

Cross Party Group on Autism - “The Accountability Gap”

6th October 2020 at 10.00 am via Zoom

Minutes

Attendees:

Alexander Burnett, MSP (Chair)	Annie Wells MSP	Johann Lamont, MSP
Daniel Johnson, MSP	Oliver Mundell, MSP	Rob Holland, NAS
Charlene Tait, Scottish Autism	Nick Ward, NAS	Kirsteen Heneghan
Andy Crosbie	Helen Calley (Minutes)	Arron Ashton
Patricia Baker	Dorothy Barbour	Neil Barbour
Rachel Birch	Kabie Brook	David Campbell
Susan Chambers	Fiona Clarke	Allison Crawford
Fiona Culbert	Henna Cundill	Dorothy Daldry
Patsy Devlin	Georgia Edkins	Angie Ferguson
Sue Fletcher-Watson	Maurice Frank	Pauline Grigor
Lorraine Harris	Jason Henderson	Joshua Hennessy
Annie Humphrey	Clare Kennedy	Niall Leighton
Sheila Mackay	Joan McCready	Callum McCrosson
Tracey McFall	Dorry McLaughlin	Marion McLaughlin
Kate Monahan	Cherie Morgan	Kirsten Mutch
David Nicholson	Ben Paechter	Nell Page
Cath Purdie	Annette Pyle	William Rae
Anna Reid	Eileen Ross	Marion Rutherford
Jan Savage	Louise Scott	Catherine Steedman
Catriona Stewart	Lynsey Stewart	David Weir
Tom Wightman	Andy Williams	

1 Welcome & Introductions

Alexander Burnett welcomed all to the meeting noting the numbers attending including MSPs and asked that questions be raised via the chat function. He then gave a review of the agenda, the main purpose of which is to discuss the Accountability Gap report. It was noted that the meeting was being recorded to aid minute taking.

2 Minutes from Previous Meeting & Matters Arising

The minutes from the meeting held on 15th January 2020 were approved as read with AB noting he Chaired the meeting.

3 Headline Findings from the Accountability Gap

AB thanked everyone who contributed to the review noting the value of shared experiences and that the findings prove work is required but he hoped the recommendations will address this. However, AB noted the current pandemic will provide extra challenges so collaboration was required.

Rob Holland gave a presentation covering the methodology of the review and demographics of respondents to the surveys highlighting the lack of support felt but benefits of improved support.



3 Key Findings.pptx

RH noted the findings under diagnosis with challenges obtaining a diagnosis, wait times and level of support dependent on locality. Access to local services has a negative impact on mental health and the difficulties in securing the appropriate level of education. More support is needed with transitions particularly for those diagnosed later in life.

Training is outdated and not at the right level and lack of appropriate housing or social care being withdrawn impact on independence. RH highlighted the 'battles' families have getting the right level of support was clear in the report as well as the lack of accountability. RH also referred to the pandemic survey results which highlighted the impact around academic progress.

RH then gave an overview of the recommendations in the report highlighting they are an aspiration, the need for an encompassing stakeholder approach and proposal for a Commissioner who will have "teeth" as an autism ally. He asked for the report not to be shared outwith colleagues as it will feature in a paper next Sunday.

AB thanked RH for his overview noting overall need to support the recommendations and monitor through to delivery.

4 Reflection on Headline Findings from the Accountability Gap

Charlene Tait echoed RH's comments and the impact of the pandemic noting for some children who were struggling with mainstream, closing schools had been positive. She thought the pandemic was an affirmation that people need people and autistic people need the right people in place to ensure they are supported. CT referred to the erosion of proactive supportive services resulting in crisis driven services believing systemic change is needed.

CT stressed the importance of a collaborative approach and the gap between the intended legislation and reality is undeniable; this needs to be closed by ensuring the right mechanisms are in place and that they are used in the right way. She referred to PDS and the Policy Team's shift from the web to people. CT thought the language around battling for support was unforgiveable and it was imperative for the relationships between central and local governments to improve.

CT advised although the recommendation of a Commissioner has been contentious generally it has been well received and there needed to be some engaging conversations around the role. She thought a Commissioner would fill a gap, be a human rights defender and work across the spectrum of stakeholders. CT also said due to shared barriers from a Policy perspective, there was kinship with people with Learning Difficulties. CT said various conversations had been held resulting in the recommendation of a Commissioner who it was hoped would be enshrined in law and have "teeth" to achieve systemic change.

CT believed the Human Rights agenda should be at the forefront of everything recognising the challenges with different priorities but there should be fundamental acknowledgement of the gap and the need for radical change.

AB noted the volume of comments in the chat asking RH to capture these and add to the minutes. He acknowledged CT's comments particularly that people need people.

5 A Family's Perspective

Kirsteen Heneghan said she was a mother of four and explained the extremely challenging circumstances around securing help and support, particularly for her son. She believed that those with autism can flourish with the right support and it should not be such a battle for families to secure this.

KH said autism affects everyone differently as her son has anxiety issues and her daughter sensory and eating issues. As a single mother, KH has many challenges to balance as well as working. Unfortunately, her son living at home was having a significant negative impact on her daughters and as there was no housing support available, KH has had to sell her home and rent a flat for her son and house for herself and daughters.

KH advised the pandemic lockdown period was even more challenging and generally, she felt "forgotten about" as her son received one call with a psychiatrist and her daughter no support. She believes college is suitable for her children but this is an additional stress for her as there is no support to organise this.

KH felt fortunate her children would be able to live independently and although strategy looks good on paper, there is no legislation or come back on LAs. She highlighted that special schools are closing and support for transitions was almost non-existent. KH appreciated there are some good examples around the Aberdeen strategy but knows of many people to get access to support. She thought nothing would change without some form of accountability or independent inspector of LAs.

AB thanked KH noting personal experiences such as hers were important and recommended she contact her local MSP.

6 A Personal Perspective

AB introduced Andy Crosbie who spoke to his presentation around employment support. He highlighted issues with his schooling but the benefit of a specialist autism unit which aided him to achieving qualifications resulting in a smoother transition to employment



AC referred to his volunteering work and day-to-day living issues advising the measures he has in place to combat these. He explained his positive experience of securing an apprenticeship at SQA but stressful process to then secure a contract role. At SQA, AC receives support noting the benefits of meeting other colleagues with autism and share experiences through the Disability Network.

AC thought he had been fortunate but provided some thoughts on what could be improved including wider understanding and mandatory training. He also shared his thoughts on the strategy and welcomed any questions.

AB appreciated AC sharing his experiences and echoed the improvement suggestions particularly on raising awareness.

7 Video from Minister for Mental Health, Clare Haughey MSP
As CH was not able to attend, participants watched this video from her.

8 Video from Councillor Stuart Currie, COSLA Spokesperson for Health & Social Care

Again, as SC was not able to attend, participants watched this [video](#) from him.

AB noted the chat reflected some disagreements about who to hold responsible urging for continued engagement.

9 Audience Questions Regarding the Accountability Gap Report

Kabie Brook queried the remit and power of a Commissioner; CT said it was hoped they would have the ability to investigate individual cases, have 'enforcement' powers and teeth in relation to bringing about direct action to enable change.

Nick Ward thought the Commissioner role would be bold and strong with no recourse but it would be reliant on legislation so take time to hopefully come to fruition. The aim is for the Commissioner to be as powerful as possible, eg, legal work and also enforce to LAs the consequences of lack of support resulting in crisis.

Sue Fletcher-Watson asked about what evaluation of the new measures will be put in place and monitoring of the impact and benefits. CT referred to the One Stop Shops which were evaluated and showed good value but sadly didn't translate to permanency. Also, external valuation is built into the PDS work. NW noted Scottish Government is undertaking independent evaluation of the Autism Strategy and it is important new strategy has clear benchmarks in place.

Tracy McFall felt the report was tinkering around edges and an opportunity for stakeholders to collaborate and provide a consistent narrative. She also highlighted that LAs have legal resources but this and advocacy is lacking for families who need it as well as the lack of funding.

CT agreed highlighting that often funding is wasted so evaluation is needed regarding what does and doesn't work as well as proactive rather than reactive care and support. AB also agreed that correct funding allocation was key and he would like to see permanent One Stop Shops.

KH had personal experience of wasted money around the volume of consultations experienced with no progress. She thought a Commissioner could be a glimmer of hope and queried the plan to implement mandatory training. Also, specifics are required, eg, the Care Inspectorate provides sets recommendations and requirements after inspections.

AB stated there needed to be more action and less talk but was wary of the additional challenges given the current pandemic.

NW said of the need to be agile given the pandemic and that recommendations like the Commissioner needed to be included in all parties' manifestos leading up to the elections. He said of the need to ensure action makes a difference to lived experience.

Annette Pyle said the Government's independent evaluation would hopefully be published in December once desk work and engagement with stakeholders including CPG members has been carried out.

10 Parliamentary Questions on Diagnosis & Next Steps

AB referred to the circulated questions noting the contradictory answers regarding gathering waiting time data. He asked for any comments advising he will pursue this with individual LAs. AB's suggestion is to turn the questions into a letter to the Minister and COSLA.

RH queried plans to collect national wait times and also the impact on wait times due to the pandemic. He said the responses show there is work to be done on wait times and a hint of publishing national waiting times which is a recommendation in the report. RH thought it helpful to refer to this recommendation in the letter to the Minister.

AB asked anyone with further questions to contact him, RH or their local MSP.

11 Any Other Business

RH showed the [TV advert](#) from SG and referred to the [Myth Busting Video](#) as well as the [Different Minds](#) website.

12 Closing Remarks

AB thanked speakers and attendees advising the date of the next meeting is to be confirmed and suggested topics were welcome.

A copy of the chat including questions and responses from the session is available [here](#).

