

Working Group 2 Meeting Minutes

16th November 2016

Number 6 One Stop Shop, Glasgow

APPROVED

Members present: **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; **Anna Cooper**, National Autistic Society; **Jane Hook**, Parent; **John Dalziel**, Skills Development Scotland; **Lynsay Haglington**, East Dunbartonshire Council/Social Work.

Guests: **James Cox**, University of Edinburgh; **Ronnie Hill**, Scottish Government; **Jean MacLellan**, Autism Network Scotland; **Donald Macleod**, National Autism Co-ordination Project.

Kirsten Hogg, has left the working group due to a change of job. Her positive contribution to the group was acknowledged

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

Review of action items

- 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.

ZR has provided the report which has been circulated.

- AP to circulate information gathered through the Transport Scotland consultation following its completion.

Circulated.

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

LS attended the meeting and updated the Autism & Employment Network on the activities of Working Group 2. They are keen to work with the Group in future. The Network recently held its annual event at the University of Strathclyde, discussing disclosure of an autism diagnosis to an employer and issues facing autistic women in the workplace. The Network is now planning an evaluation of its work to date and to confirm its priorities for the future; LS will continue to sit on the group to bridge its work with that of Working Group 2 as appropriate.

- 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.

Circulated.

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

Done.

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

Shared.

- AC to provide information to LS on her work undertaken with Glasgow Caledonian University.

ACTION POINT - AG to find out who to speak to at the National Autistic Society in AC's absence.

- 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.

Discussed below.

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

Circulated.

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

Discussions have been held.

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

This meeting has not yet gone ahead and will be rescheduled.

ACTION POINT - JF to forward a potential date to AP to meet discuss meeting with Maureen Watt.

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

Deferred to next meeting

- LS to contact autism lead officers to gather known examples of peer support networks.

LS reports that this is a work in progress, with strong examples already uncovered, including some that grew organically out of other projects not originally intended as peer support networks. LS also said that a question will be inserted into the questionnaire sent to delegates of the Autisms & Transitions roadshow events 6 months after attending, asking whether they have engaged with any parent support networks since attending the event.

ACTION POINT - LS to provide a list of examples of peer support networks ahead of the next meeting of the Working Group.

The group discussed the value of parents and carers peer-support networks, through which post-diagnostic might be shared, as well as details of respite care and support following medical appointments. It was suggested that information for carers ought to be available at frontline services such as in doctors' surgeries, and that support group details could be shared through out-of-hours contact such as texts and emails, as with a current pilot at Gartnavel Hospital. It was suggested that a representative of the Scottish Government's carers team join this discussion at the next meeting of the Working Group, and that they or another carers' representative might have a permanent presence on the group in future.

ACTION POINT - AP to invite a representative of the Scottish Government's carers team to join the next meeting of the Working Group to discuss how the group might constructively engage with carers issues.

ACTION POINT - SRR to provide information to the group on the pathway to engagement for carers and carers groups.

ACTION POINT - LS to ask Thom Kirkwood of the Strategy's Wider Engagement Group about sharing any information he has gathered in his work on any peer support networks and specifically carers networks.

LS' list of peer support networks and SRR's information on pathway to engagement to frame discussions with the carers' representative at the next meeting.

AP also updated the group on an action point from the meeting in May: NT to invite a representative from GIRFEC to attend the next Group meeting to feedback about their work. This invitation is to be to the next meeting initially with potential for a permanent membership going forward.

AP met with Ronnie Hill of GIRFEC on 15th November and discussed the Principles of Good transitions 3 document. He will be offered a permanent place on the group in the New Year.

2. Refreshing the Strategy

The Working Group has been joined today by Jean MacLellan and Donald Macleod of Autism Network Scotland / the National Autism Co-ordination Project to facilitate discussions on the refreshing of the remit and memberships of the Governance an individual Working Groups. These discussions are intended to focus on whether items of each group's Work Plan can be edited or updated to ensure that constructive progress can be made by each group moving forwards.

Self-Directed Support Scotland is currently looking at numbers of people with autism and/or learning disabilities who are 'falling through the gaps' of assessment, believed to be the majority of people with these conditions. Different criteria is set and applied by different local authorities, with different levels of service resulting for people in different places. People are often unaware of what to expect from services as there is no single set of eligibility criteria nationwide, which leads to issues such as social isolation going unchecked. It was suggested in the group's discussion that the voice of the young person is often going unheard in the process and that what might be required was a national approach similar to Getting It Right For Every Child; an initiative towards Getting it Right For Every Adult.

JF made the broader point that parents and young people need information and awareness of the realities of transitions into adult services. Providing that information should be thought of as part of a broader transitions pathway. As young people move into adult services, any reduction in services should happen gradually a 'supported letting go', rather than an abrupt change. SRR described how he has encountered an opinion from people accessing support services that necessary changes are only effected when they meet the requirements of broader national strategies; changes might be needed but if they are not previously suggested by the strategy, they tend not to be actioned. DM described how this feeling was one often encountered by himself and JM on their visits to local authorities around Scotland.

It is felt that the Scottish Strategy for Autism requires measurable outcomes and accompanying methods for the Working Groups to be able to assess the impact of their work specifically. In order to measure such outcomes however, clear data is required to know the number of people diagnosed/undiagnosed, the services they access or need to gain access to, and the stages of their journeys. This issue has been discussed since the inception of Working Group 2 and is regularly discussed, including as part of this meeting's agenda.

The Association for Real Change are currently surveying young people with additional support needs, their families and carers on their experiences of transitions to contribute to available data, with results due for publication early in 2017.

DM asked the group to also consider other areas of work that it considers important and that might be reflected in its future membership.

JF and SRR raised criminal justice as an area currently being worked on by ARC and People First Scotland through the Supporting Offenders with Learning Disabilities (SOLD) network. This is linked to the delivery of the Keys to Life.. A recent consultation with SOLD members pointed towards issues for people with significant communication needs, including autism, who are accused of convicted of an offence. There are opportunities for development at different points in the criminal justice system to address the need for change.

Until now, extending the membership of the group has been an organic process as the work of the group has developed and required further input. This refreshing of the group creates the opportunity to decide future directions the group might wish to move towards.

A further area that might require representation is in healthcare. AP described how recent developments in areas such as support for people with complex needs and with the need for out-of-area placements ought to make this a priority. The appointment of Mark MacDonald MSP as Minister for Childcare & Early Years also invites consideration as it becomes clear how support for autistic children appears in his remit.

It was also suggested that there might go on to be more than the current three working groups depend on how the process of refreshing the groups goes on to unfold.

DM also updated the group on the most recent developments on Working Group feedback to the report on the investigation into the death of Ms MN, saying that following the collation of this feedback further contributions were being encouraged from local authority autism leads.

3. Principles of Good Transitions – Autism Supplement

LS has completed a consultation on her draft of the Autism Supplement to Principles of Good Transitions 3, receiving feedback from service providers, parents and carers of autistic people that will be incorporated into the final draft wherever possible.

Further supplements to the core Principles document are being written aimed at people with complex needs and people with life-shortening conditions.

Timelines have been established for publication that will allow the document to be launched at the Scottish Strategy for Autism Fifth Annual Conference on 16th January 2017.

4. Transitions data sources

The group was asked to consider what the best use of available data would be and how might we measure its successful use.

The group went on to discuss [SEEMIS](#), a recording system for all children with additional support needs in schools in Scotland. It is a system that is widely used and offers an accurate method of recording numbers of children with diagnosed as autistic. As part of

the system, teachers are asked to estimate young people's trajectory in terms of education and employment.

SRR described new participation measures being developed by Skills Development Scotland which aim to show where young people are in the education system, including tracking those not eligible for support by SDS. The data they hold requires analysis for further details. IH said that the information held in this was potentially more valuable than that sought from the 2011 census as it records more than simply the numbers of young people with an autism diagnosis and actually traces their trajectory of support, education and employment. The data from SEEMiS is available online; IH suggested that better understanding of this data enable the group to see more clearly how best to support both autistic adults and young people. JF pressed the importance of mining the available data sets for practical suggestions and conclusions.

ACTION POINT - IH to select key information he holds on SEEMiS to share with the Working Group.

LS suggested that the data on people with autism held by the Scottish Learning Disabilities Observatory might be available by the next meeting of the Working Group in the New Year.

Transitions Research

JC described at length the work he had been asked to do in the Midlothian area in his role at the University of Edinburgh, on transitions to adult life and services for people aged 14 to 25 with conditions such as autism, as well as complex disabilities and life threatening conditions. With a focus on the lived experience of individuals and families receiving support, it was expected prior to beginning that GIRFEC would be the primary source of support of the approximately 30 families taking part; this has proven in practice to be third sector organisations proving the main sources of support and information. The work is intended to provide a narrative of the transition process and is due for publication in March 2017.

A key theme to arise is the importance of continuity in navigating transitions between services or between stages of education. Experiences have been shared of children being well-supported in school or in college only to see that support end at the transition, leaving the individual in a kind of limbo. This can be highly detrimental to the individual and improvements thereafter are often only incremental. Trusted support from an individual or service ending, whether in education, service provision or a social worker, can be a huge loss to the individual and their family if it does not continue; it is furthermore distressing to the professional to see the supported individual suffer for their inability to continue in their role.

A well-managed package of care can help mitigate the changes in the psychological process of moving from children's to adult's services and to help to navigate the 'constant lightning strikes of having autism'. There are many different models for these transitions in operation. The Principles of Good Transitions 3 will offer a key opportunity to understand the 'DNA of good work' in transitions and to create training programmes based on this good practice, in education, criminal justice, and many other areas, though it will take a number of years to fully implement these changes.

In the group's discussion, it was stated that elements of successful transitions include the engagement of the different stakeholders throughout the process, from the individual to their families and carers to the support staff and those of the educational establishment being transitioned to/from. It is important that all understand the nature and model of the process and what is to be expected from it, and that the process is ongoing rather than 'one good meeting'. JC stated that there was understanding of the GIRFEC model among some respondents while others had not encountered it. He described the need to 'make people players in the process rather than people it happens to'. He also described a specific lack of support in areas such as sexual development and social support in many cases; AP noted that the Autism Toolbox resource included information for school staff in this area. Tracey Francis' report, [Life on the Edge of the Cliff](#), was also cited as a useful resource.

JC concluded that in the majority of cases, the successful transitions observed often were as result of dedicated, persistent individuals both among those going through transitions themselves and among professionals providing support, with positive attitudes and personal capability, that made the greatest difference impact on the transitions succeeding more than any one policy. These instances offer examples that can be utilised and replicated as good practice, but, as JF noted, transitions ought to be considered as a lifelong process to be gone through and supported where necessary.

5. Links with Innovation Fund projects

The list of Innovation Funded projects relating to transitions has been provided. AP has a further meeting with Inspiring Scotland arranged do discuss these projects that JF is welcome to attend. JF declared that Working Group 2 is keen to engage with Inspiring Scotland on establishing links with any projects that share its areas of interest.

ACTION POINT - JF to review list of Innovation Funded transitions projects to discuss how the Working Group might go about establishing links with them.

6. Links with Lead Officers

The Work Plan has been shared with Lead Officers and is available on the Scottish Strategy for Autism website. JF spoke on transitions for young autistic people and the impact of national work on commissioning local services at the Autism Strategy Lead Officers and Support Providers Collaboratives event at the University of Strathclyde on 14th September.

7. Older Transitions 'Think Tank'

The 'think tank' is in development, with LS having spoken to NHS Education for Scotland about how it might feed into their training framework. To be discussed further at the next meeting.

8. Review of May 2016 Work plan and next steps

To be picked up at the next meeting.

9. AOB

SRR described how the Scottish Funding Council is providing transitions training in colleges and universities and is receiving positive feedback, with further pilot schemes a possibility.

ACTION POINT - SRR to provide AP with his notes on Scottish Funding Council's transitions training in colleges and universities.

10. Date and time of next meeting

Wednesday 15th February 2017, 11am to 1pm, Collins Building Room 202, University of Strathclyde.

It was noted that this would be the last Working Group meeting that Ian Hood will attend, as he will shortly be retiring. Ian was thanked for his invaluable contribution, particularly in helping us to make sense of sometimes complex data sources. We wish him well for the future.

KEY MESSAGES

Working Group 2 is looking at the *Goal: Access to appropriate transition planning across the lifespan*.

The Working Group is in agreement that it has reached a useful point in the progress of its Work Plan to review its objectives and update these to reflect changes in the autism landscape in Scotland. In common with the Governance group and Working Groups 1 and 4, it welcomes the opportunity to also review its membership and to potentially invite new members to join discussions to both further its historical aims and work effectively in new areas of key interest to autistic people in Scotland.

We are pleased to have supported the content and dissemination of the Principles of Good Transitions 3 and its Autism supplement. These set out a clear framework for better and more coordinated approaches to transitions for young autistic people and their families.

The Group is working to utilise the available data from numerous sources to bring into better focus the key requirements of demographic groups within Scotland's autistic population. We wish to achieve a clearer picture of levels of unmet needs of autistic people and work with others to develop solutions where unmet need exists.

We are also pleased to continue to actively share learning and promote the importance of transitions with autism strategy lead officers across Scotland and are looking forward to establishing communication with projects funded through the Autism Strategy Innovation fund via Inspiring Scotland.

ACTION ITEMS

ACTION POINT - AG to find out who to speak to at the National Autistic Society in AC's absence.

ACTION POINT - JF to forward a potential date to AP to meet discuss meeting with Maureen Watt.

ACTION POINT - LS to provide a list of examples of peer support networks ahead of the next meeting of the Working Group.

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