



**Impact of COVID-19 on
transition planning for young
people with additional
support needs—and those
who support them**

*Supplement to ARC Scotland's parent
and carer survey published in
July 2020*



Scottish
Transitions
Forum





ARC Scotland and the Scottish Transitions Forum

ARC Scotland is a charity that advances knowledge, practice and policy in health and social care for the benefit of people with learning disabilities or other additional support needs. We are committed to supported people being at the heart of their services and communities.

The Scottish Transitions Forum is facilitated by ARC Scotland and aims to improve the experiences of young people aged 14 – 25 who require additional support and who are making the transition to young adult life.

The Forum has over 1000 members, including professionals from all sectors, young people and their parents and carers. Membership is free and open to anyone who shares our vision.

This report is one of a range of initiatives by the Scottish Transitions Forum to help ensure young people who need additional support, their families and those working with them, have the information and support they need during the COVID-19 pandemic. For more information, visit www.scottishtransitions.org.uk/.

In particular, we have produced the following resources:

- [COVID adapted version of Principles into Practice](#): To help coordinate contingency planning
- [COVID-19 – a legislation summary](#): A guide to the key actions relevant to transitions under emergency legislation in the Coronavirus Act (CVA) 2020.
- [Transitions planning and coronavirus – what happens now](#): Information for parents and carers on what they need to take into account in preparing for life beyond school.

scott.read@arcuk.org.uk
rebecca.williams@arcuk.org.uk
tracey.francis@arcuk.org.uk

0131 663 4444

Association for Real Change is a registered charity:
Registered Charity No 285575
Scottish Charity No. SCO39129

1. Introduction

“If we are to recover both inclusively and fairly, we will need to review what is already not working for this population. This will include learning from the Coronavirus emergency and examining the structures, systems and processes that exist in our services and communities, which create barriers for people with learning/intellectual disabilities living their best lives, and what innovative solutions we can use to overcome them. To do this right will require strong leadership and a commitment to the equality and human rights of people with learning/intellectual disabilities in Scotland.”

SCLD, “The Impact of Coronavirus on People with Learning Disabilities and their Parents, Carers and Supporters”, June 2020

Following our report *Impact of COVID-19 on transition planning for young people with additional support needs: views of parents and carers*, published in July (<https://scottishtransitions.org.uk/survey-results-views-of-parents-and-carers-on-the-impact-of-covid-19-on-transition-planning-for-young-people-aged-14-18-with-additional-support-needs/>), we consulted with Scottish Transitions Forum members to gather insights they had gained through their own contacts with parents and carers of young people with additional support needs during and after lockdown.

We asked members to share their reflections, experiences and findings about life for young people and their families during the pandemic. Some had conducted formal surveys among their service users and kindly shared the results with us. Others had gathered data less formally, either through conversations with families they support or through anecdotal evidence shared by colleagues and team members.

We wanted to place our own report findings in the context of other organisations’ observations, to see how closely experiences and concerns correlate. We also wanted to capture and share the wide range of valuable learning that has taken place over this period, to ensure future service planning and delivery is as responsive as possible to evidenced need based on issues and challenges young people and their families themselves are reporting. Thirdly, we wanted to give organisations and individuals an opportunity to reflect on what they had experienced during and after lockdown, and what they had learned or changed in their practice as a result.

This was not a formal process. The invitation was extended to all Scottish Transitions Forum members, and individuals and organisations decided for themselves if they wished to take part. Eleven responses were received including transitions practitioners from two local authorities; two people responding in an individual capacity; and the remainder from third sector organisations working directly with young people and families.

“Parents who are supporting and providing ongoing care to relatives with Profound and Multiple Learning Disabilities (PMLD) are physically and mentally exhausted. The deterioration in parents’, carers’ and relatives’ mental health is a major issue that requires immediate attention. If expectations are that parents and carers will continue providing this role without formal support they will reach breaking point. Often it’s forgotten that parents and carers have other roles in life too, such as supporting and caring for elderly parents.”

PAMIS

2. Summary

Reports

The following were all observed by or reported to members who responded to our call for information.

Impact of lockdown on families

“As my son is entering 6th year at school I am so aware that we are really on the countdown now to his leaving school and what next! I have to confess I am a bit nervous about things getting put in place in time.”

Parent

- In some areas **adult social workers ceased being allocated** to families. This resulted in families experiencing difficulties planning, agreeing and implementing actions relating to transition.
- **Budget decisions in some areas were postponed indefinitely**, making it impossible for families to identify, commission and access appropriate services in time to support a smooth transition. Assessments and screening for resource allocation also stopped altogether in some areas.
- Some families reported **transition planning had been suspended** even for those with very complex needs.
- Parents reported **confusion and miscommunication around shielding**, with a lack of clear advice.
- Many respondents commented on **the increased pressure on parents and families** during lockdown, both in relation to immediate support needs and future planning/provision.
- Many parents found **all direct support available to young people ceased abruptly** when lockdown began. This left families to cope with meeting essential support and personal care needs as best they could, including round-the-clock care.
- **A lack of input from allied health professionals** was reported.
- Social work input and level of contact has differed across areas: there have been both **positive and negative responses to the change in engagement by social services**. Some parents would have welcomed greater engagement, others reported having less contact felt like a pressure being lifted.
- **Transition preparation had ceased to be supported** in some areas, including applications to college or other services.

“Transition is an anxious time for young people and their families so the uncertainty of how their support will look due to COVID has undoubtedly increased those anxieties.”

Perth & Kinross

Impact of lockdown on service providers

“Due to COVID, transition planning has become very difficult with many existing plans having to halt or change as a result of the crisis ... In the initial weeks of lockdown limited planning could be progressed as existing services were diverted to other priorities, college closed, care providers were unable to commence support for transition and schools were closed.”

Perth & Kinross

- Respondents commented on the **lack of information and support for staff**, including a lack of specialist training, to guide them in carrying out key duties and statutory obligations safely under lockdown conditions.
- **Difficulties accessing personal protective equipment (PPE)** brought challenges for some services.
- Organisations reported **inadequate means in place to support cross-sector working**, particularly evident between children’s and adult services. This was felt to have had a negative impact on transition planning, which may depend on a joined-up approach.
- Individuals and organisations drew attention to a **lack of capacity in the system**, and suitable respite and care services being non-existent.

“We have found new ways of working, more working from home, using Near Me for visits and Teams for meetings. We envisage that these adapted ways of working will continue as a way forward.”

Scottish Borders

Concerns

Immediate concerns identified

The following concerns were identified or highlighted by members as a result of their engagement with families during and after lockdown.

- That **transitions were not seen as a priority** during lockdown. Concern also expressed that this remains the case as lockdown restrictions are eased.
- **Delays in the decision making are adding to stress and anxiety** for families. Failure to agree, plan and fund appropriate support is likely to have a far reaching effect on young people’s ability to come out of lockdown, re-engage with the wider world, and implement future plans.
- Withdrawal of essential services, in some cases literally overnight, led to **families being expected to plug gaps in support** without appropriate respite or help.
- **Mental and physical exhaustion** on the part of families and carers.
- Families losing out through having **limited or no access to specialist skills** and support services.
- **Confusion/miscommunication over shielding.**

- Young people **missing out on opportunities to prepare for transition** by being unable to visit new services and meet staff, potentially jeopardising a sustainable transition.
- Families report **uncertainty around social distancing**, including within school, day services and transport.
- Colleges report calls from **anxious parents who have heard nothing from school or social work** about planning and next steps.
- Concern that **restricted opportunities for partnership working and data sharing** could lead to vital information not being passed to the right agencies.

Concerns for the future

“We ... have concerns about a potential bottleneck forming of disabled school leavers waiting to get social care and needs assessments before they can access post school destinations.”

Lead Scotland, Briefing for Scottish Government—Potential Impact of COVID-19 on Disabled Further and Higher Education Students

- Parents have expressed concern that **delaying transition for their young person may mean their eventual transitions budget could be reduced**. This was a particular concern among parents of young people with complex and multiple needs.
- Organisations expressed concern **parents/carers of young people will be left to continue filling gaps in support** despite months with no respite.
- There is considerable concern around the **financial impact of COVID** and its effect on budgets and the availability of support.
- Fear that **lack of capacity and resources in the system** could mean services parents were expecting to rely on may no longer be available to them.
- Concern about the **reduction of opportunities for young people with additional support needs**: that social isolation will increase, courses be disrupted, volunteering opportunities reduced, and employers less willing to provide jobs for people with disabilities or other support needs.
- Increased challenges for **young people and parents/carers who lack basic digital skills**, the confidence to engage, or access to technology. Fear that Zoom calls may be relied upon to replace face-to-face support.
- Ongoing and long term **impact of heightened anxiety and exhaustion on mental health and resilience**.
- That reliance on the family to provide essential support may lead to a **long term reduction in young people’s ability to progress towards independence** and to fulfil their potential.
- Concerns around the **sustainability of flexible or online approaches** and young people’s ability to engage.

“Transition will be different from what it was.”

PAMIS

3. Shared experiences

We asked members to share their thoughts, plans and responses to the challenges presented by COVID-19 and the national emergency, along with examples of families' experiences where they had permission to share these.

As a professional I am deeply distressed by what has been happening with transition generally and particularly under COVID. Our pilot project was set up in 2018 in two AS schools in Edinburgh with two strands—supporting leavers and families in their last year, as a 'bridge' with social work; and working with families of 14+ pupils to start earlier discussion of life after school. When COVID struck we opened to all AS school leavers in the city, although our challenge was that we couldn't get hold of all head teachers and although it was already March social work did not know all the names of those leaving.

We proposed that providers form a consortium to provide a transition hub. Two providers worked with us and two micro hubs offered rolling programmes of activities in August and September on developing skills to support your young person in adapting and adjusting to the adult world.

Based on our experience we would suggest that, even more so post COVID, a 'transitional environment' between school and whatever destination a young person moves towards is essential for young people and their families.

Claire Edwards, Transition Support Project

LIVED EXPERIENCE OF TRANSITION IN COVID TIMES

Bob is 18 years old and lives in the Glasgow area. He was educated in a school a short distance from his home and was in his final year.

Bob has Profound and Multiple Learning Disabilities (PMLD) so the transition from education to adult services was always highly likely to be a time of additional stress, worry and anxiety for his parents and carers. PAMIS provided 1:1 bespoke support to the family to assist and guide them through the various aspects of transition, working in partnership with education, health and social work to ensure the process was as seamless as possible.

Overall the transition experience was positive for the family. Their adult social worker was allocated in good time and the necessary assessments and transition plans were completed. A Self Directed Support budget was agreed and allocated, enabling adult services to be secured for both day and overnight respite. The family were relieved, although still apprehensive.

The positivity was short lived. When the national lockdown was implemented in March 2020 schools and vital support services closed their doors. The adult day service this young man would have transitioned to remains closed. The adult overnight respite facility is operating at reduced capacity and is therefore unable to offer any support.

Bob is no longer affiliated to education, nor is he affiliated or known to adult service providers. He remains at home, with his mum providing all of his physical support and care needs 7 days per week, morning, noon and night.

PAMIS

Positive experiences and examples of changes in practice—Perth & Kinross

In Perth and Kinross, the local authority made a carer's sitting service available to all.

There were limitations on the level of planning that could be undertaken, but virtual meetings have taken place across schools, children's services, health and other partner agencies. Information gathering for assessments was begun for young people leaving school in 2022 and additional support is being provided in school until October for this year's leavers to help with transition.

A new Transition Lead Agency Group has been established and work has begun on an improved transition pathway to give young people, families and carers a better understanding of the transition process and support available, with plans for a transitions information webpage and pack to support the pathway.

P is a young person with a learning disability within a mainstream school. At age 16, school felt there were limited opportunities for him and suggested he leave at the end of 4th year. Both parents and the transition worker felt that this was not in P's best interest, maintaining he would benefit from remaining in school. A timetable was put in place and P remained until the end of S5, due to leave in 2020. He benefitted from the additional year, though concerns were raised around his maturity to cope full time at college.

A virtual transition meeting was set up towards the end of the summer term with all relevant parties, and as a result of a partnership approach a transition plan was put in place. P will now access college one day a week and day opportunities one day a week, and have 12 hours support from a care provider to support him at college during break times and on an additional 2 days per week. P and his family are pleased with the positive outcome.

C has a learning disability, ADHD and high anxiety. She has been subject to a Compulsory Order with Secure Authorisation due to high level or risk-taking behaviour. C has been supported in secure units, where she has done well. Work has been undertaken to support her into the independent living cottage in preparation for moving back to her home area and into her own tenancy.

The child disability, youth services, education and transition teams have worked together closely on a plan to provide C with a smooth transition from an out of area provision. Skills being built in her current resource include travelling independently to and from Perth. The plan is for her to move to supported accommodation until a core and cluster supported provision is available. COVID has delayed this, but delays are being managed within the transition plan. Early planning and good working partnerships have led to a positive outcome.

“Transition workers maintained contact with the young people and their families by telephone, contacting them regularly to provide support, reassurance and where relevant an update on progress.”

Sharing experiences and examples of changes in practice—Scottish Borders

EXAMPLE 1

Parent with two young people with learning disabilities who have very different needs: one has been shielding, which has meant the other young person has been unable to attend school and both young people and parent have suffered low mood throughout the lockdown.

We provided telephone support throughout. The transitions plan now needs to change in line with the ongoing COVID 19 guidance as the original plan for one of these young people cannot currently be actioned.

EXAMPLE 2

Young person who stopped attending school due to COVID 19 returned to school until the summer break and will return to school after summer until the October break. This is an additional term post the school leaving date to support transition.

This, along with short break suspension, has caused an increase in the young person's anxiety levels. One parent has been home working some days but this has proved stressful and difficult due to the anxiety levels and demands of the young person. Telephone support has been provided throughout and an increase in direct payment has been put in place. The transition plan needs to change in line with the ongoing COVID 19 guidance as the original plan for this person cannot currently be actioned.

In the Scottish Borders 11 young people with additional support needs left school this year having had their transition planning halted or disrupted due to lockdown.

Planning has been difficult for us to achieve and this has been stressful for families, who have coped amazingly well in being creative about supporting their young people in these difficult times.

Covid19 has also had an impact on workers who have found it more difficult to progress their work with families and schools.

We have found new ways of working, more working from home, using Near Me for visits and Teams for meetings. We envisage these adapted ways of working will continue as a way forward.

We developed easy read information around COVID to support actions and activities.

Identified actions going forward

- Consider how to get information about transitions planning to families and young people and into schools in the autumn term as a priority for both social work and education.
- Develop new ways of working out transitions planning with changed opportunities available due to COVID.

“Some young people’s transition plans have had to change due to the new ways of delivering daytime opportunities. This includes college courses starting as online only and volunteering opportunities being reduced. Some young people and families are anxious about the uncertainly ahead.”

4. Looking ahead

Key priorities

Respondents identified the following as key priorities as we continue to live with the effects of the coronavirus.

- Make full use of adapted ways of working and the possibilities offered by technology, but do not rely on these to replace in-person or face to face support.
- Instead of looking to restore previous patterns of provision, use the opportunity to make cultural shifts in service development and delivery to improve flexibility.
- Both schools and social work need to consider as a priority how to get information about transitions planning to families and young people in the autumn term.
- Maintain regular contact with young people, families and other agencies to establish how best to meet individual need.
- Ensure policy decisions taken to kickstart the economy take the needs of disabled people into account – for example, impact on benefits.
- Ensure parents and carers are properly supported by providing information and signposting to appropriate services.
- Some young people who have been isolated for an extended period will require an increased level of support to be able to access existing services.
- Tackle digital skills gap among young people and families as a matter of urgency.
- Restoring, maintaining and supporting social activities and employment opportunities will be essential in combating exclusion, poverty and social isolation for young people and families.

We therefore see this as an opportunity for the sector to think about a cultural change which could improve access and flexibility, complementing traditional ways of offering education for the future.

Lead Scotland, Briefing for Scottish Government—Potential Impact of COVID-19 on Disabled Further and Higher Education Students

5. Conclusion

Respondents provided information and experiences gathered by or shared with them during lockdown and in the first weeks of eased restrictions.

As time goes on, it is clear we are far from the end of the pandemic and evident that the impact of COVID-19 has radically changed how organisations function for the foreseeable future.

The concerns observed or raised by Scottish Transitions Forum members reflect many of those identified in our survey of parents and carers, in particular:

- Disruption to transition planning
- Impact on current and future finances and budget allocation
- Sudden major changes to personal care and support provision, even for the most vulnerable

- Impact on the mental and physical health of parents and carers
- Restricted access to education/training and employment opportunities for young people with additional support needs.

In addition, members highlighted the impact on services and service providers.

- High levels of stress among staff who have found it difficult to progress their work among families and schools
- Lack of clear guidance around how to work safely with young people and families
- Difficulty accessing information to pass on to families regarding next steps and available support
- Limited availability of personal protective equipment (PPE)
- Mental and physical exhaustion.

However they also clearly recognised that current circumstances present a unique opportunity to review the planning, processes and support available to young people and their families, and make significant shifts in how services are developed and delivered. This is seen as a chance to establish new ways of working that were previously regarded as too difficult or challenging to implement.

These include embedding more flexible approaches to education and training to improve accessibility for young people with additional support needs; making better use of IT technology to connect with families and support partnership working, for example in transition planning meetings; and a greater emphasis on providing carers with the support and services they need.

The concerns of young people and their families, and those supporting them, demonstrate a fear that seamless transition is in jeopardy in many areas with the associated risk of vulnerable individuals and families requiring intensive additional support well into the future. It is vital that young people with additional support needs, and those who support and care for them, are not left behind in the search for the “new normal”.

Ensuring transition preparation, planning and support is established as a key priority will make sure young people who need extra support to transition successfully to adulthood can play a full part in the social and economic recovery from the pandemic and its long term effects.

If you would like to discuss this report or find out more about the work of ARC Scotland and the Scottish Transitions Forum please contact: tracey.francis@arcuk.org.uk

Useful links

Scottish Transitions Forum

Impact of COVID-19 on transition planning—parent/carer survey

<https://scottishtransitions.org.uk/survey-results-views-of-parents-and-carers-on-the-impact-of-covid-19-on-transition-planning-for-young-people-aged-14-18-with-additional-support-needs/>

Transitions planning and coronavirus—what happens now?

<https://scottishtransitions.org.uk/parent-and-carer-network/transitions-planning-and-coronavirus-where-to-start/>

Coronavirus and transitions—Briefing Paper 1

<https://scottishtransitions.org.uk/coronavirus-and-transitions-briefing-paper-one/>

ARC Scotland

We're all in this together—the impact of Covid 19 on the future of social care. Survey of the social care workforce in Scotland

<https://arcscotland.org.uk/wp-content/uploads/Were-all-in-this-together-The-impact-of-Covid-19-on-the-future-of-social-care.pdf>

Scottish Commission for Learning Disability

The impact of coronavirus on people with learning disabilities and their parents, carers and supporters

<https://www.sclld.org.uk/wp-content/uploads/2020/06/SCLD-Coronavirus-Report-FINAL.pdf>

COVID resources

<https://drive.google.com/drive/folders/12eeoc9z-0yD8apzgOgfDfIKbRlnk5Nhi>

Self Help guide <https://www.sclld.org.uk/covid-19-guided-self-help-booklet-series/>

Lead Scotland

Lead Scotland briefing for Scottish Government—Potential impact of COVID-19 on disabled further and higher education students

<https://www.lead.org.uk/wp-content/uploads/2020/09/Lead-Scotland-briefing-COVID-.pdf>