

EXECUTIVE SUMMARY
TRANSITIONS PROJECT
FINAL REPORT

DEPARTMENT FOR HEALTH AND SOCIAL CARE

A photograph of a woman and a young girl at an outdoor event. The woman, on the left, has blonde hair tied back, wears sunglasses, a blue denim vest over a white top, and a white bib with the number '77'. She is smiling and looking towards the girl. The girl, on the right, has long dark hair and is wearing a white floral off-the-shoulder top and a black patterned skirt. She is holding a green bag and looking down at it with a slight smile. The background is a blurred outdoor setting with trees and other people.

contact

For families with disabled children



This project is a result of the aspiration from the Department of Health and Social Care (DHSC) to fund a project to support parent carers to navigate the transition from child to adult services as their child approaches the age of 18.

In autumn 2019 Contact, Carers Uk, National Development Team for Inclusion and the National Network of Parent Carer Forums formed a consortium and 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.

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. 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.



Department
of Health &
Social Care



Executive Summary

INTRODUCTION

Parent carers, like all of us, have hopes and dreams for their child's future – friends, a job, somewhere safe to live, and for them to be as independent as they possibly can be.

A key stage in the lives of a young person with special educational needs or disabilities (SEND) and their families is transition – a term commonly used to denote a young disabled person's move from child social and health care services to adult services.

Finding relevant information

We know that the majority of young people with SEND look to their parents or carers for information about their options and support once they get older. This means it's important that parent carers are equipped with as much knowledge about their child's options as possible as well as about their own rights and options as a carer of a young adult.

But although there is a wealth of information and resources available about transition it can be difficult for parent carers to find and navigate. Families tell us that there is no one trusted place they feel they can go to to find the information, support and advice they want and need about preparing their child (and themselves) for adult life, and really importantly, that they:

“don't know what they need to know”.

The Transitions Project report outlines the steps taken by a consortium of charities and organisations - Contact, Carers UK, The National Network of Parent Carer Forums and the National Development Team for Inclusion, identifies the challenges and unmet needs for parent carers at this particular time in their child's life and makes recommendations for what could help to make lasting improvements and change.

 You can read the full Transitions Project report at contact.org.uk/transition-project-final

The consortium worked with parent carers and other key stakeholder, to understand the issues and produce a comprehensive and unique online information hub housed on Contact's website to help families plan and prepare for their child's move into adulthood.

WHY WE DID THIS WORK

One ambition of the Carers Action Plan 2018-2020 was to ensure synergy between the Care Act 2014 (mainly for adults in need of care and support, and their adult carers) and the Children and Families Act 2014. This is particularly important when young people with SEND 'transition to adulthood' and the baton is passed from children to adult services.

This project stems from this ambition and was funded by the Department of Health and Social Care to:

‘support parent carers to navigate the transition from child to adult services as their child approaches the age of 18’.

OUR APPROACH

The project team researched and collated existing resources for parent carers on preparing for adult life and gathered new evidence from parent carers about their experience and concerns through surveys, workshops and focus groups. This included:

- Carers UK – [State of Caring survey](#) – the first research of its kind to compare carers’ assessments for parents before and after transition
- Contact’s [Parent Carer survey](#) of nearly 600 people about their experience of the transition process
- Stakeholder workshops and focus group meetings

WHAT OUR RESEARCH TOLD US

67% the vast majority of parent carers we asked told us that they didn’t feel that their own outcomes were considered during this crucial stage of their child’s life

When asked about how informed they felt about key areas of the transition process such as health and wellbeing, education options and good quality care for example

70% rated housing and supported living as the area they were least informed in

64% stated personal skills and development, for example independent living, as the area they were least informed in

Of those parents whose young person had already gone through transitions:

24%+ said there was somebody who coordinated the process

17%+ agreed that practitioners communicated with each other

37%+ felt that practitioners were supportive of the young person and their wishes

In addition:

85% of parents told us that there were gaps in services (service not available or only partly available) with the main areas identified as respite and day services or activities, health and mental health services and social care

The overriding message was that they ‘didn’t know what they needed to know’ and felt they were often left to try and navigate a complex system alone.

KEY THEMES

Key themes emerging from our research made it clear that parent carers were looking for improved information, advice and support on a number of issues including:

- When they should start thinking about preparing for the transition into adult life.
- Financial assessments and what changes when a young person becomes an adult such as personal budgets, direct payments and other benefits changes.
- Education options beyond age 16.
- How their son or daughter can access health and social care services once they turn 16.
- Their own health and wellbeing and their right to a carers assessment.
- Employment options for their child when they are older.
- Independent living such as housing and supported living options.
- How to ensure their son or daughter is cared for and supported in the future when they are no longer able to.

WHAT WE DID NEXT

With support from Contact's highly experienced information team a new area on Contact's website called "Preparing for Adult Life" which includes 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.

To help parent carers know where to start when they don't know what they need to know, Contact's webpages also include vital information about preparing for adult life, support, and advice in a "common questions tool" that helps direct parents to what they need to know simply and easily.

THE CONSORTIUM'S RECOMMENDATIONS TO THE DEPARTMENT OF HEALTH AND SOCIAL CARE (DHSC)

Whilst we hope our new online resource will make a big difference, listening to families through this project has shown us that a different approach is needed to ensure their experiences of preparing for adult life improved forever, and for everyone. It goes beyond information provision – positive change 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.

As a result we have made a number of recommendations to help achieve positive lasting change, including:

- The establishment of 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.
- Investment in a Family Leadership Programme to support and train up parents and practitioners to work alongside each other, using person centred and co-production approaches to raise awareness and challenge negative perceptions and low expectations.
- Continued funding for the Preparing for Adult Life online information resource developed by Contact to ensure it remains current and useful.

- Further exploration by Carers UK and Carers Trust of what works well for parents as their children become older.
- Development of a “transition” leadership programme that brings together strategic leaders across children and adult services to develop a stronger pathway between the two.

Our consortium will seek ongoing dialogue with the DHSC to ensure the challenges and experiences of parent carers continue to be prioritised to help achieve the improvements this project has highlighted.

 You can read the full Transitions Project report at contact.org.uk/transition-project-final



We are Contact,
the charity for
families with
disabled children.

We support
families, bring
families together
and help families
take action
for others.




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 www.contact.org.uk

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