

# Cross Party Group on Autism

24<sup>th</sup> January 2022 at 2.00 pm, via Zoom

## Minutes

### Attendees:

Alexander Burnett, MSP (Chair)	Annie Wells MSP
Rob Holland, NAS (Secretariat)	Emma Walker (Speaker)
Pam Duncan-Glancy MSP	Jean Foggarty, SA (minutes)
Kate Monahan (Speaker)	Stephanie Callaghan MSP
Stephen Caulfield, NAS	Joseph Long, Scottish Autism
Margaret Smith (Speaker)	Dorry McLaughlin, Scottish Autism

Susan Chambers	David Ferguson	Richard Ibbotson
Kabie Brook	Andrew Crosbie	Steve Billingham
Patricia Hewitt	Jay Brownlee	Pauline Grigor
Edward Fowler	Ruth Young	Iain Templeton
Jamie Ferrie	Ben Paechter	Suzanne Kinross
Annie Humphrey	Jasmine Ghibli	Meg Thomas
Sheila Mackay	Hayley McMurray	Dougie Morgan
Clare Macer	Sara Hampson	Michelle Graham
Gillian Shuttleworth	Henna Cundill	Fiona Clarke
Gordon Barlow	Callum McCrosson	Stephanie Bain
David Taylor	David Campbell	Fran Foreman
Rachel Birch	Marie-Claire MacAskill	David Nicholson
Angus Nelson	Rodger Watt	Edward Fowler
Louise Moth	Morgan Innes	David Ferguson
Eamonn Custance	William Rae	Steve Kent
Cath Purdie	Anna Sonley	Bee Vellacott
Leanne McNeill	Tom Wightman	James Barbour
Susan Fullerton	Roisin Loughran	Linda Singer
Charlie MacKenzie-Nash	Andy Williams	Fiona Culbert
Lynn McClung	Dominic Craig	Maurice Frank
Catherine Steedman	Wendy Ferguson	

### 1 Welcome & Introductions

Alex Burnett MSP welcomed everyone to the first meeting of 2022. Pam Duncan-Glancy MSP will be speaking today. Rob Holland will be feeding back some thoughts from the Accessibility group on how the meetings can be made as accessible as possible.

Alex Burnett mentioned that Zoom has its own challenges and a meeting was held on how to improve these challenges.

Today's meeting will be focused on the transition to Adulthood, which has been raised often. The transition from child to adult services, which can be particularly challenging for many autistic people, is due to a lack of support. Many describe transition as a 'cliff-edge', where support comes to an end when they are due to leave education. Data from our Accountability Gap report, which this Cross-Party group published back in 2019, found that two thirds of autistic people & families did not receive the appropriate support.

AB acknowledged today's speakers – Emma Walker from Camphill, Kate Monahan, Margaret Smith from Partners in Advocacy, and Pam Duncan Glancy MSP.

The Minutes of the previous meeting of the CPG on Autism have been taken as read.

## **2 Feedback from the Accessibility Meeting**

Rob Holland, Acting Director – National Autistic Society Scotland, fed back on the discussion held at the recent Accessibility Meeting about how CPGs could be made as accessible as possible. Moving forward there will be regular accessibility meetings with a written summary.

In summary, issues around the length, pace and complexity of language used at the CPG were raised and the secretariat agreed to brief the Convener and speakers on this moving forward.

There was also agreement that the Zoom chat function was a useful tool for many but a recognition that it can become 'busy', difficult to follow and in some cases quite intense or overwhelming.

Moving forward the group suggested that when using the chat attendees try to:

- focus comments on pertinent and key points rather than a frequent commentary.
- refrain from using the chat function while a speaker is presenting (unless to flag an access issue). This will help people focus on the speaker.
- avoid jargon and acronyms in the chat and explain points clearly.

If anyone would like to participate in an accessibility meeting going forward, please e-mail the CPG's Secretariat.

## **3 Campaigning to Improve Transition**

Emma Walker – Director of Camphill Scotland, an organisation supporting around 600 people individuals, including children, many of whom are autistic people.

EW spoke about her involvement in the Transitions Bill and Camphill Scotland. She also spoke to her organisation's internal / external priorities; for instance, Camphill's policy work to extend the immigration health surcharge exemption. EW outlined the way in which Camphill Scotland engages with the legislative process at Holyrood.

EW detailed the 'journey' this Bill has taken, from initial ideas / conversations with colleagues in the third-sector, through to its being a 'proposed' Bill at the Scottish Parliament today.

EW stressed her belief that the Transitions Bill should be made into law as soon as practically possible. She invited those CPG members who are looking to support Camphill and / or learn more about Camphill's work to get in touch at: [Emma@camphillscotland.org.uk](mailto:Emma@camphillscotland.org.uk).

## **4 A Family Perspective**

Kate Monahan – a co-Founder of 'Because We Matter', a charity providing support to children, young people, and their families.

KM is a strong advocate for this Transitions Bill. KM shared her family's personal experience of autism and learning disability, with reference to her son, Wilf. Kate's own work in Aberdeenshire after she gathered with other parents facing similar circumstances, where they discussed their mutual experiences of social service provision.

KM outlined the repeated set-backs her family faced when dealing with their local authority. She touched on the high number of meetings, reports, and assessments undergone, and how the eventual positive consensus which emerged on her son's care was inexplicably overturned by administrators. KM believes that the Bill is key to preventing other families facing what she did, since it would place on a statutory footing existing guidance.

AB thanked KM for her attendance and contribution.

## **5 The Importance of Advocacy**

Margaret Smith – Partners in Advocacy.

MS spoke to the work of 'Partners in Advocacy', an organisation providing free and confidential advocacy support to those who need it. She outlined this work in detail by way of a case study.

MS explained that the PiA team are frequently involved with casework on issues stemming from incomplete / non-existent transitions, and individuals' own lack of awareness of their rights.

She went on to explain about the impact of 'Independent Advocacy', a free service which helps people have their voices heard, their rights upheld, and their views taken into account when important issues are happening in their lives, especially during transition. A young person would be allocated a support worker who can speak up for them to help resolve their issues.

MS believes that this project has had a huge impact on the people with whom they've partnered. In particular, MS points to improvements in self-confidence amongst the young people involved, particularly with respect to personal decision-making.

<https://www.partnersinadvocacy.org.uk/>

AB thanked MS for her attendance and contribution. He emphasised MS' message that there are many groups out there who can direct you to appropriate services and give you support.

## **6 Pam Duncan-Glancy MSP's Proposed Disabled Children and Young People (Transitions to Adulthood) (Scotland) Bill**

AB introduced Pam Duncan-Glancy MSP, Scottish Labour Member of the Scottish Parliament for the Glasgow region, acknowledging her already significant impact on disability rights both inside and outside of Holyrood to date.

PDG gave a status update on her Member's Bill, which seeks to make it a statutory requirement for local authorities to create a transition plan for each child and young person. Doing so would significantly improve the transition out of school-age education for many autistic people.

The Bill would compel the Scottish Government to create a national strategy for transition. The Scottish Government would also be required to make a named Minister responsible, who would ensure that the strategy is met.

PDG remarked that she has been overwhelmed with the level of support the Bill has received to date, especially from Campbell Scotland and Inclusive Scotland.

She went on to give the group some insight into her own lived experience as a disabled person. Pam recalled the stresses of her own transition, and how each attempted to move forward was met with equivocation on the part of her local authority.

PDG remarked on the significant gap in employment rates between non-disabled and disabled / autistic people. She argued that if this isn't addressed then it will be much harder to adequately address transitions for young people of school-age. She also connected this to aspiration, and how disabled young people's own outlook on their life & career is often distorted by the failings of their service providers, who do not allow the young person to reach their fullest potential.

PDG continued by acknowledging that this Bill is not a 'silver bullet – it won't fix everything. The Bill is part of a "bigger jigsaw" to reduce the considerable burden on people at a crucial point in

their life and to ensure that service agencies are clear on their responsibilities. Pam is absolutely determined that young disabled people are given a chance and equal opportunities.

PDG told the group that she is liaising with both the Law Society and COSLA to ensure that the Bill is in good shape for its Stage 1 debate.

AB thanked PDG for her attendance and contribution.

RH informed the group that we would track the Bill's progress, and assured members that there will be plenty of opportunities to engage with Pam's Transitions Bill.

## **7. Discussion**

Jasmin Ghibli posed a question to the speakers on the 'Tiger Mum / Dad' phenomenon. Jasmine sought to underline PDG's remarks – this Transitions Bill is a great thing, and will help to ensure that local authorities deliver for young people. PDG thanked Jasmine for her kind comments on the Bill.

PDG explained that whilst this proposed legislation is important, legislation alone is not the only answer. She stressed the need to work collaboratively with COSLA on issues of social care and education, and why it is important to start transition process earlier than age fourteen.

Maurice Frank stated that the Bill must not involve compulsory interventions for treatment. He stated his opinion that being obliged to make a transition plan could put the child at risk of being trapped in an abusive situation.

Susan Chambers stated that she is an autism campaigner of twenty years. She posed a series of questions on the long-term direction of support available to autistic people – Where will our lives be? How will the Bill be implemented? She expressed some scepticism on how this Bill's potential will be realised, given the track-record of similar items.

Charlie MacKenzie-Nash shared some lived experience of their time in school-age education, touching mainly on bullying and expulsion, but also on how home-schooled individuals may be left behind. PDG reflected on how the Bill may need strengthening in this respect, ensuring that those not in full-time education are supported.

Andrew Crosbie explained that there is a general lack of education in schools on disability rights. He shared his lived experience on his topic, saying that he left school in 2013 knowing nothing of his rights. He only became familiar with disability rights legislation upon moving into full-time employment in the public sector. He underlined the well-known statistic that only 1-in-5 autistic people are employed. Andrew expressed an opinion that the 'modern apprenticeship' scheme only offers employment from 18-24 months – with no exit strategy. Andrew went on to speak to autism, employment, and rural affairs, outlining how autistic people living in the Highlands and Islands are lack in opportunities. He stressed that Highlands Enterprise should be doing a programme of work in this area. PDG concurred with much of what Andrew said, offering to go and share more information with him on Highlands Enterprise. PDG agreed that we must look to put disability rights onto the school-age curriculum.

AB thanked PDG again for her participation and making time to attend the CPG. He urged those in attendance to contact their local / regional MSPs with a view to their backing Pam's Bill.

Stephanie Callaghan MSP – SNP, Uddingston and Bellshill. SC stressed her personal support for the Bill and her eagerness to work with PDG on this issue. SC explained that she is involved in her local area with ARCH, (Autism Resource Coordination Hub).

SC sought to reassure members that a considerable amount of resource is being put into autism, via pilots and programmes; however, she empathised with those who say that things are not changing quickly enough 'on the ground'. She also believes that we should be reflecting more on the positives.

AB thanked SC for her attendance and contribution.

AB explained that if anyone has any questions on policy or strategies then they should be going directly to their own MSP, or through the CPG. Any questions should be sent to the Secretariat, run by the National Autistic Society Scotland and Scottish Autism.

AB agreed to write to the Cabinet Secretary for Education and Skills, outlining the membership's broad support for PDG's Bill. All present were in agreement.

## **8. Response from the Co-Convener**

AB reiterated that the next pre-CPG meet on accessibility would be held W/B 4<sup>th</sup> April 2022.

AB reflected on potential future agenda items for the CPG, with diagnosis, autism & women / girls, employment, and education all appearing.

Finally, AB thanked all of the speakers for their contributions, and also remarked on the CPG's high attendance – in comparison to many CPGs.

## **9. Date & Topic of Next Meeting**

TBA.

## **10. AOB**

No other items were raised by those present.

### **Written Contributions made in the 'Zoom' Chat Function**

*Each of the entries below are verbatim lifts from the 'chat transcript', as provided by Zoom. Only those contributions marked with a 'C' at the time have been included in these Minutes, in line with what the Secretariat set out in the pre-meet papers. Consequently, the entries below may not 'flow' as a conversation; however, many are effective as stand-alone remarks.*

**Steve Billingham:** C: Are there any examples of Local Authorities who get transition support right who can be used as a best practice blueprint?

**Jay Brownlee (NT, Parent/carer):** C: It is important to ensure transition is managed well for those who don't have high needs in childhood. My daughter manages pretty well while at home and highly supported so doesn't have anything even close to a CSP but there is no way she could live as a completely independent adult without support., With the right support there is no need to wait for her to struggle and fall apart before helping her live the fullest life she could.

**tomwrightman:** C Of course, transitions aren't just limited to the ones being discussed. My son, who is over 40, is soon to move into the community, after living for 20 years in NHS accommodation. He needs as much support as anyone else.

**Jay Brownlee (NT, Parent/carer):** C: How do we get the right help at the right time when waiting lists are so long? By way of example: my daughter was only able to be referred to the children with disabilities team after a diagnosis was made. She waited 4 years for a diagnosis

and now has waited more than a year to be assessed by the SW team...#

**Tom Wightman (Pasda):** C Transitions don't end at 26. Transitions continue throughout life.

**Steve Billingham:** C: Will any resulting legislation include those with additional support needs but maybe no specific diagnosed disability. If not how can we ensure it does? Their need for additional support doesn't just disappear.

**Sheila Mackay (home):** C what about transition into independent living? So many barriers for people to make the move out of the family home in their adult life.

**Jay Brownlee (NT, Parent/carer):** C: It is co-ordinating care and services that makes me question how I would ever go back to work/stop claiming carers allowance. It often takes more time than the care needs.

**Charlie MacKenzie-Nash:** C. Are we going to cover transition out of children's healthcare services as well? The gap in autism knowledge between e.g CAMHS and adult mental health services is appalling. So many young autistic people finally get support in camhs after years, only to turn 18 and end up misdiagnosed, detained in an adult acute unit that is traumatic for autistic people and end up heavily medicated

**Fiona Culbert:** C The concerns raised are more about power than about policy. Having legislation about universal human rights and the support to ensure they are met eg universally accessible advocacy and legal advice (and not the current post code). It also has to be acknowledged that transition is not just about leaving "school" it is about leaving statutory education, many young people often due to unmet need are home educated or in private school provision. So much more needs done to develop participation in decision making at local and national level to the point non professionals are actually viewed as equal and valued partners

**Edward Fowler:** C: Many families voted for an Autism Bill but ended up with an Autism Strategy which many local authorities did not implement how can we ensure that we get a Transition Bill.

**Charlie MacKenzie-Nash:** C since so much of this bill centres around education, especially schools, how will it protect children and young people for which school was not a supportive environment and left early or were home educated?

**ian.templeton (Partners in Advocacy):** C: Fantastic stuff Pam - where independent advocacy can support through stage 1 and onwards we'd be delighted to input

**Jay Brownlee (NT, Parent/carer):** C: What are the implications of not meeting these timescales?  
(e.g. I was told high school transition would start in p6 and it didn't start till p7, with zero implications for not meeting those timescales)#

**Jasmine Ghibli:** C. Yes, sometimes it is too late at the transitioning age- but if we recognise transitioning as something beyond an age range but instead a greater period in someone's life.

**Fiona Culbert:** C Agree, it is a fine line

**Sheila Mackay (home):** C Lots of really good strategies and I also agree that implementation gets missed usually due to lack of follow up and lack of coordination of services.

**Jay Brownlee (NT, Parent/carer):** C; we need to move towards not allowing covid to be a scape goat. I am sure if I speak to policy makers none of our issues accessing services etc would be anything to do with covid, but the people on the ground still use it almost daily when I am trying to access support for my children.

**Gordon Barlow: C:** People with subtler presentations of autism, often referred to as 'high functioning' autism, maybe the least likely cohort of the autistic spectrum to be identified as requiring support, whether it be general or specific support, advocacy input, especially beyond age 16, let alone recognising their own need for it. How can this be addressed?

**susan Chambers:** C It is still unclear who will be involved in the future to implement the intentions of the bill. There are many barriers to delivery of any services and unsure who will learn the lessons of past failures to implement current policies and human rights. What is stopping action now? How can the CPG support the implementation failures? I have written to my MSP many times but was referred to government policy.

**Fiona Clarke:** C Most education and work environments are harmful/aversive for autistic people. This is important to address as Stephanie said, so that there are options for appropriate places to transition to.

**Wendy:** C: Transition is important, and ongoing support into adulthood is essential. Sadly the fight for accessing appropriate services continues in adulthood - with all of the added complexity and responsibility that brings.

ENDS.