenth birthday to inform choices and planning for the future. An assessment can be requested at any time before the young person's eighteenth birthday and they do not need to have an EHCP to request an assessment for adult social care.
NDTi Preparing for Adulthood (PfA) programme and resources	The PfA programme was commissioned by the Department for Education in 2011 to help embed the new Children and Families Act legislation and code of practice for SEND. NDTi created a resource hub on their website, which is still active. The contract ended in 2022, but the Preparation for Adulthood support continues under the RISE partnership (Research and Improvement for SEND Excellence), which NDTi is part of.
Person-centred planning facilitated processes (Big Plan, MAPs, PATH)	Person-centred planning processes are facilitated in a structured order and usually involve everyone who knows the focus person well. There are some good examples of facilitated planning happening with children and young people – for example, MAPs being created by the Educational Psychology team in Wolverhampton for children in early years settings and moving between schools as a future aspirational approach, and Big Plans being offered at schools in Scotland for young people preparing for leaving school.
Person-centred planning and thinking tools (e.g. Helen Sanderson Associates)	Person-centred planning tools are individual processes or templates which have often originated from, or have been developed out of, the longer facilitated processes. They are tools which are designed to be used with and by the focus person and the people who know them well. They can be helpful in developing EHC plans, Life Plans and Support plans. They can also help to provide evidence in assessments for future support, and reviews. Examples include One-Page Profiles, Circles of Support, 'Dreams' (or North Star), and Good day/Bad day.
Transition Information Network (Council for Disabled Children)	The Transition Information Network is a source of information and good practice for disabled young people, families, and professionals. It's a specialist network of the Council for Disabled Children set up to provide targeted information and resources about transition through online resources, publications, and events.

Example	Description
NICE guideline: Transition from children's to adults' services for young people using health or social care services, February 2016	This guideline covers the period before, during, and after a young person moves from children's to adults' services. It aims to help young people and the people who care and support them have a better experience of transition by improving the way it's planned and carried out. It covers both health and social care.
Preparation for Adulthood: Young people with a learning disability and autistic young people legal guide – Local Government Association, November 2023	What does the law say? A legal guide for council staff including lawyers and social workers.
Into adulthood resources hub: Council for Disabled Children	The resources hub brings together a wide collection of practical advice, guidance, and toolkits on preparing young people for adulthood.
DFN Project SEARCH: transition to work programme	DFN Project SEARCH is a national charity that enables young adults who have a learning disability or autism spectrum condition to secure meaningful permanent employment.
Transitional safeguarding resources: Partners in Care and Health	A collection of resources developed by the Transitional Safeguarding Reference Group, hosted by Partners in Care.
Language that cares:TACT	TACT fostering and adoption: Changing the way professionals talk about Children in Care.
Partners in Policymaking: In Control	Partners in Policymaking and associated courses help people understand how the health and social care system works, organise meetings, and present questions without getting frustrated. All Partners in Policymaking courses aim to help find solutions to improve people's lives and give participants the confidence to work in partnership to enable them or their loved ones to have choice and control over their lives.
IPSEA (Independent Provider of Special Education Advice)	A leading charity in the field of SEND law in England, providing free and independent legal advice and support to families of children and young people with SEND. IPSEA also provides training on the SEND legal framework and works to influence policy at both a local and national level.
National Minimum Standards for SENDIAS services – Council for Disabled Children	SENDIASS stands for Special Educational Needs and Disabilities Information Advice and Support Service. There is a SENDIAS Service in every local authority in England. The National Minimum Standards set out what is expected from SEND Information, Advice and Support services, including the Local Offer.

Example	Description
Special Needs Jungle	Special Needs Jungle creates easy to understand resources, articles, and information for family and friend carers of children with special needs, disabilities ,and health conditions to better enable them to navigate the special needs system.
Bringing Us Together	Bringing Us Together is led by parents of children and young people with a variety of Special Educational Needs and Disabilities. They offer a variety of workshops and resources to support family and friend carers.
In Control: Information about Self-directed support resources for Children and Young People	In Control is a national charity working for an inclusive society where everyone has the support they need to live a good life and make a valued contribution.
Gloriously Ordinary Lives	Seeing support through a different lens, with a 'whole of life approach'. Gloriously Ordinary Lives offers 'five tests' as a lens for viewing any support that is being considered.
IMPOWER: Valuing SEND	Valuing SEND (with Lincolnshire County Council). From 2020 to 2021, IMPOWER supported Lincolnshire County Council to implement a range of interventions at scale with a focus on delivering better outcomes by responding earlier and/or differently to meet children's needs.
Doncaster Council: Preparation for Adulthood	Doncaster Council have included a focus on preparation for adulthood in their Adult Social Care Local Account (2025). They have undertaken a review of their current arrangements to identify what is working well, what needs to change and improve, using surveys (led by young people) asking about people's experiences, people's stories about their experiences, workshops and focus groups with young people and practitioners. Key developments include a tool (dataset) that helps to identify young people over the next 3 years who will likely require some support from adult social care to plan for the future and working with young people to co-produce a 'rights' document – which sets out young people's expectations from the local authority.
ADASS West Midlands: Autism and Parental Blame research	The Autism and Parental Blame research project seeks to understand how parents of autistic children experience parental blame when they approach health, education, and care services for support. The report, Autism and Parental Blame: Blamed Instead of Helped, is intended for professionals, policymakers, researchers, and anyone who is interested in improving the lives of autistic children, young people, and their families.
AccessAva: Access Social Care	AccessAva is an online tool for asking questions and seeking information relating to social care law. It provides Easy Read information, and template letters for navigating the social care system.

Lived experience workshops and story-gathering

We held two online lived experience workshops, listening to family and friend carers with experience of the 'preparing for adulthood' process. We also heard from adults who had been through the preparation for adulthood process themselves, and a senior advice coordinator from Access Social Care – an organisation which provides free legal advice to people with social care needs, helping to achieve a better quality of life – and examples from people in caring roles.

Discussions in the workshops covered:

- access to information and options
- advocacy and self-advocacy
- future planning (next steps and whole of life)
- having control
- understanding rights
- the emotional and mental health impact of the process
- the value of parent and carer networks
- consistency of language and information between children's and adults' services
- consistency of process
- professional empathy

Some of the people who were involved in the lived experience workshops and research stages of the project shared their stories on video.

Watch the stories here: https://communityreporter.net/TLAP

> "Family and friend carers are having to sacrifice work and other priorities to manage their caring role and coordinate services around the young person"

Co-produced online survey

A key aim of the project was to co-produce a survey which could be shared more widely. We partnered with Gobby, a qualitative online survey tool which enabled us to capture individual narratives in data form to shape and support recommendations.

The survey questions were created using the narratives which had been shared by family and friend carers in the lived experience workshops. We gathered people's comments and stories and grouped them into key ideas.

The project team met with members of the National Co-production Advisory Group (NCAG) to discuss and refine the survey questions. The Gobby online survey was then built and circulated to parent and carer networks nationally.

The survey questions:

1. In this survey, we are using the term 'transition'. Describe your preferred wording or terminology when planning for transitions to adult social care.

2. In your own experience, what age did the transition planning process start?

3. What region are you in?

4. What would be the specific information you need as a parent/carer when supporting transition planning?

5. What information do you think should be included in young people's transition plans to ensure consistent and personalised support in the future?

6. In your opinion, what role could advocacy and self-advocacy play in supporting a good transition to adulthood?

7. How can parent/carer networks have a role in supporting transitioning to adult social care?

8. What are your top three tips for advising professionals supporting young people transitioning to adult social care?

9. Do you have any other thoughts about how the transition process could be improved or done in a different way?

Participants were also asked to share demographic data, which was in a pre-set response format.

Some charts have been included in the body of the report. A full set of charts is available in the appendix (p28).

Key themes and data

The online survey was open to responses for eight weeks. Responses were collated and sorted into key themes for the report. The project team worked with members of NCAG to review the survey responses and agree key themes. This was supported by the narratives shared in the online workshops and individual conversations with the project team. The full range of data from the survey is available in the appendix.

Key themes from survey responses are shown in bold type, with sub-headings shown in brackets underneath:

Planning for adulthood

(Planning; Moving; Preparing; Becoming; Adulthood)

The survey asked participants whether they thought 'Transition' was an acceptable description for the process of moving from children's service to adults' services. Survey participants could share their preferred words and phrases. The range of responses were themed under 'Preparing' or 'Planning' for adulthood, but the majority of responses implied a planning element as part of the process. A number of participants implied that it should be about planning for the whole of life.

"Transition is a service-focused word, 'preparing to move into adulthood' would give more indication of what the process means"

"Transition means different things to different people"

"Transition is not a thing for young people and their families. The system has created this problem! There's no 'moving', it's just about getting older!"

"I think the word 'transition' needs to be put in the bin! I think we should scrap using the word 'transition' because we're acknowledging someone is going on a journey and it's high time for the focus to be purely on the person making that journey rather than the transactional process that they're undergoing"

"'Moving out of care' and 'leaving care' were the terms used for me. It was all 'closure' language. There was nothing positive, constructive, strengths-based or person-centred. It was all about leaving a process. The descriptions were derived from the terminology of the Children's Act legislation at the time…."

"Our language needs to purely centre around the person making the journey, not the journey itself"

"The words 'adult' and 'adulthood' can be extreme pressure for some young people. We're not all ready to grow up at the same time, and talking about being an adult can be a really scary concept"

Accessible information

(Where to find information; Feeling confident that information is up to date and relevant; Receiving information in a format which is accessible for young people, family and friend carers; Translation into other languages).

Many survey responses included the theme of 'Accessible information' which applies to the ability to access relevant information in a format that is easy to understand for both young people and the people who care for them, who are helping to guide them through the process.

> "Transition is not a thing for young people and their families. The system has created this problem! There's no 'moving', it's just about getting older!"

> "I kept asking for accessible information so that we could explain what was going on, and it was horrendous"

This could include using Plain English rather than 'service language', accessible information formats such as Easy Read, audio descriptions, and translation into other languages. This theme also covers how and where people can access the information they need to make informed decisions and ensure that they have been made aware that this information is available to them.

"Information, there is a lack of it – what should happen and when. Too much pressure and presumption that family and friend carers go out and find this information"

"Language changed dramatically and created confusion. Jargon like transition, MCA, DOL's, best interest decisions, access to the community, personal advisors, court of protection are now commonplace"

"Having someone to explain it to them in terms they would understand would really help –there's too much jargon and lingo, for parents and young people"

"I kept asking for accessible information so that we could explain what was going on, and it was horrendous"

Options available

(Support options; Life skills development; Aids and equipment; Transport; Housing options; Community connections and opportunities; Further education options; Work and volunteering opportunities; Apprenticeships; Advocacy services; Navigating, planning and brokerage support; Personal budget options enabling self-directed support).

This theme relates to awareness of the options available for young people and the people who care and support them during the planning for adulthood process. This covers a wide range of options including support services, aids and equipment, transport, housing options, community connections and opportunities, further education options, work and volunteering opportunities, apprenticeships, advocacy services, planning and brokerage support, and personal budget options including self-directed support.

It also covers the need for a navigator or coordinator to support the young person and the people who care and support them with exploring options and planning for what makes sense for their personal circumstances and preferences.

"Options for work, support for financial planning, independent living, mental health ,and the services that are on offer to help. Everyone is unique."

"The current process doesn't support aspirational future planning"

> "Language changed dramatically and created confusion. Jargon like transition, MCA, DOL's, best interest decisions, access to the community, personal advisors, court of protection are now commonplace"

> "A key worker is required, that would ensure that all areas are assessed and provided for – this should NOT fall to parents"

"SEND parents' loudest message for PfA is that information in MAINSTREAM school is inadequate and inconsistent for their SEND child"

"A key worker is required, that would ensure that all areas are assessed and provided for – this should NOT fall to parents"
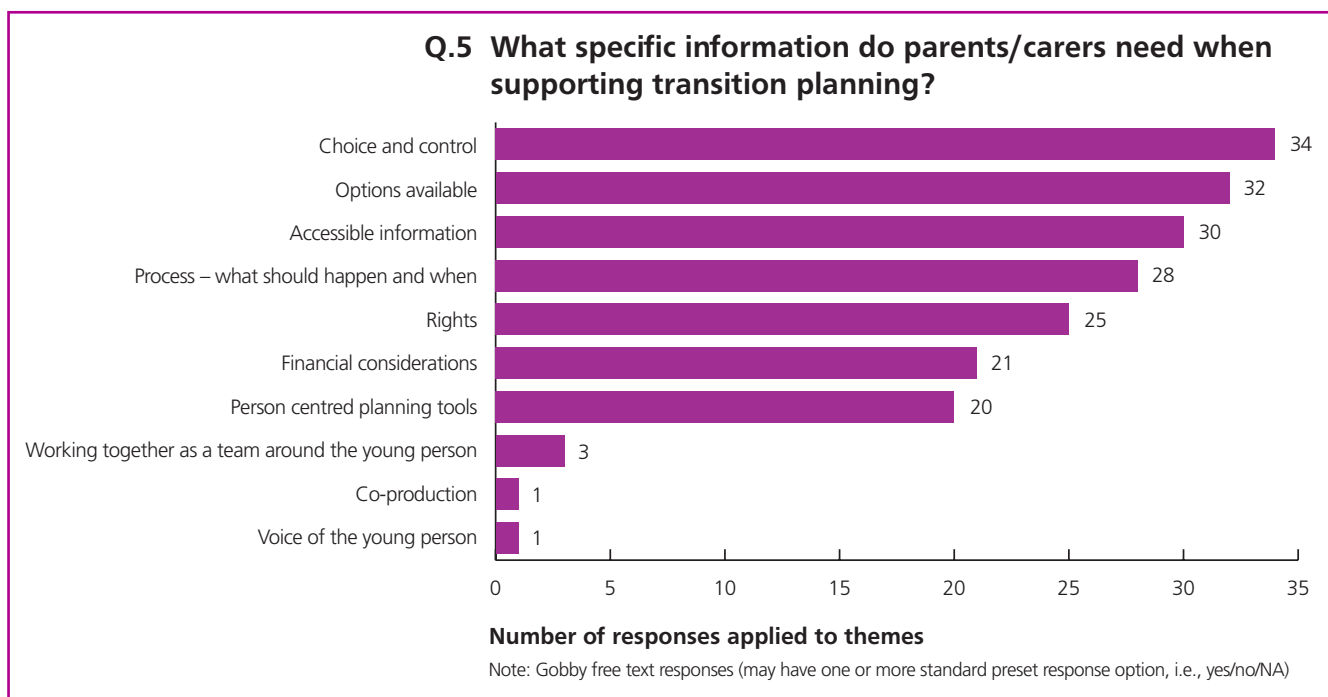
Choice and control

(Self-directed support in the EHCP process; Self-directed support in adult social care and health; Advocacy)

This theme relates to the underpinning principle of choice and control within the SEND code of practice and Care Act guidance. People should be supported to make informed choices about how they want to be supported and how their support is arranged and administered. The option for self-directed support is enshrined both in the Children and Families Act, and the Care Act.

In order to exercise choice and control, people need to be aware of their options and to be given the opportunity to exercise choice that meets their personal preferences. The voice of the young person should be at the heart of the process, which may include the need for advocacy involvement to ensure that the young person's voice is independent and distinctive throughout the process.

Choice and Control scored as the strongest response theme to question 5: What specific information do Family and friend carers need when supporting transition planning? and question 7: In your opinion, what role could advocacy and self-advocacy play in supporting transitions to adulthood?

Q.5 What specific information do parents/carers need when supporting transition planning?

Theme	Number of responses
Choice and control	34
Options available	32
Accessible information	30
Process – what should happen and when	28
Rights	25
Financial considerations	21
Person centred planning tools	20
Working together as a team around the young person	3
Co-production	1
Voice of the young person	1

Number of responses applied to themes

Note: Gobby free text responses (may have one or more standard preset response option, i.e., yes/no/NA)
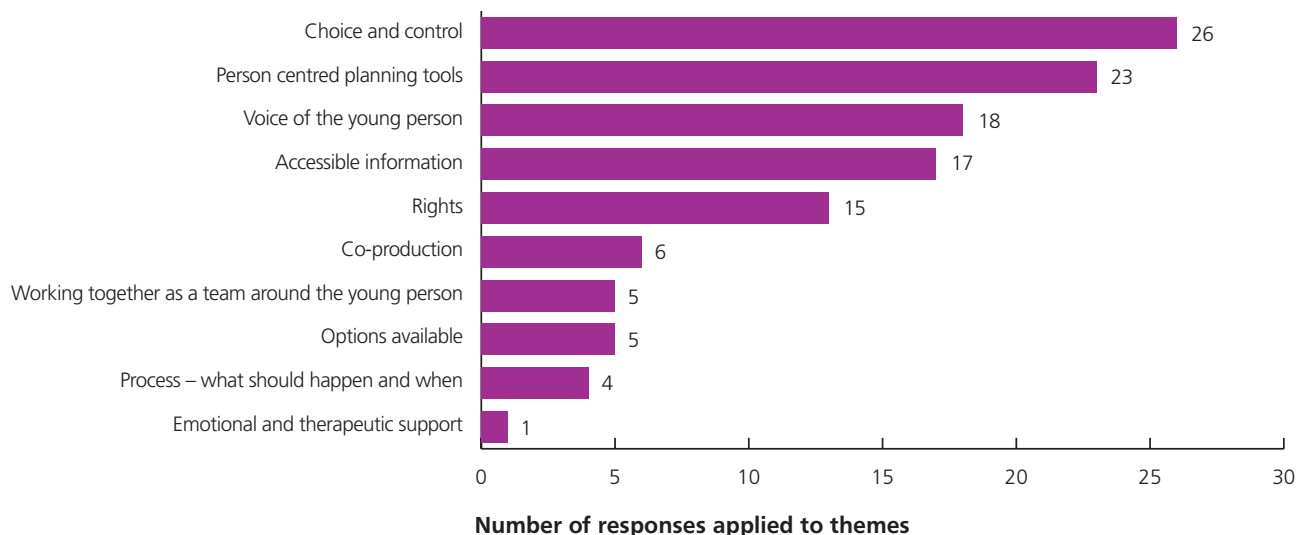
"A lot of the leg work was done ourselves"

"Parents have to be proactive"

"The young person should be asked their opinion and if not able to give it, a trusted adult e.g. a parent should always be listened to and consulted"

"We were given the link to the 'local offer' to look at. It was so depressing. It was only segregated specialist provision or GCSE entry. That didn't feel right. The local college were offering a BTEC course in Dance. Musical theatre is who she is! She went there from college. We agreed the EHCP, and she receives 1:1 support there"

Q.7 In your opinion, what role could advocacy and self-advocacy play in supporting transitions to adulthood?

Theme	Value
Choice and control	26
Person centred planning tools	23
Voice of the young person	18
Accessible information	17
Rights	15
Co-production	6
Working together as a team around the young person	5
Options available	5
Process – what should happen and when	4
Emotional and therapeutic support	1

Number of responses applied to themes

Note: Gobby free text responses (may have one or more standard preset response option, i.e., yes/no/NA)

Process – what should happen and when

(Children and young people who are not eligible for EHCP; EHCP planning; Planning for adulthood; Introduction to adult social care; Social care/personal budget; Key worker or coordinator).
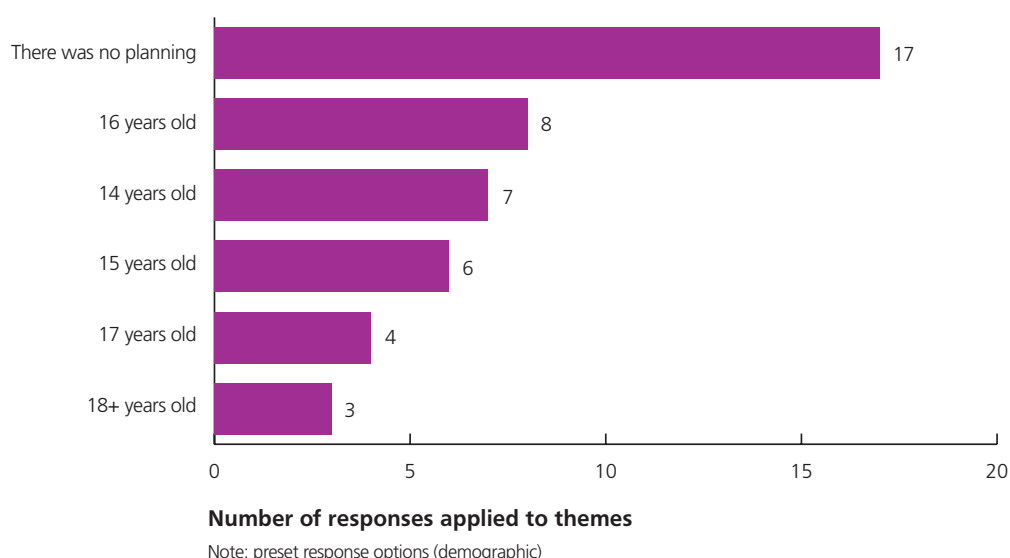
This theme covers the range of responses offering suggestions and insights into what happens at different stages of the process of planning and moving from children's services to adults' services. It includes having a clear understanding of the statutory guidance, the age of the young person at the different stages of the process, being clear about which professionals are involved in which aspects of the process, and a consistent person, such as a key worker or coordinator, to stay with the young person through the process.

This theme also covers the entitlement to different statutory funding sources, (e.g., Health, Social Care and Education) the amount of budget available to the young person, and the different ways of receiving and managing the budget such as Direct Payments/Personal Health Budgets and Individual Service Funds/Third Party budgets, particularly where the young person and the people who care for them are choosing to self-direct their support, alongside financial means-testing for social care funding and personal contributions.

Process- what should happen and when scored as the strongest response theme to question 10: Do you have any other thought about how transitions could be improved or done in a different way?

Q.3 What age did transition planning start for the young person?

Category	Value
There was no planning	17
16 years old	8
14 years old	7
15 years old	6
17 years old	4
18+ years old	3

Number of responses applied to themes

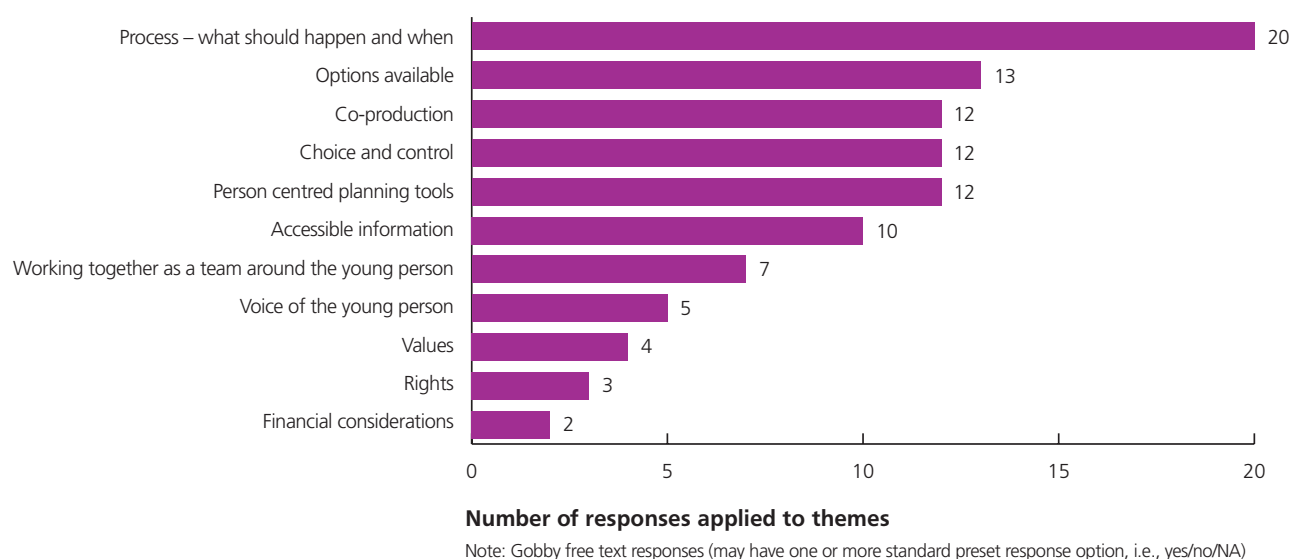Note: preset response options (demographic)

"Strangers are completing assessments with little input from me because he is considered an adult, yet he requires 100% support"

"It's about having an ordinary life, regardless of age"

"We have a 'tell us once' service that straddles absolutely everything when a person dies…why haven't we got the functionality of that for social care? Particularly for transition…"

In response to question 3: What age did transition planning start for the young person? The most popular answer was **'there was no planning'**

Q.10 Do you have any other thoughts about how transitions could be improved or done in a different way?

Category	Value
Process – what should happen and when	20
Options available	13
Co-production	12
Choice and control	12
Person centred planning tools	12
Accessible information	10
Working together as a team around the young person	7
Voice of the young person	5
Values	4
Rights	3
Financial considerations	2

Number of responses applied to themes

Note: Gobby free text responses (may have one or more standard preset response option, i.e., yes/no/NA)

Rights

(Legal rights: Children & Families Act/SEND code of practice; Legal rights: Care Act; Legal rights: Mental Capacity Act; Statutory Advocacy; Complaints process and challenging decisions; Parent and carer rights).

This theme covers a range of responses relating to people being aware of their rights within legislation, their eligibility for support, entitlement to different services, and knowing how to challenge if they did not think their rights were being upheld. This also related to the understanding of changes to legal frameworks when the young person becomes 18 years of age, which may impact on the way decisions are made, and the role of family and friend carers in decision-making once the young person becomes 18 years old. The right to statutory advocacy support (EHCP process, Care Act, IMCA. IMHA and NHS complaints) is also covered under this theme.

Information for family and friend carers on their own rights, and the fact that they should not be assumed to continue caring for their young person in adulthood, is also covered under this theme.

"I went from Mum and voice for my non-verbal child with profound disabilities to nobody"

"Parents are told when their child turns 16-18 that they no longer have rights and yet are left to bear all the responsibility"

"If I don't advocate for my son, who will?"

Person-centred planning tools

(Person-centred principles – Young person at the centre; Individual person-centred planning tools; Facilitated planning process approaches – PATH, MAPs, Big Plan; Person-centred reviews).
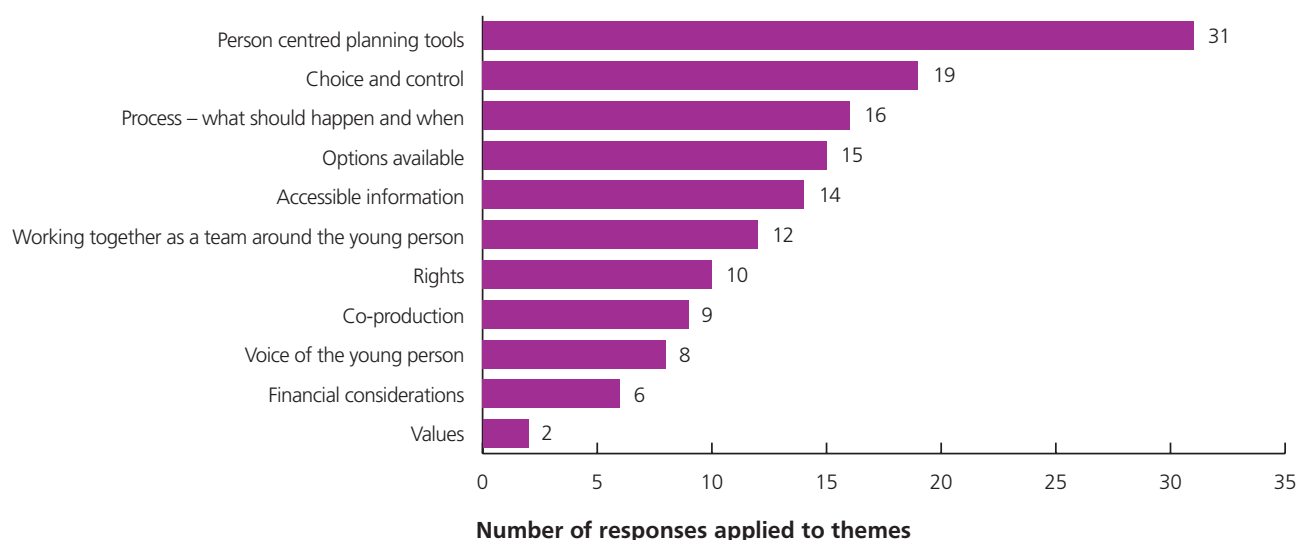
This theme covers the principles, tools and processes of person-centred planning, which enable aspirational and strengths-focused future plans which are centred around the young person to be developed. Elements of these tools (such as circles of support and one-page profiles) can be helpful in bringing together strengths-based information about the young person, but there is also the consideration of using facilitated planning processes such as PATH, MAPs and Big Plan which can support creative and flexible planning around the young person, involving all of the people who know them well. This should not be seen as the same as the EHCP process itself, but it can be a helpful way to gather the detail for an EHCP, and a way of reviewing plans to ensure that services are held accountable to the person-centred planning outcomes. A person-centred plan can follow the young person into adult support environments, workplaces, and many other contexts, because it follows the person rather than being owned by the service which is supporting them.

Person-centred planning tools scored as the strongest theme in responses to question 6: What information should be included in young people's transition plans, to ensure consistent and personalised support for their future?

Q.6 What information should be included in young people's transition plans, to ensure consistent and personalised support for the future?

Theme	Responses
Person centred planning tools	31
Choice and control	19
Process – what should happen and when	16
Options available	15
Accessible information	14
Working together as a team around the young person	12
Rights	10
Co-production	9
Voice of the young person	8
Financial considerations	6
Values	2

Number of responses applied to themes

Note: Gobby free text responses (may have one or more standard preset response option, i.e., yes/no/NA)

"Promoting independence, recognising abilities, developing skills, and celebrating success should be an everyday experience for our young people"

"We used the 'Big Plan' supported in Edinburgh through the school – supplemented by our own independent research into options"

Financial considerations

(Welfare benefit entitlements; Arrangements for managing finances; Formal legal arrangements for financial decision-making) .

This theme covers the different financial considerations which need to be explored by people who are navigating the process. This includes entitlement to welfare benefits, financial means-testing for social care funded support, disability related expenditure, Lasting Power of Attorney, DWP appointeeship, and court appointed deputyship via the Court of Protection.

"Financial impact – where provision is offered, there are hidden costs e.g., furnishing supported living accommodation and indemnity/ insurances"

"We need guidance on how to get them the benefits they need. It is like walking into a maze with no help or instructions!"

"It's effectively a full-time job and nobody pays you for it…because there are countless meetings all of the time, and they expect you to be there. I can't take on work to earn myself some money"

"Your young person's financial contributions to their care is a massive issue because their disability related expenditure is not taken into consideration properly"

> *"We need guidance on how to get them the benefits they need. It is like walking into a maze with no help or instructions!"*

Working together as a team around the young person

(Key worker/coordinator role; The role of family and friend carers as part of the team; Key professional roles; Support providers).

This theme relates to a wider range of responses indicating the need for stronger collaborative working between agencies, professionals, and different support settings. This theme also strongly indicates the role of family and friend carers as part of the collaborative working process.

"An advocate/key worker would be great to sort out all the needs holistically, they need to work as a team with family.

"Think about the whole person and the whole family, not just today and what's going to tick that box!"

"Please remember that we're in this to support you as well as our young adults and please, instead of changing the horses on the merry-go-round, change the whole merry-go-round and make it a pathway with equal partners"

"Think about the whole person and the whole family, not just today and what's going to tick that box!"
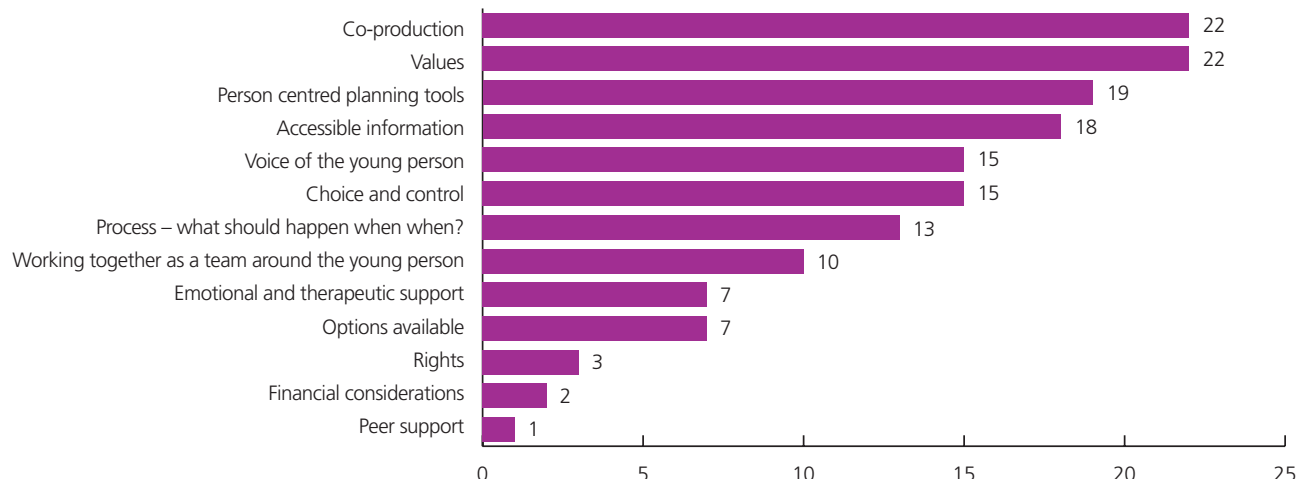
Co-production

(Co-production of individual plans; Co-production in developing and delivering training; Co-production in developing policy, Processes and services).

This theme relates to co-production, involving the young person and the people who care and support them as key roles in the development of support plans and arranging practical support around the young person. This also covers the wider context of co-production where young people, family and friend carers can offer support to others, deliver training, and work in equal partnership with strategic decision-makers in developing policy, processes, and services relating to young people moving into adulthood.

Co-production, Values and Person-centred planning tools scored as the strongest response themes to question 9: What three tips would you give professionals supporting young people into adult social care?

Q.9 What three tips would you give professionals supporting young people into adult social care?

Theme	Number
Co-production	22
Values	22
Person centred planning tools	19
Accessible information	18
Voice of the young person	15
Choice and control	15
Process – what should happen when when?	13
Working together as a team around the young person	10
Emotional and therapeutic support	7
Options available	7
Rights	3
Financial considerations	2
Peer support	1

Number of responses applied to themes

Note: Gobby free text responses (may have one or more standard preset response option, i.e., yes/no/NA)

"Co-produce – put the person at the true centre and be asset based"

"Parent and carer networks could help by providing information, advice, and training to families, young people, and practitioners"

"Parent and carer networks have the ability to represent views of parent carers strategically and can bring groups together to ensure co-produced pathways"

"Stop what you're doing! Co-produce and co-design from scratch with people with lived experience"

Emotional and therapeutic support

(Support for family and friend carers; Support for wider family members who are impacted e.g., siblings; Support after a diagnosis).

This theme relates to the emotional cost involved in taking care of a young person, and the additional stresses of navigating the planning and preparation process for adulthood. Participants shared traumatic experiences, and the need for emotional support to be able to continue with their parenting and caring responsibilities. This could include the wider impact on other family members, such as siblings. This theme covered responses about the emotional and therapeutic support needed for both young people and the people who care for them after receiving a diagnosis and processing the impact of this on them.

"There's no recognition of the impact fighting for SEN education has on family relationships and peer friendships"

"Family and friend carers are having to sacrifice work and other priorities to manage their caring role and coordinate services around the young person"

"It feels like you're walking through a maze or that you were falling through the air but never hitting the bottom"

"I've had a lot of support put in place by carers' organisations, which has been a godsend really"

"As a carer, my health has absolutely deteriorated because of the stress I have encountered in battling the system for my daughter"
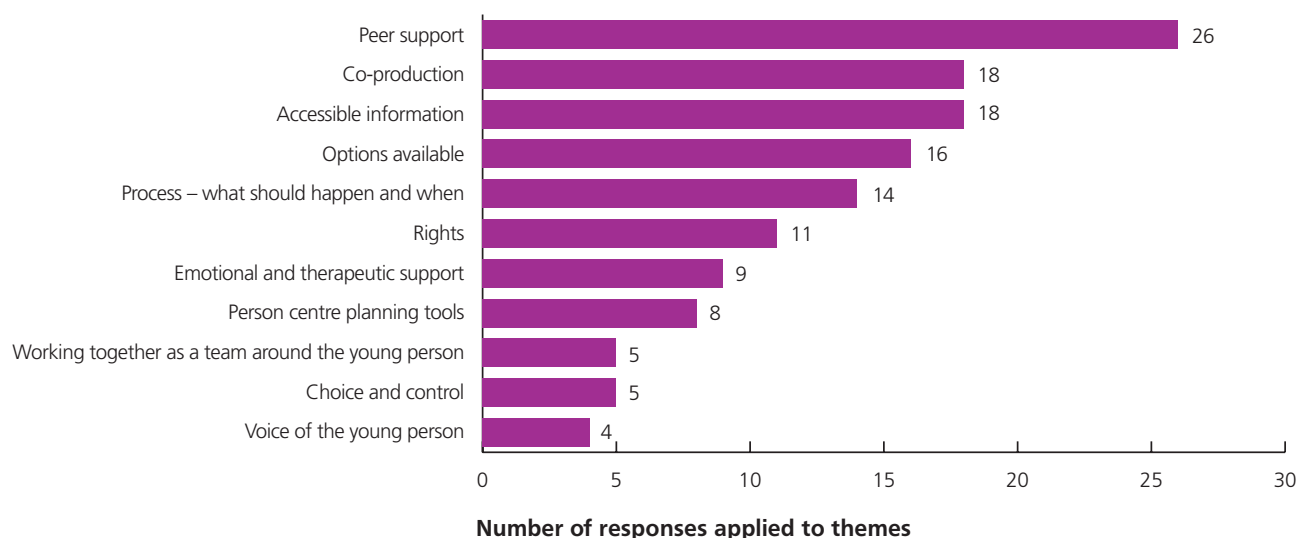
Peer support

(Sharing knowledge; Standing alongside others; Strong networks which create opportunities).

This theme relates to a significant proportion of responses indicating the value of peer support, lived experience insight into what is needed, shared knowledge, and standing alongside others going through the same process. This theme also covers the responses which signalled the strength of peer networks to create and develop opportunities for young people and the people who care for them.

Q.8 How can parent/carer networks have a role in supporting transition to adulthood experiences?

Theme	Number of responses
Peer support	26
Co-production	18
Accessible information	18
Options available	16
Process – what should happen and when	14
Rights	11
Emotional and therapeutic support	9
Person centre planning tools	8
Working together as a team around the young person	5
Choice and control	5
Voice of the young person	4

Number of responses applied to themes

Note: Gobby free text responses (may have one or more standard preset response option, i.e., yes/no/NA)

"Some of the best information I've found has been via parent carers networks"

"The biggest source of information has been other parents…being in groups and talking to other parents…"

Values

(Values; Principles; Approaches)

This theme relates to underpinning values, principles and approaches to supporting young people and the people who care for them through the process of moving from children's services to adults' services, including the approach and demeanour of professionals, practitioners, and services involved. Parental blame was also mentioned in some of the survey responses and in the online workshops.

"I don't like to be called 'The mother' by professionals"

"It's about people doing what they say they will do, when they say they will do it or just staying in touch with some empathy about how tough it is – manners really. Sending emails that make you panic on Friday afternoon before they leave the office that make you panic all weekend. People not thinking we are sitting at home with nothing else to do and are 100% available anytime they want..."

"They gave me a badge which said 'Father', and I said, 'I'm not a catholic priest!'… don't call me Dad – I'm not your Dad! I've got a name. I'm not just a Dad – there are other aspects of me that I want to be valued as well"

"There's a lack of aspiration – "He won't do that" – "We've always done it that way" – "That's how we do it" – attitudes and lack of ambition/ options being the core issue"

> "The biggest source of information has been other parents…being in groups and talking to other parents…"

> "I don't like to be called 'The mother' by professionals"

Voice of the young person

This theme relates to a range of responses highlighting the importance and central focus on the voice of the young person throughout all stages of the process. This includes provision of advocacy support to ensure that the independence of the young person's voice is promoted and enabled.

"It's important to have advocacy available and accessible and not just for one subject at a time"

"Self-advocacy opportunities should be available in all areas"

"Everyone should have an opinion on their future, and this should be taken into account by the careers/local authority when finding placement"

Recent aligned work

Throughout the duration of the project, we spoke with colleagues from other projects and organisations working on aligned themes. Below are a few of the recent pieces of work being undertaken to explore and address aligning themes and ideas.

IMPOWER/ADASS report: Preparing for Adulthood, 2024

The report was produced following a 'round table' discussion with key organisations and leaders. It outlines strategic challenges for local authorities, and offers some key ideas for systems leaders, focusing on alignment of ages, areas, and cultures and a focus on whole person, whole life, whole family, and whole community.

Partners in Care and Health are preparing to publish some guidance for Children and Young People with Learning Disabilities and Autistic Children and Young People in Spring 2025. This will be available on the Local Government Association website when it has been published.

National Development Team for Inclusion (as part of RISE partnership) are currently operating two programmes of work. One is targeted at SEND improvement for local areas, and another is developing a 'what works in SEND' programme.

Recommendations

These recommendations are anchored in lived experience narrative, and it is important that they are acknowledged, valued, and developed into more detailed actions to influence and impact transformation in the way we think, speak about, and support preparation for adulthood. Further analysis and co-production work is needed, working in partnership with people who contributed to this project and others with strong experience, knowledge, and insight so that we understand the detail of how these recommendations could be developed as a 'whole of life' approach, supporting better self-direction, and aspirational future planning and support.

The recommendations bring together the lived experience narratives shared, the key themes, and supporting data from the online survey:

1. Ensure social work practitioners are fully trained and literate in both legal frameworks and eligibility criteria, understanding how they intersect, and removing the artificial 'cliff edge' which has been created by having two separate processes.

2. Provide clear, consistent, and accessible information for young people and the people who care and support them. This includes using clear and consistent language across all stages of life.

3. Make person-centred planning available to young people likely to need support into adulthood, including those not eligible for an EHCP. Planning should be aspirational and regularly reviewed.

4. Provide a coordinator role (e.g. key worker or navigator) to support the young person and the people who care and support them throughout the process.

5. Provide better support to young people and the people who care and support them to self-direct and create personalised solutions for support.

6. Develop integrated budget and commissioning options which move seamlessly into adulthood, supporting more flexible and creative planning and support solutions, and better outcomes.

7. Adopt a values-driven, 'whole of life' approach.

8. Co-production of legislation, national and local policy, and services with young people and the people who care and support them.

Conclusion

Taking a qualitative approach to this piece of work ensured that we were able to capture present day issues and the lived experience of young people and the people who care and support them. From the results we have been able to identify real-life impact and subsequently used this data to inform the basis of our recommendations.

The most popular key themes in responses to the survey were: choice and control, person-centred planning, peer support, co-production and process – what should happen and when.

Young people's aspirations, strengths, and interests should form the basis for future planning at all ages and stages of their development and lifespan. Early planning conversations should promote person-centred support for all young people, including those who do not meet the eligibility for an EHCP, but still need support. There should be no distinction between levels of need, and there should be clear understanding and recognition of overlapping and intersectional issues which can impact on the process. The young person's voice should be the central focus, and these conversations should be continuous through all ages and stages of development.

Family and friend carers are valued roles in the planning and coordination of support around the young person. They are experts in what good support looks like, and they are strong advocates for their young people. Their voices and insights matter. They have their own rights, and their support as carers should not be overlooked or minimised. Professionals and practitioners supporting people through the process need to work together with young people and the people who care and support them in a trauma-informed and non-judgemental way, enabling good communication and co-production.

Seamless, overlapping communication, aligned and accessible language and practice between children's and adults' services professionals and practitioners is required so that we can adjust our approaches from being specific to the adolescent stage of a young person's life and begin to think more about a 'whole life' and a good future. Strategic leaders, decision-makers, and practitioners need to have a good understanding of both legal frameworks to support better cohesion between Children and Families Act, and Care Act duties. There should not be a 'cliff edge'. It does not exist in real life for people outside of the context of statutory support and services. There should not be different language and terminology used between social care teams and roles.

There are differences in eligibility criteria between children's social care and adult social care. This change needs to be coordinated by practitioners who are knowledgeable about both sides of the process, and who understand both legal frameworks and the accompanying

guidance. Some young people may not be eligible for social care under children's services but may meet the Care Act eligibility criteria as an adult. Young people and the people who care and support them should receive support to understand this.

If we begin to adopt a 'whole of life' approach to commissioning, planning and support, we can explore bold, creative, and preventative approaches in commissioning and resourcing which are ethical, values-driven, and person-centred; but we need to explore how integrated budgets for education, health and social care from 0 to 25 years can play a part in supporting smooth, personalised preparation for adulthood, without any pause to direct support needs being met and good lives being lived. Further exploration into the use of Individual Service Funds and Third-Party Budgets as a vehicle for seamless budget management would be a helpful starting point.

Self-directed support can play a much stronger role in people living good lives for their whole lives, but we need clear and consistent ways of supporting people to practically navigate the choice and control which is offered to them within policy and guidance. Their natural resources, relationships, and community networks, coupled with personal budget resources can play a key role in removing the artificial 'cliff edge' which has been created by services and systems.

The ethnicity demographics from the survey revealed an overwhelming majority response from white ethnicity backgrounds. Future co-production work needs to seriously consider and plan for involvement with people from global majority communities to ensure a representative spread of voices and narratives across all communities and ethnic backgrounds. Reflection and debrief will be an important part of learning from this project to support better engagement, participation, and co-production in next steps.

Critically, any development of new ways of working needs to be co-produced with young people and the people who care and support them so that we do not continue repeating the same challenges, issues, and messages of the past decades. Any next steps emerging from the recommendations in this report should be co-produced to build on the work which has been started. Authentic co-production needs to be planned with timescales and budgets that allow for meaningful participation and contribution, including supporting and elevating the voices of young people, making reasonable adjustments for access and inclusion, and creating accessible communications assets to support the process.

"How many more studies raising the same issues do councils need to actually get on and address them? Families with lived experience have, for two decades, offered their solutions to improve young people's preparation for adulthood – it's time to make it real!" – Rachel Mason, NCAG Member

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Appendix: Charts and data from Gobby online survey

Question set

1. 'Transition' is a term often used when planning for adult social care. Describe wording or terminology that you would prefer to see being used, if applicable*

2. What ethnicity do you belong to?**

3. What age did transition planning start for the young person?**

4. Which UK region/nation did the transition take place in?**

5. What specific information do parents/carers need when supporting transition planning?*

6. What information should be included in young persons transition plans, to ensure consistent in person I support for their future?*

7. In your opinion, what role could advocacy and self-advocacy play in supporting transitions to adulthood?*

8. How can parent/carer networks have a role in supporting transition to adulthood experiences?*

9. What three tips would you give professionals supporting young people into adult social care?*

10. Do you have any other thoughts about how transitions could be improved or done in a different way?*

    * Note: Gobby free text responses (may have one or more standard preset response option, i.e., yes/no/NA)

    ** Note: preset response options (demographic)

Survey engagement

Number of respondents by question

Question number	Number of respondents
1	50
2	51
3	45
4	45
5	38
6	34
7	30
8	30
9	30
10	26

Number of respondents

Note: questions in blue were preset response options for respondents to choose/create a single option

■ **Multiple response question**   ■ **Single response question**

Survey engagement

Number of unique responses by question

Question number	Number of respondents
1	16
2	3
3	6
4	10
5	53
6	47
7	35
8	34
9	53
10	30

Number of respondents

Note: questions in blue were preset response options for respondents to choose/create a single option

■ **Multiple response question**   ■ **Single response question**
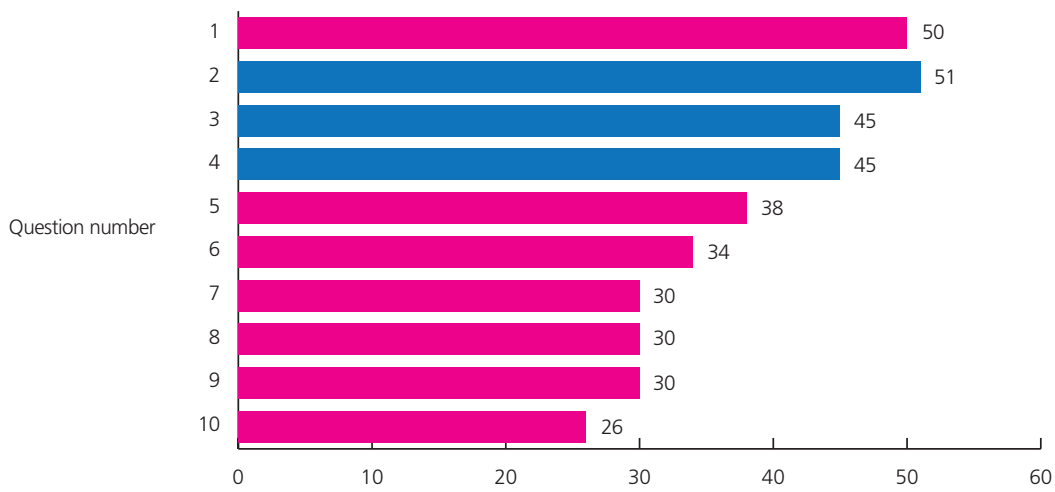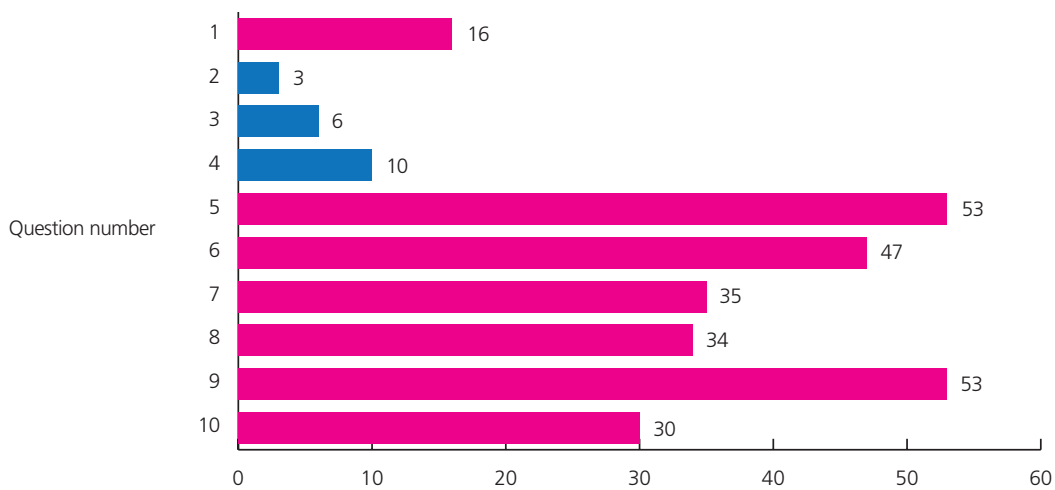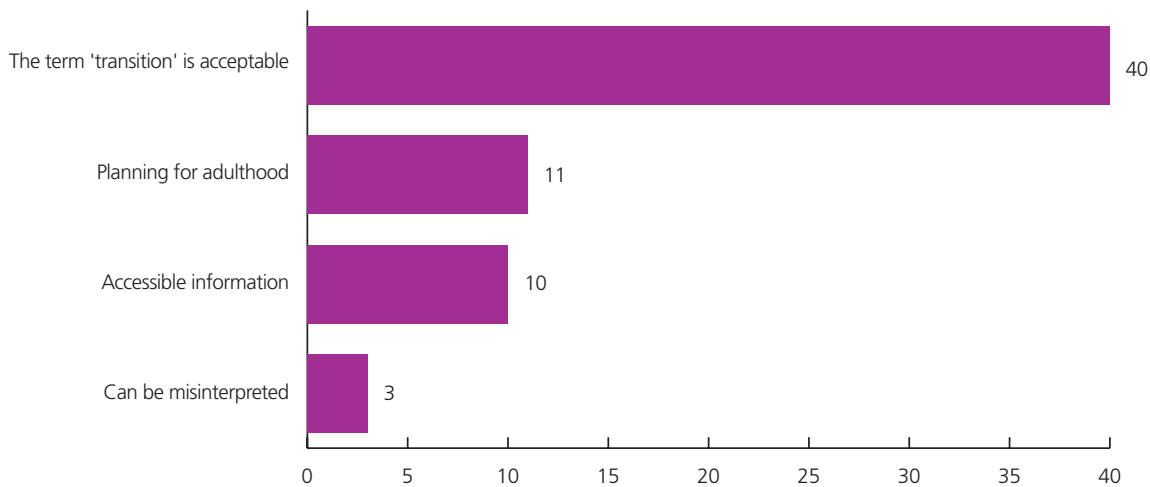
Themes and number of related responses, by question

Q.1 'Transition' is a term of a used when planning for adult social care. Describe wording or terminology that you would prefer to see being used, if applicable.

Theme	Number of responses
The term 'transition' is acceptable	40
Planning for adulthood	11
Accessible information	10
Can be misinterpreted	3

Number of responses applied to themes

Note: Gobby free text responses (may have one or more standard preset response option, i.e., yes/no/NA)

Demographics and number of related responses

Q.2 What ethnicity do you belong to?

	Number of responses
White – British, English, Scottish, Welsh, Northern Irish, or another white background	50
Prefer not to say	1
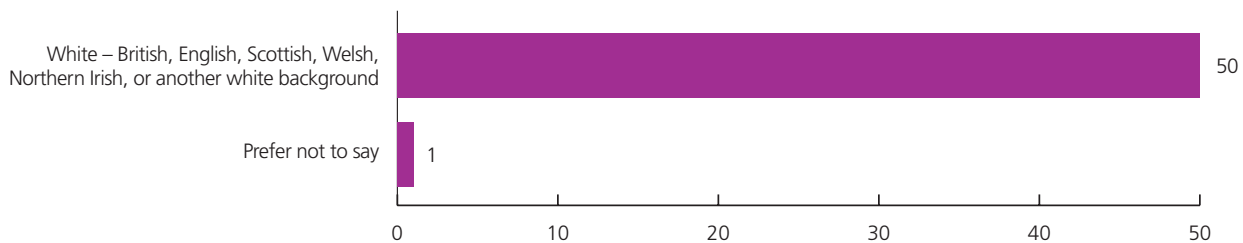
Number of responses applied to themes

Note: preset response options (demographic)

Note: The graph above relates to survey responses only. In the wider project (especially the online workshops) we had wider representation from different ethnic backgrounds.

Demographics and number of related responses

Q.3 What age did transition planning start for the young person?

Category	Value
There was no planning	17
16 years old	8
14 years old	7
15 years old	6
17 years old	4
18+ years old	3
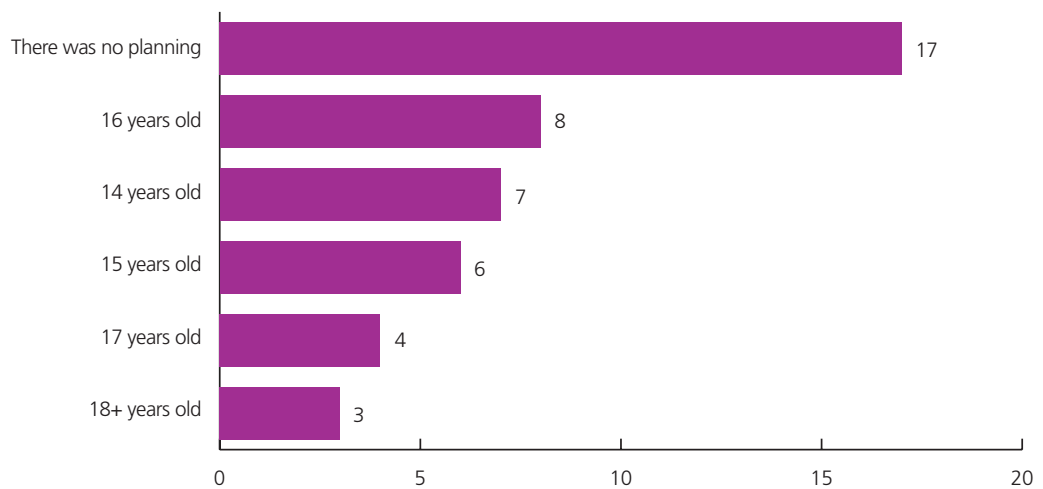
Number of responses applied to themes

Note: preset response options (demographic)

Demographics and number of related responses

Q.4 Which UK region/nation did the transition take place in?

Category	Value
East of England	8
South West	8
North West	7
South East	6
London	4
North East	4
East Midlands	3
West Midlands	3
Scotland	1
Yorkshire and Humber	1

Number of responses applied to themes

Note: preset response options (demographic)

Q.5 What specific information do parents/carers need when supporting transition planning?

Theme	Responses
Choice and control	34
Options available	32
Accessible information	30
Process – what should happen and when	28
Rights	25
Financial considerations	21
Person centred planning tools	20
Working together as a team around the young person	3
Co-production	1
Voice of the young person	1

Number of responses applied to themes

Note: Gobby free text responses (may have one or more standard preset response option, i.e., yes/no/NA)

Q.6 What information should be included in young people's transition plans, to ensure consistent and personalised support for the future?

Theme	Responses
Person centred planning tools	31
Choice and control	19
Process – what should happen and when	16
Options available	15
Accessible information	14
Working together as a team around the young person	12
Rights	10
Co-production	9
Voice of the young person	8
Financial considerations	6
Values	2

Number of responses applied to themes

Note: Gobby free text responses (may have one or more standard preset response option, i.e., yes/no/NA)

Themes and number of related responses by question

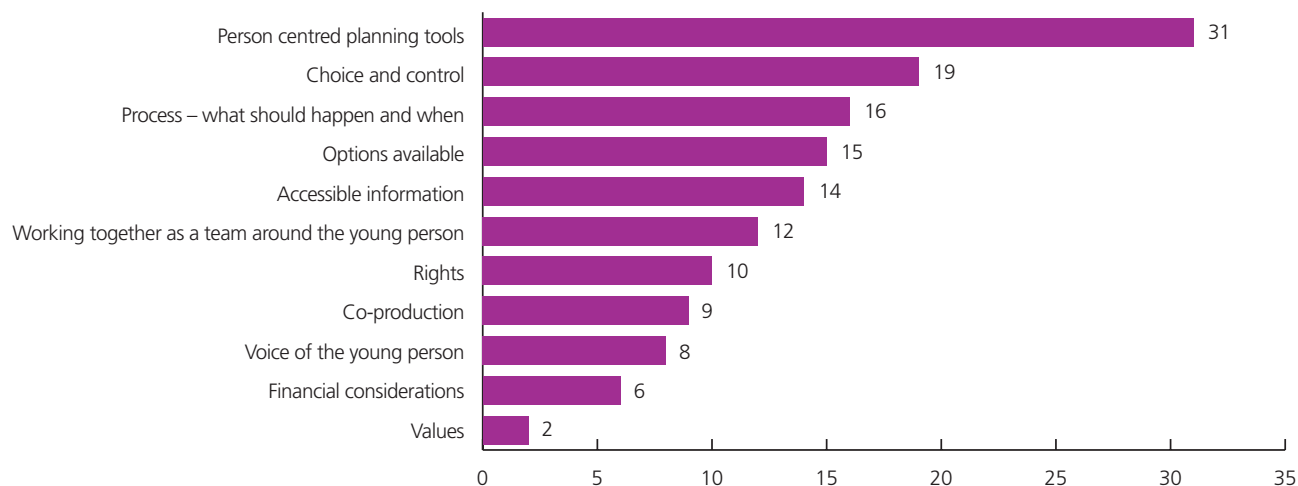**Q.7 In your opinion, what role could advocacy and self-advocacy play in supporting transitions to adulthood?**

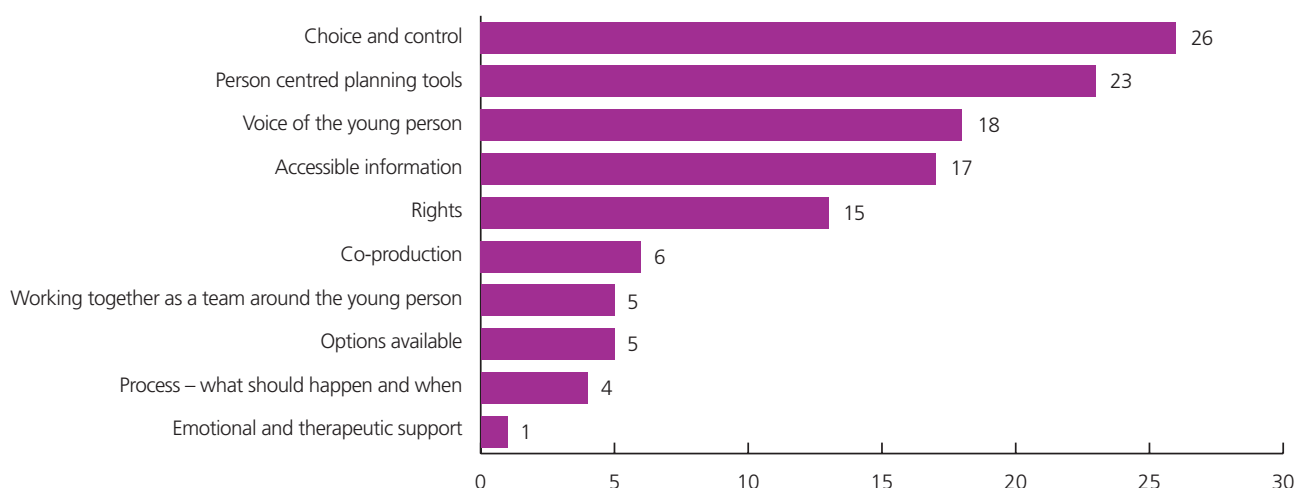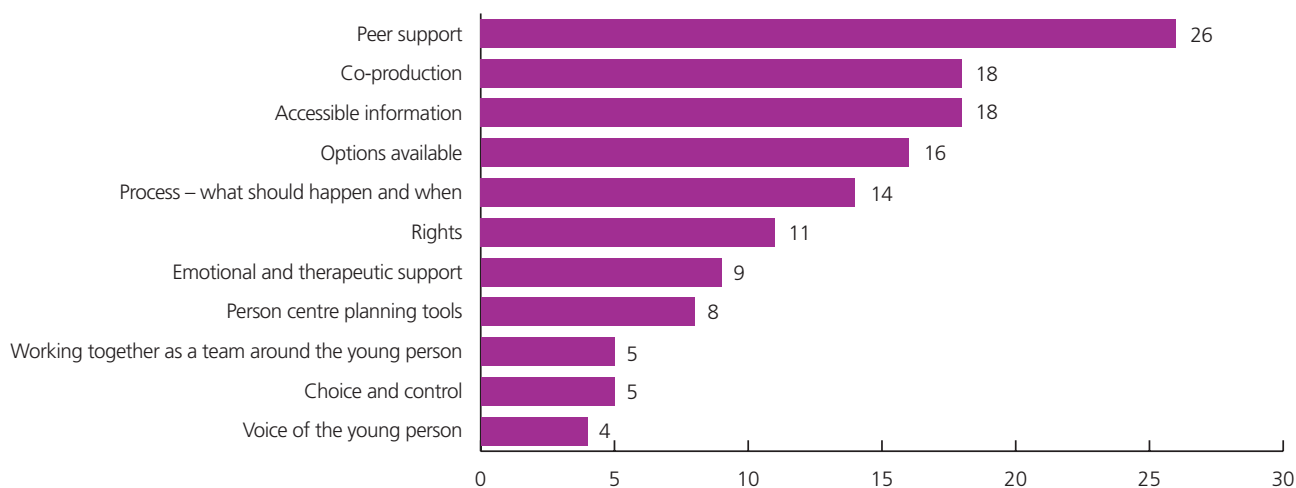| Theme	Number
Choice and control	26
Person centred planning tools	23
Voice of the young person	18
Accessible information	17
Rights	15
Co-production	6
Working together as a team around the young person	5
Options available	5
Process – what should happen and when	4
Emotional and therapeutic support	1

Number of responses applied to themes

Note: Gobby free text responses (may have one or more standard preset response option, i.e., yes/no/NA)

Themes and number of related responses by question

Q.8 How can parent/carer networks have a role in supporting transition to adulthood experiences?

Theme	Number
Peer support	26
Co-production	18
Accessible information	18
Options available	16
Process – what should happen and when	14
Rights	11
Emotional and therapeutic support	9
Person centre planning tools	8
Working together as a team around the young person	5
Choice and control	5
Voice of the young person	4

Number of responses applied to themes

Note: Gobby free text responses (may have one or more standard preset response option, i.e., yes/no/NA)

Q.9 What three tips would you give professionals supporting young people into adult social care?

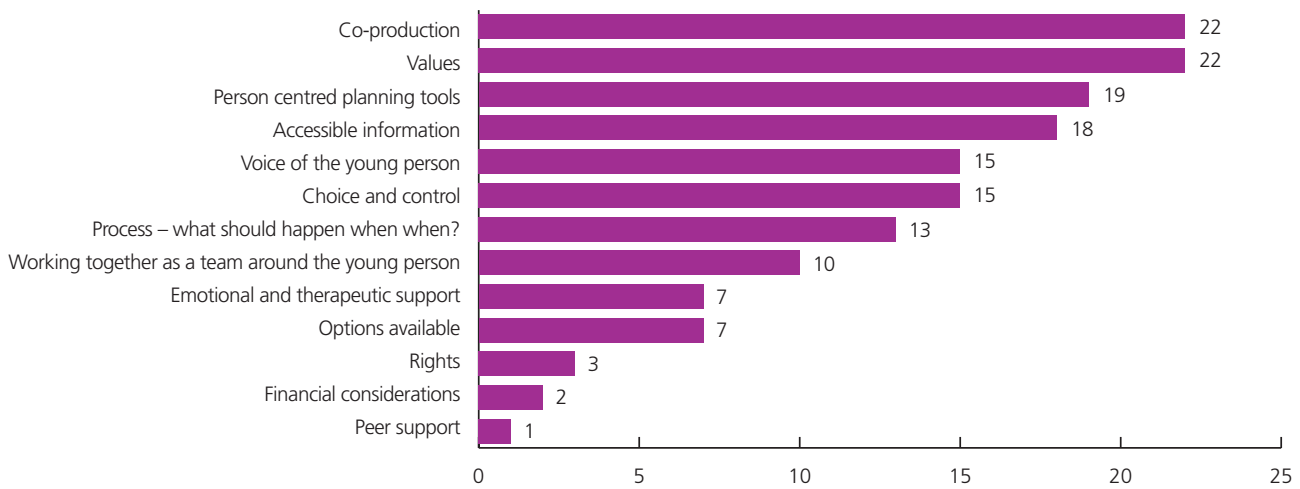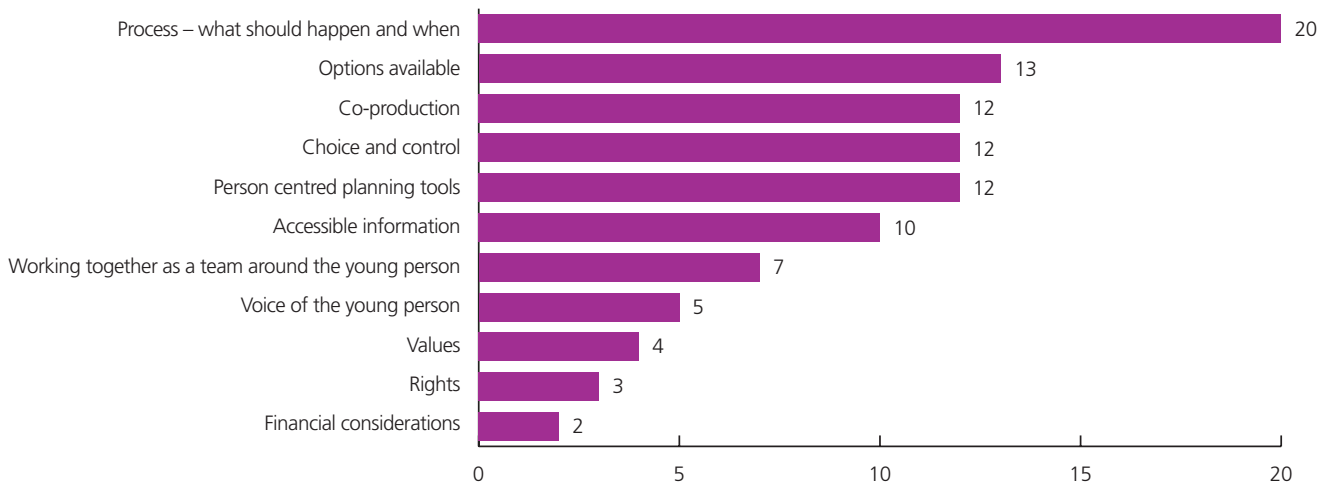| Theme	Number
Co-production	22
Values	22
Person centred planning tools	19
Accessible information	18
Voice of the young person	15
Choice and control	15
Process – what should happen when when?	13
Working together as a team around the young person	10
Emotional and therapeutic support	7
Options available	7
Rights	3
Financial considerations	2
Peer support	1

Number of responses applied to themes

Note: Gobby free text responses (may have one or more standard preset response option, i.e., yes/no/NA)

Q.10 Do you have any other thoughts about how transitions could be improved or done in a different way?

Theme	Number
Process – what should happen and when	20
Options available	13
Co-production	12
Choice and control	12
Person centred planning tools	12
Accessible information	10
Working together as a team around the young person	7
Voice of the young person	5
Values	4
Rights	3
Financial considerations	2

Number of responses applied to themes

Note: Gobby free text responses (may have one or more standard preset response option, i.e., yes/no/NA)