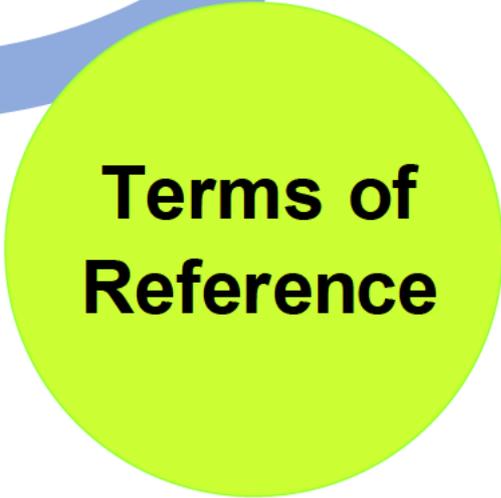


Coronavirus (COVID-19)
**Dementia, Autism and
Learning Disability
Stakeholder Group**



**Terms of
Reference**

V0.1

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1. Title

Coronavirus Dementia, Autism and Learning Disability Stakeholder Group

2. Accountable to

The Coronavirus Dementia, Autism and Learning Disability Stakeholder Group (DALDG) is a leadership & partnership working group reporting to the Scottish Government Dementia, Autism and Learning Disabilities Policy team within the Directorate for Mental Health. It is accountable to the Minister for Mental Health.

The Group is not established on a statutory basis. It is therefore not subject to the formal public appointments process and the requirements of the Code of Practice for Ministerial Appointments to Public Bodies in Scotland. Members are appointed by Scottish Ministers, taking into account the views of the Chair and existing members.

3. Purpose of Group

Scottish Government recognises the importance and value of Partnership Working between key stakeholders and the importance of lived experience shaping government policy.

The Coronavirus pandemic is having an unprecedented impact and it is important that Scottish Government continue to work together to meet the emergency faced by the country whilst at the same time protecting those people who live with Dementia, are Autistic, have a Learning Disability, and their families and carers.

The Coronavirus Dementia, Autism and Learning Disability Stakeholder Group (DALDG) has been established to:

- provide recommendations and advice to Scottish Ministers, by request and proactively, on the policy and practice options being developed.
- Inform, engage and take collective action on key issues identified that require national strategic leadership in response to Coronavirus.
- Work in partnership to ensure that the needs of the represented vulnerable populations are considered.
- Provide timely feedback from Scottish Government to stakeholders on key policies and initiatives relevant to vulnerable populations.

The DALDG will work alongside Scottish Government to:

- Be sighted on and consider issues and proposals
- Raise concerns or issues to inform the agenda for discussion
- Feedback the partnership position on issues

4. Roles and Responsibilities

In facilitating continued and strengthened Partnership Working during the pandemic, the DALDG members will ensure their respective constituencies are engaged and their views represented, including:

- those with lived experience
- Families and carers of vulnerable populations
- Employee's
- Professionals

The Chair of the DALDG will:

- Report action points and any concerns from the DALDG meeting to the Minister for Mental Health
- Report actions and discussion points from the Scottish Government to the DALDG.

In the event that the DALDG are unable to achieve assurance or resolution, the Chair of the DALDG will be able to escalate the concern to the Cabinet Secretary for Health and Sport via the Scottish Government Director of Health and Social Care.

5. Membership

Name	Representative Group and Title	Contact
Nick Ward	Director, National Autistic Society Scotland	[REDACTED]
J Pearson	XXX, Alzheimers Scotland	[REDACTED]
Charlene Tait	Deputy Director, Scottish Autism	[REDACTED]
Charlie McMillan	Director, Scottish Commission for Learning Disabilities (SCLD)	[REDACTED]
Kirsty Gilchrist	XXX, Inspiring Scotland	[REDACTED]
[Redacted]	Strategic Lead, Scottish Government	[REDACTED]
Jan Savage	XXX, Enable	[REDACTED]
H Simmons	XXX, Alzheimers Scotland	[REDACTED]
Theresa Shearer	XXX, Enable	[REDACTED]
Julia Abel	XXX, Inspiring Scotland	[REDACTED]
Frank McKillop	XXX, Enable	[REDACTED]
Rob Holland	XXX, National Autistic Society Scotland	[REDACTED]
Hugh McAloon	Deputy Director Mental Health, Scottish Government	[REDACTED]
Kenneth Fleming	XXX, Scottish Commission for Learning Disabilities (SCLD)	[REDACTED]
Allison Crawford	XXX, Inspiring Scotland	[REDACTED]
[Redacted]	Dementia Policy, Scottish Government	[REDACTED]

[Redacted]	Autism and Learning Disabilities Policy, Scottish Government	[REDACTED]

6. Chair

XXX, Scottish Government

7. Decision Making

Members will engage in open and honest discussion to support decision making.

8. Frequency of Meetings

The frequency of meetings will be reviewed on an ongoing basis but will be scheduled fortnightly. Meetings will be scheduled for 3 pm on Thursdays.

9. Papers

- A call for agenda items will be issued by 18:00 on the Tuesday prior to the weekly Thursday meeting.
- An agenda will be issued on the morning of the meeting by 10:00.
- An action note, including key decisions, will be drafted by the secretariat and issued prior to the next meeting.

Any papers provided from the Group to Scottish Government Ministers or officials will become subject to the usual FOI requirements. This means that any e-mails, notes, initial or formative advice and communications to Scottish Government Ministers or officials, would immediately become Scottish Government documents for the purposes of FOI. The Scottish Government can apply exemptions to withhold certain information, for example if policy is still being formulated, but may not be applicable for other types of information. Documents withheld for policy development reasons are likely to become appropriate for release in the future, once policy in this area is fully formed

10. Confidentiality

Confidentiality with regard to discussion of sensitive information should be observed at all times. Information and papers sent to Group members are intended for viewing by those members only. There should be an assumption that papers will contain Official Sensitive level information and thus should not be shared with colleagues or third parties, either in hard copy or electronically, and their content should not be discussed outwith the Group. Only papers which have been explicitly marked for wider distribution should be disseminated further.

11. Behaviours and Expectations

All members are expected to contribute to achieving the purpose of the Group, operating within the following expected standards of behaviour:

- Contributing information and resource to achieving the goals of meetings and agenda items
- Promoting open discussion by sharing information in a timely manner with due respect for others
- Maintaining confidentiality regarding sensitive information
- Attend the majority of meetings
- Observe good time keeping
- Take individual responsibility for engaging and completing tasks delegated to them

Participation in the Group will not be remunerated.

Meetings will be attended by named members, and support workers if required, only. Substitutes will usually not be accepted, apart from by prior agreement with the Chair.

12. Lifespan

The Group will function for the duration of the period that the Scottish Government is stood up on an emergency footing in response to Coronavirus (COVID-19) including the exit strategy formulation phase.

The Group will review its Terms of Reference on an ongoing basis and 6 months from approval.

Terms of Reference Agreed:	
Signature:	_____
Date:	_____

Key Information

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Approver	Coronavirus Dementia, Autism and Learning Disability Stakeholder Group (DALDG)
Approved by and Date	
Contact	[Redacted]
File Location	

Revision History

Version	Date	Summary of Changes	Name	Changes Marked
v0.1		Initial Draft.		
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Approvals

This document requires the following signed approvals:

Version	Date	Name	Role	Signature

Distribution

This document has been distributed to:

Version	Date of Issue	Name	Role / Area

Coronavirus weekly Dementia, Autism and Learning Disabilities Stakeholder meeting

BRIEFING

Date: 04 June 2020

Time: 1500 hrs

Location: [Microsoft Teams meeting link](#)

APOLOGIES

- Apologies from:
 - Minister MH
 - Hugh McAloon
 - Charlie McMillan (Kenneth Fleming attending)
 - Nick Ward (Rob Holland attending)

AGENDA ITEM 1 - MATTERS ARISING FROM 28 MAY 2020:

[REDACTED]

AGENDA ITEM 2 – CONTINUATION OF TRANSITION AND RECOVERY DISCUSSION

- **Feedback from Kirsty G (IS) from the LD subgroup:**

Priorities

- **Inclusive economic recovery** – any skills and investment planning throughout Scotland needs to consider people with LD from the very start.
 - E.g. Fair Start partner/fund local LD specialist employment organisations to ensure consistent coverage for people with LD
- **Digital Exclusion** – those who have no access to hardware or to broadband/data and/or the skills or agency are not having their voice heard during these times. A clear strategy to overcome digital exclusion for people with LD is needed.
- **Overcoming all barriers to statistics gathering for people with LD**, including identification of those with PMLD, or Downs Syndrome within those stats.
- Once in a lifetime opportunity for **system redesign that is all inclusive, collaborative co-designed with individuals, families, organisations** present in local communities acting as brokers, drivers and advocates
- Legislation that encompasses support to live life as a citizen

Underlying principles

- Human Rights approach to underpin everything
- Accessibility in all forms of communication (digital and offline) from the start – including for those with complex/ sensory needs
- Everything is done with the involvement from the very beginning of individuals/ families for everything –
- All people with LD have the right to and access an authentic adult life – to study, work, accommodation, relationships etc. as an assumption
- Rebuild the capacity of society/ the new world to be accessible and inclusive – if that's right, then everything else will fall into place

AGENDA ITEM 3 - EMERGING ISSUES:

[REDACTED]

AGENDA ITEM 4 – ANY OTHER BUSINESS

[REDACTED]

END

Coronavirus Dementia, Autism and Learning Disabilities Stakeholder meeting

READOUT

Date: 18 June 2020

Time: 1500 hrs

Location: [Microsoft Teams meeting link](#)

APOLOGIES

- Minister for Mental Health

ITEM 1 - Matters arising from 04 June 2020

[REDACTED]

ITEM 2 – Continuation of Transition and Recovery Discussion

- Discussions continued on the Transition and Recovery theme. Coronavirus has fundamentally changed almost all areas of society. Coronavirus recovery will likely continue for the next 12 to 18 months, possibly beyond.
- Recognizing where people have coped well, while acknowledging there are those who haven't
- Where collaborative efforts between Dementia, Autism and Learning Disabilities exist and where there are limitations.
- There is a need for the SG to identify what work will continue, what is paused and what new work will be required
- How can we capture innovation from Coronavirus
- How Mental Health can influence the education and employment issues faced by our populations
- How to balance the public health need against the right to a meaningful life
- **SG to produce a more formal document which captures these points and issues.**

ITEM 3 - Emerging Issues:

[REDACTED]

ENDS

Coronavirus Dementia, Autism and Learning Disabilities Stakeholder meeting

READOUT

Date: 02 July 2020

Time: 1500 hrs

Location: [Microsoft Teams meeting link](#)

APOLOGIES

- Minister for Mental Health
- Hugh McAloon, Deputy Director

ITEM 1 - Matters arising from 18 June 2020

[REDACTED]

ITEM 2 – Continuation of Transition and Recovery Discussion

- SG discussed that the priority would not be on the production of strategies over the next few months, but instead on new services. This was supported with the “transition and recovery slide July.pptx” document.
- SG described a shared vision exists across Dementia, Autism and LD about the right support in the right setting at the right time.
- SG explained new activity will be on rights based principles with an emphasis on equalities.
- *Dementia* – suggested priorities around services and supports recovery, social care reform agenda, palliative care and modernization.
- *Autism* – suggested priorities around advice and support, mental health, social isolation and loneliness and exploring a commissioner. Continuation of national campaign work, Pre and post diagnosis support, education and employment and training of professionals.
- *Learning Disabilities* – suggested priorities around accessible information, mental health, social isolation, digital exclusion, restarting day services, carer resilience and delayed discharge. Continuation of work around annual health checks, Coming Home work, Gender based violence, restraint reduction and PBS and employment.
- SG explained importance of resilience of the 3rd sector throughout.
- There was agreement around the need to recognize and grow the contribution the 3rd sector makes, and recognize the immediate challenges around finances. Regional and national level has seen how 3rd sector has stepped up in this crisis and we must recognize and help them grow. Glasgow University (Nick Watson) is doing research on impact of covid on 3rd sector.
- There was discussion on how to gather evidence within 3rd sector and how to inform funding decisions going forward. Risk of creating or continuing inequalities if this isn't done right.
- Discussion on the short-termism within funding and sustainability should be a factor, not just resilience. Require to consider sustainability of core services as well as innovate on new ones.
- **Group to consider what data/evidence would be appropriate**
- **SG to seek input from 3rd sector colleagues to help shape discussion**
- Agreement around importance of connectivity and collaboration. Will require engagement of COSLA. It was recognized there is an opportunity to celebrate the collaboration that has already occurred.
- Discussion around perceived unaccountability of HSCPs and difficulty in accessing decision makers.
- **IS to share strategic conversation document.**
- Importance of considering international learning and evidence.

- Discussion and agreement on the need for more defined work on data collection and visibility of our populations within data.
- Discussion around document displaying an aspiration to transform. A flourishing life requires a flourishing sector.
- SG confirmed plans to publish a document for wider engagement. There was agreement this supports accountability and transparency.

ITEM 3 - Emerging Issues:

[REDACTED]

ENDS

Coronavirus Dementia, Autism and Learning Disabilities Stakeholder meeting

READOUT

Date: 16 July 2020

Time: 1500 hrs

Location: [Microsoft Teams meeting link](#)

APOLOGIES

- Minister for Mental Health
- Hugh McAloon – Scottish Government
- COSLA

ITEM 1 - Matters arising from 02 July 2020

[REDACTED]

ITEM 3 – Continuation of Transition and Recovery Discussion

- SG explained that Ministers have requested that Dementia has a separate document to Autism and Learning Disability. Members agreed they were relaxed about the documentation of the objectives but were keen to continue practical collaborative working on common goals over the course of the Transition and Recovery period.
- The timeline of the document was discussed – **SG to send out draft framework for comments with deadlines.**
- SCLD mentioned the benefit of completing a Human Rights and Equality Impact Assessment.
- **SCLD to share Article 31 documents.**
- The vision was discussed, and suggested edits were proposed. **Vision to be agreed via email.**

ITEM 4 – Any other Business

[REDACTED]

ENDS

Coronavirus Dementia, Autism and Learning Disabilities Stakeholder meeting

READOUT

Date: 30 July 2020

Time: 1500 hrs

Location: [Microsoft Teams meeting link](#)

APOLOGIES

- Minister for Mental Health
- Hugh McAloon – Scottish Government

ITEM 1 - Matters arising from 16 July 2020

[REDACTED]

ITEM 2 - Emerging Issues:

[REDACTED]

ITEM 3 – Continuation of Transition and Recovery Discussion

- A first draft will be submitted to Ministers imminently. Next steps will be to consult further we will seek further comment as part of a wider consultation. Members agreed with the importance of autistic people and/or people with learning disabilities being involved in the launch.
- Members will note that a Human Rights approach is central to the new framework.
- Dementia will be dealt with under a separate plan.

ITEM 4 – Any other Business

[REDACTED]

ENDS

Coronavirus Dementia, Autism and Learning Disabilities Stakeholder meeting

READOUT

Date: 13/20 August 2020

Time: 1500 hrs

Location: [Microsoft Teams meeting link](#)

ITEM 1 - Matters arising from 30 July 2020

[REDACTED]

ITEM 3 – Continuation of Transition and Recovery Discussion

- SG explained that a further round of consultation was occurring prior to a submission being sent to the minister based off initial internal feedback. An additional extra-ordinary meeting was held on Thursday 20th August to facilitate this discussion.
- Members were thanked for their comments so far and those who had not yet submitted comments on the revised draft agreed to share with all members. There were broad comments around consistency of language and a re-ordering to put Human Rights front and centre in the framework.
- There was discussion around the proposal of a Commissioner. Members agreed that this proposal underpinned all other themes within the framework and was a priority. Members wished for a stronger form of words committing SG to implementation. SG explained that the lifetime of the plan was 18 months and it wouldn't be possible to implement a commissioner in this time. There were also nuances around political handling. Members requested a meeting with the Minister in order to discuss this in further detail.
- Members highlighted the desire for Human Rights to be reworked throughout the document, and framed specifically to people with Autism/LD.
- ADHD requires some context, once its inclusion is explained it makes sense.

ITEM 4 – Any other Business

[REDACTED]

ENDS

Coronavirus Dementia, Autism and Learning Disabilities Stakeholder meeting

READOUT

Date: 27 August 2020

Time: 1500 hrs

Location: [Microsoft Teams meeting link](#)

ITEM 1 – Update on Scottish Government Structure

[REDACTED]

ITEM 2 – Review of deliverables

- Members broadly welcomed the changes to the transition documents.
[REDACTED]

ITEM 3 – Review of workplan

- SG explained that although there was an initial rush to complete the document to avoid it being lost in a 'sea' of recovery plans across government, it doesn't appear as if this is happening. This affords the group extra time to refine the document.
- Members broadly agreed that the transitions document was almost at a stage members would be happy to take forward.
- SG explain that authority had been granted to scope out a transitions framework, but further authority would need to be sought to move onto the next stage
- It was agreed for a final round of refinement to take place, followed by presentation to the Minister. Following receipt of feedback, it is intentioned to move onto a round of external consultation prior to a loose publication date of early November.

ITEM 4 – Membership

[REDACTED]

ITEM 4 – Any other Business

[REDACTED]

ENDS

Coronavirus Dementia, Autism and Learning Disabilities Stakeholder meeting

READOUT

Date: 24 September 2020

Time: 1500 hrs

Location: [Microsoft Teams meeting link](#)

ITEM 1 – Emerging Issues

[REDACTED]

ITEM 2 – Review of Framework

- Members were in broad agreement that the framework was now ready for further consultation, and SG confirmed they would submit to Minister for Mental Health for initial feedback.
- This would then be taken forward for a round of SG internal consultation followed by external with stakeholders.
- Members discussed the lifetime of this strategy, with broad agreement that an extension to 2 years would be beneficial, taking the Framework to 2023 and allows a more realistic timeframe for some of the bigger commitments. However, the ‘quick wins’ should be time-bound much sooner to provide confidence that change is happening and progress is being made.
- Members discussed the benefit of a delivery/tactical plan to run alongside the framework, with potential for a joint programme approach. This will be progressed when the Framework is further developed. This plan would allow differentiation between tangible changes versus cultural ones.
- Members agreed SG should develop a presentation ‘pack’ to run alongside the framework to assist with the consultation.

ITEM 3 – Consultation

- Members were shown two options for potential consultation. The [Consultation Platform](#) allows for a set Question and Answer format. [Dialogue Platform](#) allows for members to vote and submit ideas and for a commentary to run alongside.
- Members were asked to consider which/if these platforms would work for their members and to consider issues around digital exclusion, how long a consultation should run for and what type of information would be useful for developing the framework further. Members discussed that hard mail copies would be needed. Members highlighted a number of channels already exist to support advertising of the consultation. This will be discussed in more detail in later meetings.

ENDS

Coronavirus Dementia, Autism and Learning Disabilities Stakeholder meeting

READOUT

Date: 08 October 2020

Time: 1500 hrs

Location: [Microsoft Teams meeting link](#)

ITEM 1 – Emerging Issues

[REDACTED]

ITEM 2 – Review of Framework

- Members discussed the Transitions and Transformation Framework. SG explained this was still with the Minister awaiting comments although preliminary feedback had been around making the achievements stand out and a need to highlight the transformational nature of the document.
- Members highlighted that the transformation will come from lived experience during the engagement stage.

[REDACTED]

ITEM 3 – Consultation

- Members reviewed the options paper from SG on consultation options.



Engagement
options paper.docx

- Members agreed that option 3, a blended approach with shorter timescales, would best serve the needs of our populations. Members were keen that the facility to submit new ideas was possible, but similarly that people who wished to submit detailed feedback were also able to. There will be a need to conduct some form of offline engagement for those who are digitally excluded.
- This would require careful planning as the presentation of some recommendations could be critical to useful and meaningful engagement on them.
- **Members to begin planning on how they will assist with an engagement exercise.**
- **SG to develop an engagement plan for discussion.**

ENDS

Transition and Transformation Framework: Leadership Group Discussion

14/12/2020



Transition and Transformation Framework: Leadership Group Discussion

- Clarity of language and definitions
- Plan needs a solid identity
- Focus on the human rights and transformation aspect
- Designing authentic engagement with people with lived experience
- We need to work together better than before

Clarity of language and definitions

- Rewrite terms that might be problematic for people with live experience
 - 'melt down'
 - 'Able'
 - 'Ability'
 - Carer's 'bearing the weight'
- Will the plan include just people in social care or everyone with autism/LD
- Need to check over the stats for consistency and clarify them

Plan needs a solid identity

- Approach must be informed by people with lived experience opposed to us informing them about it.
- Need to be clear on the balance of transition and transformation (recovery not liked so much as a term)
 - Transformation must be clear for human rights to be realised
 - Transition is important in understanding the new context and worsening situation of people with LD and autism as a result of the pandemic.
- Currently unclear what the plan is (strategy, bridging plan, recovery), timescale's and what comes next.
- Need to be clear on what comes next
- Need to be clearer on the timescale's
- Need to be clearer where the wider autism and LD strategies and work comes into the picture.

Focus on the human rights and transformation aspect

- Transformation should focus on realising human rights
- Ensuring that there are choices
- Need to be careful not to set too high expectations on transformation
 - Need more time to engage with people about what transformation would mean to them.
- Transformation lacks detail and could be fleshed out (i.e. self directed support)

Designing authentic engagement with people with lived experience

- Need to undertake facilitative inquiry to listen deeply to lived experiences (including harder to reach people)
 - Testimonies
 - Advice line data
 - listening exercises
- Risk in the plan of doing the same things we always do.
- Lack of lived voice in the plans engagement e need to stand back and listen

We need to work together better than before

- We need to break the SG internal silos
- We need to take into account we all have lower energy right now.
- We know the usual 'what'
 - We lack the hows
 - Need to know what the what's look like in our new context we live in.
- For example the increase in mortality rates
- We should not make the what call ourselves - we need more voices
- Need to consider what might come up as we move out of covid