

Department for Health and Social Care

# Transitions Project

## Final Report



A report from Contact, NDTi, Carers UK and NNPCF  
April 2020

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## Introduction

The Carers Action Plan<sup>1</sup> 2018-2020 set out a wide range of ambitions to improve the lives of thousands of carers. One of the visions was to ensure a synergy between the Care Act 2014 and the Children and Families Act 2014. This synergy is particularly important at a stage when young people with Special Educational Needs and Disabilities (SEND) “transition to adulthood” and where there is a need to ensure a passing of the baton between children and adult services.

This project is a result of the aspiration from the Department of Health and Social Care (DHSC):

*“1.14 The Department of Health and Social Care will fund a project to support parent carers to navigate the transition from child to adult services as their child approaches the age of 18.” (DHSC 2019/20)*

In autumn 2019 the consortium members (listed below) successfully tendered for the project work, commencing in November 2019, and completing in March 2020.

In the context of this report members of the project group have been guided by the principle that carers are experts by experience, and to the people they support they are invaluable. However, carers own needs can be forgotten and neglected. Through our work on this project we heard from carers who aspire to lead an ordinary life with their families. They had hopes and dreams for their young people, a job, friends, somewhere to live and to be as independent as they could be. They also wanted to be able to lead their own lives, to work, spend time with their friends and partners and take part in social activities outside of the family home.

An [Executive Summary](#) of this report is available.

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## About the consortium and partners

The Consortium for the project comprised the following members:

- [Contact](#) (lead contractor)
- [Carers UK](#)
- [National Network of Parents Carer Forums \(NNPCF\)](#)
- [National Development Team for Inclusion \(NDTi\)](#) who also hosts the Preparing for Adulthood (PfA) regional facilitators across England.

The Consortium members were well placed to reach out to parents and carers of young people and younger adults across the country.

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<sup>1</sup>[“Carer’s Action Plan 2018-2020: Supporting carers today”](#) Department of Health and Social Care 2018

## Contact and NDTi

Members of the Disabled Children's Partnership, a consortium of 70+ voluntary organizations, chaired by Contact CEO Amanda Batten. Contact also hosts the National Network of Parent Carer Forums (**NNPCF**), supporting 151 forums with 90,000 parent carer members.

## Carers UK

The largest local network of carers' organisations, with around 300 in England, links to 1,000+ carers and local organisations through broader awareness work and provide the Secretariat to the Association of Directors of Adult Social Care (ADASS) Carers Policy Network.

## NDTi

Work in all local authorities through regional networks as part of the DfE funded Preparing for Adulthood programme<sup>2</sup>, encompassing parents and young people, and practitioners across education, health and children and adult's social care and the voluntary sector to share best practice.

To complement the consortium a stakeholder group was also formed with membership as follows:

- [Alder Hey NHS Foundation Trust](#)
- [Dimensions UK](#)
- [Local Government Association](#)
- [Council for Disabled Children](#)
- [Social Care Institute for Excellence](#)
- [Association of Colleges, SEND Lead](#)
- [The National Association of Special Educational Colleges](#)
- [Oxfordshire Family Support Network](#)
- [RIP STARS at Portsmouth University](#)

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## What we did

The project consisted of the following key strands:

- research and collation of resource and evidence on transition
- collecting and collating feedback and evidence from surveys and events to inform what parents and carers experienced and needed improving

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<sup>2</sup> [Preparing for Adulthood](#) - PfA website

- development of an online information for easy access to materials using our findings from this project.

A project manager led the strands and worked across all consortium partners and stakeholder members.

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## Project Activity

### Previous evidence on Transition

There is already a plethora of information and resource available on transition to adulthood but most of this resource is not in one place. Contact took the lead on research of existing materials to capture so that they could be added to a toolkit for easy access for families.

A call for information with stakeholder members, and other interested organisations such as Disability Matters UK, gave us further resources and consent for them to be held within one place for the development of the Information hub. This also included speaking to stakeholder partners and a range of professionals in local authorities.

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### Carers UK – *State of Caring*<sup>3</sup> survey

This survey and the subsequent report compared the experiences of assessments under the Children and Families Act (2014) and the Care Act (2014) of parents with disabled children pre-transition, during transition, and post transition.

This fresh research was used to inform the project about the experiences of parents/carers; their own need for assessment and support, and the opportunities which they hoped to see in the lives of their adult children with additional needs.

The Carers UK survey looked specifically at the experiences of assessments or reviews from its State of Caring 2019 research using two identified groups:

- those with a child under 18 (717) - group one, and
- those with a child aged 18-24 (46) - group two.

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<sup>3</sup> [State of Caring report](#)

It then looked at those who had experienced an assessment or review in the last year:

- for group 1 this was 17%
- for group 2 this was 32%.

Carers UK then compared these two groups on identical criteria, outcomes, and so on. Carers UK also looked at key demographic data.

This survey fed into the large group conversations, where we encouraged parents and carers to consider any positive experiences they had and to think about what works well in ensuring they feel supported. Through this approach, we captured some heartening stories.

The findings from this survey told us the following:

- Parent carers with a young person close to or beyond transition to adult services are far more likely to also be caring for an adult, most likely a parent or a spouse. This makes the Care Act (2014) a very useful tool because it focuses on the carers' needs and all the caring that is undertaken. It also highlights the fact that there are also other important things going on in parent carers' lives at this time which will stretch their time, capacity, health and wellbeing. This is why it is even more important for good transition, so that those juggling multiple caring roles can manage
- the cohort were caring most intensively for at least one son/daughter with multiple and complex disabilities and are therefore most likely to be in need under the Care Act definition.

### **Carers assessments in relation to parent carers**

In terms of assessments, the survey identified that we are still not reaching the kind of volume of assessments and reviews needed according to carers' experiences.

However for those who had received a carer's assessment or review in the past 12 months those caring for 18 to 25 year olds were:

- more likely to report better consideration of their needs compared with parents caring for their disabled child/ren under 18
- more likely to report better consideration of whether they were 'willing and able' to care in their carer's assessment
- were much more likely to include better consideration of their wish to continue working or return to work in their carer's assessment
- this suggests that a carer's assessment under the Care Act and the shift in focus from a disabled child to a disabled adult could be positive for parents of disabled young people as they move into adulthood.

There were still a number of parents who felt that key areas were not fully considered, or who did not get support in the run up to and following transition. Appropriate commissioning at the right levels would address this. This may be a resource issue for some local authorities and is also referenced in the table below, through the other engagement work with parents.

This is the first research that Carers UK knows of comparing carers' assessments for parents before and after transition and highlighted some really useful findings that helped shape later work of this project, alongside Contact's survey and the work with parents and disabled young people. The findings were endorsed by parent carer forums.

## **Practice points arising from the Carers UK research**

### **Carers Assessments**

The results suggest that putting the carer at the centre through a carer's assessment and the provisions of the Care Act 2014 could be beneficial.

### **Caring for older parents as well as children**

Parent carers are very likely to start caring for a parent around the time of transition for their son or daughter which will have an impact on their ability to care. This is why a holistic assessment under the Care Act 2014 could be vital.

### **Carers health and wellbeing**

The poor health and wellbeing status of parents means that Section 1 of the Care Act (2014) is also a useful potential focus, to concentrate on the long term wellbeing of the parent. This would make successful assessments for parent carers under the Care Act (2014) and a focus on wellbeing very compatible with the Healthy Living Consensus from Public Health England.

### **Help across local authorities**

A Care Act (2014) assessment has the ability to influence the determination of any other person being cared for. For example, it can result in additional support to the other adult being cared for for example, an assessment under the Care Act (2014) may involve the input of several authorities. For example, mum lives in another local authority and they are responsible for potentially putting in more care if the carer is also looking after a son with complex disabilities and conditions – again this could be beneficial.

### **Who is responsible for support?**

Clarity of responsibility for carers' support through Continuing Healthcare and their journey through into adulthood is vital for parents.

### **Return to the work place**

There seems to be a link between caring and increased paid work once the disabled son or daughter reaches 18+. This positive finding could be sensitively explored further in support and guidance to parents, since so many parents, particularly women, have given up work to care.

This links well with the reflections and themes identified in the stakeholder groups of what parents found did not always work well for them during transition.

### **Access to technology**

Technology still has more potential to provide support in a variety of ways and needs to be explored further. This was brought out by parents in the later workshops, with a wish for greater knowledge about how tech can help provide support in caring and for the young person with disabilities.

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## **Stakeholder events**

### **London: 'Talking about tomorrow' event**

Over 60 parent carers and practitioner/providers attenders. We heard from a young person and a parent who shared their lived experiences, and received presentations from two leaders in the field - Julie Pointer, Children and Young people Lead NDTi, who spoke about the evidence base for positive transition and Emily Holzhausen OBE, Carers UK, who shared the differences between the Care Act (2014) and Children and Families Act (2014), and the findings from the State of Caring survey.

Following the presentations small group discussions gave parent carers the opportunity to think about and share their own experiences around what currently works well during transition, and what elements of transition need to be improved.

### **Rotherham: Focus Group**

A smaller focus group was held in Rotherham using the main themes from the London session. 15 parent carers attended this session along with some practitioners from 8 localities. As part of this session parent carers from Sheffield shared their Transition Pathway guide<sup>4</sup> - a guide put together by parent carers on transition in their area. The group also heard from the Rotherham Parent Carer Forum (PCF) which has developed both the Rotherham Charter and Genuine Partnerships<sup>5</sup>, the latter of which includes quality indicators for coproduction with families.

These two events were designed around our initial research activity and four main themes emerged:

- the need for improved information and advice

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<sup>4</sup> [Sheffield Transition Guidance for Parents](#)

<sup>5</sup> [Genuine Partnerships](#)



- the need for high quality support and advocacy
  - ease of access to services for families, including eligibility and timeliness
  - attitudes and cultures of those working in services and beyond including the need for more training/workforce development.
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## Learning from stakeholder events

Below is a summary of what parent carers said within each theme. A full breakdown of all feedback by theme is included in Appendix One.

### The need for improved Information and advice

#### *What parents and carers told us works:*

- Early discussions especially about benefits: Personal Independence Payment (PIP) and Employment Support Allowance (ESA). Understand how finances will change
- Help to understand how person-centred planning works, what it is/what it means/how it translates to life
- Making sure you understand the Mental Capacity Act and how it applies to your young person, understand how deputyships work

#### *What parents and carers told us is NOT working:*

- Lack of Information on financial assessments and what young people must pay for services. Understanding where young people need to pay (personal budgets/direct payments)
- Care Act and rights to carers assessments not clear, not made known to parents/carers and not resourced for working age people with LD and their parents/carers
- Lack of information on employment options including good specialist careers advice
- The Local Offer does not always stipulate the law and rights of parents/carers around transition

### Need for high quality support and advocacy

#### *What parents and carers told us works*

- Develop empowerment and support independence
- Think about advocates for adults but make sure they understand the vulnerability of your young person, especially if they present as being more able than they are
- Counselling may be useful for parents/carers. Support for coming to terms with being a carer

### *What parents and carers told us is NOT working*

- Not enough support for young people with medical needs and without an EHC plan. They still need help

### **Ease of access to services, including eligibility and timeliness**

#### *What parents and carers told us works*

- Support for travel training including in schools
- Joined up working and planning
- More supported employment opportunities across the country
- More LA's with employment champions

#### *What parents and carers told us is NOT working*

- Services currently cease or pause or are not available when a young person turns 18
- Young people having to "fit" into what is available now due to lack of creative market development (commissioning)

### **Attitudes and cultures of those working in services and beyond**

#### *What parents and carers told us works*

- Work collaboratively
- Better training for disability advisors at job centers
- Higher expectations from children's social workers of what young people can achieve
- Make sure planning is individualised/outcomes based/empowering and strengths based

#### *What parents and carers told us is NOT working*

- Short term contracts and zero hours don't work for this group of young people
- Poor employer attitude can cause work placements to break down
- Parent carers are sometimes better informed than staff

*"Do the best that you can to look after your own mental health. Research, research, research, talk to those in the know - other parents".*

*"Look after yourself no matter how hard life gets. You can only support your children if you appear cheerful. Be positive with your children but always honest."*

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## Engagement with young people

A meeting was held with FLARE the young person's group facilitated by the Council for Disabled Children on 25th January, at their regular meeting held in London.

This session gave good insight into what young people with SEND felt their parents needed to know about transition and how parents/carers can best support and enable them during transition. The key message from them was that they felt it was important to make sure young people are able to take charge of decision making during their own transition.

*“Do not give up fighting for your young person’s basic rights to an education, for a reasonable transition to adult services and to the relevant support that is needed for them to be happy and taken seriously into adult life with the same opportunities and 'normal' child or young person should be able to expect.”*  
(FLARE group member)

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## Transition Parent Survey

A new survey of parent carers (open between Feb and March) specifically asked about their experiences of transition. This survey was co-produced by the consortium and shared widely across all our networks and those of the wider Stakeholder group. The full responses can be found in Appendix Two and a summary is shown below. A full report and analysis is being produced.

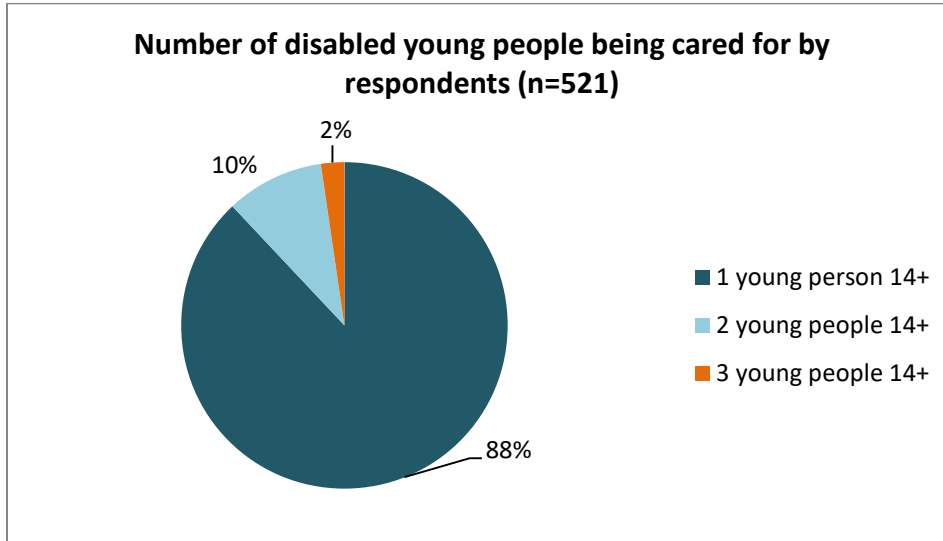
### Survey Summary

596 responses were received and 578 passed the screening question i.e. were based in England are caring for / have cared for a young disabled person aged 14 or above. Responses came from 124 out of 151 local authorities.

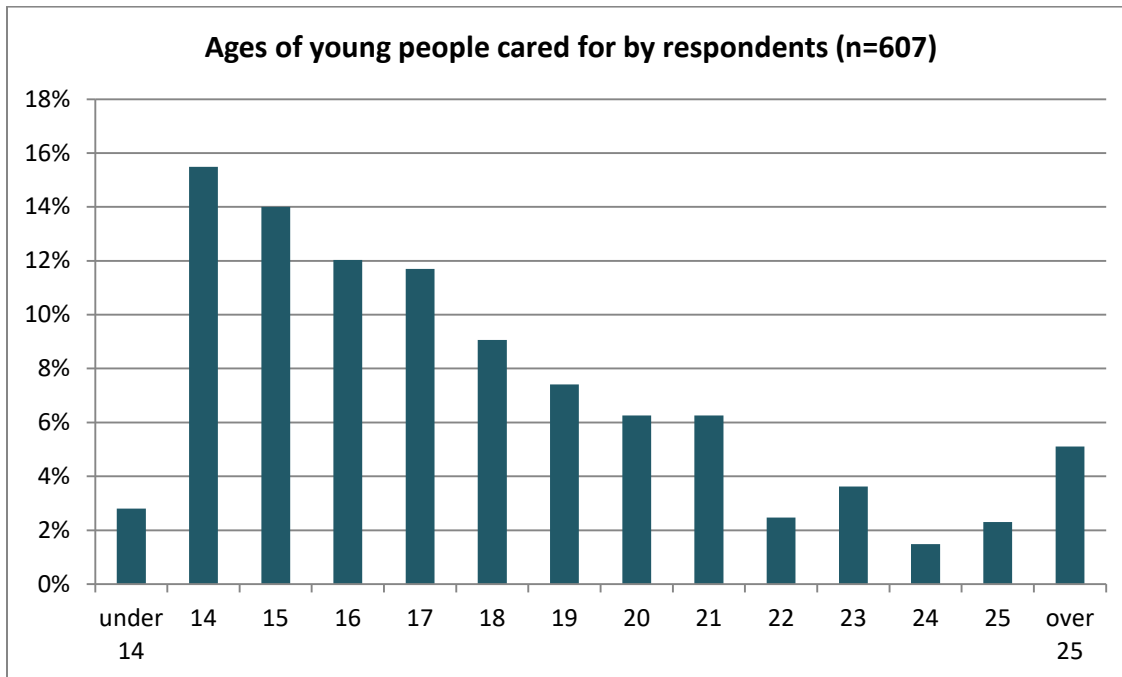
Parent carers of disabled young people aged 14+ were surveyed in order to find out their concerns around transition to adulthood; and their experiences, feedback and advice to other parents if their young person had already been through transition.

The respondents were also asked for the disabilities or conditions of their young people and how many young people they were caring for.

### Numbers of young people being cared for



### Ages of young people at time of survey



## Parents' past experiences of transitions

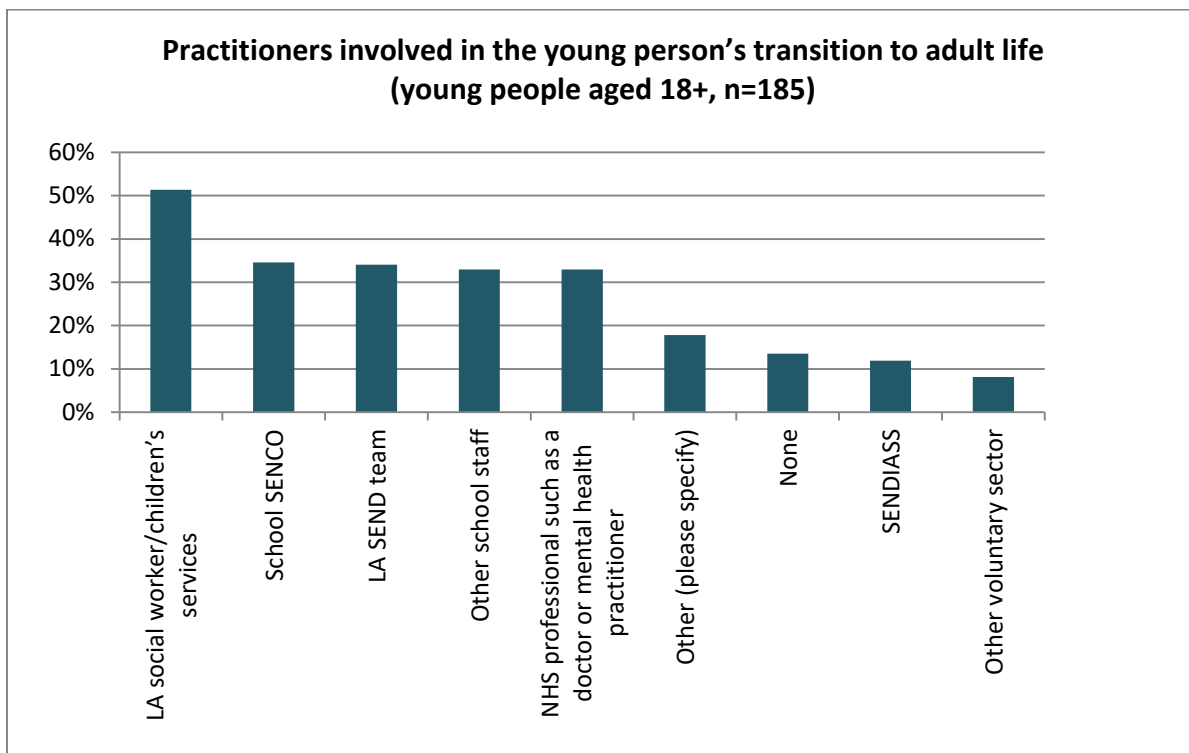
Those who had a young person aged 18 or above (244) answered a series of questions relating to their past experiences of transition. Each of these questions typically had between 120 and 190 responses.

- 56% had a care and support plan
- 33% had been assigned a personal budget.
- 49% of parent carers say the young person was involved in their plans, and their views considered.
- 31% say the young person was supported in their transition to adulthood before they turned 18.
- 28% of parent carers have had a carer assessment or review in the last 12 months.

When asked about whether they had examples of good practice to share up to 14% of parent carers answered that they were “not sure”. This may be that for those with older young people the parent carer simply didn't remember or it may be that there was a lack of communication from professionals involved.

Of those practitioners who were involved during the transition process it was practitioners from children's services that were most likely to have been involved.

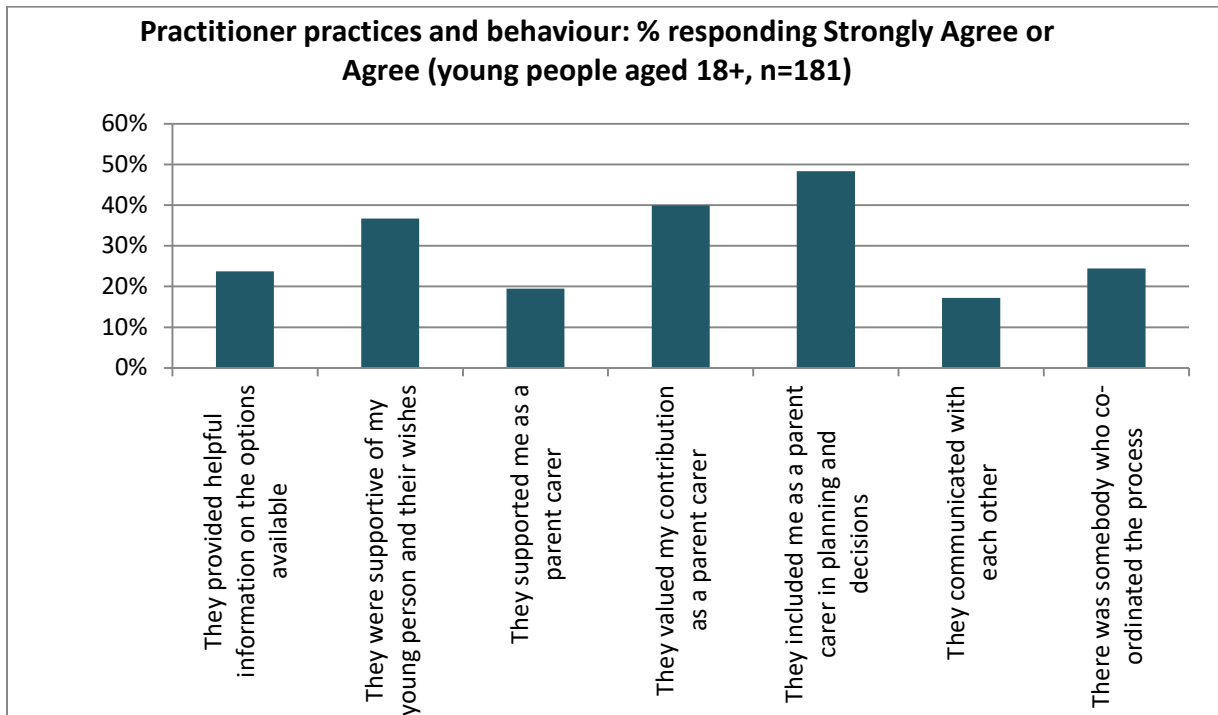
## Practitioners involved in transition



When asked if practitioners had taken the needs of parent carers into account during transition 45% said none and 25% said that the local authorities Adult Services had taken their needs into account.

We also asked a series of questions about the behaviour of the practitioners involved in transition, regarding coordination, provision of information, communication, co-production and listening to the views of families

### Parents views of practitioners



These figures are worryingly low and could be an indicator of why the overall experience of transition from children's to adult services is not a positive one for families.

A free text box captured additional views of parents experiences. These responses have been themed as follows (more details of responses by theme are in Appendix 2).

You can read the [full survey results report](#).

## What parents told us about the quality of support

*Parents having to do things on their own and/or fighting battles, rather than support being provided.*

*Not getting any support; support being of poor quality or not adequate; lack of information or guidance.*

*Delays; cliff edges; unreliable services; and high staff turnover.*

*Limited service provision and issues around other service provision including mental health; healthcare, and adult services.*

*Good support from services are also mentioned, most frequently around education (many respondents' young people are still in education) but also health, social care, mental health, transitions team, social worker.*

## What helped the most in meeting parent/carers needs

*Support groups and speaking to other parents.*

*A charity or other local organisation.*

*The young person's education provider.*

*Nothing (respondent cannot identify a helpful service or practice)*

*The parent's own skills, actions and determination.*

## What went well during transition

*Getting a good outcome for the young person, or the young person getting funding or Direct Payment for their needs.*

*The young person's education provider.*

*Nothing (respondent cannot identify something that went well).*

*Specific practitioners, and specific behaviours from practitioners such as flexibility and good communication.*

## What could have gone better or was a particular challenge

*Coordination between services, wanting someone to coordinate the process.*

*Information and guidance.*

*For the law, statutory guidance and best practice to be followed.*

*Gaps in services, availability of services that are suitable to the young person; and being discharged from a service with nothing else in its place.*

*Communication issues and other attitudes and behaviours from practitioners, in particular not being listened to.*



## What advice would you give to other parents.



## Outcomes for young people and parent carers

We also wanted to know which outcomes were considered for the parent carer and for the young person, when planning for the young person's transitions to adulthood.

The most frequent response on this question for parent carers was *none* (67%). For young people the most frequent outcome areas positively impacted were education and employment (51.4%) closely followed by health and wellbeing (50.7%). As a free text follow-up question, we asked questions on what could have been done differently to improve outcomes for the parent carer, and for the young person.

We also asked whether services were available to meet the outcomes identified:

- 55% said No
- 30% said Partly, and only
- 11% answered Yes.

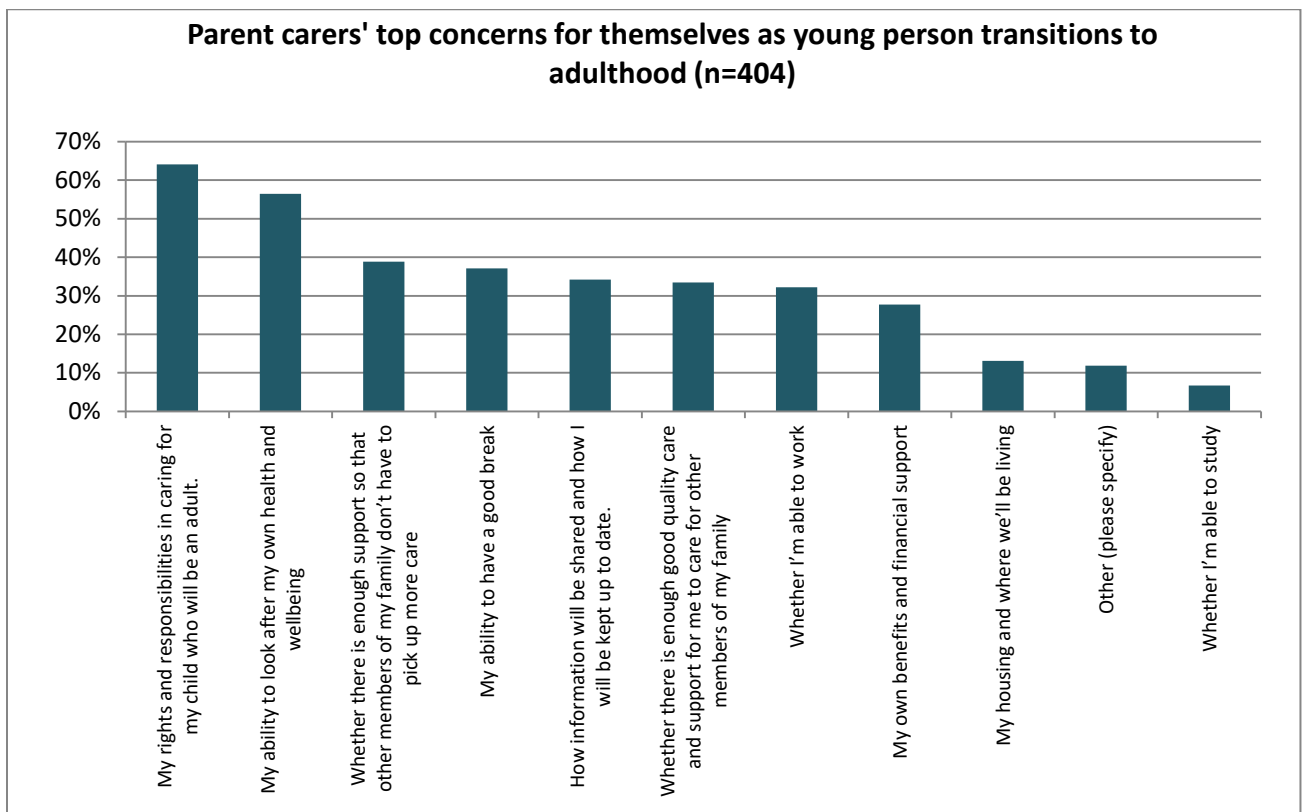
When asked about gaps in services and support there was a majority view that there were gaps on every level, or no services were provided at all. Main service areas identified were respite and day services or activities, health and mental health services and social care.

## Concerns around transitions to adulthood

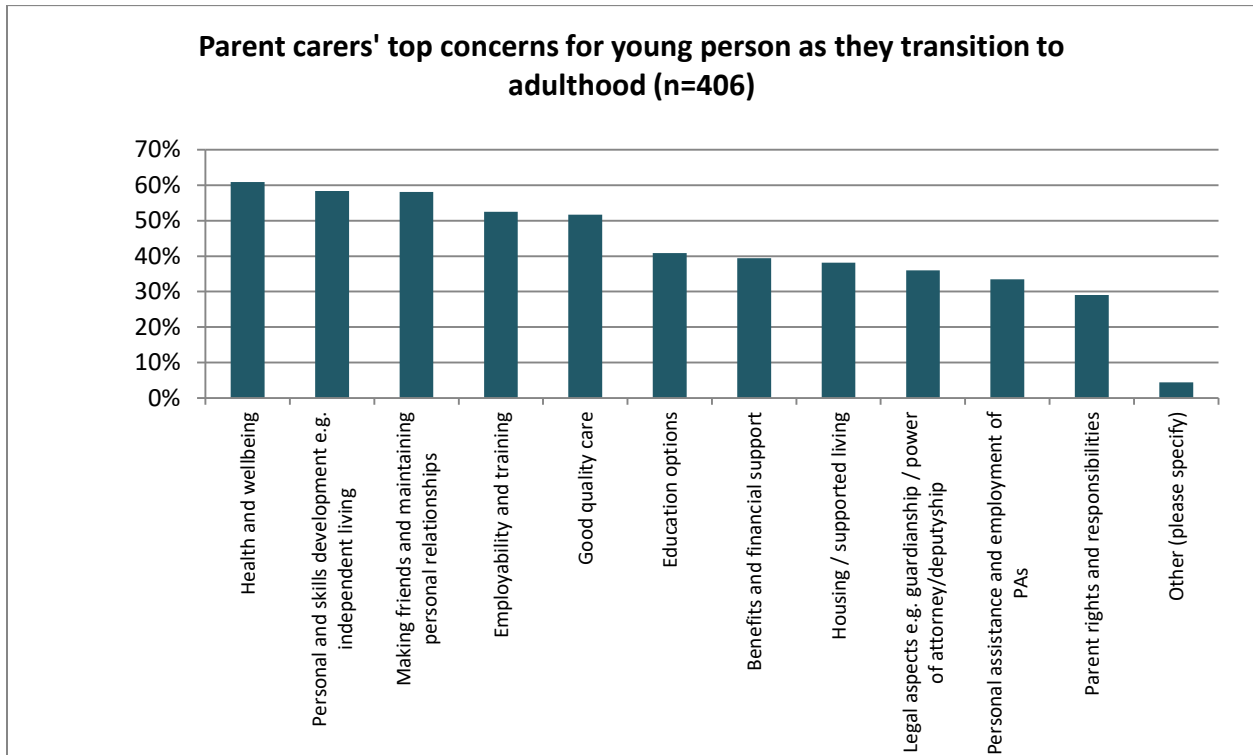
All respondents were asked the following questions including those who had young people in the 14-17 age bracket. Questions were answered by between 400 and 410 respondents, and we asked the respondents to tick their top 3 concerns for themselves and concerns for their young people

The responses are summarised below.

### Parents concerns for themselves



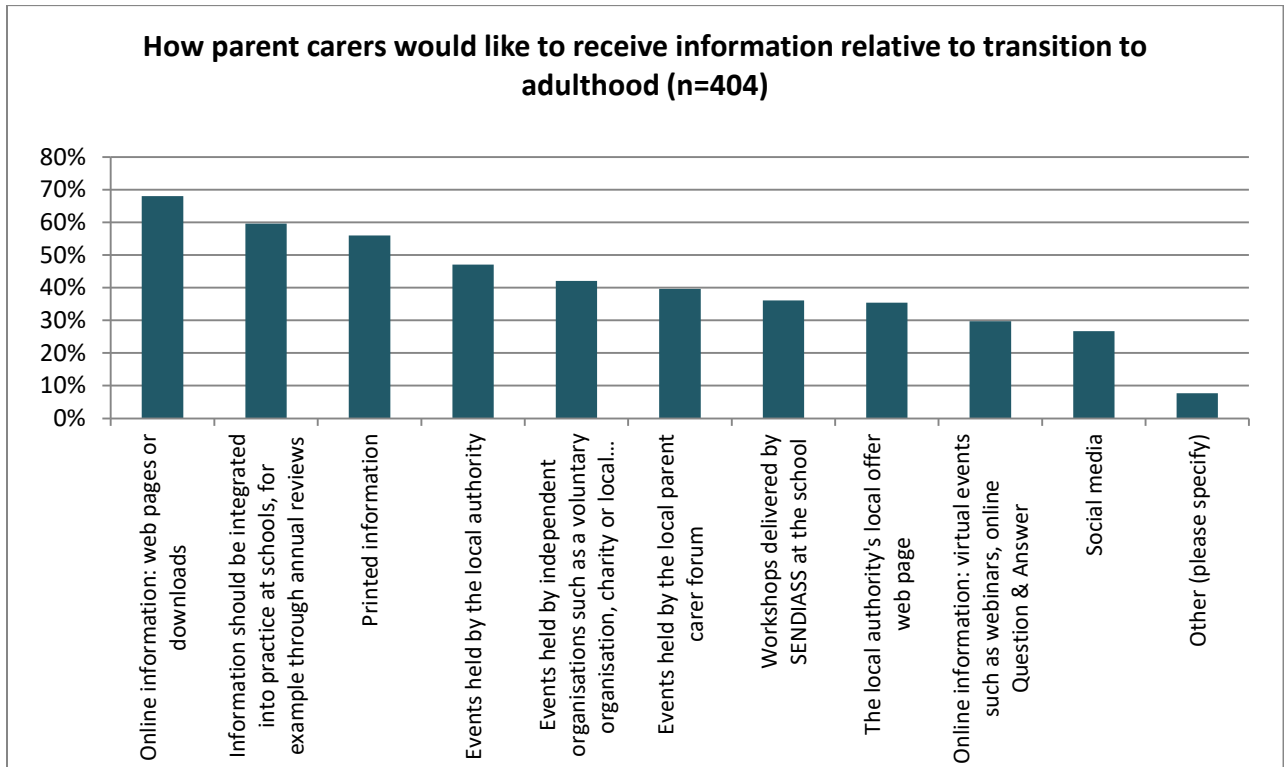
## Parents concerns for their young person



When asked about how informed they felt about these topics, over 40% of respondents felt that they were not well informed on all of the topics with 70% rating housing and supported living as the area they were least informed in and 64% stating personal skills and development e.g. independent living.

When asked how parent carers would like to receive information on their young person's transition we received the following responses:

## How parents like to receive information



*"I've learned far more from other parents."*

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## Developing an online information hub

Contact's highly experienced information team have analysed the feedback from the stakeholder events, survey and helpline enquiries to determine the overall content needed. A wide range of organisations in the field of transition have also shared examples of positive approaches and existing resources. This research and feedback have enabled us to build a new area on Contact's website called "Preparing for Adult Life" and it will include information and links to:

- Education, Health and Social Care
- Transition planning
- Benefits and Money
- Making Decisions
- Independent Living
- Getting a Job
- Growing Up, Sex and Relationships
- Wills and Trusts

Parent carers have shared with us that they "don't know what they don't know" which has led to an uncertainty on which questions to ask. To help make this easier for families the webpages will include a "common questions tool" that will help direct them to what they need to know simply and easily. Contact's online, helpline and family finances teams will also be able to use the new web pages and links to guide families that need more support navigating the information.

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## Recommendations

*"A child's access to support should not be determined by a parent's education, their social capital or the advice and support of people with whom they happen to come into contact... Children and parents are not 'in the know' and for some the law may not even appear to exist. Parents currently need a combination of special knowledge and social capital to navigate the system, and even then are left exhausted by the experience. Those without significant personal or social capital therefore face significant disadvantage. For some, Parliament might as well not have bothered to legislate."*  
(Education Select Committee on SEND, October 2019)

Whilst many parent carers will not use the language “social capital” the essence of the select committee report suggests without social capital parent carers can face a discriminatory and inequitable system that can cause confusion and bewilderment.

Throughout this project the Consortium has sought to listen to the lived experiences of young people and families as they “Prepare for Adult Life”. The views, wishes and feelings of young people with special educational needs and disabilities are therefore at the centre of this report and we are extremely grateful for the time and honesty they gave freely to us by attending events, sending feedback or filling in surveys, especially knowing that for many of them transition to adulthood had already happened.

Below we have summarised the key challenges and reflections that parents, carers and young people told us about and some of the examples of good practice that we encountered to illustrate what could be possible and help improve things for more families.

## Information and advice

### Issue or challenge

Lack of information on:

- benefits
- housing and supported living
- carers rights – including to assessment.

### What can be done

- Introduce an expectation that all Local Offers should include information on the Carers Act and Carers Assessments
- Introduce an expectation that all Local Offers should include a link to the *Preparing for Adult Life information hub* which needs to be reviewed and updated regularly

Create and keep under review a comprehensive information offer to include:

- Generic information on PIP, ESA, Universal Credit, Housing Benefits
- Links to the Care Act and Carers UK website on carers rights
- Information about the Mental Capacity Act and Wills and Trusts
- Increased capacity from Contact’s Family Finance Team to develop the following advice and online resources:
  - Universal Credit for young people toolkit
  - Benefits at Transition webinar
  - Universal Credit factsheet for young people
  - Personal Independence Payment parent guide

- An up to date online common questions tool on benefits and finance around moving into adulthood
- Helpline - Information, advice and support by telephone, email, and social media channels to parent carers
- 1:1 call back telephone appointments providing specialist advice and benefit calculations for families –where a child is turning 16

### Best practice examples

- Care Navigators - - Leicester, Leicestershire & Rutland Health Partnership Trust care navigators attend and support health planning from Year 9 annual reviews to adult services
- North East Lincolnshire Carer Assessment Guide<sup>6</sup>
- Contact’s Family Finances team already offer support to navigate the benefits system and provide advice on individual circumstances but this is done by just two people and does not provide the capacity requirements identified during this project.  
<https://www.contact.org.uk/advice-and-support/benefits-financial-help/>

## High quality support and advocacy

### Issue or challenge

- Lack of advocates for parent carers who use a person centred approach
- Lack of advocates for young people
- Limited or no access to emotional support for parent carers around wellbeing and beyond caring, for example further learning or employment

### What can be done

- DHSC to introduce a requirement for all advocates to complete accredited person centred training
- NDTi is responsible for the delivery of the Advocacy Quality Performance Mark (QPM)<sup>7</sup>, the only Quality Mark for organisations offering independent advocacy. The QPM is only awarded to organisations who can demonstrate that they provide excellent services in line with QPM standards and the advocacy charter
- Fund Speciality counselling for parents and carers who do not meet eligibility criteria that includes support to re-engage with employment and how to navigate changes in benefits

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<sup>6</sup> [NE Lincolnshire parent carer guide](#)

<sup>7</sup> [QPM](#)

- Commission further research or fund pilot schemes to innovate with technology to support employment and independent living, and also how it can help parent carers cope emotionally, practically and improve their work prospects.

### Best practice examples

- Carers UK<sup>8</sup> has a number of advice materials for carers on returning to work

## Access to services, including eligibility and timeliness

### Issue or challenge

- A one size fits all approach to commissioning services
- Not enough understanding or research into how technology can support people with disabilities
- Lack of clarity around Continuing Health Care criteria from children's to adults
- Lack of clarity around eligibility for young people as they reach transition age.

### What can be done

- A clear understanding and use of person centred approaches and planning during transition
- Commission bespoke support to enable people to be part of their community. Remove barriers to support and embrace innovative and technological solutions (Further research into the role and benefits of assistive technology in supporting independence)
- Clarity of responsibility of carers support through continuing healthcare – to be agreed as a matter of urgency so that carers assessments can be holistic
- Ensure transition planning happens early and includes support for young people to prepare for adulthood, before year 9. This planning needs to happen for all young people with SEND including those without an Education, Health and Care Plan
- Further investment / greater accountability for Local areas to ensure there is a clear pathway for parents who are not eligible for carers support linking them to of support within local communities.

### Best practice examples

- Five day offer<sup>9</sup> – using a personal approach to support young people and their families once they leave school to enable an interesting and fulfilling adult life, such as the Calderdale Five day offer, and its bespoke approach and personal navigation.

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<sup>8</sup> [Carers UK advice and support](#)

<sup>9</sup> [Calderdale five-day offer](#)



## Attitudes and culture including training

### Issue or challenge

- Parents and carers put their own needs at the back of the queue, and often feel guilty for asking for support
- Silo working across agencies
- Low expectations by some professionals towards young people as they go through transition, for example around employment

### What can be done

- Children and adult practitioners to ensure they consider the needs of parent carers
- Build parent carer capacity and ensure they have the knowledge about what is available for a good transition
- Ensure that across agencies young people and parent carers are at the heart of service design and understand true co-production
- Joint working between health and social care partners
- Further develop the curriculum in schools and colleges to ensure expectations around employment are high for young people with SEND

### Best practice examples

- Understanding true co-production – Genuine Partnerships developed the 4 principles of coproduction, welcome and care, value and include, communicate, and work in partnership to build trust between partners. <https://genuinepartnerships.co.uk/>
- The development of supported internships has opened new opportunities for young people with SEND to have a robust pathway into employment – for further details look at the Preparing for Adulthood website<sup>10</sup>
- Some schools have redesigned their curriculum to support a greater transition experience for their young people, one example is the Nexus Trust Post 16 project<sup>11</sup> at the Abbey School and another is the World of Work<sup>12</sup> project at the Castle School.

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<sup>10</sup> [Preparing for Adulthood](#)

<sup>11</sup> [Nexus Post 16 Project](#)

<sup>12</sup> [World of Work – Castle School](#)

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## Recommendations to achieve positive lasting change

Below is a summary of recommendations the Consortium would like to make to the DHSC based on our learning throughout this project.

### **National Transition Board**

Establish a National Transition Board to include representatives from DHSC, DfE, DWP, Office for Disability Issues, Voluntary sector champions, young people and parent and family carers.

### **Family Leadership Programme**

Investment in a Family Leadership Programme to support and train up parents and professionals to work alongside each other, using person centred and co-production approaches to raise awareness and challenge negative perceptions and low expectations.

### **Preparing for Adult Life Information Hub**

Continued funding for the maintenance of the Preparing for Adult Life Information Hub to ensure it remains current and useful.

### **Joint training for practitioners and parent carers in person-centered approaches**

DHSC, DfE and DWP to invest in joint training for practitioners and parent carers in person centred approaches for assessment, planning and reviews. This would ensure young people and their families can plan for a great future with high aspirations, accessing the Preparing for Adulthood pathways as described in SEND Code of Practice (chapter 8)<sup>13</sup>.

### **Further guidance to schools and colleges**

Support the production of further guidance to schools and colleges, and health and social care providers, regarding person centred assessment and planning.

### **Good practice**

Pilot support mechanisms for parents and carers and other good practice identified in in this report in a small number of local areas or a single region.

### **Explore what works for carers of young people over 18**

With Carers UK and Carers Trust, explore what works well for parents as their children become older adults, piloting again based on effective models such as the Oxfordshire Family Support network<sup>14</sup>.

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<sup>13</sup> [SEND Code of Practice – chapter 8](#)

<sup>14</sup> [Oxfordshire Family Support Network](#)

### **Promote the “Preparing for Adulthood Information Hub” May 2020**

Promote the information pages across government departments, via social care guidance and recommend all Local Offers and adult information are linked to it so that all parent carers find their way to it.

### **Transition leadership programme**

Consider a “transition” leadership programme that brings together strategic leaders in both children and adult services to develop a stronger pathway across the two, following the principles of co-production and person-centred planning.

### **Funding for specialist finance advice**

Reduce the in-equality gap created by the need for “social capital” by providing increased funding for specialist finance and benefits advice and guidance such as the Contact Family Finance team model.

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## **Next steps for the project**

We hope this project and the development of an online “Preparing for Adult Life Information Hub” hosted on the Contact website, will make a difference to some of the issues identified but it will not solve everything on its own.

The challenges young people and parent carers face as a result of culture and attitudes will need a different response, including action and long term commitment to embed real change.

### **Ongoing challenges**

The issues and challenges that this project has identified are **beyond** families needing more information, they shine a light on the need for a **different approach** to ensure family experiences of transition improve forever and for everyone.

These changes will only happen if continued and sustained effort, attention, funding and accountability continues to be placed on Education, Health and Social Care partners, but also that the wider community values the skills, gifts and strengths of this group of young people and their families.

When agencies work well together, believe that young people can achieve and young people, their parents/carers feel empowered, the outcomes can be extraordinary.

The Preparing for Adult Life Information Hub will be live from the 7<sup>th</sup> May and the consortium will be gathering feedback and evidence on usage and experience of it throughout 2020/21. We will continue to make adjustments and amendments as we receive feedback and parents and carers once they start to use it.

We plan to use **Carers Week 8<sup>th</sup> – 15<sup>th</sup> June** to promote the Information Hub, an executive summary of this report and the full findings of the survey.

## **A note about Coronavirus**

Our recommendations are based on what we know can work based on our extensive collective experience of working with and supporting parent and family carers for many years and from the heart felt feedback from the families that gave their precious time to share their views and experiences with us because they want others to have better experiences than they did.

Whilst the investment has been welcome and we will continue to work collaboratively as a consortium and across the sector to share the information hub and act on what families say they need from us, now more than ever we need to be attuned to getting the support and information right for families preparing for adulthood.

The impact of the coronavirus pandemic and the temporary legislative changes to the Children and Families Act 2014 and the Care Act 2014 means that there is potential for further confusion, uncertainty, delay and opportunities lost to get it right. For some families, not only are they coping with the uncertainty of a virus with no cure, job losses and economic instability but they are also anxiously wondering what, if anything will happen to help them and their son or daughter, grow up, start college, leave home, get a job achieve and their ambitions.

An offer to fund some individual support for these families to navigate not just the usual challenges but also the additional ones of this exceptional situation, would be warmly welcomed by all consortium partner.

## Appendix One – feedback from stakeholder events

### Advice and Information

What parents and carers told us works/recommendations	What parents and carers told us in not working
Using parent knowledge to support others – parent to parent lived experience	Lack of information on future options, including supported living/living with parents – <i>“you don’t know what you don’t know”</i>
Early discussions especially about benefits: Personal Independence Payment (PIP) and Employment Support Allowance (ESA). Understand how finances will change	Information on financial assessments and what young people must pay for services. Understanding where young people need to pay (personal budgets/direct payments)
Early thoughts about pensions – yours and your young person Separate out finances, yours, and your young person	Information on employment options including good specialist careers advice
Welfare benefit navigators	Simple, clear benefits system that does not penalise those who want to work
Research assessment process beforehand. E.g. Carers assessment and have a practice	Care Act and rights to carers assessments not clear, not made known to parents/carers and not resourced for working age people with LD and their parents/carers
Understand how person centred planning works, what it is/what it means/how it translates to life	The Local Offer does not have enough information about employment pathways/options
Think about admin early – get good at doing admin or find some support	We do not have the knowledge that young people will be safe in the workplace
Think about the order to do things in	How to start, what is the process and how can we get help to navigate the system

Make sure you understand the Mental Capacity Act and how it applies to your young person, understand how deputyships work	<b><i>“It feels like you need a law degree including rights of young people at SEND support level”</i></b>
Start early with your planning	Information on volunteering opportunities as a step into work
Have a lead consultant role like the Pediatrician in the Community for health and social care services for adults with learning disabilities and/or autism	The local offer does not always stipulate the law and rights of parents/carers
Understand that at 16 all letters will go to the young person – you may not be told this and the young person may not go to the appointments	Sharing of information across health to benefit holistic support and treatment
Make sure preparation for adulthood is developmentally appropriate	Lack of preparation for families
Understand the impact of a young person’s diagnosis in a realistic way	
Think about an acute liaison team for young people with a learning disability	
Help to understand Continuing Health Care Assessments – what is needed versus what you get	
Think about outcomes and the long-term prognosis for your young person	
Develop good transition pathways	<b><i>“Local Areas do not provide data or take this seriously enough”</i></b>
Follow the <u>NICE standards</u>	
Develop appropriate sign posting	
Think about digitalizing plans/use videos to understand how to support someone well	

Signpost to appropriate resource for preparing for adulthood	
<i>“Don’t assume parents know everything”</i>	
Think about Post 16 transition arrangements a year in advance of the March transfer	
Think about a National, rather than a Local Offer to ensure minimum standards and rights in all localities	

## Support and Advocacy

What parents and carers told us works/recommendations	What parents and carers told us is not working
Join your forum as soon as you can	
Become the key worker – invite professionals to meet you and prep well beforehand	Support for young people with medical needs and without an EHC plan. They still need help to navigate the system
Think about advocates for adults but make sure they understand the vulnerability of your young person especially if they present as being more able than they are	
Understand young people’s rights (shared decision making)	
Develop empowerment and support independence	
Know your sources of support	
Develop a greater understanding that young people can work and still need support	

Develop more roles for those who can bridge and foresee problems in the workplace – someone who knows the young person well/job coach/mentor	
An advocate to deal with young person's finances	<i>"My son is 16 years old and has complex needs. He does not have the mental capacity to make decisions for himself. What happens with his finance and care decisions once he turns 18? Who makes them?"</i>
Counselling may be useful for parents/carers. Support for coming to terms with being a carer	

### **Access to services, and eligibility and timeliness**

What parents and carers told us works/recommendations	What parents and carers told us is not working
Buddying/mentoring to support young people in work	Services currently cease or pause or are not available when a young person turns 18
More opportunities to try work	Young people having to "fit" into what is available now due to lack of creative market development (commissioning)
Specialist recruitment agencies (or well-trained current agencies)	
Support for travel training including in schools	
Enough of the right housing options so young people can work	
Guaranteed support for those who need just a little bit of help	
More Supported Internships	



More supported employment opportunities across the country	
More LA's with employment champions (such as Hackney)	
Transition exception register	
Annual GP health checks	
Mandatory training for social care and health on autistic spectrum conditions and learning disabilities	
Joined up working and planning	
Transition nurse	
School – off site and outreach support for young people with complex needs	
Funding to Parent Carer forums from CCG's/NHSE/DHSC to promote Education, Health and Care pathways	

### Attitudes and culture including training

What parents/carers told us works/recommendations	What parents and carers told us is not working
Different messages that show what is positive and possible – good stories	<i>"I had to teach the social worker who didn't know what SEND/COP was. EHC role compromised"</i>
Messages from schools and professionals that young people with SEND <i>can</i> work	<i>"We lost carers due to attitudes"</i>
More reasonable adjustments from employers, for example Easy Read application forms and interviews	<i>"We lost a work experience placement due to attitudes"</i>

Opportunity to build relationships between employers and young people	<i>“Parents and carers are stressed and losing their goodwill”</i>
Adapted interviews and work trails	Short term contracts and zero hours do not work for this group of young people
A navigator within the health sector who is a lead consultant for LD	GP’s do not know enough to take on the Lead Professional role (not enough time)
Disabled young people that are visible in the world of work	
More employers who will take people on with a learning disability, Local Authorities/NHS etc	
Better training for disability advisors at job centers	
Parents have a voice, young people have a voice, be persistent/challenge/be prepared	
Equal rights for all – professionals must listen and hear	
Work collaboratively	
Make sure planning is individualized/outcomes based/empowering and strengths based	
Robust data about health inequalities, e.g. LD deaths that were avoidable	
Good health and health promotion	
Guidance on how to influence commissioning	

Invest in social care for working age adults, including workforce development and training	
Higher education and universities to support positive assessment approaches	
Higher expectations from children’s social workers “what do you need now to be as independent as you can be?”	

## **Appendix two – summary of parental views from free text questions in the Transition survey**

### **Comments on the quality of support received during transition:**

- Parents having to do things on their own and/or fighting battles, rather than support being provided when it is needed. Services are considered not to be proactive.
- Not getting any support.
- Support being of poor quality or not adequate.
- Delays; cliff edges; unreliable services; and high staff turnover.
- Issues in the provision of education including EHCPs.
- Coordination between services.
- Issues around other service provision including mental health; healthcare, and adult services.
- Lack of information or guidance.
- Limited service provision.

Good support from services are also mentioned, most frequently around education (many respondents' young people are still in education) but also health, social care, mental health, transitions team and social workers.

### **What was most helpful in meeting the parent/carers own needs?**

- Nothing (respondent cannot identify a helpful service or practice);
- Support groups and speaking to other parents;
- The young person's education provider;
- The parent's own skills, actions and determination;
- A charity or other local organisation;
- Other services.

### **What went well during the young person's transition?**

- Nothing (respondent cannot identify something that went well);
- The young person's education provider;
- Getting a good outcome for the young person, or the young person getting funding or Direct Payment for their needs;
- Specific practitioners, and specific behaviours from practitioners such as flexibility and good communication.

## **What could have been done better and what was a particular challenge?**

- Coordination between services, wanting someone to coordinate the process.
- Information and guidance.
- Everything.
- The process not starting early enough.
- Communication issues and other attitudes and behaviours from practitioners, not being listened to.
- Issues around specific services such as adult services and education.
- Delays in services.
- Gaps in services, availability of services that are suitable to the young person; and being discharged from a service with nothing else in its place.
- More support for the parent carer.
- For the law, statutory guidance, and best practice to be followed.
- Funding issues.

## **What advice they would give to other parent carers about how to look after their own needs as their young person transitions to adulthood?**

- Being well informed.
- Getting support from other parents in a similar situation, including joining support groups.
- Self-care and the importance of looking after yourself.
- Attitude, such as being assertive and asking for what one wants, preparing for a battle, and not giving up.
- Being organised.

## **What could be done differently to improve outcomes for parent carers**

- Practitioner attitudes and communications;
- The system looking out for parents' needs, which includes carers assessments but also support around the whole family, support to work, support before there is a crisis.
- Information and guidance.
- Coordination between services.
- Some say they do not know what could have been done better – in some cases because their outcomes were supported, in other cases because there was no support and they do not know what good looks like.
- Availability of services including respite.
- Starting earlier, planning better.
- Being listened to and not having to fight for services.
- Resolving funding issues, not putting money over the young person's outcomes.
- Following the law and best practice.

## What could be done differently to improve outcomes for the young person

- A better focus on the young person's needs and outcomes, including person-centred planning.
- Availability of services including independent living arrangements, and young people not being discharged from a service without another service to take its place (cliff edge).
- Everything.
- Starting earlier, planning better - including having defined pathways or timelines.
- Practitioners listening to parents and young people and communicating better.
- Coordination between services.
- Support around specific outcomes such as socialising and being included in the community; independence; employment; health needs; education.
- Resolving funding issues, not putting money over than the young person's outcomes.
- Information and guidance.
- Having a support worker or a mentor.
- A small number say nothing could have been done better.
- Attitudes and behaviours from professionals such as understanding of the young person's condition; being more proactive; following the law and best practice; less staff turnover.