



**Alzheimer
Scotland**
Action on Dementia

**Prevent.
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ndcan
National Dementia Carers
Action Network



The Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN), supported by Alzheimer Scotland, welcome the opportunity to respond to the proposed Disability Commissioner Bill.

SDWG and NDCAN welcome the proposed Disability Commissioner Bill. The underlying principles of promoting and protecting the rights of disabled people are both commendable and without reproach. The proposed Disability Commissioner Bill presents an opportunity for the rights of disabled people to be upheld in a fair and equal way, and for the voices of disabled people, including people living with dementia, to be heard. The Bill seeks to address the barriers and inequalities faced by disabled people, an approach reflected in the work of SDWG and NDCAN.

It is widely recognised that the needs of disabled people often go unmet, and that disabled people often face significantly greater inequalities in all areas of their lives. For people living with dementia, these challenges were highlighted by the Covid-19 pandemic since they were disproportionately negatively affected by the virus and the measures put in place to prevent its spread. The needs and rights of disabled people have fallen behind those of other protected groups in the drive for equality. SDWG and NDCAN acknowledge the need for a greater focus on meeting the needs and rights of disabled people, including people with dementia.

Framework for the proposed Disability Commissioner

It is important that the Disability Commissioner has autonomy to exercise their role, free from undue influence and pressure from other authorities, organisations or individuals. SDWG and NDCAN members agree that the Disability Commissioner should remain independent of the Scottish Government. This will allow the Commissioner to act impartially in the best interests of disabled people and to avoid any potential conflict of interest in the delivery of its functions.

It is essential that the Disability Commissioner is held accountable for their actions or inactions to ensure the effectiveness of the role and the delivery of its aims. SDWG and NDCAN agree that the Disability Commissioner should report directly to the Scottish Parliament and be subject to scrutiny that serves to ensure the Commissioner is achieving their objectives.

Additionally, it is important that the Disability Commissioner is transparent in delivering the work defined in the description of the role. An open approach to communicating with the disabled people it works with is vital, and a process of regular reporting and the provision of updates would be both helpful and welcome to keep disabled people and the wider public informed about their work and progress.



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Definition of Disability

The proposed definition of disability in the Bill is broad and largely inclusive, representing all types of disability. While SDWG and NDCAN welcome an inclusive approach to recognising disability in all its forms, members of both SDWG and NDCAN have reservations about the scope of the proposed Disability Commissioner and the ability for them to represent individuals across such a broad spectrum of disability effectively. We are concerned that the representation of people with dementia will be diluted and will become lost in the delivery of a service that is too big and unable to recognise the uniqueness of a condition such as dementia. We also have concerns that physical disability may take precedence over hidden or fluctuating conditions, such as dementia, that are less easily identifiable as disabilities and that are often perceived to be a lower priority.

The perception of dementia as a disability has long been a difficult issue to resolve. Dementia is not always recognised by people, including people living with dementia, as a disability. As such, SDWG and NDCAN are concerned that access to support from the Disability Commissioner may be impacted by this interpretation of disability, or the degree of perceived disability, by those most in need of the support offered by the Commissioner. The issue of awareness needs to be addressed to ensure that the proposed legislation provides the accessibility needed to those who might otherwise be unsupported and unrepresented.

Additionally, the proposed definition of disability must be clear about the inclusion of individuals who do not have a confirmed diagnosis of an illness or condition that would otherwise, by the existence of health or care needs, be determined as a disability. For example, many people experience symptoms of dementia long before reporting concerns to a medical professional, and for some, the path to a confirmed diagnosis is long and complex. Delays in diagnosing dementia have also become greater since the pandemic. As such, it may take a significant period of time for a confirmed diagnosis to be achieved but individuals may experience disability, and the challenges and barriers associated with being disabled, prior to that time. It is important that individuals with challenging health issues are recognised as being disabled, even without the label of a diagnosis. SDWG and NDCAN are keen to ensure that the definition of disability is both clear and inclusive.

Legislative Approach

Scotland is recognised as having some of the most innovative and progressive legislation in the world and has a strong record in placing human rights at the heart of its policy and legislation. However, the failure to implement and deliver the legislation makes it difficult to achieve the intended policy outcomes. Disabled people must still overcome challenges including barriers to services, employment and resources, regardless of the laws and strategies aimed at reducing inequalities and tackling discrimination. The lack of accountability and governance for existing policies and frameworks, to ensure



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that they are implemented and delivered effectively and consistently, means that the existing legislation is not achieving its aims in terms of both outputs and outcomes for disabled people.

SDWG and NDCAN agree that a new, legislative approach is required and must provide a robust framework to ensure that the Disability Commissioner is able to implement the enforcement and governance of existing policies to better meet the needs of disabled people. A Disability Commissioner would have a role in ensuring consistent and effective implementation of existing policies through a process of accountability, and it is essential that the enforcement and governance role of the Disability Commissioner is clearly defined and, most importantly, enacted. Action must be taken where policy is not delivered in practice, or providers fail to implement legislated measures. The Scottish Parliament will also have a responsibility to act on the Disability Commissioner's reports as part of the accountability framework.

Scope of the Disability Commissioner Role

The Disability Commissioner needs to have the power to inform and influence policy and legislative responses on behalf of disabled people. Policy drives transformational change so the Disability Commissioner must be able to inform and influence change at a level that creates the opportunity for the largest impact for the largest number of people. The Disability Commissioner will have a role in promoting the rights of disabled people, as well as acting as an advocate for disabled people in facilitating change. As such, it is essential that the Disability Commissioner is able to review and respond to policies and law affecting disabled people as a method of representing the views and reflecting the needs of the people they serve.

SDWG and NDCAN believe that the Disability Commissioner should promote and encourage best practice and shared learning between service providers, key stakeholders and the third sector. The Commissioner should be able to enforce the implementation of guidance and frameworks established on the basis of best practice through a process of accountability. Existing disabled people's organisations have established relationships with specific disabled people communities and are able to reflect the needs and wishes of their stakeholders so must be involved in the communication of best practice and shared learning. Importantly, the voice of lived experience is also needed to inform best practice. The experience of individuals who are in receipt of services or resources is essential in offering insight into the successes and failures in respect of meeting their needs.

SDWG and NDCAN support the Disability Commissioner's right to investigate Scottish Public Bodies and service providers. There can be no restriction in their ability to carry out investigations in ensuring that the rights of disabled people are protected, and that inequalities or discrimination are challenged. Investigative powers would serve as a further tool in the framework for governance and accountability. SDWG and NDCAN would expect that the Disability Commissioner will only carry out investigations with



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good cause, and in a fair and equal manner, and that guidelines for investigative powers would be developed to ensure that investigative powers are used appropriately.

Clarity needs to be sought in the ability of a Disability Commissioner to work alongside other organisations that hold existing powers for upholding disability rights. It will be vital for the Disability Commissioner to have in place agreements or memoranda of understanding with existing organisations that share a similar remit to avoid the duplication of work and to facilitate the co-operation and collaboration between the organisations, where necessary.

The Voice of Lived Experience and the Third Sector

SDWG and NDCAN strongly advocate for the inclusion of the voices of lived experience in developing and influencing the role of the Disability Commissioner. As member-led organisations, SDWG and NDCAN provide an opportunity for individuals to find unique, powerful, and innovative ways to use their own voices and to represent the collective voice of their respective communities of people living with dementia and their carers in Scotland. This consists of active voices, quieter voices, and hidden voices. We recognise our ability to influence change through our campaigning work and awareness-raising which is driven by our desire to tackle stigma and inequalities. We believe that these voices need to be heard by the Disability Commissioner to enable them to understand the real-life challenges of living with a disability, or supporting someone living with a disability, and to act in response to those issues and concerns.

The third sector plays an essential part in providing the support required to ensure that the rights of disabled people are protected and that their needs are met. The Disability Commissioner cannot replace the work of individual disabled people organisations but needs to work in collaboration with organisations on various issues. SDWG and NDCAN are supported by Alzheimer Scotland, the leading dementia charity in Scotland. Alzheimer Scotland has a clear and focussed understanding of the issues affecting people living with dementia and their carers, and uses its knowledge and influence to represent those groups of people. The Disability Commissioner must utilise that specialised knowledge and understanding to be informed about the condition-specific issues that affect people. Given that the role of the Disability Commissioner will be to represent individuals across the disability spectrum, the value of condition-specific knowledge held by various disabled people's organisations will be vital in informing the work of the Disability Commissioner, as well as recognising that the third sector brings many solutions to issues within the health and social care sector. The Disability Commissioner can have confidence in the role of third sector organisations, and member groups such as SDWG and NDCAN, in campaigning to keep the needs of people affected by condition-specific issues on the agenda.



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Financial Implications

SDWG and NDCAN recognise that there will be a cost implication for the introduction of a Disability Commissioner, however, it is one that is necessary to meet the needs of disabled people and to enforce their rights. SDWG and NDCAN believe that the Scottish Parliament should meet this cost and allocate a proportionate budget that enables a Disability Commissioner to carry out their functions to the best of their ability, without the prohibition of budgetary constraint. This includes allowing for sufficient resources, including employed staff, to enable the Disability Commissioner to deliver an effective service that meets the needs of disabled people. The cost-effectiveness of the Disability Commissioner can be measured against outcomes for disabled people, not just in financial benefit but also in improvements in quality of life through access to services and increased participation.

Nonetheless, SDWG and NDCAN believe it is important that appropriate measures are taken to minimise costs wherever possible, and that the Disability Commissioner is fiscally accountable. The Disability Commissioner has a duty to protect the public purse and should make responsible spending decisions. Resources should be shared wherever possible without compromise to the delivery of services.

SDWG and NDCAN are keen to consider any future proposal regarding the budget allocation for the Disability Commissioner.

Equalities & Sustainability

The underlying principles of the proposed Bill ensures that disabled people are treated fairly and equally, and not to the detriment of any other protected characteristic. We believe that consideration should be given to how accessibility to the Disability Commissioner can be practicably achieved for people of all backgrounds to achieve equality of access.

If the Disability Commissioner can achieve their aims, including reducing stigma and tackling discrimination, then SDWG and NDCAN recognise that the proposed Bill can achieve a more “just society” for future generations.