



Impact of COVID-19 on transition planning for young people with additional support needs: views of parents and carers

*A survey of parents and carers of
young people with additional support
needs aged 14—18*

June 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

Impact of COVID-19 on transition planning for young people with additional support needs: views of parents and carers

1. Introduction

This report sets out findings from an online survey of parents and carers of young people between the ages of 14 and 18 with additional support needs to gauge how lockdown has impacted this group and the young people they care for, and gain an insight into how COVID-19 is shaping families' concerns for their young person's future.

Transition is a formative experience for young people and their parents and carers. It should be viewed as a process that unfolds over several years and not a single 'event', such as leaving school. However this group of parents/carers were chosen as their young people were most likely to be at a critical stage of their transition during lockdown restrictions for the COVID-19 pandemic. During this time families would normally expect to be gathering information and receiving support to explore their young person's future options and, for those in the final year of school, having a transition planning meeting to agree actions and next steps.

The survey ran over 3 weeks (12 – 31 May 2020) and received responses from 131 people from 26 of the 32 local authority areas.

We were particularly concerned to gain a more detailed understanding of the experiences of parents and carers of young people who were due to leave school this summer. 50 responses came from parents in this group. These have been analysed and highlighted separately.

The term 'additional support needs' includes young people with learning disabilities, autism, physical disabilities, sensory impairments, complex health conditions, mental health difficulties, those who are care experienced (including those with experience of secure care or young offender institutions), and young carers. It applies to all young people who require additional support, including those with high and complex support needs, and those who may not meet the eligibility criteria for adult social care support.

Future actions to be carried out by ARC Scotland as a result of this learning are shown in Section 5: Next Steps.

We would like to thank PAMIS, Down's Syndrome Scotland and Contact for their help in shaping the survey content.

"I feel this transitioning has been left to the last minute with little to no thought for the young people involved."

Parent

2. Summary: all responses (131 in total)

Many of the concerns parents expressed around transitioning into adulthood and adult services are long running issues that were previously identified in ARC Scotland's report [Facing the Future Together](#) (published in 2017) and should not solely be attributed to the COVID-19 pandemic. In summary these were:

- Many parents and carers struggle to get the support they believe their children need.
- Parents and carers are often challenged by their child's transitions.
- There is a lack of formal planning for transitions.

However it is clear from this survey that the challenges of COVID-19 have exposed areas where established systems and processes, when under severe pressure, are not effective enough to ensure that appropriate pathways, services and support structures remain available to the most vulnerable young people, and their families and carers.

Many parents and carers expressed concerns that a smooth, supported transition is unlikely to be possible under current circumstances. These concerns were most pressing among those whose young people were expecting to leave school in June 2020.

Key findings

- More than half of parents and carers (56%) are anxious or very anxious about their young person's transition. A further 23% said they were "quite anxious". Many expressed concern about their own and their young person's health and wellbeing.
- 19 respondents (15%) did not know when their young person should be formally leaving education. Some expressed a preference that the planned school leaving date should be delayed.
- Nearly 70% of respondents either had not had a transition planning meeting or did not know if they had had one.
- 89% of families taking part in the survey either have no written transitions plan or are not aware of having one. There were concerns that plans previously made would be negatively affected by the pandemic.
- About a third of people (33%) said they had been contacted about transition planning since the lockdown began on 19 March.
- Most contacts (68%) had come from social work (38%) or school (30%).
- Most parents and carers (60%) are unhappy or very unhappy with the information they currently have on transition.
- Most respondents (63%) expect schools or social services to provide information on the transition process and planning support.
- Most parents and carers (64%) are still unaware of the ILF Transition Fund.

Other concerns:

- Coming out of lockdown following a long period of isolation.
- The impact of social isolation on their young person.
- Engagement with home learning.
- Longer term impact of COVID-19 on their young person's independence.
- Finance.

3. Responses

3.1. Parents /carers of June 2020 school leavers

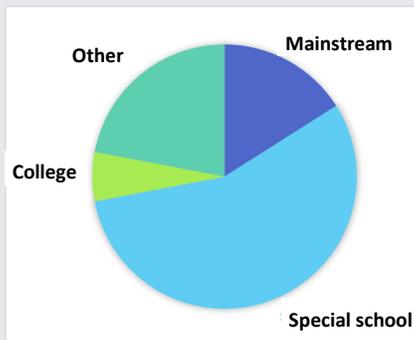
A total of 50 respondents from 20 Local Authority areas said their young person was due to leave school in 2020.

The survey findings reflect how far COVID-19 and the experience of lockdown has increased and intensified stress around what families already regard as a challenging experience.

- On average parents and carers in this group reported a high level of anxiety about transitions (66% said they were quite anxious, anxious or very anxious) and 62% said they were either unhappy or very unhappy with the transitions information they currently have.
- Slightly over half of respondents (56%) had had a transition planning meeting. Meetings were more likely to have taken place for pupils in a special school setting rather than mainstream.
- Less than a third (22%) said their young person had a written transition plan. More than two thirds (78%) either had no written plan or did not know of one.
- Two thirds (68%) had been contacted about transitions planning since lockdown began with most of the contact coming from social work.

“My daughter has missed 3 months of transitioning, meaning two key visits to adult services have not been able to happen. If my daughter has nowhere to go in August what will happen?”

Education setting



Mainstream	8
Special school	28
College	3
Other	11

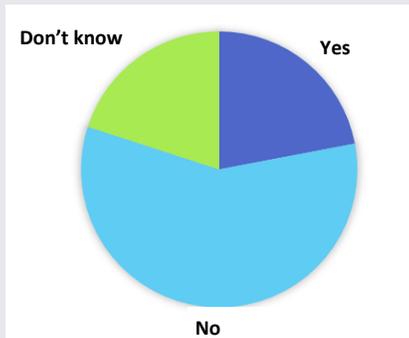
“Other” included support base within school, home schooling, and residential settings.

Has your young person had a transition planning meeting?



Yes	28
No	20
Don't know	2

Does your young person have a written transitions plan?



Yes	11
No	29
Don't know	10

How do you feel about your transitions experience so far?

Respondents reported feeling high levels of anxiety around transitions right now, with an average score of 2 (quite anxious) on a scale of 0 (very anxious) to 5 (very happy).

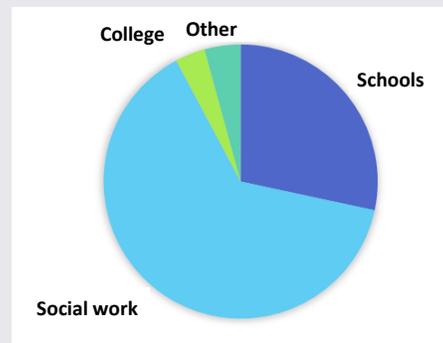
They reported an average of 2 (not happy) in terms of the information they have about transitions, on a scale of 0 (very unhappy) to 5 (very happy).

Since the lockdown began, has anyone been in touch about transitions planning?



Yes	34
No	16

If yes, who was this?



School	8
Social work	18
College	1
Other	9

"Other" included transitions workers, voluntary sector organisations and multiple services.

There were specific concerns around the impact of COVID-19 on the chances of making a smooth transition.

"Supported transition from school to adult services – [I'm] concerned this may not happen now."

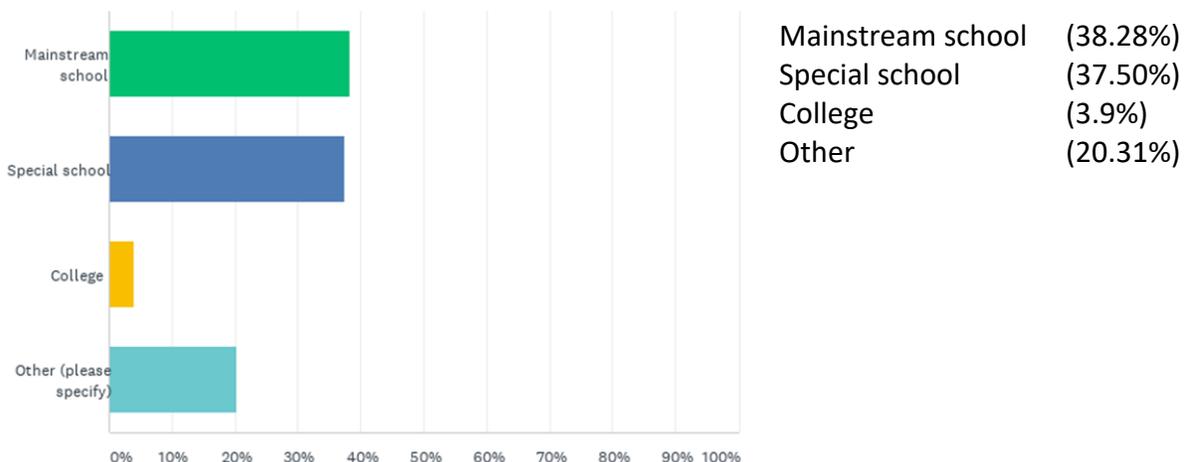
"What will attending college look like and will she still have a place on the course?"

"I worry that it will be impossible to get her out into the world again."

3.2. All respondents

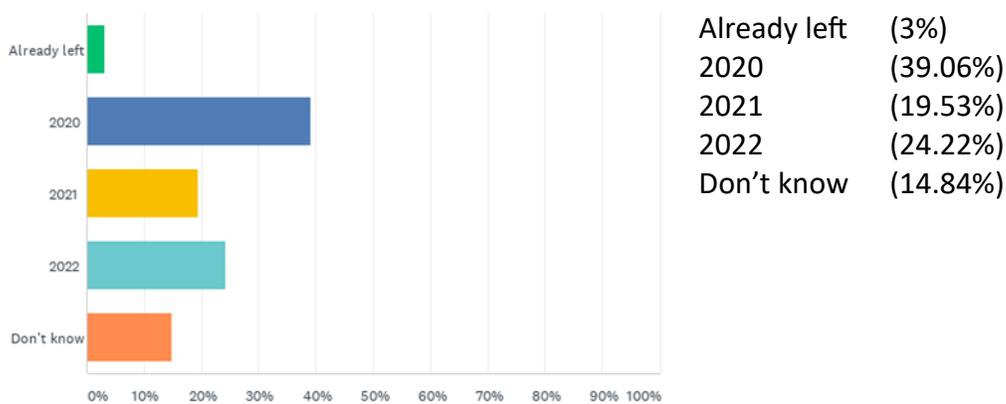
A total of 131 respondents took part from 26 of Scotland's 32 Local Authority areas. Their responses are shown below.

Is your young person in:



There was an almost equal balance between those in mainstream and special school provision. A small number were already attending college, while those who selected "other" mostly had a mixed provision – part mainstream, part special provision or with additional support. Two respondents were home educating.

When should your young person formally leave education?



The majority of respondents (39%) had young people expecting to leave education this year.

19 respondents (15%) did not know when their young person should be formally leaving education. This could be for several reasons, including:

- They don't know what their options are around remaining education.
- They don't know what alternatives are open.
- They haven't yet made a decision.

“Why is he being asked to leave school earlier than planned?”

“My social worker has been proactive, however obviously COVID situation has thrown everything up in the air. I don’t know when transition will start for my child due to current situation and whether he will leave school this year or whether this will be extended.”

“My boy should officially leave next year but due to his not coping at school had decided to take him out this June. I’m stuck in limbo as he thinks he’s going back to school. He has had no transitions meetings.”

Others expressed a preference that the planned school leaving date should be delayed.

“I think school should be extended for a year for our guys especially. Many can’t/won’t do school work at home, with the social distancing aspect I doubt our kids will be safe to return to school any time soon – especially when in more than one high risk category and parent at home also vulnerable health wise.”

“Is there an option for leavers to stay at school until Christmas?”

“Social work are looking to find him a place to go but if they can’t I would prefer he stayed at school. He talks all the time about going back and his teachers and the children in his class. I don’t have the heart to say he’s not going back.”

Please tell us how you are feeling about transition right now (where 0 = very anxious and 5 = very happy)

0	16
1	56
2	29
3	18
4	6
5	4

Most respondents (79%) said they were feeling very anxious, anxious or quite anxious about transition. Ten people said they were happy or very happy.

The degree of anxiety uncovered by this survey is significant in terms of the potential impact on wellbeing among parents and carers, and their confidence in their ability to support their young person effectively through this time of major change. For many young people and families, face to face support was withdrawn at the beginning of lockdown. This left parents and carers to manage as best they could.

“Mental health, hers and mine. Coping with working (in a school), being expected to work from home, home school and manage a young person with a learning difficulty.”

“He won’t let me sleep either because he’s scared about me getting ill from C-19, so constantly checks on me all night.”

“I’m exhausted and my mental health is shattered.”

Some respondents also reported anxiety about the detrimental impact on their young person's wellbeing:

"[I'm concerned] that this will set my son's anxiety too high for him to continue with his planned transition into training."

"What if it makes him suicidal?"

"I worry more now about how he will self regulate when he leaves home, particularly sleep schedules, as I'm having to tell him when to sleep and eat now that his day lacks school routine."

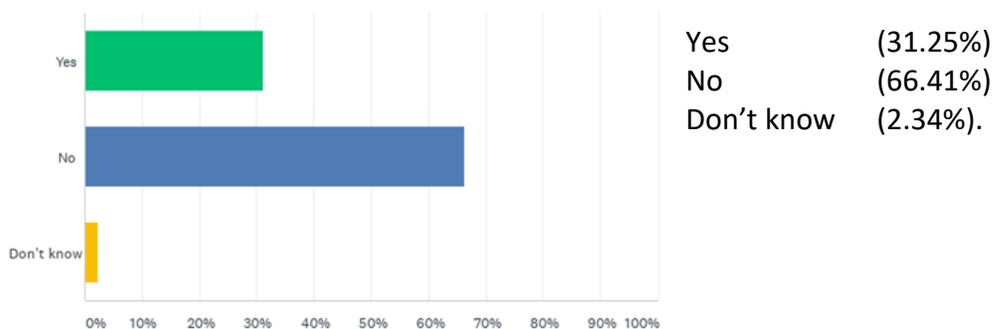
"My daughter was anxious about transition before lockdown so I am extremely worried about how she will deal with it having lost so many months."

"I don't know what's happening and worry if this is not handled properly it will so upset him."

However one respondent indicated that lockdown had a positive impact.

"The situation has taken the pressure off her. We can work more on her mental health."

Has your young person had a transition planning meeting?



Nearly 70% of respondents either had not had a transition planning meeting or did not know if they had had one.

Those not in their last year of school might not normally have had a planning meeting yet anyway. However 40% of those due to leave in June (20 families) had not had a transition planning meeting when lockdown began.

Concerns were raised that those due to leave school this year may face narrower opportunities or a more challenging route into further education, training or work than normal. Parents and carers also expressed concern that delaying assessments and budget planning will prevent support packages being in place and so limit their young people's choices.

"Don't know what my child is transitioning to as this has not been agreed and funding is not sorted. This is my primary concern."

"It would be horrible to think that the inevitable cuts coming after this pandemic affect the support they receive in school, college and the transition between them."

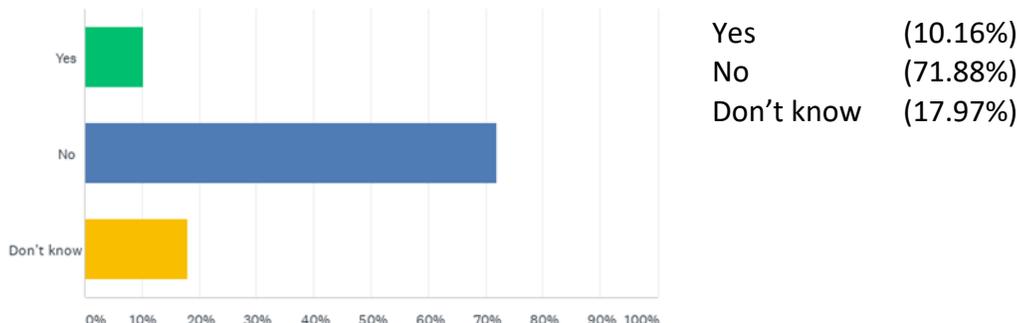
Concerns about practicality of holding meetings and accessing new services during the pandemic were also noted:

“Is it even feasible/realistic for my child to attend a new service when she is shielding/regarded as clinically high risk?”

“How will we be able to proceed with transition planning should shielding be extended?”

“Not able to get to the new project they had just started at because we don’t have a car and need to go by public transport, and we can’t.”

Does your young person have a written transitions plan?



Transition plans are required to ensure a shared understanding of next steps and agreed actions. Nearly 90% of families taking part in the survey either have no written transitions plan, or are not aware of having one.

“[I’m afraid of] being dumped in adult services without assessment and having self directed support cut and young person’s views never ascertained. Just ignored.”

“College has said he cannot return, we do not have a destination as all services full. I work so what will happen to him?”

“How [do] I support my son to continue with his planned transition given there has been no time scale set?”

“Social work assessments have also been held up – when will funding be in place?”

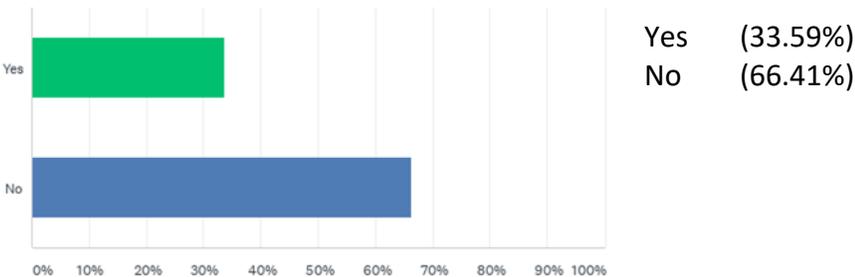
Some raised concerns that transitions plans that had previously been made would be affected by the pandemic:

“Transition was going very well and now it might be difficult to fall back in.”

“Transition will look very different to how we expected.”

“Supported transition from school to adult services, concerned this may not happen now.”

Since the lockdown began, has anyone been in touch about transitions planning?



About a third of people (33%) said they had been contacted about transition planning since the lockdown began on 19 March, with around two thirds (66%) saying no one had yet been in touch.

“I feel everything has been put on hold and the only person trying to get meetings virtually and in place is me.”

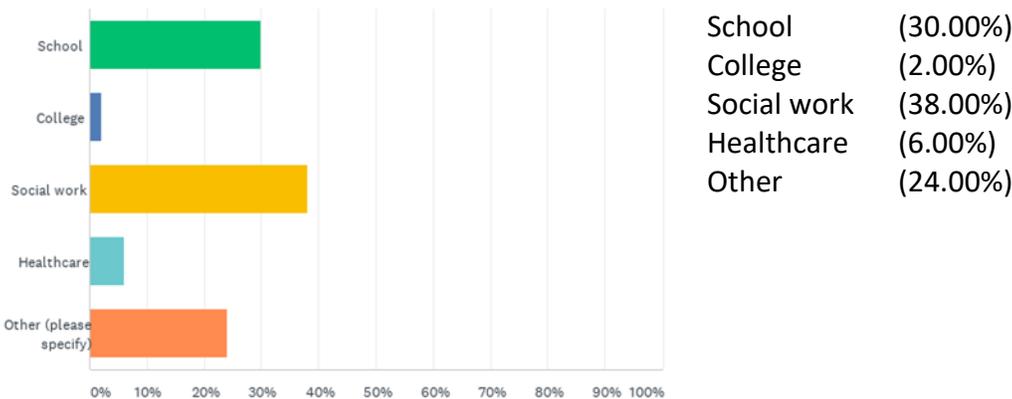
“My son was offered to keep in touch virtually but he has been too anxious to take up this offer.”

“We have been left behind. She has been given no support, help, or a general call to ask how she is doing. Nothing.”

“Children and adults with complex disabilities have been failed and basically left with poor support during this coronavirus pandemic. It’s appalling that professionals involved with families have just dropped off the radar (this is our personal experience anyway).”

“School and adult resource centre phone weekly and this is great for me to keep in touch, but my young person does not engage with them. Not sure how to progress with either as I don’t know what we’re going to be entitled to next school year ... Would like to start discussing the plan with young person so we can prepare for the next stages!”

If yes, who was this?



Of the third who said they had been contacted since lockdown, most contacts had come from social work (38%) followed by school (30%).

Most respondents who ticked “other” said they had done this because they answered no to the previous question. One person said they had had contact from all the agencies listed.

“No one other than school pastoral care has checked how he is. How will you support mental health after school? Have no confidence at all that he’ll be supported.”

“I had one transition meeting in October/November and heard nothing since then about the questions I asked in school. I have asked the same questions to the social worker who called, waiting to hear back now.”

Some parents and carers are unsure of who to make contact with when necessary.

“Who do I speak to if things go wrong?”

“Who is involved/who should be speaking to me?”

Two respondents highlighted positive aspects from their experiences of being contacted by services.

“I appreciate agencies are doing their best under the circumstances.”

“Young person is in foster care so funding is done through social work. Have had plenty of phone update and video calls, emails etc from social work and prospective transition placement.”

How happy are you with the information you have about transitions (where 0 = not at all happy and 5 = very happy)?

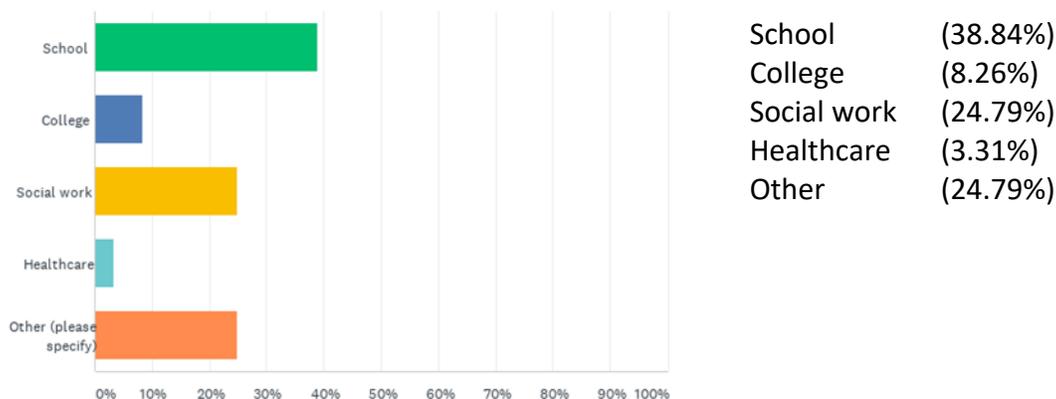
0	14
1	64
2	21
3	16
4	9
5	4

Most respondents (77%) said they were very unhappy, unhappy or quite unhappy with the information they have about transition.

22% were quite happy, happy or very happy.

“Why are parents not given a transition package that explains the whole process, who is likely to be involved, timescales etc ... it’s worrying enough having a profoundly disabled child without finding out no information available, very little guidance and precious little support when it comes to one of the major changes that your child is about to experience, their transition from children’s services to adult services.”

Where do you think might be the place to find the information you need?



Most respondents (63%) expect schools or social services to provide information on the transition process and planning support. A small number looked to healthcare professionals for information around transition to adult life and adult services.

There was a wide range of responses for 'Other', perhaps reflecting the general lack of clarity felt around the pathway through transition and the support available.

Some respondents (10%) indicated all of the above should share responsibility for disseminating information.

Other sources of information were identified as: charities; friends; the internet; universities or colleges; Scottish Government.

Do you know how to apply to the ILF Scotland Transitions Fund?

Yes	(35.71%)
No	(64.29%)

Most parents and carers (64%) are still unaware of how to apply to the ILF Transitions Fund. A link was provided to click for more information.

4. Other concerns and questions about transitions during the pandemic

We asked what parents and carers would most like to ask about in relation to transition, and also about their specific concerns related to the impact of COVID-19.

Coming out of lockdown

Concern was expressed about the difficulty of coming out of lockdown following a long period of social isolation, and the likely challenges for young people in re-engaging with normal life. Parents of this year's school leavers identified this as particularly acute for young people who will be going into unfamiliar settings with new people.

"The longer he is at home, the harder it is to get him back into some kind of normality, given that home is his safe space. I really fear for his future."

Social isolation

Parents recognised the adverse impact of social isolation on their young person's wellbeing.

"It's had a big impact, my child is used to being very sociable to being stuck in a house miserable with myself – not being able to explain her feelings, with being non verbal, or understanding the whole coronavirus situation."

"He has a good understanding of why things are different but still struggles with following rules for being outside (wearing a face mask for example) so he ends up not going out at all."

Impact on education/training

Many parents said their young person had struggled to engage with learning through lockdown, in some cases because of generally heightened anxiety and in others difficulty adjusting to the change of setting or methods of teaching/communication. There was interest across all respondents around extending time in school to provide a chance to make up lost ground academically, and among parents and carers of this year's school leavers, to prepare more fully for transition.

"Home school is difficult ... I support him accessing work as following all the announcements from the teachers on Teams is quite challenging, he's starting to feel he may prefer to leave school as he is finding this so hard."

"The school [is] leaving my child by the wayside and not focusing on his needs while concentrating on the mainstream needs of typical children."

"My young person responds well to isolation and not having the usual day to day challenges. I fear the skills we've spent 19 years working on will quickly become undone."

Impact on independence

There was great concern expressed at the impact of the pandemic on young people's developing social skills, and the potential long term effect on their progress towards personal independence.

"Undoing years of work towards independence – increased isolation and long term physical and mental health deterioration."

"My daughter is in the high risk category therefore I think it will take away independence opportunities as there will be a continued risk to her health."

Finance

For many parents and carers, the financial fallout from COVID-19 is a pressing concern, especially where budget decisions have been delayed or where parents require support to be in place to allow them to return to work.

"Delay in Scottish Child DLA. My son would have qualified for the additional age extension, now may miss out."

"What will happen to him and how will I support him financially?"

5. Next steps

As a result of these findings, ARC Scotland will pursue the following short term (COVID-19 specific) and longer term actions.

COVID-19 actions

Given the time imperative for getting transitions right for those leaving school or college in June 2020, we have progressed these actions in parallel with analysing and reporting the survey findings.

- Work with partners (Contact, ENABLE Scotland, Independent Living Fund Scotland, Differabled, Cairn Legal and Lead Scotland) to hold a series of COVID-19 webinars to provide parents and carers with information about the concerns raised in this survey. At time of writing, booking for these seminars is open: <https://scottishtransitions.org.uk/parent-and-carer-network/transition-planning-in-extraordinary-times/>
- Provide guidance and support to key local partners (social work, schools, colleges, health, Skills Development Scotland) to:
 - i. Coordinate an approach to transitions throughout the pandemic.
 - ii. Ensure there are plans in place for all young people who are at a critical point of transition.
 - iii. Provide information and support to parents and carers.

See: <https://scottishtransitions.org.uk/7-principles-of-good-transitions/principles-into-practice/>

- Produce COVID-19 specific resources for parents and carers, to support them in meeting their young people's needs at a time when the normal pathways may be unclear: <https://scottishtransitions.org.uk/parent-and-carer-network/transitions-planning-and-coronavirus-where-to-start/>
- Work with the Scottish Government and other national partners to help ensure that the experiences of parents and carers inform national policy throughout the COVID-19 pandemic.
- Contact partners who provide wellbeing support for parents and carers to make them aware of the findings of this survey and the particular pressures that those caring for young people in transition are currently experiencing.

Longer term actions

As we note in the introduction, many of the concerns expressed by parents/carers concerning transitioning into adulthood and adult services are long running issues that were previously identified in ARC Scotland's report *Facing the Future Together* (published in 2017) and should not solely be attributed to the COVID-19 pandemic.

Through our continued leadership and facilitation of the Scottish Transitions Forum, ARC Scotland will:

- Test an improvement framework for transitions called 'Principles into Practice' to be used by all practitioners to address the concerns young people and families tell us are most important to them, to understand the barriers to good practice, and to help develop solutions to overcome them.
- Work with ILF Scotland to continue to increase awareness of the Transition Fund and the possibilities this provides to help young people achieve their goals.
- Create a network of parents and carers to inform and guide the work of the Scottish Transitions Forum and ensure we produce information and resources relevant to their needs.
- Work with parents and carers to develop a digital transitions application to provide essential information to guide them through their young person's transition, and enable them to feed back on their experiences to those responsible for planning services in their local area.
- Work in partnership with young people with additional support needs to inform the work of the Scottish Transitions Forum and ensure young people's voices and views are at the centre of our work.

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