

**Aberlour Response to the Scottish Government's Learning Disabilities, Autism and Neurodivergence Bill Consultation**

**April 2024**

**About Aberlour**

Aberlour is Scotland's largest, solely Scottish children's charity. Delivering more than fifty services across Scotland, we work with disadvantaged, marginalised and discriminated against children, young people and families, providing services and support in communities around the country. We help to overcome significant challenges families face, such as the impact of drugs and alcohol, growing up in and leaving care, poor mental health, living with a disability, or the impact of poverty and disadvantage. We aim to provide help and support at the earliest opportunity to prevent problems becoming intractable or spiralling out of control. We are committed to #KeepThePromise and to the incorporation of the UNCRC. This means working every day to make rights real for the children, young people, and families we support and being unwavering in our ambition to ensure all of Scotland's children have an equal chance regardless of their start in life.

**Introduction**

Aberlour deliver services across Scotland that support children, young people and families with a range of needs. We support families affected by disability through our community-based family support services, as well as our dedicated disability residential and short breaks services. We also provide safe, loving, and nurturing homes for children who can't live with their families through our residential children's houses and fostering services. Our family support services work with children and families at home and in the community, often in partnership with schools, to help and support children with the challenges in their lives and at home that impact on their lives. We work with families to understand the, often intersecting, challenges and stressors they experience and to ask them what will best help them and their children. This allows us to develop trusted relationships, find solutions together and ultimately help children, young people and their families thrive.

Despite the progress made through incorporation of the UNCRC and towards the incorporation of four further UN human rights treaties into Scots law, it is clear there is still much work to be done to protect, respect and champion the human rights of all our citizens in culture and practice across Scotland. Furthermore, despite decades of data gathering, developments in terms of legislative provision and public and political understanding of the specific, additional, and alternative needs of people with learning disabilities, autism, and neurodivergent people, we too often see their rights not being upheld. The rights breaches that these communities continue to experience daily remain pervasive.

Aberlour therefore welcomes the Scottish Government’s consultation to explore how we best support and further enhance the rights of people with learning disabilities, autism and neurodivergent people, the national conversation it has prompted, and the opportunity to respond. Furthermore, we welcome the Scottish Government’s expressed and visible commitment to co-design throughout this process with people with lived experience. We commend the Scottish Government for being ambitious in the proposed scope of the Learning Disability, Autism and Neurodivergence (LDAN) Bill and as a rights respecting organisation fully support the intentions to develop bespoke legislation to help transform the lives of communities of people whose rights are most at risk.

Echoing the views of the LEAP<sup>1</sup> Aberlour believes it is critical that we all understand that what benefits and promotes the rights of people with learning disabilities, autistic and neurodivergent communities, benefits Scotland as a whole. However, despite our commendations we believe the Scottish Government must be clear and confident about the intended direction of travel and tangible improvements that will be achieved through any proposed legislative provision. On balance, from the views and voices of children, young people, families, and the Aberlour teams that support them, we are unclear about whether the proposed Bill will achieve its intended purpose and therefore cannot support the proposals within this consultation.

The consultation paper recognises a catalogue of failures which have, and continue to, impact on the capacity of people with learning disabilities, autism, and neurodivergent people to thrive in our society. However, it is our view that the complex and cluttered landscape of ongoing activity listed alongside largely supplementary legislative proposals in the consultation read as a catalogue in and of itself. We believe that for the long-awaited transformational change people with learning disabilities, autism and neurodivergent people demand and deserve to be realised, the scope and focus of any action, legislative or otherwise, alongside mechanisms for achieving this change must be clear and defined. We do not believe the proposals set out in this consultation will achieve this.

We believe there needs to be a paradigm shift in the way people think about difference. This shift would be best supported by a Bill that helps create the legislative backing for a broader structure of support grounded in a social model of disability where people don’t need to be bound to a label to access support. In order to achieve this, policy and legislation must be structured around the experiences of people and how these align with support needs they might have, rather than the intricacies and difficulties of naming and defining specific communities.

### **Developing Aberlour’s Consultation Response**

To inform our response to the consultation we endeavoured to support children, young people and families whom it is intended this Bill will impact upon to share their views and experiences of life as people with learning disabilities, autism or neurodivergent people. The length and complexity of the consultation document presented a challenge in how the aims and intentions of the Bill could be effectively communicated. Most young people with whom we endeavoured to engage did not recognise themselves as people with learning disabilities, autism, or as neurodivergent, regardless of diagnosis. Furthermore, the limited consultation period has not ensured the necessary time to read, digest and respond to the labyrinth of proposals outlined, to support children, young people and

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<sup>1</sup> <https://www.gov.scot/publications/learning-disabilities-autism-neurodivergence-bill-consultation/pages/3/>

families to gather a full or complete picture of possible change and the impact it may have on their lives.

Recognising these challenges, we have chosen not to respond to the full consultation document in detail. We have instead responded to questions that are most relevant to our work and to the children, young people and families we work with and where we heard a view either from young people we work with or from the Aberlour teams and services providing their support.

Together these insights and observations respond to the following themes and sections:

- Reach and Definitions
- Overarching Themes:
  - Statutory Strategies
  - Mandatory Training in the Public Sector
  - Independent Advocacy
- Specific Themes:
  - Relationships
  - Transitions to Adulthood
  - Accountability

### **Including children and young people in co-design**

Aberlour is Scotland's largest, solely Scottish children's charity. It is always our intention to respond to policy proposals and consultations both in collaboration with and on behalf of children, young people and families we work with. Furthermore, we work to ensure children and young people have been meaningfully involved in processes and decision making that affects their lives and the lives of those they care about. Our journey to respond to this consultation raised questions about where the voices of children and young people were currently reflected in the consultation document. It was noted that the lived experience panel was made up entirely of adults and a parallel panel to garner children and young people's views had not been created.

Moving forward, development and implementation of the LDAN Bill, or any corresponding policy development in this area, must be co-produced with people with learning disabilities, autism, and neurodivergent people of all ages. As equal rights holders, it is fundamental that children and young people have a role in shaping not only legal reform, but also the culture of change required to deliver transformational change in the lives of people with learning disabilities, autism, and neurodivergent people in Scotland.

#### **Part 1: Reach and definitions: who should the Bill include?**

**Is there anything else you think we should consider in relation to this topic?**

***“Current systems have gotten quite fixed on severity of disability rather than what is the support needs of this person”*** (Assistant Director, Aberlour)

People with learning disabilities, autism and neurodivergent people need to be the guiding authority on how their identities are expressed or defined through this Bill. Most young people with whom we sought to engage through our services were unable to understand their diagnosis or did not recognise themselves as having a learning disability, autism or being neurodivergent and therefore we do not feel we can offer a representative view in this regard.

We can however offer our own insights as a provider of support for children and young people with learning disabilities and autism as well as more complex physical health needs, and their families. Aberlour believes that the identities discussed within this consultation are recognised and owned by an ever-growing number of people within of our society. Society is changing, and our understanding of difference needs to change alongside and at pace with this. Our services report a varying and patchy picture of public and community-based support for children and young people with learning disabilities, autism, and neurodivergent people. This occurs not only between postcodes or families, but within them too. Families with multiple children with a range of different needs have varying experiences of support where one child has a positive experience, and another does not. We are pleased to see the Scottish Government’s recognition of the benefits of taking a whole person approach to policy development. However, we believe this should go a step further and take both a whole person and whole-family approach.

We are concerned that the naming of the LDAN Bill in combination with proposals laid out under this section, have the potential to leave us too focused on categories, labels, and diagnosis, leading us down a well-trodden and misdirected path that fails to adequately respond to the needs of all. Through attempting to separate out and define potentially co-existing identities and support needs, medical models of support provision could prevail and the social model of needs-led, whole-person, whole-family support which we advocate and champion, be overshadowed.

Through this consultation we recognise the Scottish Government’s ambition to avoid just this by taking a broad approach, using what it describes as ‘very broad terms’ of neurodivergent or neurodivergence. However, the voices and views we have heard in considering our response, both internally and through external partners, have expressed discomfort or challenged this proposal, indicating that it is unlikely to obtain consensus.

Aberlour services report that the need for a diagnosis or definition to access support and the speed at which diagnosis can be obtained have in many instances hindered transitions and other efforts to provide necessary whole-person and whole-family support.

**Case Study:**

KC was a young person formally supported by Aberlour Options Moray. In the words of her supporting worker, she was,

*“Let down, she didn’t get the support she needed. Adult services don’t understand her needs and didn’t listen to her. She is now living a life that is dangerous for herself. She is putting herself at risk. She makes friends on TikTok and then is travelling around the UK to see these people”.*

KC has no formal diagnosis of a disability. The team in Moray feel her learning disability is a direct result of her childhood trauma. Since moving on from children's services, KC has gone from full time support to her own unsupported tenancy. The team in Moray feel that her lack of diagnosis has been the whole issue in this story. They care deeply for KC and said,

*"If someone just took the time to sit and speak to her, they would know she doesn't have capacity".*

We are concerned for the children and young people who are slipping through the cracks, as a result of no diagnosis and no support.

***"We cannot ignore children's needs because they do not have a diagnosis, nor should we provide children with additional support that they don't need just because they do have one"*** (Aberlour Staff Member).

For those who do have a formal diagnosis, and/or recognise them, our services and young people report that diagnosis or recognised labels have not always been routes to adequate post-diagnostic or ongoing support. Services report hearing young people being referred to as *"not disabled enough"* to reach thresholds of support and similarly families tell us about the challenges of accessing support for children with *"lower levels of support need"*.

***"My diagnosis came in primary school and now I'm all the way here, but because I don't know about autism I'm scared to ask for more help. What if it's not as bad as I really think? Life has become harder for me over time, and I don't know if that's because of my autism or not"*** (Aberlour Young Person).

We also heard from services that a closer look needs to be taken at flawed support assessment processes. Whatever direction or action the Scottish Government takes in order to get this right. We need these processes to take a closer look at the child or young person, their family and their collective support needs, not allow narrow definitions or diagnoses to become barriers either practically or because they cause us to lose sight of the person and lead to assumptions being made about their needs.

We believe what is most important, either through this Bill or alternative policy processes, is that neurodivergent people, people with autism and learning disabilities are empowered to know and claim their rights. A label is only useful if it helps them to do these things and through our work with children, young people and families we know this is not always the case.

We urge the Scottish Government to invest in and apply needs-led social models of provision and resource allocation that listen to and recognise what children, young people and families living with learning disabilities, autism or neurodivergence tell us they need to thrive.

## **Part 2: Overarching Themes**

### **Section 1: Statutory Strategies for Neurodivergence and Learning Disabilities**

**What do you think?**

**Is there anything else that we should consider in relation to this topic?**

***“If families and communities can’t see how it [a national strategy] is working for them, then it is useless”.*** (Aberlour Staff Member)

Aberlour believes wholeheartedly in the necessity of clear national and strategic direction in the pursuit of any fundamental societal change, legislative or otherwise. If the necessary improvements in the lives of people whose rights are most at risk are to be made, the Scottish Government must provide a clear shared vision and implementation priorities that public service providers can work towards achieving.

In relation to people with learning disabilities, autism, and neurodivergent people, Aberlour services are overwhelmingly positive about the concept of national and local strategies. However, equally they report frustrations about the realities of those that had come before. In many instances, such as with Keys to Life<sup>2</sup>, these have been ostensibly ambitious, but have not achieved the change they intended.

Principally, Aberlour believes that without a truly co-produced approach and buy-in from national and local stakeholders, then a national strategy will fail to have the impact or lead to the transformative change that people with learning disabilities, autism and neurodivergent people in Scotland want and deserve.

Secondly, and critically, is the associated accountability mechanism. Without clear and agreed lines of accountability for national and local bodies in the delivery of the strategy, any strategy will effectively be useless. Legal duties requiring all relevant bodies to report on progress on all areas within a national strategy are also essential. As is local and national capacity and adequate investment and funding to resource strategy development, implementation and sustain necessary change.

As previously highlighted involving people with lived experience of all ages is vital in developing any strategy or plan which intends to meet the needs of all people with learning disabilities, autism and neurodivergent people. However, we also urge caution with regard to ongoing consultation on every aspect of what that strategy should be, and the resource commitment in relation to this. The evidence is already clear from what people with learning disabilities, autism and neurodivergent people, and the organisations and advocates that support them, including children, young people and their families, have already told us. We know what change is necessary and their priorities are clear in order to act in the here and now and begin to make the necessary change that will benefit people with learning disabilities, autism or neurodivergent people.

## **Section 2: Mandatory Training in the Public Sector**

### **Proposal 1: Mandatory Training for Public Services**

**What do you think?**

**Do you agree with this proposal? If so, please tell us why?**

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<sup>2</sup> <https://www.gov.scot/binaries/content/documents/govscot/publications/strategy-plan/2013/06/keys-life-improving-quality-life-people-learning-disabilities/documents/keys-life-improving-quality-life-people/keys-life-improving-quality-life-people/govscot%3Adocument/00424389.pdf>

***“Some professionals are really mindful and considerate in how they treat everybody, and some aren’t. That lack of consistency is the problem as well as a general lack of understanding or empathy in terms of responses to types of behaviours”.*** (Aberlour Staff Member)

***“We need to be brave and challenging of professionals about how they engage with young people”.*** (Aberlour Staff Member)

Aberlour agrees with the Scottish Government’s finding that there needs to be greater awareness and understanding of neurodivergent people and people with learning disabilities across public bodies. This also extends to people with Autism and other people who think about and see the world in different ways.

We are therefore supportive of Proposal 1<sup>3</sup>, for a programme of mandatory training for public service providers in Scotland.

Echoing our response under Part 1 of this consultation, we believe that there is a need for greater awareness and understanding of difference across Scotland. The consultation document recognises this necessity, especially when people with learning disabilities, autism and neurodivergent people are trying to access help, support and services, and to exercise their human rights

Our services reported that public services’ knowledge of how to appropriately support and engage with children and young people with learning disabilities, autism and who are neurodivergent was patchy and inconsistent. Where some services reported excellent experiences with social work teams and other public service professionals, including within health and justice services, others said it was not always clear whether the specific needs of children and young people were understood or recognised, particularly with regards to communication.

In all instances, it was clear that the most successful outcomes occurred where the child or young person, alongside the people who knew them best, were asked about their support needs and how these could best be met rather than assumptions being made on the basis of a person’s age, diagnosis or lack thereof.

#### **Case study**

L is a former resident of one of Aberlour’s residential houses. He does not hold a formal diagnosis but is believed to have autism and a learning disability. L is still supported by the Aberlour team through a bespoke supported living package created for him in partnership between Aberlour and the local council. This was agreed as the council listened to Aberlour’s concerns about L struggling to form new supportive relationships. L also struggles with change and communicating with new people, particularly professionals. Early in his new tenancy L’s key worker noticed he was getting very upset and anxious about letters received from the housing department regarding unpaid arrears. His key worker at Aberlour agreed a special arrangement with the local housing department to have all future letters sent to his social work team rather than L directly to remove this stressor.

<sup>3</sup> <https://www.gov.scot/publications/learning-disabilities-autism-neurodivergence-bill-consultation/pages/9/>

There was a period where L was unable to access health care through his local health centre as due to his age the receptionist wanted to communicate directly with L, not his supporting workers. His supporting worker tried to explain to the health centre receptionist that L did not feel able to speak directly to her, but “*couldn’t get past her*”. Eventually, L’s key worker contacted the local LAC nurse who supported them to put in place an arrangement where L’s key workers could communicate directly with the doctor on L’s behalf. Since then there have been no issues supporting L to access health care as required. Without the support of his key workers, things could have looked very different for L.

We are supportive of a tiered approach to training design and delivery. We believe this will help mitigate concerns reported by our services for the potential erosion of specialism in respect of autism and other specific conditions if a broad-based approach to delivering inclusivity training was developed and delivered.

We welcome and support the Scottish Government’s commitment to “*ensuring that people with lived experience are involved in developing training programmes*”. We heard from our service teams about the difference this makes in terms of quality, authenticity and in terms of “*changing hearts and minds*” of a nation which needs to alter and develop its understanding and perceptions of neurological differences.

In respect of quality, we believe it is essential that there is national consistency in terms of content and quality of any training delivered and that any inputs are delivered as part of a wider package of continual professional development and practice rather than as one-offs.

#### **Is there anything else that we should consider in relation to this topic?**

***“Without Aberlour I wouldn’t be as social as I am today. Without them I would be at home all the time. My family don’t understand a lot so having this [Aberlour] is good because its people who understand more and know all about it [neurodivergence and autism]. (Aberlour Young Person).***

For families where one or more children, or the parents themselves, had a learning disability, autism or are neurodivergent, services and young people alike highlighted the importance of parents and carers having the necessary tools and understanding to best support their children.

Highlighting again the need for meaningful participation and engagement of those with lived experience and for whom the Bill is intended to benefit – including children and young people – we believe consideration should be given as to how a robust, consistent structure for learning can be co-developed and co-delivered with children, young people, parents and carers living with learning disability, autism and/or neurodivergence.

#### **Case study: Aberlour’s participation in Together to Thrive Project, Dundee**



Together to Thrive<sup>4</sup> is a collaborative approach to improving the mental health and wellbeing of children with neuro-developmental needs. It is based on a 'task sharing' model of delivery.

Task sharing builds on community organisations and mental health providers' strengths and helps both to take on important new roles, so they can meet the needs of the community, build the skills and confidence of community-based staff to deliver evidence informed interventions and develop and strengthen new referral pathways. Two staff members from Aberlour Options Dundee recently engaged in this pilot project.

With a current CAHMS waiting time of 3-4 years for new referrals to be assessed, an analysis of referral trends was conducted pulling out the primary reasons for referral which included things like trauma, sleep difficulties and sensory issues experienced by children and young people. Several community providers engaged in training with CAHMS to give them the tools and resources, to in turn, work with parents and carers to build their understanding of these issues and share these tools for responding to them and, where possible, prevent escalation.

The experience of Aberlour Options Dundee was that parents really benefited from this. They were able to look at their own responses to their children's behaviours and make necessary changes. Parents involved reported *"huge improvements in their family lives"* sharing that through changing their responses to their children's behaviours, *"thinking about how they can fit into their child's world rather than wondering why the child doesn't fit into theirs"* they had managed to start doing things together again like attending weddings, or going on holidays which they would have previously avoided for a number of reasons, including the associated anxiety.

This pilot project provides a model for how whole-family support for families living with learning disability, autism or neurodivergence can be delivered in a way that responds effectively to both individual children's and wider families' needs.

## Section 5: Independent Advocacy

Is there anything else that we should consider in relation to this topic?

***"What is missing is people who have experience of working with children with complex communications needs and the promotion of children's rights rather than carers rights".*** (Aberlour Staff Member)

Under Article 12 of the UNCRC every child and young person who is capable of forming their own views has the right to express those views freely in all matters that affect them, with those views being given due weight<sup>5</sup>. In order to make sure this right is realised for children and young people with learning disabilities, autism or who are neurodivergent it is vital we have the right structure of sustainably funded support, including independent advocacy, to make this possible.

What is clear is there is a lack of advocacy services for these children and young people. Advocacy services that do exist for families living with a disability are mostly focused on parents and carers. We

<sup>4</sup> <https://www.parliament.scot/-/media/files/committees/public-audit-committee/correspondence/2023/adult-mental-health-mh-foundation-scot-to-pac-21-nov-2023.pdf>

<sup>5</sup> [https://www.unicef.org.uk/wp-content/uploads/2019/10/UNCRC\\_summary-1\\_1.pdf](https://www.unicef.org.uk/wp-content/uploads/2019/10/UNCRC_summary-1_1.pdf)

heard from young people, and Aberlour colleagues that support them, that simply legislating for a right to independent advocacy would not help neurodivergent people and people with learning disabilities and autism secure their human rights. Experiences of existing and available advocacy services and support are not always positive for children and young people. In one instance we heard that a young person did not feel listened to by their advocate. Others Aberlour services reported that where advocacy support was available, children and young people often didn't know about it, or for those supporting children and young people through children's hearing processes, the advocates did not always seem to have the necessary understanding of learning disabilities, autism, or neurodivergence to effectively communicate and advocate on those children and young people's behalf.

Another challenge for young people in these communities who often struggle with relationship building was a lack of consistency in the individual providing advocacy support. Services were clear that this needs to be the same person on a continual basis. We believe that in order to strengthen the provision of any roll out of advocacy provision it would need to be accompanied by a clear communications campaign and other awareness raising activities, to highlight children and young people's right to access advocacy services and how they can be supported to do that.

### **Part 3: Specific Themes**

#### **Section six: Relationships**

**Is there anything else that we should consider in relation to this topic?**

***“There are lots of things I would like to be involved in but too much thought process around it with the social side, the peers and also again, doing it alone”.*** (Aberlour Young Person).

Article 23 of the UNCRC states that a child with a disability has the right to live a full and decent life with dignity and, as far as possible, independence and to play an active part in the community<sup>6</sup>. Furthermore, governments must do all they can to support children with disabilities and their families. In addition, Article 31 of the UNCRC states that every child has the right to relax, play and take part in a wide range of cultural and artistic activities<sup>7</sup>. It is clear from what our children, young people, their families, and the people who support them, tell us is that these rights are not being fully realised.

We are unclear whether the proposals in this bill would achieve the scale of change necessary to address the barriers that too often exist for our children and young people with learning disabilities, autism or who are neurodivergent to have these rights fulfilled. We know from our work that concerning inadequacy of support for these children and young people to get the help they need to make friends or to do things with people like them, or of a similar age in their communities.

<sup>6</sup> [https://www.unicef.org.uk/wp-content/uploads/2019/10/UNCRC\\_summary-1\\_1.pdf](https://www.unicef.org.uk/wp-content/uploads/2019/10/UNCRC_summary-1_1.pdf)

<sup>7</sup> [https://www.unicef.org.uk/wp-content/uploads/2019/10/UNCRC\\_summary-1\\_1.pdf](https://www.unicef.org.uk/wp-content/uploads/2019/10/UNCRC_summary-1_1.pdf)

The lack of appropriate community spaces tailored to children and young people's specific needs is a prevalent issue and a reduction in, or in some areas a complete absence of, community-based day services for children and young people with learning disabilities, autism or who are neurodivergent. Our services report young people transitioning out of school at 18 and only able to access activities for adults in day centres where the age demographic of people accessing these community services is heavily skewed towards much older people. If young people are to be supported to develop and maintain positive relationships with people in their local communities that these should be people of a similar age and stage: *"Young people need to be with other young people"*.

For those children and young people with autism or who are neurodivergent who live in Aberlour's residential children's houses we see a lack of relationships being able to be developed outside of a given service or residential house, resulting often in situational relationships rather than established friendships. Similarly, this is often the consequence of a lack of access to appropriate spaces and places where children and young people can socialise or meet with others their age or with similar interests. For these young people there is a significant concern that they are missing out on important relationships and opportunities and learning gained from interaction with peers.

Our services right across Scotland supporting children and young people with learning disabilities, autism and who are neurodivergent report that inclusion and accessibility are significant issues. They have highlighted that community clubs specifically for children and young people with learning disabilities, autism and who are neurodivergence in many cases, simply do not exist, or where there are local community clubs open to all children and young people they were not accessible for a range of reasons. These include: a lack of people to support a young-person to attend semi-independently; clubs or groups designed for those of a particular age which did not match the developmental stages or particular needs of supported children and young people; and environments simply not being inclusive. In one instance a young person with Down's syndrome was asked not to return to an acting class because they were too distracting to the other young people.

The Children and Young People's guide to this consultation indicates its intention to *"make sure that neurodivergent people and people with learning disabilities get information about relationships, what different relationships will be like and how to stay safe"*<sup>8</sup>. In our view, the challenge here goes beyond extending provision of Relationships, Sexual Health and Parenthood education as proposed. In practice, safeguarding considerations can mean young people are unable to go out in the community without a supporting adult. This can make it difficult for young people to meet others and to have intimate relationships. Safe spaces where this could be made possible are essential, as well as giving young people the tools to understand what a safe consensual relationship involved. We feel strongly that everyone should be empowered exercise their right to have relationships, intimate or otherwise, but that the teams around young people need to be able to support this in a safe way for each young person. The proposals in this consultation do not offer any view on how the right of young people with learning disabilities, autism or who are neurodivergent to have such relationships can best be fulfilled in a way that addresses these challenges.

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<sup>8</sup> <https://www.gov.scot/binaries/content/documents/govscot/publications/consultation-paper/2023/12/learning-disabilities-autism-neurodivergence-bill-consultation/documents/children-young-people-transitions-adulthood-easy-read/children-young-people-transitions-adulthood-easy-read/govscot%3Adocument/children-young-people-transitions-adulthood-easy-read.pdf>

## Section 14: Children and Young people - Transitions to Adulthood

Is there anything else that we should consider about Children and young people: Transitions to adulthood?

*“Transitions are about everybody involved in these kids’ life’s, it’s about community”.* (Aberlour Staff Member)

*“I don’t think people with neurodivergence should have to do that [move home] alone. There is so much to think about, moving your stuff, money struggles, getting a job...”* (Aberlour Young Person)

Transitions are often a time of significant anxiety and stress for young people we work with. The consultation document outlines the complexity of current transitional arrangements for young people with learning disabilities, autism or who are neurodivergent as they approach adulthood. This complexity was echoed by our services: *“The greatest challenge is knowing what the process is”*. We believe there must be a focus on work that is already happening to improve young people’s transitions and make sure that children and young people’s voices are at the centre of all decision making that happens to inform and influence their transition and ensure their needs are met. There must be consistency and clarity so young people, their families and those that are important in their lives, as well as the teams that support them, know and understand what that transition will look like and to plan and prepare for the change that will be happening a young person’s life.

In our experience the timing of transitions can be rushed and seemingly poorly planned with the young person unable to exercise any agency. We know that for some young people transitions happening quickly once they have been discussed with the young person can be a more positive experience and limit uncertainty or anxiety about the upcoming change. However, this does not mean transitions in such circumstances cannot be planned appropriately and in a way that meaningfully involved the young person.

What is crucial is the support that exists for young people beyond their transition. Maintaining the important relationships in young people’s lives, supporting their connections within their community and ensuring access to meaningful opportunities to learn and thrive. Unlike care experienced young people who may go onto further or higher education once they leave school, young people with learning disabilities, autism or who are neurodivergent, and for whom further or higher education is not an option, don’t have similar financial support to access additional learning or skills development opportunities. Therefore there is inequitable focus on the future aims and ambitions of those young people and how they can be supported to achieve them, and this must be addressed.

### Part 4: Accountability

#### Option one: A new Commission or Commissioner

It is our view that creating a new Commissioner role would be the best option to ensure accountability through an independent role with statutory powers and duties to champion the rights

of all people with learning disabilities, autism and neurodivergent people, in order to challenge government and drive the change required for those rights to be respected, protected and fulfilled.

We believe the Children and Young People's Commissioner model is a good example of the role of an individual office holder that is equipped with the powers and duties that would effectively enable them to hold government to account and maintain progress in promoting and safeguarding the rights of all those with learning disabilities, autism or neurodivergent people.

However, as we have highlighted previously, labelling and definitions are not always helpful, and so some consideration should be given to what this Commissioner is called to best reflect the broad community of people across Scotland they will be advocating on behalf of.

For further information contact Martin Canavan (Head of Policy & Participation)  
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