The Right to Live
INDEPENDENTLY
Pre-Budget Submission 2020
Irish Wheelchair Association is Ireland’s leading representative organisation and service provider for people with physical disabilities. With our 20,000 members, over 2,500 employees, 57 local community centres and 2,000 volunteers, we are a groundswell of people across Ireland calling for the rights of people with physical disabilities to be met.

Irish Wheelchair Association has a vision of an Ireland where people with disabilities enjoy equal rights, choices and opportunities in how they live their lives, and where our country is a model worldwide for a truly inclusive society.

Budget 2020 provides this Government with a chance to listen and to respond to the needs of people with physical disabilities in their communities, homes and lives. We urge you to meet the needs of Ireland’s citizens and to join us in building an inclusive and accessible Ireland.

In 2018 Irish Wheelchair Association:

- Provided 1.3 million hours of Assisted Living Service to 2,246 adults and children.
- Managed 43 wheelchair accessible and affordable homes.
- Connected people with their communities through our fleet of 119 accessible buses.
Executive Summary

Our Three Recommendations for Budget 2020:

1. **Assisted Living Services:**
   Commit to carrying out a comprehensive piece of work involving the Central Statistics Office to establish the unmet need for personal assistant services. Allocate a budget for personal assistant services that allows people with disabilities to have their quality of life based on their rights and choices, rather than available funding. See page 6.

2. **Social Housing:**
   Ensure that all social housing projects supported by capital funding from the Department of Housing, Planning and Local Government deliver 7% of integrated wheelchair accessible social housing units. See page 12.

3. **Transport:**
   Commit to wheelchair accessible transport across all transport services – taxis, buses, and trains. See page 16.
MEET
NIAMH NÍ RUARI

Niamh Ní Ruari (25) is a young mother of one and a budding journalist. Niamh is living with an extremely rare form of cancer called central nervous system neurodegenerative langerhans cell histiocytosis or LCH for short.

Born in the UK, Niamh developed an early form of this condition when she was just three years old. She was diagnosed and treated in Manchester. She was later diagnosed with a neurodegenerative condition at age 13 years and became a wheelchair user when she was 18 years old.

Niamh graduated with a degree in Journalism in 2017 and is currently seeking to enter the workforce. A bright, chatty and determined woman with a two-year-old toddler and loving partner, she is keen to be a strong voice for others. To achieve this, she needs to know that the Irish Government and political representatives are behind her to create the conditions that will enable her to reach her potential.

To thrive and live an independent, happy life, Niamh needs personal assistance hours that are tailored to fit her life and support her independence. This will be even more vital if she gains employment and balances this with parenting. She needs to be able to travel freely, independently and spontaneously, and she needs a home in which she can raise her family that is adapted to her wheelchair and mobility specifications.

Niamh isn’t asking for much. As a citizen of Ireland, she’s asking for the kinds of services that able-bodied people take for granted, services that will break down barriers, so that one day it won’t matter that she uses a wheelchair.

Read more about Niamh’s life throughout this report and about how you can support her in turning her hopes and rights into a reality.
Niamh and her personal assistant, Meilan Xu, cook pasta together. Niamh’s personal assistant service is vital for her to carry out household tasks for her family.
Irish Wheelchair Association is one of the largest providers of assisted living services for people with physical disabilities in Ireland, which is funded by the HSE.

Assisted Living Services, carried out by skilled personal assistants, is the cornerstone, foundation and life blood of community services for people with disabilities. This service not only assists with tasks that people with disabilities cannot do for themselves, but also supports people to engage fully in their community, to live independently, progress with further education and for many to take up employment.

Personal Assistants provide the arms and legs for people with disabilities and are essential to ensure that they can live equal and independent lives alongside their peers.

Niamh needs more personal assistant hours.
Like any new parent, adapting to life with a baby was incredibly joyful for Niamh, combined with the usual lack of sleep and learning curve.

Doing all of this from a wheelchair added an extra challenge. Niamh was allocated a personal assistant, who has proved vital in supporting her to carry out household tasks so that family life is stable and organised.

Niamh, her partner Yeff, who is Colombian, and her two-year-old son Ethan, live in her parent’s house, alongside her brother. Yeff is in college studying horticulture and both her parents work, so during the day Niamh needs a personal assistant to tackle chores she finds difficult to navigate. Niamh is assigned fourteen hours a week of personal assistance. That equates to less than three hours a day, Monday to Friday.

“I feel that I need more hours,” she says. “When the baby came, everything was everywhere. And he’s not a small baby anymore, he’s a toddler.” Ethan now goes to creche, which gives Niamh a small window of time to get the shopping, tidy or sort laundry with her personal assistant.

It’s important that she keeps as mobile as possible to build her strength up and she exercises on a Motomed self-peddling bicycle at home, with help from her personal assistant. She also attends a weekly medical appointment in Beaumont Hospital and Irish Wheelchair Association’s gym to be weighed.

With so many appointments and a small child, every minute she has with her personal assistant is precious.

Niamh thinks the reason behind her limited allocation is because she lives at home with her parents and that even though they work, they are counted as available carers.

“My Mam works in town and my Dad’s work is based at home, so they think that he can attend to my needs, but that’s not the case. When he’s upstairs working, he’s working. But the HSE doesn’t see it that way, which is frustrating.”

“The HSE thinks if you’re living at home, your family can help you. But my family is working.”
There is a major problem in the way the Government sees or understands what a personal assistant service is. This service is not home help, it is not a care package, but a way of life that enables a person with a disability to do all the things you and their peers take for granted. Irish Wheelchair Association constantly sees the HSE trying to stretch hours in the personal assistant service due to the chronic lack of investment.

Individuals who receive a sufficient personal assistant service can:
- Live independently with dignity and respect
- Participate in everyday activities similar to their peers e.g. work, social, sports etc
- Contribute, both financially and through participation to Irish society

Individuals who don’t receive a personal assistant service or receive an inadequate service can be:
- Depending on family members, often ageing parents, to support them, removing their opportunity to live with dignity and respect
- Individuals living in environments, which are unsafe due to their disability
- Confined to live behind their own front door, never having the opportunity to interact with their community
- Individuals who have no opportunity to participate in society or take up employment

People who do not have an adequate personal assistant service are discriminated against by society and treated as second-class citizens. They are condemned to live without the basic supports required to live a life of freedom and choice and without access to many of their human rights.
People with disabilities are now living longer in their communities and therefore require additional support. Personal assistant services have continuously been ignored by consecutive governments with no meaningful additional funding being put in place to support the growing needs and demand for the service.

Irish Wheelchair Association, as a leading provider of personal assistant services for people with physical disabilities, estimates that over 60% of individuals currently receiving personal assistant services require significantly more hours than they’re receiving. There is a vacuum of verified data in relation to the number of people who actually require this service.

**In Budget 2020 the Government must:**

- Commit to carrying out a comprehensive piece of work involving the Central Statistics Office to establish the unmet need for the personal assistant service

- Allocate a budget for the personal assistant service that allows people with disabilities to have their quality of life based on their rights and choices, rather than available funding

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United Nations Convention on the Rights of Persons with Disabilities Article 19 specifically mentions **PERSONAL ASSISTANCE** stating that:

‘Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance.’
Personal Assistant Services

Niamh with her partner Yeff O’Sullivan and personal assistant Meilan Xu
Getting onto the property ladder is challenging for any young person, but when your accommodation requires specific circulation space and accessibility because you are using a wheelchair, it adds a whole new level of complexity.

On top of that, people with physical disabilities face many extra barriers, which can affect educational opportunities and contribute to unemployment and a lack of income.

One of the core values promoted by Irish Wheelchair Association is independence; the aspiration and belief that people with a physical disabilities in Ireland can achieve their right to an independent life with equal access to opportunities, services and supports within their communities. Consequently, people should have the right to a home of their own.

Yet people with physical disabilities have always faced obstacles to finding suitable accommodation due to the lack of forward planning for including fully wheelchair accessible social housing with appropriate design within a set number of units in all social housing projects.
Niamh has lived at home with her parents and brother all her life, but now with two new family members, her partner and her son, space has become tight. “The house isn’t fully adapted, so it’s not comfortable with so many people there now.

“There are a lot of marks in the house from hitting into things,” says Niamh. “I need to be very careful with the chair. I bash into the kitchen and sitting room doors.”

Niamh joined the social housing list after she had her baby in 2016. She was recently contacted about a possible house in North Dublin, but has yet to see if it suits her needs.

Despite having a third level education, Niamh will bear the additional burden of discrimination, as she continues to search for a job, in addition to managing her health. Being able to afford a house of her own, while facing these challenges, would be out of reach.

There are many people with disabilities who have been waiting for up to ten years or more for an appropriate, accessible home. Their voices must also be heard and their rights met.

In total there are 5,095 people with disabilities waiting for suitable social housing. In 2016, people with disabilities were the single largest group in need of housing.

“The house isn’t fully adapted, so it’s not comfortable with so many people there now.”

Niamh is hoping for a wheelchair accessible home in which she can raise her young family
In Budget 2020 the Government must:

- Ensure that all social housing projects supported by capital funding from the Department of Housing, Planning and Local Government including Part V and Regeneration Housing, deliver an agreed 7% of integrated mainstream social housing units that are wheelchair accessible to an agreed best practice design standard as demonstrated by Irish Wheelchair Association.

1. The Minister for Housing, Planning and Local Government must direct local authorities to review their approved social housing lists and identify the number of people/households who require wheelchair accessible housing

2. The Minister for Housing, Planning and Local Government must direct every local authority to maintain a register of all wheelchair accessible social housing in their area and occupancy status

3. In consideration of identified housing needs and emerging needs due to the ageing population the Minister for Housing, Planning and Local Government must direct that all local authorities should require every social housing pipeline project to demonstrate at Capital Appraisal Stage the inclusion of a minimum 7% of fully wheelchair accessible housing, which would increase based on the approved housing list and the demand in the area

Irish Wheelchair Association is offering to work with the Minister to establish targeted procedures to achieve the above outcomes.

United Nations Convention on the Rights of Persons with Disabilities Article 28 on Adequate Standard of Living and Social Protection states:

“that governments must ensure access by persons with disabilities to public housing programmes.”
Transport is key to people with physical disabilities realising their independence. When it comes to holding down a job, socialising or going on holidays, just getting there can often be the greatest challenge to overcome.

Deputy Tommy Broughan TD recently highlighted the disappointing response received from the National Transport Authority and Department of Transport on their commitments to improve accessibility of public transport. According to his research, it would take less than €125 million to make public service buses and trains wheelchair accessible.
Niamh and her personal assistant Meilan wait for a bus. Niamh sometimes waits for two hours to get on a bus after her medical appointments as there is no room for her wheelchair.
Niamh needs a transport system that doesn’t discriminate

Niamh’s weekly hospital appointments are a regular part of her life. She’s currently undergoing chemotherapy to treat her condition. Unable to drive, she relies on public transport when she leaves the house. Getting on a bus is something Niamh does not look forward to, as she never knows whether she will be allowed to board.

“I have been refused to get on the bus a number of times, because one wheelchair user might be on the bus, or a pram that isn’t folded up,” she says. “I have been refused coming home from my hospital appointments at the stop outside Beaumont Hospital. They only come once an hour, so I could be waiting two hours for a bus.”

Many people would get a taxi, rather than sit for two hours at a cold bus stop. But that freedom isn’t possible for wheelchair users like Niamh.

“Numerous times my partner and I have been in town and have been hoping to get a taxi home,” she says. “You cannot flag one down...If I am in my powerchair, which I always use when I am alone, I can’t get a taxi.”

Living in Dublin, Niamh doesn’t use the train service too much. But she recalls a recent trip to Maynooth. “I booked the wheelchair space online but there were lots of people getting on. They took up the wheelchair space. They saw me but didn’t care and there was no one to tell people not to stand there.”
In Budget 2020 the Government must:

**Taxis**
- Apply extra weighting to taxi operators with accessible vehicles in tender processes when awarding State contracts.
- **Manage the €1m subsidy scheme** currently awarded to taxi operators, who purchase accessible vehicles through the National Transport Authority, to increase a nationwide spread of accessible taxis.
- **Set a target that 15% of all taxis should be accessible by 2020.** Currently 10% of the fleet is accessible.

**Bus Éireann**
- Commit funding for a nationwide network of accessible coach stops to be in place by 2020 alongside ongoing purchase of accessible coaches. At present, 86% of Bus Éireann coaches are wheelchair accessible. Yet little or no truly accessible coach services are currently running due to the lack of accessible coach stop infrastructure.

**Irish Rail**
- **Funding to ensure a fully wheelchair accessible rail service that provides for freely available ramp systems and on hand staff support to guarantee access to trains and allocated wheelchair spaces.** Many trains and train stations continue to provide significant barriers for commuters with disabilities. There are many unmanned stations around the country and commuters with disabilities are faced with the uncertainty that ramps or space will be available when they arrive at the station even with 24 hours notice, stopping people with disabilities making travel plans spontaneously or in emergency situations.

**Benefits**
- Reinstate the **Motorised Transport Grant** and **Mobility Allowance** to assist in covering the cost of transport. Six years ago, the Government withdrew the Motorised Transport Grant and the Mobility Allowance with the promise it would be replaced with a new scheme. People with disabilities are still waiting.

Both of these schemes are vital to people with disabilities at a time when our public transport system and infrastructure is still not fully wheelchair accessible. People with disabilities rely on taxis where possible to get to hospital appointments and their local post office especially in rural areas and the mobility allowance and motorised grant went part of the way to cover these costs or help someone buy their first car.

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**United Nations Convention on the Rights of Persons with Disabilities**

Article 9 on accessibility asserts that

“member states enable persons with disabilities to live independently and participate fully in all aspects of life. State parties shall take appropriate measures to ensure persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications.”