



INCLUSION IRELAND

National Association for People with an Intellectual Disability

Submission to the Department of Public Expenditure and Reform

**On 'Our Public Service 2020: Public Service
Development and Innovation Framework'**

September 2017

**This document is written in font 12 Verdana in line with Inclusion
Ireland plain English guidelines.**

1. About Inclusion Ireland

Established in 1961, Inclusion Ireland is a national, rights based advocacy organisation that works to promote the rights of people with an intellectual disability.

Inclusion Ireland uses a human rights-based approach to its work. This recognises persons with an intellectual disability as rights holders with entitlements, and corresponding duty bearers and their obligations. Inclusion Ireland seeks to strengthen the capacities of persons with an intellectual disability to make their claims and of duty bearers to meet their obligations.

The vision of Inclusion Ireland is that of people with an intellectual disability living and participating in the community with equal rights as citizens, to live the life of their choice to their fullest potential. Inclusion Ireland's work is underpinned by the values of dignity, inclusion, social justice, democracy and autonomy.

2. Introduction

Inclusion Ireland welcomes the opportunity to contribute to the Department of Public Expenditure and Reform's (DPER) consultation on the reform and development of the public service.

The public service in Ireland includes a broad range of organisations, including civil servants in government departments, teachers, health and social care workforce, the Gardaí and local authority workers. People with disabilities interact with the public service on a daily basis so it is important that the public service can meet their needs.

2.1 Proposed Public Sector Development and Innovation Framework

The Department of Public Expenditure and Reform have developed a draft framework for the development of the public sector. Three high level goals have been identified:

1. Delivering for the public
2. Innovating for the future
3. Developing the people and organisations of the public service

This submission identifies the key actions that can deliver on these three high level goals for people with disabilities.

3. Delivering for the public (Goal 1)

Inclusion Ireland has identified the following key actions that would support the more effective and efficient delivery of quality, accessible services to disabled members of the public.

3.1 Move to a commissioning model

The Public Sector Reform Plan contained a commitment to explore a commissioning model as an alternative method of delivering human, social and community services. DPER commissioned a review of the evidence on commissioning and engaged in a public consultation process with a view to developing a commissioning model. However, progress on this seems to have stalled since late 2015.

Services for people with disabilities are currently funded through block grants to large service providers. People with disabilities have little or no say in how this money is allocated or spent. As a result, people with disabilities are forced to accept services and settings that are unsuitable and do not take into account their wishes.

Disability services were funded €1.7bn in 2017. A Value for Money and Policy Review of Disability Services was unable to determine whether there is value for money from this spend¹. Much of it is spent on models of service provision that do not support community inclusion, choice, control or independence for people with disabilities.

Inclusion Ireland is campaigning for a change in the way services are funded beyond the traditional block grant system. Commissioning is a cyclical process by which public bodies assess the needs of people in an area, determine priorities, design and source appropriate services and monitor and evaluate their performance.

Good commissioning should work within a societal value framework²³. This means that public money should be spent on services that maximise values, such as equity, accountability or quality.

¹ Department of Health, *Value for Money and Policy Review of Disability Services*, 2012.

² *Programme for Partnership Government*, 2016.

³N O'Connor, *Commissioning for Communities* (Dublin, 2016).

Effective commissioning could result in better outcomes for people using the service; give people more choice and control and increase the quality of services.

Recommendations:

- Replace block grant funding with a model of commissioning for outcomes for all human, social and community services and establish an independent commissioning body
- Collect and publish the data needed for commissioning to succeed, including data disaggregated by gender, ethnicity and disability
- Ensure the funding of services is linked to positive outcomes for people using those services and supports the public good
- Involve people with disabilities at all stages of the commissioning cycle so that they are involved in making decisions about what services are needed as well as evaluating the effectiveness of them

3.2 Implement a model of personal budgets

The Value for Money and Policy Review of Disability Services recommended the restructuring of disability services in Ireland through personalised supports and more effective systems of resource allocation. Internationally, personal budgets are acknowledged to result in better outcomes for persons with disabilities.

The Programme for a Partnership Government commits to 'devolve budgets to the person'. This step is taken "in recognition that personalised budgets provide an individual with more control in accessing services, giving them greater independence and choice".

The Task Force on Personalised Budgets, established last year, will report by the end of 2017. The National Disability Inclusion Strategy commits to "examination of the recommendations of the report of the Personalised Budgets Task Force, with a view to introducing the option of availing of a personal budget as one approach to individualised funding".

Inclusion Ireland has compiled a document outlining the essential principles of personal budgets. These include that personal budgets should be available to all persons with disabilities regardless of age or complexity of needs, should be cross-departmental, should be outcomes

focused and should be flexible and responsive, changing as circumstances change through the lifespan.

Recommendation:

- Make a personal budget available to all persons with disabilities, irrespective of age or complexity of support needs

During Inclusion Ireland’s consultation on the development of the public sector, we received the following feedback on how public services can be more effective and efficient

- As with all people, people with disability prize autonomy. Giving the option of personalised budgets is the direction public services must go with an understanding of the rights and preferences of the individual first and foremost
- Individualised funding and personal budgets is the only effective way forward
- Allow additional time to explain clearly to the person what’s happening. Not everything has to be rushed.

3.3 Provide high quality, accessible and responsive public services

During Inclusion Irelands consultation with our stakeholders on this submission, the need for high quality, accessible and responsive public services emerged as one of the key issues.

3.3.1 Quality, responsive services

From our advocacy work, we are familiar with a number of instances where public sector organisations have failed to demonstrate awareness of equality issues or of the rights of persons with disabilities. It is important that all those working in public sector organisations have training on human rights and equality as well as the specific needs of different customers. All those working in the public sector should also be aware of their obligations under the Public Sector Duty.

Decision making on social welfare applications provides an example where there is much scope to reform practice to deliver a better service to the public. The quality of first instance decision-making in 2016 regarding

Disability Allowance, Domiciliary Care Allowance and Carer's Allowance was so poor that over 50% of these decisions were overturned on appeal, either wholly, partially or by a revised initial decision.

In the case of Disability Allowance, 72% of appeals taken to the Social Welfare Appeals Office were overturned on appeal. This is a worrying statistic due to the fact that it took over 17 weeks for an appeal on Disability Allowance in 2016. These persons, entitled from the beginning to a payment, were placed in a financially precarious position as a result of the poor decision-making within the Department of Social Protection (DSP).

Greater resources and training for DSP staff regarding the eligibility criteria and their application in decision-making to Disability, Domiciliary and Carer's Allowance would result in a more equitable service for persons with disabilities and their families. Improvements to the accessibility of the application process, through the provision of plain English and easy to read forms and information as well as a more user friendly process, would support the public in making their initial application, in line with meeting the public-sector duty.

3.3.2 Accessibility

Public services and public spaces should be physically accessible to all members of the public. However, people with disabilities experience many physical barriers to their full enjoyment of the community, such as lack of accessible transport or public spaces or lack of accessible toilet facilities.

Universal design refers to designing and building environments that can be accessed, understood and used by all people to the greatest extent possible regardless of their age, size or disability. It is a fundamental condition of good design rather than a special consideration for a minority of people. The principles of universal design should be incorporated at all levels of Ireland's planning strategy.

Standard disabled toilets do not meet the needs of all people with disabilities. Changing Places facilities are different from mainstream accessible toilets in that they include both a hoist and a height-adjustable changing bench. They have been designed to put health, safety and dignity concerns of the person with a disability to the fore. Access to toilet facilities is a basic requirement for people to be able to access public services.

As well as physical accessibility, there is a need for information to be accessible to all. Information on public services, websites, application forms, brochures, complaints processes and all other forms of information should be made available in a range of accessible formats.

Information should be communicated in plain English as standard but also available in easy to read formats, ISL, braille and in video formats. The publication of the Department of Social Protection's 'Make Work Pay' report in all of the above formats provides an example of good practice in this area. Government department and public sector agencies should issue information on policy changes and any updates in accessible formats.

The consultation document outlines plans to make more public services available online. While providing online access to services such as Revenue or Passports Online can be convenient for some people, it is not a suitable mechanism for everyone.

Information from the Census indicates that people with disabilities are less likely to use the internet than non-disabled people. They are more likely to use in-person services rather than online services⁴⁵. It is important therefore, that digital services do not replace in-person services.

Where online services are provided, they must be accessible to persons with disabilities. Websites should be less text-heavy and should use plain English at a minimum. Websites should also incorporate accessibility features such as the website being responsive to the width of a person's screen (mobile phone, laptop, tablet or desktop etc.) and suitable for use with screen-readers; use of images so people can easily navigate around website; and installing Texthelp's BrowseAloud App that offers digital accessibility features.

Recommendations:

- Ensure all public services staff are aware of human rights and equality issues and are actively promoting rights and equality, in line with the Public Sector Duty
- Use Universal Design principles in design of public spaces

⁴ CSO, *Census 2011: Our Bill of Health*, 2011.

⁵ National Disability Institute, *Banking Status and Financial Behaviors of Adults with Disabilities* (USA, 2017).

- Changing places, fully accessible toilets, should be installed across the country in both urban and rural areas.
- Provide information in a range of accessible formats including plain English, easy to read, audio and video
- Provide online services as an option to access public services rather than a replacement for in-person services
- Consult with the public on the usability of online services and allow a broad range of persons to test them before they go live

During Inclusion Ireland's consultation on the development of the public sector, we received the following feedback on how public services can deliver better service to people with disabilities

- Use people with disabilities in training for customer service
- People with disabilities are people first and should be treated with respect and not treated as stupid or an inconvenience
- Have their access officers work with all disabilities and get training on people with intellectual disabilities
- Easy read information. More pictorial aids.
- Accessible websites with audio versions of info/forms
- Wherever there's online booking for something, always be obliged to include people with disabilities in that. No music venue lets you book a wheelchair space if you're using a wheelchair, nor does Irish rail. It's a terrible nuisance and is discriminatory.
- If a person looks for information, give it through the medium they contacted in. For example, if a person emails, reply by email instead of "give us a ring". That is a constant problem I find.
- Ease of access needs priority. Sometimes the red tape involved in applying and receipt of allowances is a huge problem for people with disabilities as well as assisting carers.

3.4 Engage and consult with people with disabilities

The goal of the public services reform plan 'Our Public Service 2020' is to deliver better outcomes for the public. Providing opportunities for people with disabilities to have their voices heard and to participate in decision making would help to ensure that the reforms actually address their needs.

In a recent comparison of the performance of Ireland's civil service with others around the world, Ireland scored lower than average on the degree of consultation with citizens on decisions taken by the civil service⁶.

Few public consultations are accessible for persons with intellectual disabilities. Many are publicised online only and most are in inaccessible language and formats. There is often a relatively short turnaround time for submissions which means that representative organisations like Inclusion Ireland have limited time to consult with stakeholders.

Participation and consultation should be genuine and not tokenistic. Currently, participation for people with disabilities and their families is minimal at best. Working Group 3 of the Transforming Lives programme (set up to implement the recommendations of the Value for Money and Policy Review of Disability Services in Ireland), have developed a plan, entitled 'Ordinary Lives in Ordinary Places' – a plan for effective participation in decision making for people with disabilities and families.

The plan will help support the emergence of decision making fora for people with disabilities and families and will support them to participate in decision making at local, regional and national levels. The plan provides a useful model for all public sector bodies in their engagement with people with disabilities.

Recommendations:

- Use various mediums for communicating about public consultations, not just online. Advertise in community spaces like libraries and primary care centres
- Publish consultation documents in a variety of accessible formats, such as easy to read, and accept submissions from the public in a variety of formats

⁶ InCiSE, *National Civil Service Effectiveness Index 2017*, 2017.

- Implement the recommendations from Ordinary Lives in Ordinary Places report and use as a model of good practice

During Inclusion Ireland’s consultation on the development of the public sector, we received the following feedback on how public services can engage better with people with disabilities

- Guarantee that the voices of people with disabilities are included on committees, reviews, boards and in the review of services
- Provide adequate support for the participation of people with disabilities to speak/be heard.
- Require easy to read information as a basic standard
- Need a national programme to develop self-advocacy
- Include people with intellectual disabilities

4. Innovating for the future (Goal 2)

Inclusion Ireland has identified the following key actions that would help to build a better public service for the future.

4.1 Make use of evidence and evaluation

A key element of planning, designing and providing public services is the gathering and analysis of data to inform planning. There are currently large gaps in the availability of evidence to inform planning. The Value for Money and Policy Review of Disability Services was unable to determine if value for money was being achieved as there was insufficient data to demonstrate efficiency and effectiveness.

Though longitudinal studies such as Growing Up in Ireland and the Irish Longitudinal Study on Ageing provide useful sources for evidence, there are gaps in data, including the lack of availability of data disaggregated by disability, gender or ethnicity.

Other important data sources such as the national measure of poverty (the Survey on Income and Living Conditions) underestimate poverty

among people with disabilities. Measurements of poverty based on income underestimate poverty among people with disabilities since for a given income level, people with disabilities have additional costs not taken into account.

Having accurate data on the number of people with disabilities experiencing poverty and the level of poverty experienced is key to implementing effective policies. Introducing disability-adjusted poverty and inequality estimates and equivalence scales would increase the accuracy of this data. This involves adjusting downwards, the incomes of households/individuals with specific needs.

The success (or failure) of policies or programmes should be measured and this evidence should be used to change how services are delivered in order to achieve better outcomes for members of the public. Measuring the success or failure of policy should focus on measuring outcomes for the public and users of services and those using services should be involved in the evaluation process.

Recommendations:

- Collect data disaggregated by disability, gender, ethnicity and make available through DPER's Open Data Portal
- Disability proof collection of data on poverty by the Central Statistics Office to determine more accurate level of poverty among people with disabilities
- Monitoring and evaluation should be components of all policies and programmes
- Develop indicators at the outset as an evaluation tool to measure impact of services.
- Involve people with disabilities in the evaluation of services. Use qualitative as well as quantitative methods of measuring impact

4.2 Plan for future population needs

According to the Central Statistics Office (CSO), the population of over 65's is set to double in less than 30 years. The CSO estimates that there will be about 20,000 more people over the age of 65 every year until 2040⁷.

⁷ Department of Housing, Planning, Community and Local Government, *Ireland 2040: Our Plan. Issues and Choices Consultation Paper*, 2017.

There is a strong link between ageing and acquired disability. Among people in their twenties, less than 10% have a disability. The likelihood of having a disability increases with age and is over 20% by age 60. From age 70 on, rates increase more sharply with 75% of all women aged 85 and over having a disability⁸.

In keeping with general population trends, people with intellectual disabilities are also living longer. While this is good news, it has an impact on policy and service provision. Future planning needs to take into account this growing population of people with disabilities and their support needs.

Health and housing are two examples where public services need to plan for future need: With regard to health, research shows that people with intellectual disabilities are more likely to experience certain health issues than the general population, such as, vision and mobility challenges, a higher prevalence rate for falls, a higher incidence of mental health and emotional health issues and an increased risk of dementia among people with Down Syndrome

In terms of housing, availability of housing is already at crisis point. By 2019, the remaining two to three thousand people currently living in congregated settings across Ireland will need to be accommodated in suitable, community based accommodation, in line with the HSE policy, Time to Move on from Congregated Settings. There are many additional people with disabilities with housing needs across the country.

As well as housing and health services, there is a need to plan for future need across a broad range of public services in order to adequately provide for the population into the future.

Recommendation:

- Use available data to plan for current and future population need.

4.3 Strengthen implementation

A new National Disability Inclusion Strategy for the period 2017-2020 was launched earlier this year. It comes two years after the expiration of the

⁸ CSO. Census 2011.

previous Implementation Strategy for what is widely regarded as a failed National Disability Strategy (NDS) 2004-2015.

The NDS made a series of commitments but none of them were fully implemented. The Education of Persons with Special Educational Needs Act has not been fully commenced; the Personal Advocacy Service under the Citizens Information Act has not been established and no government department has published a sectoral plan since 2006.

Planning for the implementation of a policy should take place while the policy is being developed. This means that those involved in developing and writing policies need to have the capacity and skills required to do this.

Recommendations:

- All policy documents should be accompanied by clear implementation plan with assigned responsibilities and timescales
- Implementation needs to be adequately resourced and monitored to ensure that actions are being implemented as intended. Progress reports should be published annually
- People with disabilities need to be involved in the implementation and monitoring of policy.

4.4 Strengthen whole of government collaboration

Disability is a complex area of policy and practice, responsibility for which does not easily fit into the role of one organisation or government department. Like all people, people with disabilities have health, education and employment needs, require social welfare payments, and have transport needs.

Working in a 'whole of government' way is necessary to achieve the positive outcomes desired across these different areas of public policy. Government departments and public bodies that work in silo's act as a barrier to reform. Political commitment, joined-up government structures, a culture of collaboration and incentives to collaborate are all important factors that support whole of government working.

Despite the commitment to mainstreaming and whole of government working, few government departments seem to have successfully

included people with disabilities in their strategies, policies, or activities. This can be seen in the lack of representation of people with disabilities in the strategic plans of some government departments. Despite many commitments to disability-accessible transport in the Programme for Government, there is no mention of how these will be implemented in the Department of Transport's strategic plan 2016-2019.

Joined up working is recognised as a key theme in the recently published NDIS. However, very few actions in the strategy involve mainstream partners. If joined up working is operating effectively, there would be less need for specific disability strategies as mainstream strategies would meet the needs of all people, including those with disabilities.

A commitment to ensuring that people with disabilities are reflected in the Strategy Statements of each government department would go some way towards addressing this.

Recommendations:

- People with disabilities should be reflected in the Strategy Statements of each government department
- Each government department should have an implementation group for the National Disability Inclusion Strategy with overall responsibility for implementation resting with the Department of An Taoiseach

5. Developing people and organisations (Goal 3)

Inclusion Ireland has identified the following key actions that would help to ensure that the organisations of the public sector and the people working in them have the right approach and the right skills to deliver quality public services.

5.1 Promote equality, diversity and inclusion

The public service is not currently representative of the population it serves. The need for the public service to employ more people with disabilities emerged strongly during Inclusion Ireland's consultation on this submission.

Just over 13% of the population of Ireland has a disability⁹. According to the most recently available data, 3.6% of workers in the public service had a disability in 2015¹⁰. The Comprehensive Employment Strategy for People with Disabilities commits to ensuring that 6% of the public service workforce is made up of people with disabilities by 2024. Government needs to make significant efforts towards increasing the employment of persons with disabilities in the public service if this target is to be met.

The Public Sector Duty under Section 42 of the Irish Human Rights and Equality Commission Act, 2014 requires public bodies in Ireland to promote equality, prevent discrimination and protect the human rights of their employees, customers, service users and everyone affected by their policies and plans. It is a positive duty. This means public bodies must move beyond reacting to discrimination or rights violations after they have happened and towards eliminating discrimination and working towards equality and the fulfilment of rights.

Recommendations:

- Resources should be provided for the full implementation of the Comprehensive Employment Strategy
- All those working in public organisations should receive training on human rights law, equality law and on their obligations under the Public Sector Duty
- All public sector bodies should carry out an equality and rights audit of their organisation, and publish an equality and rights statement
- Public bodies should report on the implementation of their equality and rights statement as part of their strategic plan and annual reporting mechanisms.

⁹ CSO, *Census 2016, 2017*.

¹⁰ NDA, *Report of Compliance with Part 5 of the Disability Act 2005 for 2015, 2017*.

During Inclusion Ireland's consultation on the development of the public sector, we received the following feedback on how public services can promote equality, diversity and inclusion

- Employ them and make their workplaces fully cater. That way, there's already some awareness rather than a sense of 'other'.
- Meet the Public Sector Duty on employment of people with disability at a county by county wide level. Provide and give adequate support for employment to be maintained.
- Through staff education, knowledge of the Disability Act and that all citizens have the same rights irrespective of disability, social standing, religion or race
- Talk to the person and don't assume their carer or support worker is automatically their voice.
- Provision of adequate supports for inclusion mitigates the disability. Disability is created when supports are not provided.

5.2 Reform public service culture and values

Through our advocacy work, Inclusion Ireland has met many people with disabilities who have told us about the culture and deep power imbalance that exists between people with disabilities and public bodies such as the HSE, and government departments. They have reported feeling powerless when negotiating services and supports or when trying to claim their rights and entitlements.

There is a need for a fundamental shift in the culture of public services; from a top down, hierarchical approach to one where the person, the family and the community is at the centre.

The National Disability Inclusion Strategy (NDIS) 2017-2020 makes a number of commitments aimed at changing culture. There is a commitment to the development and roll out of a reform and culture change programme under the objective of ensuring that people with disabilities are treated with dignity and respect and free from abuse.

There is also a commitment to changing the model from one of “care” to one of “support” to achieve independence. This is welcome and is more reflective of the social model of disability.

Reforming culture requires the engagement of multiple stakeholders, including people with disabilities, service provider staff and management, commissioners of services, government departments and regulatory and professional bodies. It should be driven by values and underpinned by principles of equality and human rights.

The Public Sector Duty has the potential to drive cultural change in the public sector as it emphasises rights and equality and requires that these are part of the ongoing work of the organisation.

Recommendations:

- The commitment in the NDIS to implement a culture change programme led by the HSE and disability service providers should be broadened to include non-disability service providers and other stakeholders.
- All public sector bodies should develop and publish own values statement in consultation with stakeholders. Annual reports should evidence how these values are upheld through the work of the organisation.

During Inclusion Ireland’s consultation on the development of the public sector, we received the following feedback on the culture and values for public service

- Myths and stereotypes need to be broken. People must be seen as adults, specifically people with intellectual disability. The infantilisation of, or constant child syndrome beliefs have to be broken. A good place to begin with is understanding of Article 19 on the UN Convention on the Rights of Persons with Disabilities.
- Equity needs to drive public services
- Inclusion should be a priority
- Fairness, equity, forward planning
- Leave nobody behind. If people need something, they need it. people should never be viewed as ‘difficult’ for complaining
- A kind and inclusive public service. Compassion, rights based, enabling.

5.3 Staff capacity and skills

An understanding of human rights law, equality law and the Public Sector Duty should be a requirement for the public sector workforce. Other general skills and capacities include customer service skills, how to produce easy-to-read documents, evaluation skills, writing in plain English and intercultural awareness.

Through our consultation with stakeholders on this submission, basic skills like listening, communication skills, patience and empathy emerged as being of key importance to people with disabilities.

Changing legislative and policy contexts mean that there is an ongoing need for public sector workers to have an understanding of new developments. The implementation of the Assisted Decision Making (Capacity) Act 2015 has implications for those working in health and social care as well as other public sector staff who interact with people with disabilities.

Changes to the law on safeguarding of vulnerable people, the implementation of a patient safety, complaints and advocacy policy and the establishment of a patient advocacy service will all require changes to practice in many public services.

The NDIS has identified that a change is required in the approach to supporting persons with disabilities from a model of care to one of support. The changing roles and demands that this kind of reform makes on frontline workers must be acknowledged and these workers must be supported to adapt to their new roles.

Recommendations:

- Training for all public services staff in human rights and equality law and policy
- Provide ongoing training and capacity building on changes in law and policy. Include people with disabilities in the delivery of the training as they are experts by experience
- There is a need for a conversation with a broad range of stakeholders, including unions, professional and regulatory bodies, as well as disabled persons organisations, advocacy groups and disabled people themselves, on the skills required to support people with disabilities to live independent lives in the community

During Inclusion Ireland’s consultation on the development of the public sector, we received the following feedback on the skills public services staff need to do their jobs well for people with disabilities

- Easy to read helps some, but they also need to know other methods of effective communication and empathy
- Irish Sign language in conjunction with Lámh would be powerful assets in any public service office
- A thing that has been lost in a lot of staff, the ability to listen and have empathy
- Time, patience, flexibility and compassion

6. Summary of recommendations

1. Move to a commissioning model of service delivery, based on outcomes and values
2. Implement a system of personal budgets so people with disabilities can choose the services and supports most appropriate to them
3. Ensure that all staff in the public services have disability, human rights and equality training and are familiar with the requirements of the Public Sector Duty
4. Ensure the accessibility of both physical spaces and information and communications
5. Use recommendations from Ordinary Lives in Ordinary Places as a model for engagement with persons with disabilities
6. Increase collection of data, make it publicly available and use to plan for future population need
7. Strengthen the implementation of policies and programmes. Involve persons with disabilities in evaluation

8. Strengthen whole of government working. Ensure that persons with disabilities are reflected in the strategy statements of government departments and other public sector organisations.
9. All public sector organisations should carry out a rights and equality assessment of their own organisation and develop, promote and implement their own equality and rights statement, underpinned by values
10. Ensure that the public services staff understand and implement new laws and policies like the Assisted Decision making (Capacity) Act. Ensure that staff have the capacity and skills to support persons with disabilities to live independent lives in the community.