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*Making Access Possible*

*“Vulnerable young people should be treated in a respectful way which takes their views into account.” - Parent*

## Moving young people with additional support needs (ASN) from council-run Children's Services to Adult Services

Report

By Friendly Access (August 2020)

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# Introduction

As any parent or carer of a child or young person with additional support needs knows, the transition planning stage from Children’s Services into Adult Services can be a significantly worrying experience.

This journey is so significant, transition planning should start at least 3 years in advance, to ensure transparency, good communication, and most importantly, to enable informed choices for the individual in care to be present - at all times. While it is comforting to know this is a legal requirement, this is not always the case in practice.

A recent investigation<sup>1</sup> conducted by The Scottish Public Services Ombudsman (SPSO)<sup>2</sup> under section 15(1)(a) surrounding care and support provided by a Local Authority (<sup>3</sup>Moray Council), was found to have several alarming failures throughout this important transition planning period.

Following this ruling, we are looking to further strengthen the practice of transition planning.

Throughout June – July 2020, we conducted a survey call for parents and carers of children/young people aged 14 and over with ASN, to share their experience of transition planning provided by Local Authorities in Scotland by completing our short survey - ‘Moving young people with additional support needs (ASN) from council-run Children’s Services to Adult Services - A survey for parents and carers living in Scotland.’

“Vulnerable young people should be treated in a respectful way which takes their views into account.”

Source: Parent

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[https://www.spsso.org.uk/sites/spsso/files/investigation\\_reports/2020.04.22%20201811019%20The%20Moray%20Council.pdf?fbclid=IwAR04MgUiNtM25IXG4t3L3CSvTR0DI2UkguKOZrFWaA\\_g-liFDSzOd04YuBM](https://www.spsso.org.uk/sites/spsso/files/investigation_reports/2020.04.22%20201811019%20The%20Moray%20Council.pdf?fbclid=IwAR04MgUiNtM25IXG4t3L3CSvTR0DI2UkguKOZrFWaA_g-liFDSzOd04YuBM)

<sup>2</sup> <https://www.spsso.org.uk/>

<sup>3</sup> <http://www.moray.gov.uk/>

## Who responded to the survey?

A total of 27 parents/carers responded to the survey from 5 local authority areas with the majority living in the Moray area.

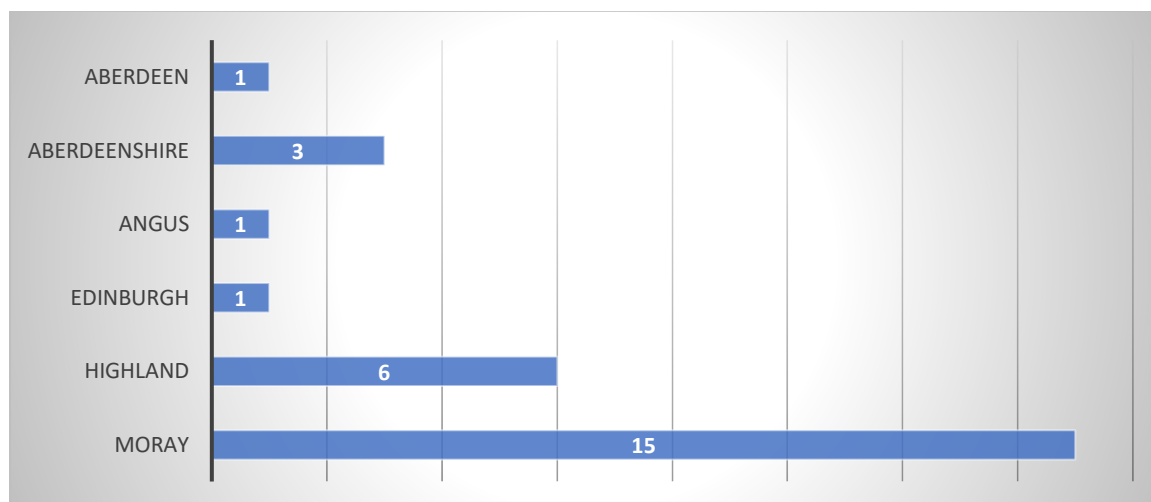


Figure 1: Number of parents/carers from each local authority area who responded to the survey (n=27).

In order to assist our research, our survey asked a series of questions detailed below, to establish the level of support and/or engagement from local authorities available to parents, carers, and children/young people. The data we collected includes, Pre, current, and post transition planning periods.

Around 50% had an IEP in place with approximately the same number currently in transition.

Despite being in the transition phase, the majority (65%) felt unsupported (Figure 10). As shown in the graphs below, most were unsure (52%) if they were offered **transition planning** or of their **rights** to that support (67%). Furthermore, most did not think the **assessment** covered their young person's needs (71%) nor **understood** the options presented to them (88%). Most also felt they were not **respected** (54%) and not **included** (58%). In the end, almost  $\frac{3}{4}$  (73%) respondents felt that their child received an unsatisfactory **outcome**.

No respondents felt they were 'fully' supported, and the majority of respondents did not feel that the options were clear, appropriate, or available.

## What we asked.....

***‘Does your child have Additional Support Needs which are supported by an Individual Education Plan (IEP), Care and Support Plan (CSP), Looked After Child (LAC), other, or none?’***

- Individual Education Plan (IEP) (13)
- Care and Support Plan (CSP) (4)
- Looked After Child (LAC) (2)
- None (4)

Other, included ‘Child’s Plan (3) and ‘Co-ordinated Support Plan’(1)

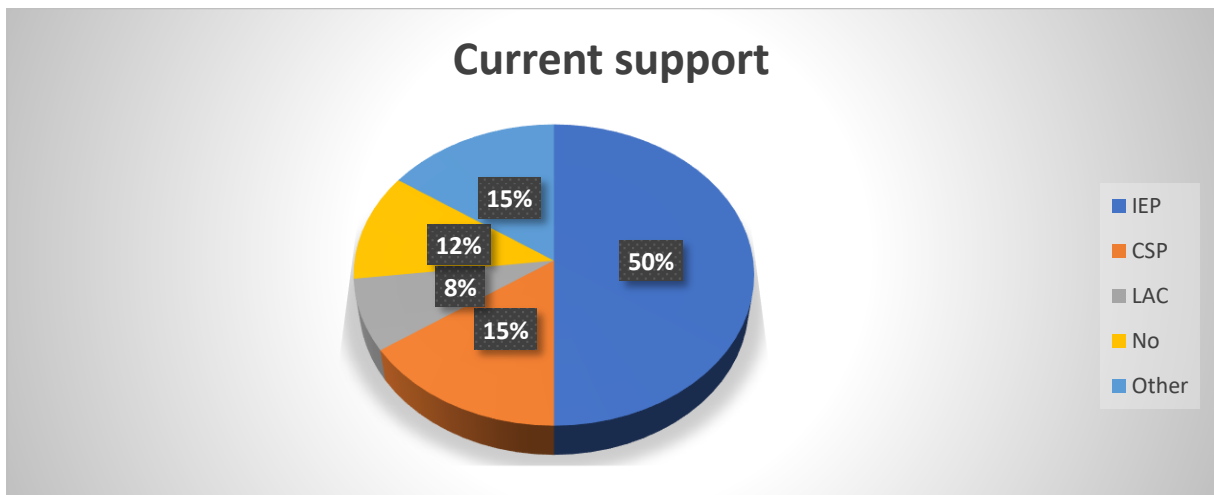


Figure 2: Current support

***‘At what stage of the transition period from Child to Adult Services is your child currently?’***

- Pre-transition period (more than 3 years prior to your child reaching the age of 18 (6)
- Currently in the transition period (13)
- Post-transition period (moved into adult services) (8)

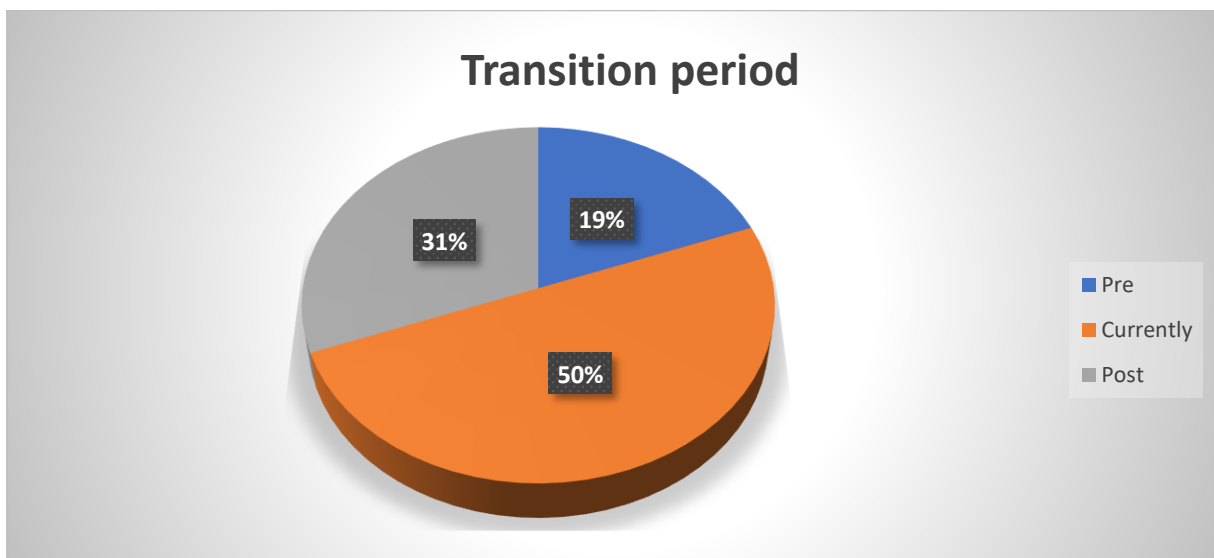


Figure 3: Transition period

### 'Was Transition planning offered?'

- Yes (3)
- No (10)
- Unsure (14)

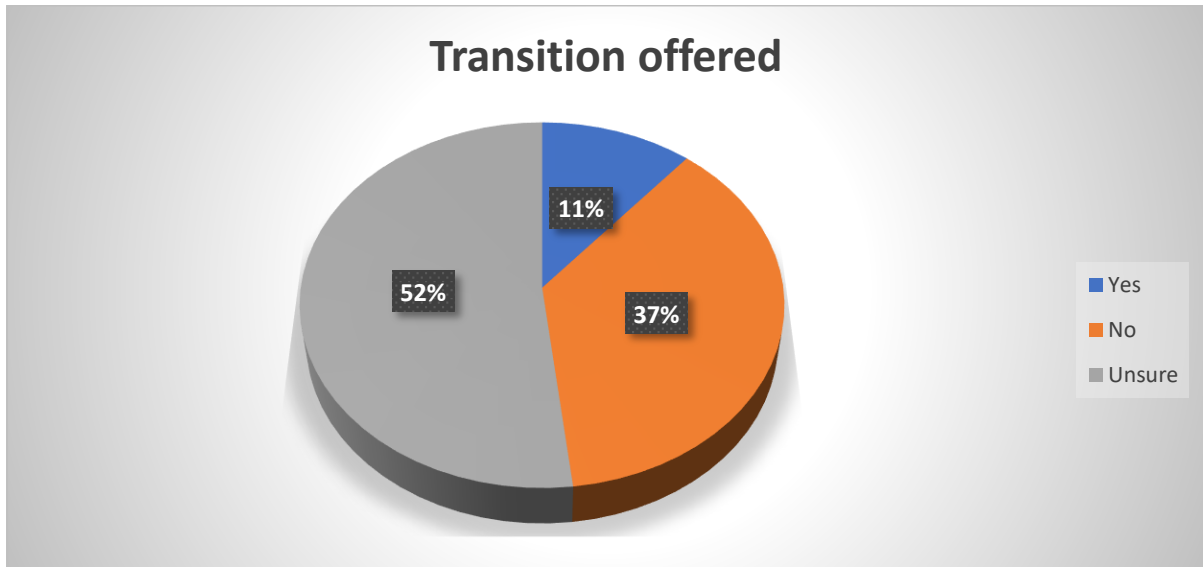


Figure 4: Transition offered

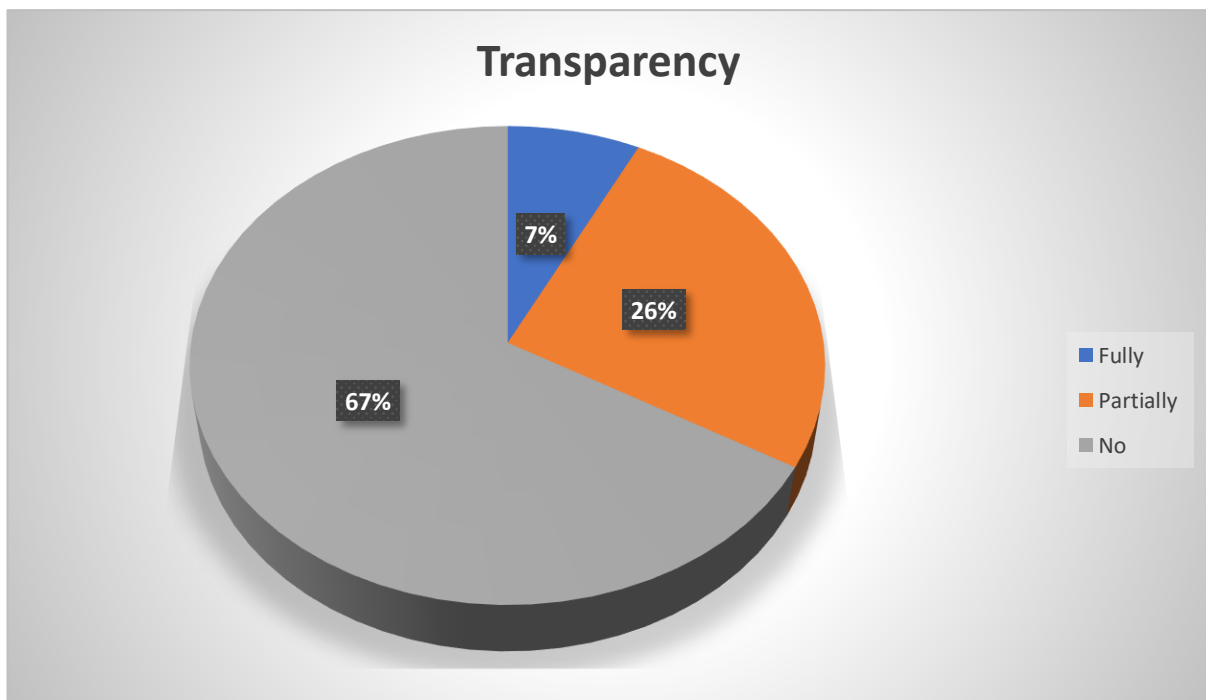
"We had to ask. I only knew to ask because a friend's daughter went through the transition a while ago. We asked Social Work shortly after daughter turned 15. Nothing has happened. The school haven't done whatever they are supposed to do (no-one 's told me what that is). The social worker didn't know how to proceed, asked her senior weeks ago, meeting to discuss is next week."

"The school pretty much said he could not have a full time timetable as he wouldn't use the hub and did everything in mainstream classes with assistance some of the time, the support teacher was not much help, I got him into college for a pathways course as he likes routine but we are again back in the position that they don't think he can progress in education, we have still applied ourselves for another course but don't know who would assist with things. He had child plans in primary and some in Secondary, but things were rarely followed through. He is now 18 we have never had social workers or anything for him and feel we don't know what is available for him."

“My daughter turns 18 in September and there has been no help with transition. Child/young adult is now 17 1/2. They have had social work involvement since 2014. They have been referred to children’s reporter multiple times, last time was January 2019, just prior to their 16<sup>th</sup> birthday - despite this heavy as involvement, absolutely no practical support has ever been received. The child/young adult has never actually talked to a social worker, ever. Their allocated social worker disappeared in July 2019. They attempted suicide in November 2019. This resulted in no mental health support and no social care support. The child/young adult has never had a transition meeting, never had a transition plan, the word ‘transition’ has never even been mentioned.”

***‘Do you feel that your local authority explained the rights your child has to access transition services and support into adulthood?’***

- Fully (2)
- Partially (7)
- No (18)



**Figure 5: Transparency**

“Adult services wouldn’t get involved until my son left school. A transitions team offered to come in while still at school which didn’t work well.”

“Several different people involved, and some were better informed of the options available, but few suitable options.”

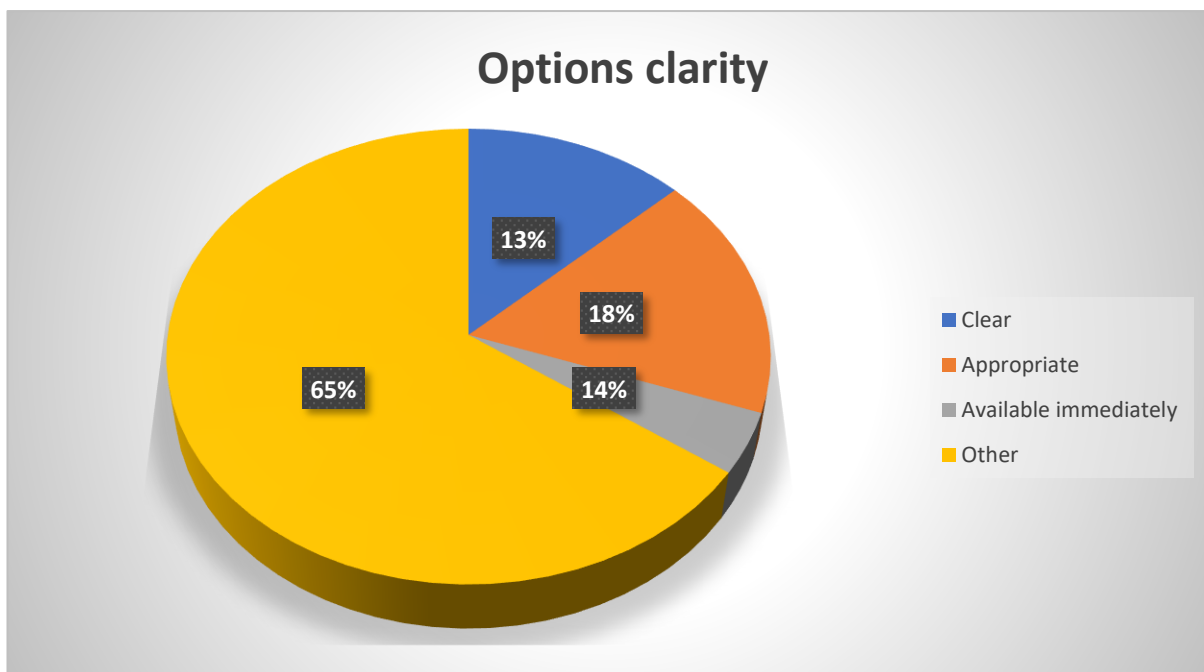
“No assistance at all. Had to leave school because of lack of support. Has found own pathway to career as a sports coach.”

“School failed to provide any support or plan. College worked on a plan to try to support her. My daughter’s education has not recovered, she still struggling to cope in that environment. At no point has anyone discussed with her ASN rights.”

“The individuals I spoke to were pleasant and personally very supportive, but all conversation focused on the lack of services, choice and future options for our young.” person.”

***‘When presented with options for transition, were they:’***

- Clear (3)
- Appropriate (4)
- Available immediately (1)
- Other (15)



“We have not been presented with options for transition. I feel anxious, as daughter turns 16 in August.”

“Unsuitable as underlying anxiety not dealt with, relevant courses not available or require qualifications to attend.”

“Had a meeting with school who gave some options, but made it clear he was on his own with the decision which he struggles with being autistic. I feel he has very much been let down. I realise he is not academic, but I think there should be things in place at secondary schools for all children no matter if they are academic or not, so they can stay on until they are 18.”

“Due to a complete breakdown, my daughter refused to back to school and I had to give up my job and find services suitable by myself as college was all that was offered.”

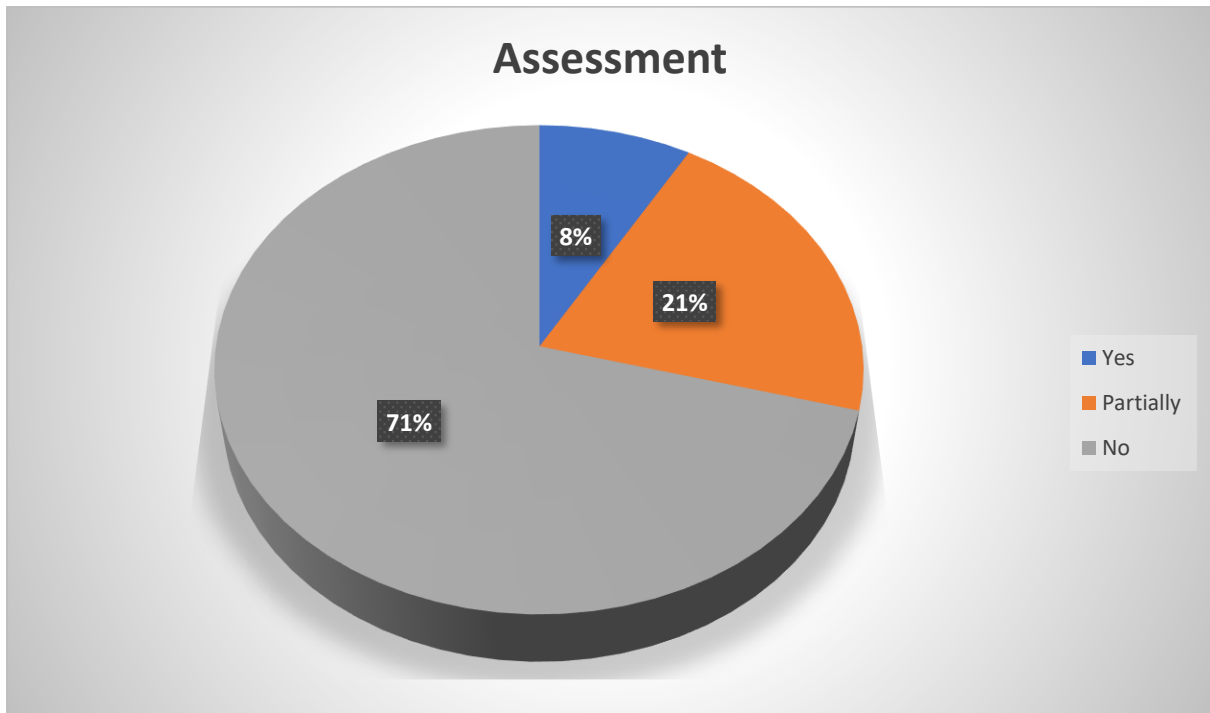
“Terrible lack of help. No support offered. EDS not understood by school. No help with dyspraxia.”

“Frustrating that most options couldn't be tried out to see if they suited my son and too much discussion about not being able to get funding and who would or could fund. Ridiculous to have to wait until a few months before he left school.

School arranged some activities themselves and he really enjoyed that option, but when he moved to adult services it wasn't continued.”



***‘Do you feel that the assessment of your child’s future needs was appropriate and comprehensive?’***



**Figure 7: Assessment**

- Yes (covered child’s physical, emotional, mental, and sexual needs) (2)
- Partially (covered some but not all) (5)
- No (17)

***‘Please tell us what information was or was not covered in the assessment.’***

“We were included in discussion about his right to access social media, but nothing mentioned as far as I remember about his sexual needs.”

“School didn’t make referrals, didn’t engage with her health professionals, she left school with no support or plan making her steps harder.”

“I had to constantly call for meetings and had to intervene to get social services and school to understand my daughter needs. This was so frustrating with no clear outcome to her future, but at that point my daughter was so stressed she had to leave.”

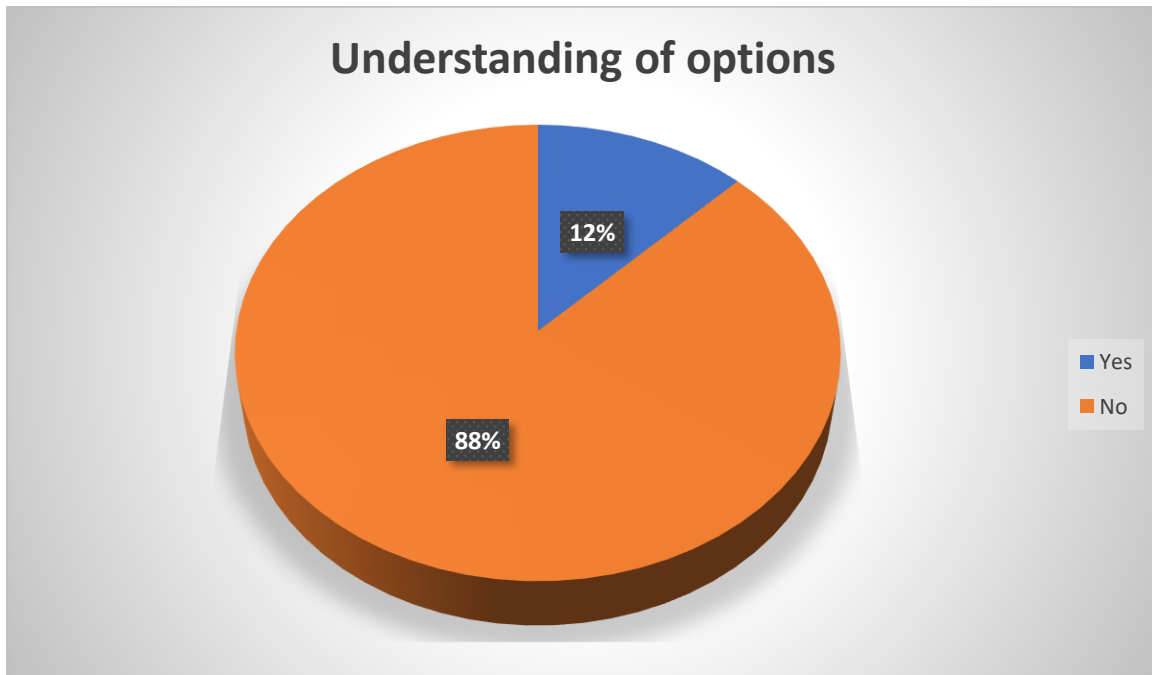
“I had to seek specific support to have a full assessment of my child's needs. I believe that if I had not pursued the agency in question with some persistence then they would not have experienced the extensive review that they eventually did. The review focused on specific communication needs and did not address their emotional, mental and social needs.”

“They did not know my child as there had been many changes in staff he had 4 different guidance teachers in 5 years and the head of support teacher did not have any interest in helping, as they think of them as adults who can make their own decisions which is not the case in some circumstances with some children with autism and mild learning difficulties.”

“2-3 years for identification of Asperger's when help was requested for anxiety issues. This was observation by Community Paed service and SLT. School said they were 'not trained' to do any assessment of what child's ASN requirements are.”

“They refused to assess saying he didn't meet the criteria. I fought it and currently waiting for a new assessment with a new social worker.”

***‘Were the options explained to your child in a way they could understand, such as using simple language, pictures or physically showing them?’***



**Figure 8: Understanding of options**

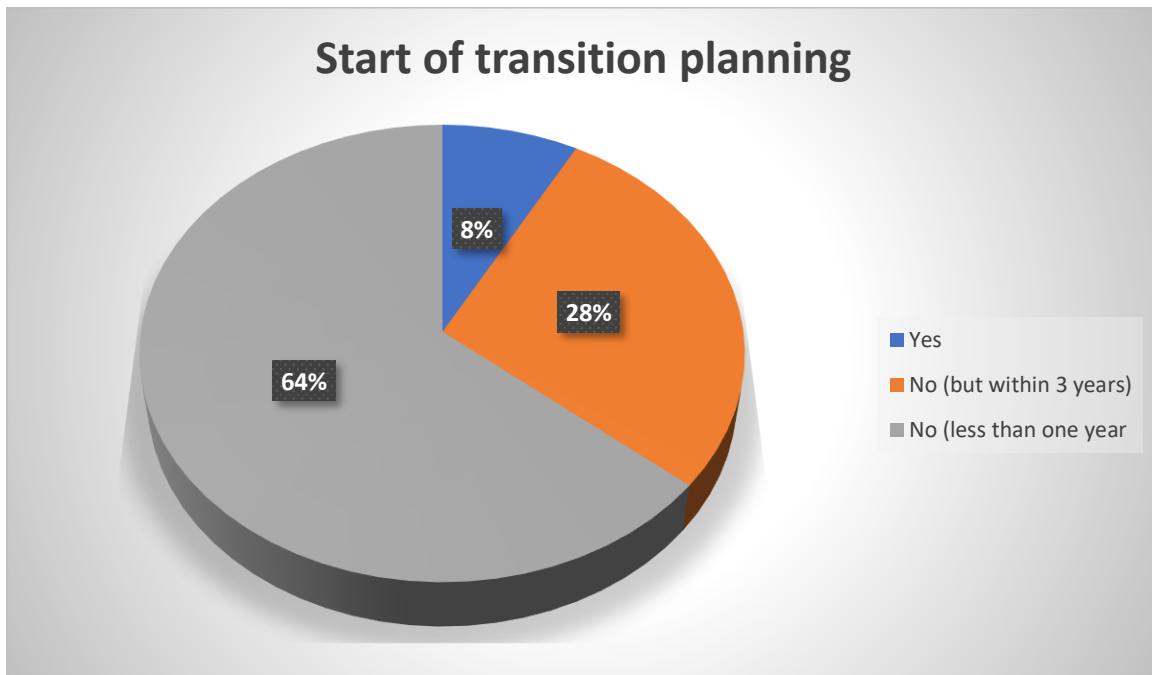
- Yes (3)
- No (21)

“I think that on the whole there were attempts to use appropriate language levels for my child. They were dependent on me being present to 'bridge' understanding gaps.”

“One lady did a list by pictures of what my daughter enjoys.”

“No one has ever discussed my daughter’s options or concerns with her. She has always been left to try to understand by herself and due to social anxiety, that leaves her unable to act.”

***'Did your transition process start at least three years before your child's 18th birthday?'***



**Figure 9: Start of transition planning**

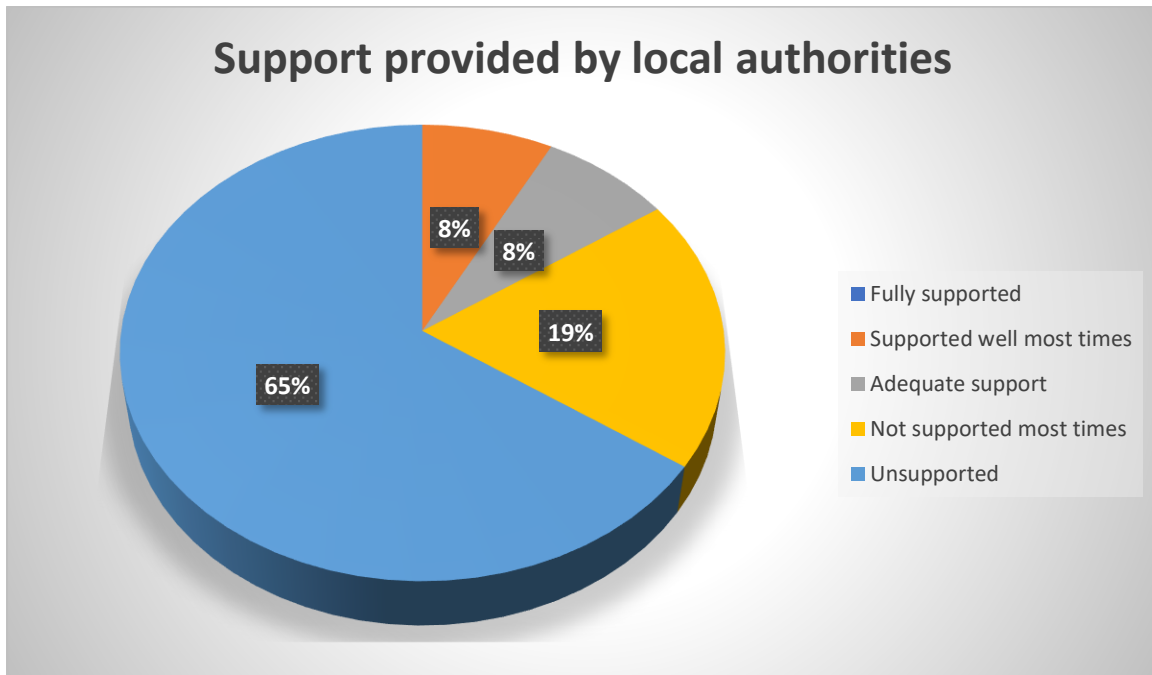
- Yes (2)
- No (but within 1-3 years) (7)
- No (less than one year) (16)

“My daughter is 16 and a half. We have not even been made aware of the transition process.”

“No transitions. Ignored her issues. No offers of support.

When she became 18 under the Rowan centre, they simple stopped offering appointments and no liaison to her own doctor and other services for YP with social anxiety, depression, a diagnosis of dyspraxia and had a mental breakdown during the previous year.”

***‘How would you describe the support you received from your Local Authority? Select the response that most closely matches your overall experience.’***



**Figure 10: Support provided by local authorities**

- I felt fully supported (0)
- I was supported well most of the time (2)
- The support was adequate (2)
- I was not supported most of the time (5)
- I felt unsupported (17)

“Having asked repeatedly for respite support, I was told on numerous occasions by social work that it was too expensive. I was told repeatedly that my son had behavioural problems. Eventually we were seen by a trainee psychologist who after many meetings told me my son had learning difficulties (yes, he has Down’s syndrome). I feel completely let down with no support/resources available to help try to understand my son’s challenging behaviour. Only since transition into adult services have I now a decent social worker, which has only really been in the past 6 or so months.”

“As we have not been informed of the transition process and have only just found out about it due to this survey, I feel extremely unsupported.”

“Things were explained okay but real issue was lack of appropriate activities and providers in area to suit his needs.”

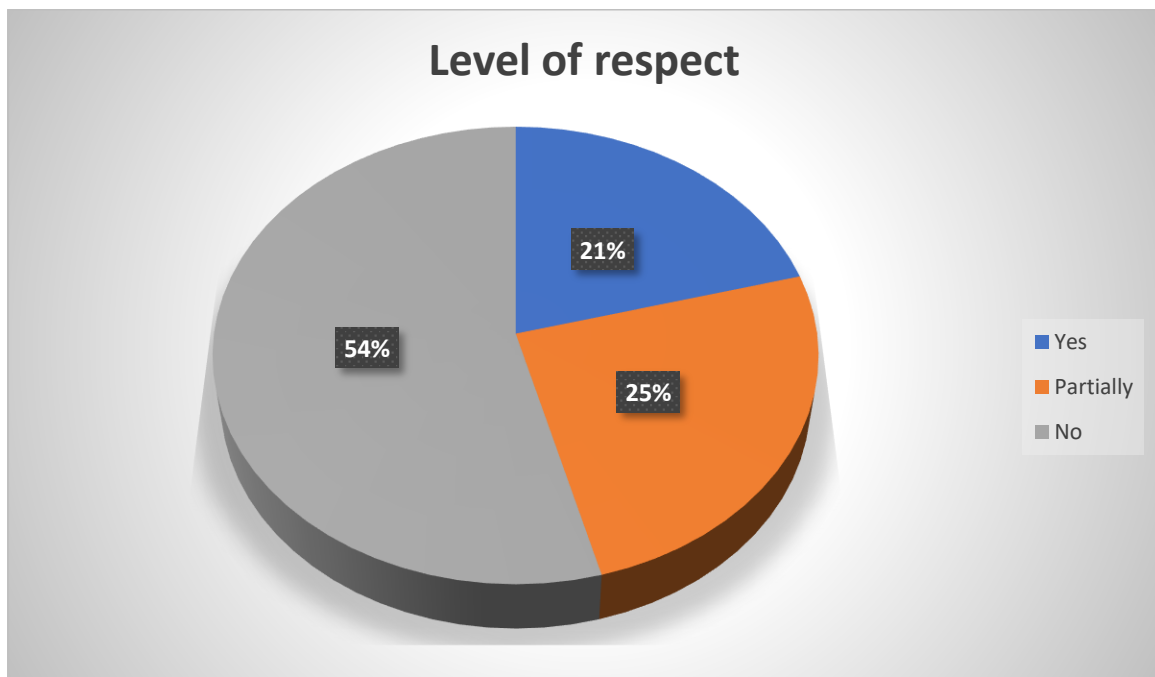
“I asked the school to help, they didn’t. I asked them for referrals they didn’t. The waiting lists of services were ridiculous with no direction given regarding other services, options etc.”

“I asked what the transition process is about 9-10 months ago. Still no satisfactory answer and no action.”

“I realise that if my child did not have me advocating for them, they would have fallen even further through the gaps in provision than they already do. 'Too able' to meet the high tariff of need required to have extensive inputs - I am conscious that they, my child, is overly reliant on me for advocacy and support and that makes me feel especially vulnerable for them. If something happens to me, what happens to my child when they are so little known to support agencies.”

“I think it’s an absolute disgrace that despite asking and chasing I have received little help apart from one telephone conversation.”

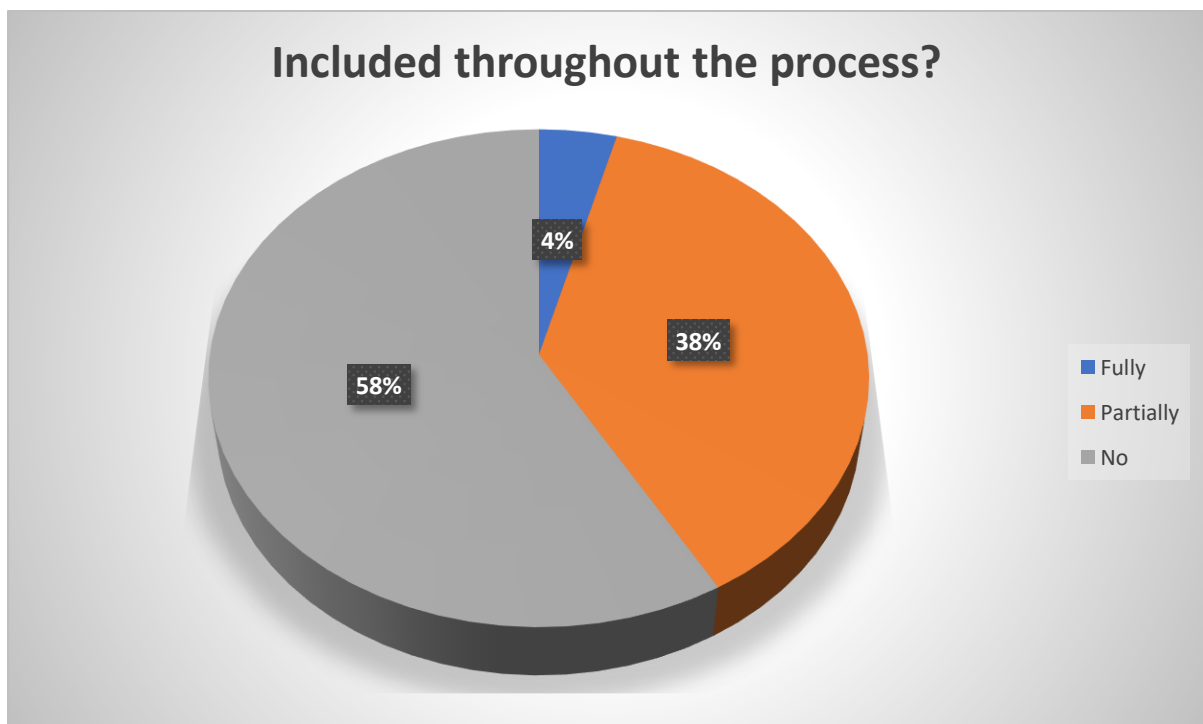
***'Do you feel you or your child were treated with respect throughout the process?'***



**Figure 11: Level of respect**

- Yes (5)
- Partially (6)
- No (13)

***'Do you feel you and your child were included throughout the process?'***



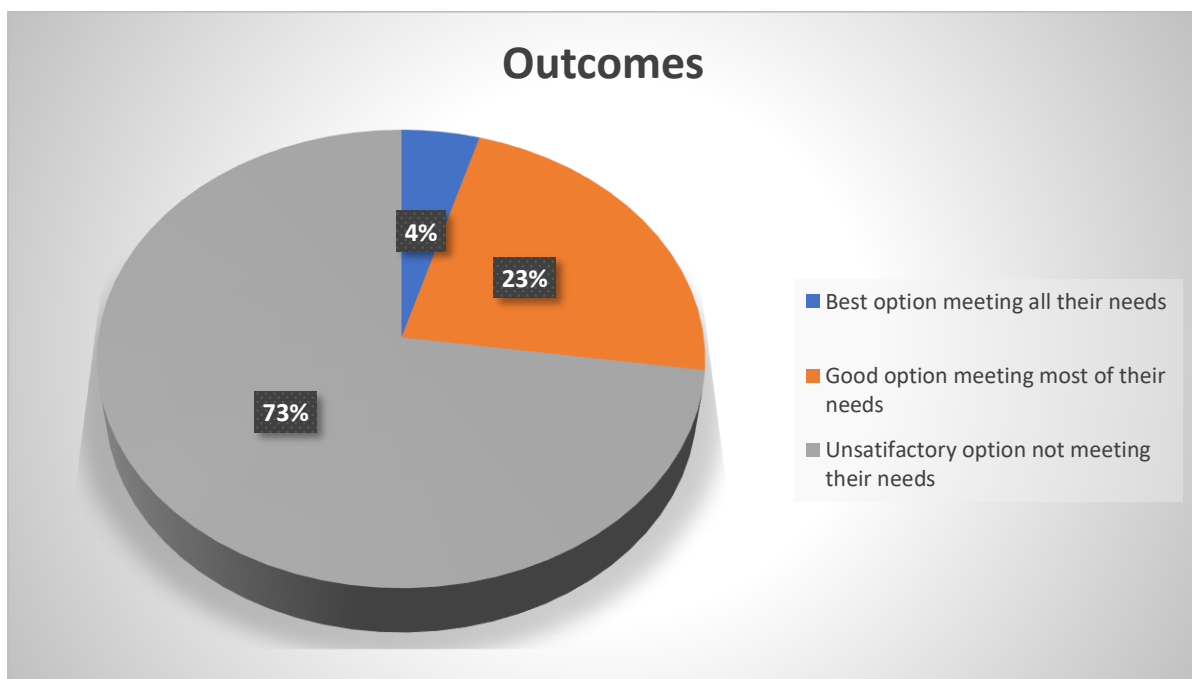
**Figure 12: Included throughout the process**

- Fully (1)
- Partially (9)
- No (14)

“Very happy. It was only my persistence that I finally got social services to agree to this as she was clearly happy with new services.”

“Hard to understand there is a process there at all.”

***‘How did it all work out?’***



**Figure 13: Outcomes**

- My child got the best option which meets all of their needs (1)
- My child got a good option which meets most of their needs (5)
- My child got an unsatisfactory option which does not meet their needs (16)

“We haven’t even been made aware of any options and I have no idea how to take this forward or who to contact.”

“The options I found myself and supporting her myself made her.”



"We have had to fight systems because she was let down by our Local Authority in supporting the diagnosis process, failed to stop bullying, social exclusion, led to long term mental health problems and struggles with general day to day life skills. Nowhere near able to be independent, to gain employment or to succeed in an education environment as cannot handle it."

"I think my child is overlooked and disregarded. My child is currently plagued by anxiety and suicidal thoughts. I have no real idea where to seek support but the consistent response I receive is that she is not a priority."

"My child will be 15 this year, and no transition planning has been mentioned for his education, or what services will be available for them when they reach the age of 16 onwards. This is quite worrying as they only have one year left in mainstream school and all that has been spoke about is a day at college. As a parent, it feels now he is at that age it feels like he has been forgotten about which is worrying."

"I am shielding my child from the process as much as possible. I find the interminable inaction interspersed with meaningless meetings very difficult. She wouldn't understand and would find the uncertainty extremely anxiety-provoking. If there are ever decisions to be made, I will involve her more."

"Not much information given to my child other than making them aware that college is the next step. We have been told it's too early, as information is only given in the 6 months prior to leaving school."

"I believe the individuals I have encountered from all services are professional and trying their best in extremely challenging circumstances where resources don't exist. I feel their frustration at being unable to support young people as they wish, but more than that, I fear for my young person and their future."

"Child out of school throughout S4 and has not attained any qualifications. Anxiety untreated. No interest in returning to school or even leaving the house."

"I've chosen the last option as hasn't been offered anything at all - I have requested she stays in school at present to try and get some help/guidance."

The results from this survey have provided a strong indication of unsatisfactory outcomes, where it is clearly evident many families are experiencing ‘being let down’. During our research, it was disappointing to learn that our survey reflects the results of other national surveys. For example, one survey conducted by ARC Scotland in 2017, which provided the framework for guidance to local authorities in good transition principles, and another in 2019-20 supporting a proposed Disabled Children and Young People’s Transitions Bill.

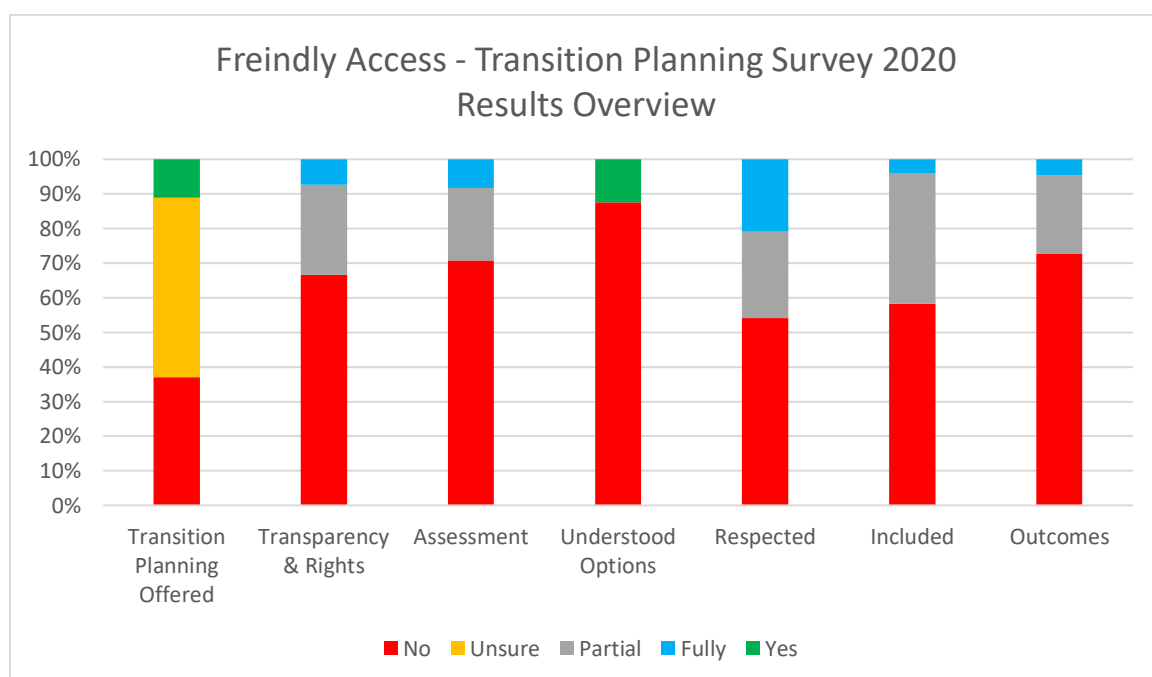


Figure 14: Results Overview

### **National Surveys on Transitions**

In 2008, [ARC Scotland](https://www.arc-scotland.org/) established the [Scottish Transitions Forum](https://www.scottishtransitions.org/) whose aim is to “improve the experience of children and young adults (14-25 years) as they make the transition to adult life”. Later, ARC Scotland published <sup>4</sup>‘Principles of Good Transitions 3’. In July 2017, the Forum published their national survey of young people with additional support needs and their parents/carers about their experiences leaving school which built on the work of the ‘Principles of Good Transitions 3’.

<sup>4</sup> <https://scottishtransitions.org.uk/summary-download/>

This was the first Scotland-wide survey focused specifically on the transition from school to adulthood for young people with additional support needs. 270 young people and 470 parents/carers responded from across all 32 Scottish local authorities. The survey targeted young people with autistic spectrum disorder, learning disability, visual impairment, hearing impairment, physical or motor impairment, physical health issues and mental health issues, as well as looked after children. Its aim included the development of a national framework to support disabled children, young people, and their families, to improve the experience of transitioning for young people with ASN.

Some of the highlights from the parents' responses are:

- The overwhelming majority (90%) of parents and carers have no written down transition plan for their child while (s)he is at school.
- While at school, only 1 in 10 are 'very happy' with the information and support their children receive from all sources. Two thirds of parents and carers say they received no support.
- Almost a quarter (23%) rated honest communication about the available options for the child as being the most important feature of a successful transaction.

The full copy of the survey report can be found here: <https://arcscotland.org.uk/wp-content/uploads/Facing-the-Future-Together-Report.pdf>

ARC's survey complemented previous research by the [Health & Social Care Alliance Scotland](#) for the [Scottish Government for Children and Families](#) which provides more in-depth qualitative analysis on the experience of 30 individuals and families. The report, published in May 2017, was 'Experiences of Transitions to Adult Years and Adult Services'. Arising from this research, well-being indicators were added to the assessment process. The findings from the ARC Scotland's survey were generally consistent with those of the Health and Social Care Alliance Scotland's research.

The full copy of the survey report can be found here: <https://www.alliance-scotland.org.uk/wp-content/uploads/2017/11/ALLIANCE-GIRFEC-Experiences-of-Transitions-to-Adult-Years-and-Adult-Services-2017-1.pdf>

## **Proposed Disabled Children & Young People (Transitions) (Scotland) Bill**

Johann Lamont's (MSP) draft proposal, lodged on 9 October 2019, is for a Proposed Disabled Children & Young People (Transitions) (Scotland) Bill to:

*Require the Scottish Ministers to introduce, and to implement, a National Transitions Strategy to improve outcomes for children and young people with a disability in the transition to adulthood, and to require local authorities to introduce a transitions plan to ensure each child and young person with a disability receives appropriate care and support before, and during, the transition to adulthood; and for connected purposes.*

The consultation period ended in January 2020. The consultation highlights many of the same issues as the Friendly Access survey, such as:

- young person is not at the centre of their transition planning.
- limited options, choices, opportunities, and positive destinations for young people with disabilities.
- transition planning is often inadequate.
- transition planning would often begin too late.
- lack of information and advice about options, opportunities and rights which has a detrimental effect on young people's ability to plan their future.

The full copy of the survey results is found here:

[https://www.parliament.scot/S5MembersBills/Johann\\_Lamont\\_MSP\\_Proposed\\_Members\\_Bill\\_16\\_June\\_2020\\_final\\_version.pdf](https://www.parliament.scot/S5MembersBills/Johann_Lamont_MSP_Proposed_Members_Bill_16_June_2020_final_version.pdf)

### **Transition Information**

Putting the survey results to the test, general Google engine searches were conducted on the 6 local authorities to see if their transitions processes were readily available for parents/carers to access. Highland, Edinburgh City and Aberdeen City Councils have dedicated webpages on transitions:

<https://hi-hope.org/directory/listing/transition>

<https://www.edinburgh.gov.uk/children-families/moving-adult-services/1>

[https://aberdeencity.mylifeportal.co.uk/child\\_to\\_adult\\_transition.aspx](https://aberdeencity.mylifeportal.co.uk/child_to_adult_transition.aspx)

Moray Council has a (draft) Transitions Policy on their website (<http://www.moray.gov.uk/downloads/file116934.pdf>). No information on transitions could be found on either Aberdeenshire or Angus Council.

### **Information on Options**

Focusing on Moray Council as the majority of respondents were from Moray, the availability and reality of the options mentioned in their transitions plan were tested. This test looked at data on supported accommodation, independent housing, funding packages and carers' support. By searching the Freedom of Information Requests (FOIs) in 2020, it reveals requests from the public about information held by the local authority yet not readily available in the public domain; meaning that unless the information is specifically requested the public may not be aware of it. Once a FOI is lodged both the question and the answer are available on the council's website and can be searched by year and/or service department.

[http://www.moray.gov.uk/moray\\_standard/page\\_53728.html](http://www.moray.gov.uk/moray_standard/page_53728.html).

Within 2020 so far, a couple of relevant questions were posed. In relation to transition housing options, there were two relevant FOIs: supported accommodation places for Adults with ASN, and disabled people on the housing waiting list. Two other FOIs looked at funding: social care assessment reductions, and support for unpaid carers.

### **Supported Accommodation for Adults with ASN**

The FOI asked for the number of places available for adults with support needs/learning disabilities in council and third sector facilities. The Council has 15 places with no vacancies and the third sector has 83 places, with no comment on vacancies. As of June 2020, there were 53 people on the waiting list for accommodation.

[http://www.moray.gov.uk/moray\\_standard/page\\_133318.html](http://www.moray.gov.uk/moray_standard/page_133318.html)

### **Disabled Housing Waiting List**

The number of disabled applicants on the housing list as at 3 June 2020 was 157. The average waiting times for disabled applicants in 2019-20 was 498 days.

[http://www.moray.gov.uk/moray\\_standard/page\\_133109.html](http://www.moray.gov.uk/moray_standard/page_133109.html)

### **Support for Parents/Carers**

National funding was allocated to the council 'for continuing to work to enable the recently established rights for Scotland's unpaid carers'. The fund was to partially support the duties under the <sup>5</sup>Carers (Scotland) Act 2016. The FOI sought answers to how the funding was spent. Moray Council received £189,000 in 2019-20 for additional funding to support carers. Between the Health & Social Care Partnership and Moray Council, almost a  $\frac{3}{4}$  (73%) of the funding went to staffing costs and the remaining quarter (27%) went unspent because the council wanted to review it before allocating the funding to another organisation's remit.

[http://www.moray.gov.uk/moray\\_standard/page\\_129527.html](http://www.moray.gov.uk/moray_standard/page_129527.html)

### **Social Care Need Assessment**

Between March and June 2020, 26 new assessment social care assessments had been carried out. There were 1,063 existing clients at 1 March 2020. During an assessment review, 133 clients had a change in service as a result of the review with 4 decreasing and 30 increasing. Thirty-seven percent (398) of packages were suspended during Covid-19 lockdown and another 81 were stopped for a variety of reasons. 451 were classed as 'open'.

[http://www.moray.gov.uk/moray\\_standard/page\\_133489.html](http://www.moray.gov.uk/moray_standard/page_133489.html)

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<sup>5</sup> <https://www.legislation.gov.uk/asp/2016/9/contents/enacted>

## Conclusion

The Friendly Access survey results have mirrored many of the same outcomes as the two most recent national surveys on the transition for young people with additional support needs. The majority of parents/carers feel unsupported, not included, and not respected, and affirms the transition process is not appropriate to their needs, is inadequate and starts too late. Overall, the issues seem to be lack of information available for parents/carers to help guide and support them through the transition process, and also a lack of information on available options to support the young person.

Looking at the information available to parents/carers about the transition process for young people with additional support needs, the council information was hard to find, if available, and buried amongst transition information for a variety of stages and abilities. There is even less information on realistic and available options as the only concrete information to be gleaned is from FOIs, which paints a gloomy picture with long waiting lists for either supported accommodation or housing for disabled people and the year on year review of support packages.

It is clear from this survey and other information that parents/carers need better support during the transition from child to adult services, to ensure that their child achieves the best outcome. It is hoped that the Disabled Children & Young People (Transitions) (Scotland) Bill will achieve that for future young people. As part of this process, Scottish Parliament will soon be calling for evidence in response to the Bill and Friendly Access aims to become involved in the submission of evidence.

“My son still has one more year at school, but I am worried for the future.”

Parent