

Working Group 2 Meeting Minutes

22nd September 2016

University of Strathclyde, Glasgow

APPROVED

Members present: Anna Cooper, National Autistic Society; Laura Dykes, Dumfries & Galloway Council; James Fletcher, ARC Scotland (CHAIR); Alistair Gilmour, Autism Network Scotland (minutes); Ian Hood, Learning Disability Alliance Scotland; Arlene Johnstone, Social Work Scotland/NHS Highland; Annette Pyle, Scottish Government Care, Support and Rights; Zoe Robertson, Perth and Kinross Council; Scott Richardson-Read, ARC Scotland; Lynsey Stewart, Autism Network Scotland.

Apologies: John Butcher, Directors of Education; Jane Hook, Parent.

John Dalziel, Skills Development Scotland; Lynsay Haglington, East Dunbartonshire Council/Social Work; Kirsten Hogg, Camphill Scotland

- I. **Previous minutes and action points** - previous minutes were approved.

Review of action items

- **ACTION POINT** – LS and SRR to use the *Digging Deeper* report, *Principles of Good Transition*, and *Outcomes Framework* to form the basis of a response to the Governance Group's request for feedback on Recommendation 11 of the report into the death of Ms. MN. This response to be disseminated for the contributions of all Working Group members.

Completed.

- **ACTION POINT** – AG to coordinate communication between Working Groups on which aspects of the Ms MN case they will focus on. Working Group 2's contributions to be shared across the Working Groups in due course.

Completed. The case is to be discussed further at the meeting of the Governance Group on Thursday 6th October.

- **ACTION POINT** - JF to feedback to the group on his meeting with the Scottish Learning Disability Observatory at the next meeting.

Discussed later on the agenda.

- **ACTION POINT** – AG to contact JB to request the overview paper on the SEEMiS information management system for circulation amongst the group, if available.

JB has informed AG that there is currently no such paper written. JB will be invited again to inform the group on SEEMiS at the next scheduled meeting.

ACTION POINT – AC to investigate whether the National Autistic Society education services use the SEEMiS system and to provide a paper on its use co-authored with ZR.

- **ACTION POINT** – IH to write a brief report on his meeting with the Bus Users Organisation including links to relevant online information.

Completed and circulated.

ACTION POINT – AP to circulate information gathered through the Transport Scotland consultation following its completion.

Done

- **ACTION POINT** – LS to share IH's report with the One Stop Shops and also signpost toward in upcoming Autism & Transitions training events. AG to also signpost the same report through ANS communications streams.

Completed.

- **ACTION POINT** – SRR to circulate 'heat map' of Scottish transitions organisations.

Done.

- **ACTION POINT** – LS to begin review of Work Plan to ensure that its terminology is in alignment with the Strategy Outcomes Document, for future review with JF.

Completed.

- **ACTION POINT** – JF to write a cover letter to accompany the updated Work Plan.

Done.

- **ACTION POINT** – AG to brand the Work Plan as an outward facing document and circulate to the list of Lead Officers with links to other useful documents.

Done.

- **ACTION POINT** – LS to confirm date for the next Lead Officers' Event in June.

Done.

- **ACTION POINT** – AG to find out dates of next meetings of the Autism & Employment Network.

Done. LS is to replace Annie Watson, following her leaving Autism Network Scotland, as representative of both the Working Group and of ANS in the Autism & Employment Network.

ACTION POINT – LS to feedback to the next Working Group 2 meeting on the upcoming meeting of the Autism & Employment Network.

- **ACTION POINT** – LS to present her draft of full autism supplement to the next meeting.

Completed and discussed later on the agenda.

- **ACTION POINT** – SRR to circulate reports from NHS Education Event on 6th May and the Scottish Transitions Forum Conference on 18th May.

The writing of this report is still in progress.

ACTION POINT – SRR to circulate his contribution to the reports from the NHS Education Event on 6th May and the Scottish Transitions Forum Conference on 18th May with the group via AG.

- **ACTION POINT** - SRR to contact health economist about speaking to next group meeting.

SRR has contacted the health economist. A report on preventative spend in the NHS is currently being written. On completion the report will be circulated to the group and the economist invited to discuss the report at a future meeting.

II. Investigation into the death of Ms MN

The response to the Mental Welfare Commission (MWC) report on the death of Ms MN requested of Working Group 2 by the Governance Group was drafted by LS and SRR and has been submitted to the Governance Group.

It is felt by this Working Group that the issues relating to transitions that feature in the case of Ms MN are key to the details of the case. Recognising the importance of making a reasoned transition when vulnerable people are leaving hospital is of crucial importance. The group feels that the adoption of the recommendations outlined in the *Principles of Good Transition 2*, its upcoming successor document *PoGT3* and its accompanying autism supplement, would be beneficial in such cases, whilst recognising that these documents are written with a focus on children's-to-adults' transitions.

The group wished to highlight recommendation 5 of the original MWC report as the recommendation to which the Principles document is particularly pertinent:

Bodies discharging people with complex needs to specialist services should ensure that there is a robust and safe process of preparing for discharge and managing the handover to specialist services, including:

- *formal discharge planning meetings, involving all relevant staff including from the care provider, sufficient to ensure effective handover of information and allow good quality care and treatment to be provided following discharge;*
- *an agreed medication care plan where there is a complex medication regime in place, to assist the care provider in managing medication, and to make clear*

whether changes to medication should be through the responsible medical officer or the GP;

- *information immediately available at discharge to the GP followed by a comprehensive discharge letter within locally agreed timescales, usually within 7-10 days. In complex cases the consultant psychiatrist should telephone the GP prior to discharge to discuss the case; and*
- *clear follow-up and secondary care arrangements which are understood by all parties involved.*

AP stated that her expectation was that key points would be drawn from each of the Working Group's reports through discussion at the next meeting of the Governance Group on 6th October to create an overall report. The group agreed that it is of paramount importance that the subsequent document be accessible to be put to the fullest of use.

III. Principles of Good Transitions Autism Supplement

LS had circulated her draft of the autism supplement to the *Principles of Good Transitions 3* document to allow the group to offer their feedback. LS was praised for creating a strong document which the group discussed in detail. The final draft of the document is due to be completed by the end of October with a suggested launch for the supplement at the 5th National Autism Conference this winter.

The group are keen that the supplement is a user-friendly, practical document that families and practitioners can apply to transitions both for those diagnosed solely with autism and those with dual diagnoses of autism and learning disabilities in their daily lives. To this end, AP suggested a desk aid might be created to complement the document.

The draft has been considered by the Wider Engagement Group and will be shared with the Scottish Transitions Forum 'think tank' and the autism one stop shops to receive practitioners' perspectives.

ACTION POINT – SRR to send LS the draft of the *Principles of Good Transition 3* document to ensure that the language is consistent between documents.

IV. Request for data

JF and AP met with representatives of the Scottish Learning Disability Observatory (SLDO) and offered their feedback on the meeting to the group.

SLDO have offered a response to the Mental Welfare Commission's recent report on the Death of Mc MN which stresses the importance of early interventions. The embedding of the Mental Health Strategy will provide useful data on autistic individuals in Scotland which can contribute to the broader understanding from several data sources.

SLDO data originally published in December 2015 is now being made more widely available and provides some illumination on the transitions of autistic teenagers. The data is based on analysis of the findings of Scotland's Census 2011; further details will not be released until the available data has been cross-checked to rule out the possible

identification of individuals from the information provided. This process is expected to take six months.

It is expected that the combined data from the SLDO and other sources will provide evidence of the practical effects of the Scottish Strategy for Autism on people's lives by 2021, including the numbers of people diagnosed the transitions they are undertaking.

Kjersti Fergusson will update the Governance Group on Thursday 6th October regarding the data obtained from the Health Information System (HIS).

Working Group 2 will discuss the data provide in greater detail at its next meeting.

ACTION POINT – AP to share electronically copies of the SLDO newsletter and other materials shared as hard copies at today's meeting, via AG.

LS is currently collating a list of transitions support offered by Scottish universities and colleges. Levels of support vary between establishments from specific services to directing autistic students toward standard welfare support.

ACTION POINT – AC to provide information to LS on her work undertaken with Glasgow Caledonian University.

ACTION POINT – All members of the Working Group to review the data-related information provided and to consider its strengths, its issues and how it can be linked to other sources of data to provide a meaningful body of knowledge of transitions undertaken by autistic individuals.

V. Links with Innovation Fund projects

There is to be an event for representatives from Innovation Funded Projects across all three policy areas on 27th October which will provide an opportunity for them to learn from each other's experiences.

ACTION POINT – AP to circulate a list of Innovation Funded Projects relating to transitions to the group via AG.

ACTION POINT – AP and JF to discuss transitions-related projects with Inspiring Scotland in order to collate information on outcomes for autistic individuals.

VI. Links with Lead Officers

JF presented at the Autism Lead Officers and Support Providers Collaboratives event on 14th September and received positive feedback for his presentation. Working Group 2 wishes to be as outward facing as possible in sharing its work and encouraging feedback.

VII. Meeting with Minister for Mental Health

JF and SRR are to meet with Angela Watt MSP, Minister for Mental Health, ahead of the launch of the *Principles of Good Transitions 3* and will also update her on the work of

Working Group 2. It was put to the group that this meeting offered an opportunity to raise questions with the minister regarding its work on transitions and other priority interests.

The group was interested to know whether work around transitions would be prioritised in the minister's remit and raised the prospect of a directive aimed at Getting It Right For Every Transition, similar to the GIRFEC (Getting It Right For Every Child) national approach in Scotland to improving outcomes and supporting the wellbeing of children and young people by offering the right help at the right time from the right people.

IH raised the question of potential methods of improving record keeping around individuals' autism data. The group was also keen to discuss how it might embed work on autism in the government's existing programme, such as its Disability Action Plan.

AP stated that there is a commitment to improving transitions for autistic people within the Scottish Strategy for Autism. Different aspects of transitions planning span across other government departments, such as education, whilst responsibility for transitions planning in local areas sits with each individual local authority. The group is therefore keen to know how it can bring other participatory elements of local and national government into the conversation on transitions.

SRR suggested a 'transitions champion' might be needed to further the cause.

ACTION POINT – AP to request that the Disabled Child's Framework authors contact JF ahead of meeting with Ms Watt.

VIII. Review of May 2016 Work plan and next steps

KH is to retain her place on Working Group 2 following her taking up of a new post at Barnardo's Scotland, subject to approval from her new employer. It is felt by the group that its work remains relevant to her new policy position at the charity.

Transitions for older people in Scotland is a key interest of the group for future workstreams. LS is in the early stages of developing a 'think tank' focused on transitions for older autistic people. Membership will be made up of key stakeholders in this field including autistic adults, parents and practitioners.

ACTION POINT – LS to feedback to the group on progress of the development of the 'think tank' on transitions for older autistic people.

The group discussed potential themes that may feature at the 5th National Autism Conference. Among these themes were the plentiful Scottish contributions to the recent Autism Europe Congress, some of which it was suggested might be showcased at the Conference.

Also discussed were peer-support networks such as Autism Rights Group Highland (ARGH) and Scottish Women's Autism Network (SWAN).

ACTION POINT – LS to contact autism lead officers to gather known examples of peer support networks.

IX. AOB

AP informed the group that the Micro-segmentation Report is expected to be published shortly in which all three Working Groups retain an interest.

X. Date and time of next meeting

The next meeting of the Working Group is scheduled for Wednesday 16th November, 11 am to 1 pm, at the Number 6 One Stop Shop in Edinburgh.

KEY MESSAGES

The Working Group has submitted a formal request for data to the learning Disability Observatory. This has been accepted and data gathering process has begun. The group has also reviewed other published census data including 'Health of people with autism and intellectual disabilities.'

James Fletcher, group chair, presented about transitions and the group work plan at National Coordination Project lead officers event 'Commissioning for autism support' on 14 September. The group's work-plan has also been branded as an outward facing document and circulated to lead officers via the National Co-ordination project and is available on the Scottish Strategy for Autism website.

Working Group 2 has supported Autism Network Scotland in the development of the content of *Principles of Good Transitions 3* autism supplement. The group wishes to help steer and promote a national conversation that improves transitions for young autistic people, in line with the strategy and the outcomes framework. This includes gathering and sharing information, advising and influencing, generating ideas and seeking opportunities to highlight the importance of support for young autistic people who are in transition.

ACTION ITEMS

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ACTION POINT – AP to circulate information gathered through the Transport Scotland consultation following its completion.

ACTION POINT – LS to feedback to the next Working Group 2 meeting on the upcoming meeting of the Autism & Employment Network.

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