

**Health & Adult Care Scrutiny Committee and
Children's Scrutiny Committee**

SEND Transitions Task Group

June 2020

1. Covid-19 Pandemic context

1.1 This Task Group concluded its evidence gathering in January 2020 and set about formulating this report and developing a number of recommendations for change. In the months following the conclusion of this work, the Covid-19 virus arrived in the UK, reaching pandemic status, causing thousands of deaths and many more people to be taken seriously ill, as well as having a dramatic impact on the nation's economy, people's personal finances and the way that we all live our daily lives. This in turn has had a radical impact on the work of County Council and the NHS in particular, as partners work together to respond to this pandemic in Devon.

1.2 During this response, local authorities, the NHS, emergency services and other partners have had to quickly and efficiently review their core purpose, reconsider all priorities and in many cases, temporarily change or stop delivering some services, directing resources to where they are most needed in order to take decisive action and respond to this crisis in the most effective way.

1.3 As Councillors, across Devon, we have seen first-hand how NHS staff, care workers, emergency services personnel, local authority officers, supermarket workers and communities have stepped up, worked together and gone above and beyond the call of duty, often risking their own health in order to keep others safe and cared for. We are all eternally grateful for their dedication and selflessness during this most challenging of times.

1.4 We also recognise that the last few months may have been a particularly difficult and worrying time for many families with children and young people with Special Education Needs and Disabilities (SEND), who have always been our focus throughout this review.

1.5 We are living in a different world to that of six months ago, and whilst the evidence gathered and conclusions drawn from our work on SEND Transitions up to January 2020 remains valid, it must be considered in the context of the current climate.

1.6 Rather than make specific recommendations for change directed at the Council and the NHS, we have drawn together some key themes and potential areas for development, which clearly emerged throughout this review. As always, Scrutiny has a key role in local democracy as a 'critical friend', and we hope that this report and the conclusions it draws are seen as a helpful and constructive aid for those who commission and deliver services to children and young people with SEND and their families.

1.7 The Task Group asks the Health & Adult Care Scrutiny Committee, the Children's Scrutiny Committee and Cabinet to endorse the themes and areas for development below. The Task Group requests that an update on progress made should be brought back to both Scrutiny Committees in nine to twelve months' time.

2. Themes and areas for development

2.1 For us as a Task Group, the key message from this review is that whatever a young person's needs, a positive and successful transition doesn't just happen. If we want to see good outcomes for young people and adults with SEND then it is essential that strong planning and the right support is put in place for young people and their families on this journey.

2.2 Transitions planning and support needs to be:

- Person Centred
- Early
- Aspirational

1. PERSON CENTRED

WHAT DOES THIS LOOK LIKE?

- Embed the learning from the Doing What Matters¹ work across all areas of practice in children's and adult's services, particularly in services which support young people through transitions;
- Enable more efficient decision making around packages of care and support, encouraging greater trust, autonomy and risk assessment at a more operational level, including making the necessary changes to the scheme of delegation in children's and adult's services;
- Embed the role of the Adult Consultant Physician (piloted at the RDE) across all hospital trusts in the Devon CCG footprint;
- Ensure that young people who do not reach adult social care thresholds have a smooth and stable transition and are able to access support/signposting to the voluntary sector where needed.

2. EARLY

WHAT DOES THIS LOOK LIKE?

- Earlier and better transition planning and conversations about the future (with a clear focus from the age of 14) for all young people with SEND, including those who are not expected to reach adult social care thresholds;
- Continue with increased investment in the Preparing for Adulthood Team.

3. ASPIRATIONAL

WHAT DOES THIS LOOK LIKE?

- Ensure that all practitioners and schools are encouraging conversations with children with SEND and their families about their aspirations after full time education in terms of college, training, apprenticeships and work, as early as possible;
- Gain additional funding to expand the number of qualified job coaches in Devon and increase the number of supported internships, supported employment and supported apprenticeships;
- Ensure that there is sufficient suitable and quality housing and supported living accommodation for young adults in the right locations, to enable independence.

¹See (para 5.1-5.56)

3. Background

Children and Young People with Special Educational Needs and Disabilities

3.1 Under the Children and Families Act 2014², local authorities, schools and the NHS have a range of duties and responsibilities towards children and young people with special educational needs and disabilities. The Special Educational Needs and Disabilities (SEND) Code of Practice 2015³ provides these organisations with statutory guidance to help them meet these responsibilities.

3.2 The Code of Practice provides a definition of Special Educational Needs (SEN) as follows:

“A child or young person has SEN if they have a learning difficulty or disability which calls for special educational provision to be made for him or her.

3.3 A child of compulsory school age or a young person has a learning difficulty or disability if he or she:

- has a significantly greater difficulty in learning than the majority of others of the same age, or
- has a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions.”

3.4 The Code of Practice also provides guidance relating to children and young people with a disability as defined by the Equalities Act 2010⁴, but states that any child or young person with a disability who also requires special educational provision, will be covered by the SEN definition.

3.5 This means that when we talk about children and young people with SEND, we are talking about a wide range of children and young people with varying needs. These needs may be physical disabilities, learning disabilities and/or mental health needs. Many of these young people will need additional support during their education but go on to need very little or no support from statutory services into their adult lives. Some young people will need ongoing support from health and/or social care services into adulthood, with a very small number of these young people with profound needs, requiring very high levels of ongoing medical care and support throughout their lives.

Joint Local Area SEND Inspection

3.6 In December 2018, Ofsted and the Care Quality Commission (CQC) conducted a joint inspection of SEND arrangements in Devon. The inspection letter⁵ concluded that there were significant areas of weakness in the local area’s practice and that as such the local

² <http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted>

³ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf

⁴ <https://www.legislation.gov.uk/ukpga/2010/15/contents>

⁵ <https://files.api.ofsted.gov.uk/v1/file/50054047>

authority and Devon CCGs must submit a Written Statement of Action to Ofsted outlining how the local area plans to address these weaknesses.

3.7 Both the Children's Scrutiny Committee⁶ and the Health and Adult Care Scrutiny Committee⁷ reviewed the concerns raised in the inspection letter and the local area's draft Written Statement of Action at their separate committee meetings in March 2019, and elected to set up a joint Task Group to 'inform and dovetail with the work in response to the findings of the Inspection, including transitions from children's services to adults' services'.

Scope of this review

3.8 A scoping meeting was held in May 2019 with Task Group Members and relevant officers present to establish the focus of this Task Group and scrutiny of the local area's progress following the joint inspection. Members agreed that in order to avoid duplication, the local area's Improvement Plan and progress against the Written Statement of Action would continue to be monitored and scrutinised through formal meetings of the Children's Scrutiny Committee.

3.9 However, given the joint inspection's findings, and pre-existing concerns Members had relating to the experience and outcomes for young people with SEND and their families as they approach adulthood, it was agreed that the Task Group would focus its review on 'transitions', and in particular:

- understanding the experiences of parents/carers and children and young people with a range of needs and disabilities, and their journey through the system;
- reviewing the local area's approach to preparing for adulthood, and the support provided to young people as they transition to adulthood.

4. Reaching adulthood

4.1 We all go through periods of transition and change during our lives, and we know that these can be difficult or stressful times. For children and young people with SEND and their families, the transition from childhood to adulthood can be particularly challenging for many reasons. Adapting to changes in school, living arrangements, health services or transport can be very difficult. This can be made all the more challenging when these changes happen all at once, and when at the age of 18, the services that young people and families are so used to relying on seem to disappear.

4.2 Uncertainty about the future leads to increased anxiety for families and young people themselves, and the changes in support structures and thresholds for services often leave families feeling as though have 'fallen off cliff edge' and feeling like they must 'constantly battle' the system to access the support they need.

4.3 If young people with SEND in Devon are to thrive into adulthood and have the best outcomes possible, we need to get 'transitions' right for every single young person we work with.

⁶ <https://democracy.devon.gov.uk/ieListDocuments.aspx?CId=428&MId=2861&Ver=4>

⁷ <https://democracy.devon.gov.uk/ieListDocuments.aspx?CId=429&MId=2854&Ver=4>

5. Person Centred Support

Disabled Children's Services: The 'Doing What Matters' Approach

5.1 The County Council has recognised that many of the services it provides have evolved over time in response to budget restrictions, increases in demand, changes to legislation and a host of other influences, which can mean that the way services are delivered are built around what works best for the Council, and not necessarily what works best for the people who receive these services. In light of this, the County Council is in the process of reviewing the way that it delivers many of its services, striving to understand what matters most to people (both service users and staff) and look at the whole system, rather than looking at individual services in silos. This then enables blockages and barriers to be identified and new ways of working to be developed and piloted on a small scale, which can then be widened out across the whole Council where successful.

5.2 One of these pilot areas was the Disabled Children's Service in the north of the County, with 'transitions' being a key part of this work. This pilot helped bring to light the experience of many families who felt powerless and unheard, saw decisions about funding and support being made by senior officers who they had never met, and felt that they were forced to fit in with a system and timescales that did not reflect the needs of their child. Using these findings, the service was able to begin to break down the system and create a new set of principles based around what mattered to children and families.

5.3 The pilot introduced a range of changes to how the Disabled Children's Service worked with families including reducing complexity in the system and the need for families to engage with such a wide range of professionals, through the introduction of a single support plan and a lead worker who takes responsibility for co-ordinating care and support across agencies. The timing of changes around transition was also a key difficulty, and so the pilot developed transitions support based on understanding and working with young people when it's right for them, not because they have reached a certain age.

5.4 The pilot also identified that decision making around support and funding was an issue, with senior managers needing to sign off a significant number of packages, resulting in drift and delay for young people and creating considerable degrees of separation between the decision maker and the family concerned.

5.5 The piloted approach puts young people and families at the centre but can mean that social workers and other staff work more intensively with families and therefore need smaller caseloads. However, this way of working can see better outcomes for young people and less demand on services in the long term because families get the support they need at the right time.

5.6 The pilot in the Disabled Children's Service has allowed some small and some more significant changes to happen, which have made a huge difference to young people and their families as they transition to adulthood.

Mental Health

5.7 Many similar issues have been highlighted in mental health services for young people. Historically, strategies and processes have required the child or young person to fit the system, but there is recognition within mental health services too that this simply does not work. Children and young people need to be recognised as individuals and put at the centre, and services need to work more flexibly around them, particularly during times of transition.

5.8 The demand for children and young people's mental health services is growing, but so is our understanding of mental health. Demand and funding will always be a challenge but health commissioners in Devon have told us that they feel in a good place to start pushing change through the system and working in a different way. Trauma informed approaches, which recognise the long-term impacts of trauma on children's development and outcomes are becoming part of common practice, and while transition to adulthood will always be difficult time, by understanding the young person's experiences, practitioners are beginning to be able to support young people better on this journey.

The Pathways Project

5.9 Turning 18 is a time of significant change and anxiety for children and young people with profound and complex needs and their families. Up until the age of 18 children and young people with co-morbidities are primarily in the care of a Paediatrician, who will co-ordinate their care with their GP and other professionals. Ordinarily this all changes when the young person reaches 18, and families must co-ordinate care with various medical services and professionals themselves.

5.10 The Royal Devon and Exeter Hospital (RD&E) listened to families when they said this was a difficult and complex change to manage, reporting that they had to see new consultants and professionals who didn't know their young people's history and needs, and that they would have to repeat their story multiple times. The RD&E also consulted with special schools who described the need for a 'grown-up paediatrician' and an 'adult Bramble Ward' (the children's ward at the hospital).

5.11 Consultants are already used for older people who have a range of co-morbidities and it became clear that a similar solution was needed to support families as their young people reached adulthood and beyond.

5.12 The Pathways Project⁸ created an Adult Consultant Physician role to mirror the Paediatrician role after the age of 18, providing support young people with complex and profound needs and their family for life, not just during the transition phase. The pilot project is pioneering and does not currently exist anywhere else in the country. Feedback from families has been overwhelmingly positive and the increased support is making a real difference for young people and their families in the area. We would like to see this role become common practice for all hospital trusts across the Devon Clinical Commissioning Group (CCG) footprint.

⁸ <https://www.devon.gov.uk/educationandfamilies/archives/8710>

6. Starting Early

6.1 One message that we have heard time and time again during this review is that transitions planning and work with young people and families is not happening early enough.

6.2 Young people who are expected to need support into adulthood should have support from adult social care services from the age of 14, but in reality we know that for the majority of young people very little transition work is happening until they are aged 17 or even 18. Trying to navigate the new world of adult social care and health services can be baffling for families, and many feel unprepared and unsupported to do this.

6.3 Special schools play a significant role in the lives of children who attend them. For parents, the school is often their main link to other services and families develop long term, trusting relationships with them. Schools such as Pathfields in Barnstaple take a proactive role in transitions for their young people by having early planning conversations with children's and adults social care and try to broker relationships for the future. It is great to hear that special schools are taking on this role supporting many families, and with continued investment in our special schools this can be continued and further developed as we go forward.

6.4 However, we have also heard of some concerning cases in residential education settings where at the end of the summer term, living arrangements for September had still not been secured. We know that consistency and certainty are of the up most importance to families of children with SEND, and whilst we recognise the resource implications of early transition planning and the complexities of finding education or care placements for young people, this lack of clear planning and clarity for families is completely unacceptable.

6.5 Recent and significant investment in new staff in the Preparing for Adulthood (PfA) Team, who play a key role in supporting young people to prepare for their transition, provides some reassurance that these issues are being prioritised and addressed. The PfA Team is focussing its work on four outcome areas; Employment, Independent Living, Good Health and Friendships, Relationships and Community. Following this additional investment, the team is now working more intensively with young people from Year 10 (age 14/15) onwards and have been working with the Local Offer Reference Group to develop toolkits to support families and young people to manage change and aspire to and achieve these outcomes.

6.6 The majority of young people with SEND will not need ongoing support through adult social care or be in receipt of significant ongoing health services. However the transition period can be just as unsettling for these young people and their families, as they learn to move forward with significantly less support in place.

6.7 In mental health services for example, we see fairly smooth transitions in areas such as psychosis where thresholds for services are similar for children and adults, but in other areas such as eating disorders, the thresholds for support are very different upon reaching 18, and so families experience a clear reduction in services.

6.8 Where young people with SEND are not expected to meet thresholds for services into adulthood, it is vital that health and social care services are having conversations with families about their expectations of support in the future as early as possible, and that young people are supported to access support through the third sector where appropriate.

7. Aspiring for independence

Skills and Employment

7.1 For many of us, going to work gives us a sense of purpose, develops our confidence and helps us to see our place in the world, as well as being the main way that we support ourselves financially. We know that people with disabilities can gain all these benefits from working, as well as having a range of skills and experience to offer employers across Devon.

7.2 However we also know that levels of unemployment amongst people with disabilities and long-term health conditions are disproportionately high compared to the general population. There are a number of reasons for this, and the County Council is working with employers and people with disabilities across the county to help more people into work, and support employers to take on staff with disabilities with confidence⁹. A three month multimedia campaign 'Ready Devon' was successful in increasing the number of Disability Confident businesses in Devon and the 'Be Ready' project is continuing to work with businesses to support them to employ staff with disabilities and raise awareness of the government's Access to Work scheme¹⁰.

7.3 Supporting children and young people with SEND to have aspirations about work and independence is a vital part of increasing the number of adults with disabilities into work, and we see the best outcomes where we work with children very early on to embed these ideas and skills. To do this effectively we need all agencies working with families to have conversations around transitions, and particularly about employment and careers (or what will happen once formal education ends). Schools have a significant role in this, and both special schools and mainstream schools should be working to increase aspirations around work and careers for their students with SEND. So much relating to a young person's life as an adult; where they will live, their financial situation, developing their identity and self-esteem, is intrinsically linked to work.

7.4 At the same time we need to be conscious of how unsettling a time reaching adulthood can be for families, and the move from education to work needs to be when the young person is ready to do this, not when they hit a certain age. We also need to make sure that the opportunities exist for young people with SEND to be supported into work in the way that is right for them, whether this is through supported internships, supported employment or apprenticeships.

7.5 Further education colleges are increasingly supporting young people with SEND to think about their future and find employment and the County Council is working with colleges to

⁹ <https://www.readydevon.org.uk/>

¹⁰ <https://www.gov.uk/access-to-work>

promote supported internships and supported employment. There are now a good range of supported opportunities set up through colleges in Devon, through both national and local employers. As an employer, the County Council is also currently trialling supported apprenticeships.

7.6 The workplace can be an intimidating and challenging environment for people with disabilities who are new to work. Further education colleges and community interest companies are now employing job coaches (usually trained enablers with additional job coach training) who support young people and adults in their place of work, enabling them to overcome some of these barriers. With the support of job coaches many young people are achieving success in their employment.

7.7 We would really like to see an increase in the number of job coaches and supported internships, supported employment and supported apprenticeships across the County, so more young people and adults can benefit from this.

7.8 People with more complex disabilities who may not be able to engage in paid work may take up work experience placements or volunteer roles. As an example, the Budleigh Community Hub has a number of volunteers who use their Personal Independence Payment to support their work experience placements. It is equally as important that we continue to support these opportunities and that all young people and adults with disabilities are able to feel part of and contribute towards their local communities.

Housing

7.9 As with employment, having conversations with young people with SEND and their families about where they might live as adults needs to happen as early as possible. There are a range of different accommodation options with differing levels of support, and it is important that young people are supported to understand these options so that they can make informed choices for their future. Equally important is the need to ensure that Devon has the right range of accommodation options developed to meet this need, supporting people to be as independent as possible.

7.10 Devon's recently adopted joint 'Housing and Accommodation Strategy, Healthy Lives, Vibrant Communities, Housing Choices'¹¹ sets out the strategic intent for people to live in their own homes and to make planned and informed choices about where they live. The strategy sets out the ambition for housing with support settings (including supported living) to be more flexible, able to support people with a wide range of needs, support people to achieve their goals and to be located within communities across Devon.

7.11 The strategy also includes a market position statement which set out potential future requirements in specific locations (Credon, Bideford, Newton Abbot and Tavistock) and provides clear guidance to housing providers about what is needed in the future. Access to technology is an important feature of good quality supporting living, as is accommodation that is affordable and transparent so people can access paid employment. Access to public transport and the community are also important factors in ensuring people have a good quality of life.

¹¹<https://democracy.devon.gov.uk/documents/s30052/Housing%20and%20Accommodation%20Strategy%20Appendix%20A.pdf>

8. Conclusion

8.1 We know that the transition to adulthood for young people with SEND and their families can be very challenging for many reasons, a number of which have been touched upon in this report.

8.2 During this review we have met passionate and skilled practitioners and senior managers who clearly want the best outcomes for young people. They are beginning to work in different ways and develop approaches which are driven by understanding the experience of families and recognising the need for services to be built around the needs of young people as individuals.

8.3 There is also clear recognition that planning for this transition needs to be happening earlier than it currently is for most young people, and we are beginning to see greater investment in this area.

8.4 We are also seeing improved aspirations for children and young people with disabilities and better support for young adults to get into work and live more independently.

8.5 We are making many steps in the right direction, however there is still more work to do if we are to ensure that all our young people with SEND have a successful transition period and are enabled to thrive as adults. We hope that the themes highlighted in this report will support the County Council, the NHS and other partners develop further improvements and ultimately better outcomes for young people with SEND in Devon.

9. Membership

Councillors Rob Hannaford (Joint Chair), Sara Randall Johnson (Joint Chair), Su Aves, Andrew Saywell and Margaret Squires

10. Contact

For all enquiries about this report or its contents please contact:
Vicky Church (Scrutiny Officer) victoria.church@devon.gov.uk 01392 383691

11. Sources of Evidence

Witnesses

The Task Group heard testimony from a number of stakeholders and witnesses and would like to express sincere thanks to the following people for their contribution and the information shared.

Dawn Stabb	Head of Education and Learning, DCC
Julia Foster	SEND Senior Manager, DCC
Andrea Morris	Senior Manager (Countywide Services), DCC

Vivienne Broadhurst	Head of Adult Care (Professional Practice, Safeguarding and Disability Development), DCC
Stella Doble	Disability Project Lead, DCC
Sara Cretney	Head of Organisational Change, DCC
Martin Barnard	Organisational Change, DCC
Sharon Matson	Head of Commissioning for Women and Children, NHS Devon CCG
Siobhan Grady	Senior Commissioning Manager for Children, NHS Devon CCG
Jasmine Heslop	Paediatric and Transition Nurse, RD&E
Beverley Leach	Clinical Lead for Disability Support, Children & Family Health Devon
Nikki Churchley	Head of Specialised Mental Health Commissioning, NHS England
Jonathan Mitchell	Team Manager, Disabled Children's Service, DCC
Cherie White	Head Teacher, Pathfield School
Joan Davey	Team Manager, Adult Social Care, DCC
Sam Eagles	Community Care Worker, Support and Advice Team, DCC
Amanda Graham	North Area Education Commissioning Officer, 0-25 Team, DCC
Sue Hollingworth	Team Manager, Adult Social Care, DCC
Alix Hoye	Team Manager, Adult Social Care, DCC
Alice Lake	Social Worker, Children's Social Care, DCC
Louise Rayment	Commissioning Officer, Adult Social Care
Liz Wood	Disability Lead, Preparing for Adulthood Team, DCC
Helen Woolway	Social Worker, Children's Social Care, DCC
Gary Patch	Assistant Director (Disability Lead), DCC
Derek O'Toole	Mental Health Commissioning, NHS Devon CCG
Julia Bonnell	Co-Chair of the Parent Carer Forum Devon
Victoria Mitchell	Co-Chair of the Parent Carer Forum Devon
Jo Olsson	Chief Officer for Children's Services, DCC
Keri Storey	Head of Adult Care Operations and Health
Khristine Norton	Employment and Skills Manager
Rebecca Hudson <i>(written contribution)</i>	Senior Commissioning Manager (Disabilities), DCC

References

Access to Work

<https://www.gov.uk/access-to-work>

Children and Families Action 2014

<http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted>

Council for Disabled Children, It Takes Leaders to Break Down Silos

<https://councilfordisabledchildren.org.uk/help-resources/resources/it-takes-leaders-break-down-siloes-cdcs-new-report-integrating-services>

Devon County Council, Children's Scrutiny Committee, March 2019

<https://democracy.devon.gov.uk/ieListDocuments.aspx?CId=428&MId=2861&Ver=4>

Devon County Council, Health and Adult Care Scrutiny Committee, March 2019
<https://democracy.devon.gov.uk/ieListDocuments.aspx?CId=429&MId=2854&Ver=4>

Devon County Council and NHS Devon Clinical Commissioning Group, Healthy Lives, Vibrant Communities, Housing Choices; A Joint Strategic Approach to Supporting People to Live Independently in Devon 2020 to 2025
<https://democracy.devon.gov.uk/documents/s30052/Housing%20and%20Accommodation%20Strategy%20Appendix%20A.pdf>

Devon County Council, Ready Devon
<https://www.readydevon.org.uk/>

Equality Act 2010
<https://www.legislation.gov.uk/ukpga/2010/15/contents>

Ofsted and Care Quality Commission, Joint Local Area SEND Inspection of Devon, January 2019
<https://files.api.ofsted.gov.uk/v1/file/50054047>

Royal Devon & Exeter NHS Foundation Trust, Pathways
<https://www.devon.gov.uk/educationandfamilies/archives/8710>

Special educational needs and disability code of practice: 0 to 25 years
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf