

# General Election 2024

A New Social Contract for Care: 10 Pledges for Family Carers





#### WHO CARES?

Across Ireland, 500,000+ people provide unpaid care for a family member, friend or neighbour who is affected by long-term illness, disability, older age or has additional care needs. Thousands of us take on new caring responsibilities every day – it can happen unexpectedly, or gradually, but almost all of us will experience care at some point in our lives.

Over the last decade, the number of carers and the volume of care they provide has increased substantially. Since 2011, the Census has recorded a 60% increase in the number of people who provide unpaid care and the number of people who care for more than 43 hours per week has more than doubled. The value of unpaid care is now worth a staggering €20 billion a year - almost equivalent to the annual budget of the HSE, and without which our health and social care systems would collapse.

#### INTRODUCTION

On November 29th, the Irish people will vote in a General Election. The 174 men and women elected to the 34th Dáil are key to building an Ireland where family carers are recognised for the immense contribution they make to families, society and the economy; where family carers feel supported not only to cope with the challenges of caregiving but also to have a life of their own alongside their caring role. A life which includes caring but is not overwhelmed by it.

Ahead of the General Election, Family Carers Ireland is urging each candidate and political party to demonstrate their commitment to Ireland's 500,000+ family carers by endorsing our 10 Pledges for Family Carers manifesto. If delivered over the term of the next government, these pledges will help achieve a new social contract for care by creating a society where family carers are properly recognised, fairly compensated for the care they provide, not excluded from support due to their means and have timely access to the services they need when, where and how they are needed.

Help us achieve this by signing up to our 10 Pledges for Family Carers.



#### 10 PLEDGES FOR FAMILY CARERS

- Establish a new nonmeans-tested Family Carer Payment to replace Carer's Allowance.
  - Continue to develop the supports and services available to family carers throughout the country (the 'Carer Guarantee').
- Implement a Respite Strategy guaranteeing family carers access to appropriate and regular respite.
- Reform the Disabled **Drivers and Disabled Passengers Scheme and** introduce a Transport Support Scheme committed to in 2013.
- Abolish waiting lists for **Assessments of Need** and give children a right to the interventions identified in the assessment report.
- Establish a statutory home support scheme that delivers highquality and affordable home care.
- Deliver a plan to realise every child's constitutional right to an education in a place and manner appropriate to their needs.
- Facilitate independent living for disabled people with appropriate choice and control over where, how and with whom they live.

- Support family carers to enter or remain in employment or education if/when they can.
- Guarantee sustainable services for family carers by funding voluntary organisations delivering Service Level Agreements on behalf of Government on a full cost recovery basis.

## 1.

#### Establish a new non-means-tested Family Carer Payment to replace Carer's Allowance.

Even before the cost-of-living crisis, households caring for a child with a profound disability faced additional costs of €244 per week - equivalent to the maximum rate of Carer's Allowance.¹ The cost-of-living crisis that has unfolded since this research was undertaken has created a much bleaker outlook for family carers. Many are now unable to afford sufficient food, heat or their utility bills and are turning to unsustainable solutions to cope, such as falling into debt, cutting back on essentials or ignoring their own medical needs. FCl's State of Caring 2024 report showed that of the 2,127 carers surveyed:

- 39% have a household income below €30,000, much lower than the national average of €55,149²
- 69% struggle to make ends meet (compared to 48% of the general population)
- 29% are cutting back on food and heat
- 71% are cutting back on non-essentials
- 23% have missed at least one mortgage or rent payment in the last year (compared to 7% of the general population).

Calls to end the means-testing of Carer's Allowance and the introduction of a Family Carer Payment have gained traction in recent years. In its Budget 2025 submission, the Oireachtas Committee on Social Protection recommended the abolition of the means test and the introduction of a Participation Income for carers by 2030.3 This call was echoed by the National Economic and Social Council and the Oireachtas Committee on Gender Equality who also recommended the introduction of a Participation Income for carers. In the interim, the Committee on Gender Equality recommended that the Carer's Allowance income disregard be increased and applicants assessed on their individual means, excluding those of their partner. Additionally, private members' motions brought before the Dáil by

the <u>Regional Independent Group</u>, <u>Sinn Féin</u> and the <u>Labour Party</u> calling for the reform or full abolition of the means test have passed unopposed.

FCI believes it is time to overhaul the outdated means-tested Carer's Allowance scheme and work towards a more equitable and genderbalanced Family Carer Payment. This new scheme would not be means-tested and would be set at a rate that values the immense contribution made by family carers and reflects the State's reliance on them.<sup>4</sup> Pending the introduction of a Family Carer Payment, the income disregard for Carer's Allowance should be increased in line with FCI's Roadmap for the Reform of Carer's Allowance to bring more caring households into eligibility.

#### How much will this cost?

In 2024, a Parliamentary Budget Office (PBO) analysis estimated a full-year cost of €375 million to abolish the Carer's Allowance means test.<sup>5</sup> This is in line with the cost estimated by FCI in 2023 of €389m p.a.<sup>6</sup> In July 2024, the Department of Social Protection estimated that it would cost an additional €600m to abolish the means test.<sup>7</sup> Please note these costs were estimated prior to the budget 2025 announcement that income disregards would be increased to €625 (single carers) and €1,250 (couples) in July 2025. Therefore the cost of abolishing the means test will be less than previously calculated.



Respondents who completed the State of Caring 2024 survey identified the abolition of the Carer's Allowance means test as the most important issue they want to see addressed by Ireland's new Government.8

<sup>&</sup>lt;sup>1</sup>MacMahon B., Boylan, H., Thornton R. (2022) Care at Home: Costs of Care Arising from Disability. Dublin: The Vincentian Partnership for Social Justice & Family Carers Ireland.

<sup>&</sup>lt;sup>2</sup> CSO SILC, 2024

<sup>&</sup>lt;sup>3</sup> A Participation Income is a form of State income support that enables and values certain forms of unpaid work. It is similar to a Universal Basic Income however the main difference is that individuals have to do something societally valuable in exchange for the money they receive. Care work is often referenced as one of the most deserving forms of unpaid work suited to a Participation Income.

<sup>&</sup>lt;sup>4</sup> For more information, see FCI and Maynooth University's report '<u>Towards a Participation Income for Family Carers'</u>.

<sup>&</sup>lt;sup>5</sup> Parliamentary Budget Office reference 2024-001-01

<sup>&</sup>lt;sup>6</sup> FCI (2023) <u>'Estimating the Cost of Abolishing the Carer's Allowance Means Test'.</u>

<sup>&</sup>lt;sup>7</sup> Estimate provided to Deputy Pauline Tully.

<sup>&</sup>lt;sup>8</sup> State of Caring 2024.



#### Implement a Respite Strategy guaranteeing family carers access to appropriate and regular respite.

FCI believes all full-time family carers should have access to the regular and appropriate respite needed to sustain a healthy balance between caring and personal wellbeing. Access to regular, quality respite is repeatedly identified as a priority by family carers and should be viewed as integral to carer support. It is deeply concerning that family carers have no entitlement to respite, meaning many care full-time, 365 days a year, without a break.



of respondents to the State of Caring 2024 survey have never received respite.

There is currently no central database that records respite provision, either nationally or regionally. This system failure is compounded by the transient nature of respite which can see a respite place re-designated as a step-down, rehabilitation or transitional care bed as needed by the HSE. A further complication is the increasingly prevalent role private companies play in respite provision.

FCI believes that the only way to establish a solid evidence base for a meaningful Respite Strategy is to create a dynamic model of respite supply and demand across the country. This would involve mapping demand for various models of respite by different carer groups (e.g. carers of older people, children with additional needs, adults with a profound disability, etc.). This data would generate a geographic map showing the range of respite capacity available across the country to these carer groups over a yearly cycle. Funding would then be allocated to Regional Health Areas to reflect the number and type of respite places required for older people, children with additional needs and people with a disability.

## 3.

Abolish waiting lists for Assessments of Need and give children a right to the interventions identified in the assessment report.

The 2020 Programme for Government (PfG) pledges to prioritise the delivery of earlier diagnostic interventions, reduce Assessment of Need (AON) waiting times and improve service accessibility.9 However, almost 5 years on and despite increased investment, few children with additional needs or their families have experienced positive change. In March 2024, a record 8,900 children were overdue an AON. Of these, 7,000 had been waiting more than three months.10 In July 2024, 13,403

children were waiting for initial contact with a Children's Disability Network Team (CDNT); 9,008 had been waiting for over 12 months. In 2023, 102,500 children were waiting for a primary care disability intervention. The failure to provide children with early intervention misses a critical window of opportunity, increasing the risk of significant developmental delay and ultimately costs the State exponentially in the long run.

FCI wants the new PfG to commit to vindicating every child's right to a timely AON. Any family that has been forced to pay privately for an assessment should be reimbursed. If the public system cannot meet demand, then the National Treatment Purpose Fund (NTPF) should be extended on an emergency basis to include psychological assessments until waiting lists are cleared. Critically, it is immoral to assess a child's needs without the intention of meeting those needs. FCI wants a commitment to extend the Disability Act to give children not only the right to an AON, but also the right to the supports the assessment report has identified within a specified time period.



#### 4.

#### Deliver a plan to realise every child's constitutional right to an education in a place and manner appropriate to their needs.

Despite having a constitutional right to be educated in a place and manner appropriate to their needs, families across Ireland continue to struggle to secure a school place for their child(ren) both at primary and second level. During the school year 2023/2024, 690 children with special educational needs received home tuition because they did not have a school place. Evidence is pointing to even greater demand for special school places in 2024/2025, with some special schools reporting a doubling in the number of applications they have received, placing even greater pressure on families.

Providing a school place alone does not satisfy the State's constitutional obligation to provide an equitable education to all children. Worryingly, even children who have a school place are being failed as they contend with a lack of appropriate support in school, reduced timetables, a failure to provide essential technology and communication devices and inaccessible school environments. Some children with additional needs have found the school experience so distressing that they avoid school or are not attending at all. FCI wants the new PfG to commit to funding a ten-year plan towards a fully inclusive model of education with therapeutic supports for children delivered within the school environment, where appropriate. Similar to Sláintecare, this plan should have cross-party support and commit to achieving the State's obligation to give every child a right to an appropriate education with all the supports and resources they need, as well as meeting its obligations under the UNCRPD, whether the child is in mainstream or special school.

<sup>&</sup>lt;sup>9</sup> Government of Ireland. (2020). Programme for Government: Our Shared Future. Pg.78. Online. Available at: https://www.gov.ie/en/publication/7e05d-programme-for-government-our-shared-future/
<sup>10</sup> Figures provided by the HSE to Deputy David Cullinane.

<sup>&</sup>lt;sup>11</sup> Figures based on the reply given by the HSE in response to a parliamentary question asked by Deputy Séan Sherlock. <sup>12</sup> Figures based on the reply given by the HSE in response to a parliamentary question asked by Deputy Séan Sherlock.

#### 5.

## Support family carers to enter or remain in employment or education if/when they can.

One in nine Irish employees juggle paid employment with caring responsibilities. The challenges these employees face are stressful and can lead them to reduce their working



hours, forgo promotion opportunities or quit their jobs altogether, with lifelong consequences on their income, career and pension. Similarly, carers who wish to avail of education or training to either support them in their return to work after a period of caregiving or to give them the practical skills they need to provide care safely must be supported. Much more can and should be done to ensure family carers can remain in work or education if/when they are able to do so.

The anomaly of imposing a €450 earnings limit on recipients of the 'non-means-tested' Carer's Benefit scheme should be abolished. The scheme should also be linked to previous earnings, in line with the pay-related benefits systems being rolled out for other schemes. The introduction of five unpaid leave days for medical care purposes in the Work-Life Balance and Miscellaneous Act 2023 is welcome, however it does little to protect the rights of workers who need to take these leave days but can't afford to because they are unpaid. FCI is calling for a statutory payment for employees who avail of the five care leave days on a similar basis to the existing five days allowed for statutory sick pay. Tax credits are an important source of support to family carers in the workforce by reducing their tax liability. Notwithstanding welcome increases to the Home Carer Tax Credit and the Dependent Relative Tax Credit, anomalies remain. We are calling for a commitment in the PfG to address the less favourable treatment of single people and those caring for a non-child relative in current tax provisions. FCI is calling for a continuation of support through the Dormant Accounts Fund to assist carers to return to employment and for an increase in the 18.5 hour ceiling for people in receipt of Carer's Allowance who want to undertake training or education while providing full-time care.

#### 6.

#### Continue to develop the supports and services available to family carers throughout the country (the 'Carer Guarantee').

In 2019, FCI first proposed a Carer Guarantee, aligned with the principles of Sláintecare, to address the postcode lottery in carer supports across Ireland. The assurance of a consistent level of supports for family carers in every part of Ireland would have an immediate practical impact on the welfare and resilience of all carers. It would also directly assist the health and social care system to achieve better outcomes at a lower cost since family carers underpin many health performance metrics such as fewer cancelled hospital appointments; better medication compliance; delayed admission to hospitals and nursing homes; reduced length of hospital stays;

and reduction in hospital readmission rates. FCI is seeking a commitment that, if elected to the next government, you/your party will commit the additional €2.7m in recurring annual funding required to deliver the Carer Guarantee and that the funding will be inflation-indexed.

7.

#### Reform the Disabled Drivers and Disabled Passengers Scheme and introduce a Transport Support Scheme committed to in 2013.



The sudden withdrawal of the Mobility Allowance and Motorised Transport Grant in 2013 following a ruling of the equality tribunal that they were in breach of the Equal Status Act was followed by a commitment from Government that they would be replaced with a new Transport Support Scheme. However, 11 years later, the scheme has still not been introduced. This failure means that for the last decade, the only transport scheme available is the Disabled Drivers and Disabled Passengers Scheme operated by Revenue which is only available to persons with a profound physical disability, with no support available to those with an intellectual or non-physical disability. FCI believes this two-tier system is grossly unfair, could be open to legal challenge and should be resolved through the introduction of an equitable Transport Support Scheme and an overhaul of the overly restrictive Disabled Drivers and Disabled Passengers Scheme.

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#### Establish a statutory home support scheme that delivers high-quality and affordable home care.

For more than 15 years, the Irish people have had to accept an inequitable long-term care system that incentivises nursing home care, through the statutory provisions of Fair Deal, while denying people their preference to be cared for at home due to the discretionary basis of home support. This is despite Article 19 of the UNCRPD and Government policy to support people to live and be cared for at home. Despite a commitment in January 2017 that this long-standing anomaly would be corrected with the introduction of a statutory home support scheme, older people and adults with a disability continue to be forced into residential care settings because the State has failed to deliver on this commitment. FCI, and the other 24 members of the Homecare Coalition, is calling for the urgent introduction of an adequately resourced, rights-based and person-centred statutory home care scheme with equality of access to high-quality, affordable home support services for adults of all ages across the country.



In 2023, Government spent €1.5bn on Fair Deal compared to €723m on homecare.



### Facilitate independent living for disabled people with appropriate choice and control over where, how and with whom they live.

Article 19 of the UNCRPD obliges the State to take effective measures to support people with disabilities to live independently with the support they need. The provision of personalised support services to enable independent living and inclusion in the community is both a right in itself and a precondition for independent living. Disabled people should be able to choose services according to their individual needs and personal preferences, and services should be flexible to meet their needs. Article 19 can only be upheld if it is accompanied by investment in an appropriate mix of housing supports, supported living, universally designed units, home supports, personal assistance services and accessible transport options. Disabled people should not be forced to live with older parents simply because they have nowhere else to go. Similarly, parents of disabled adults should be able to enjoy seeing their child living independently during their lifetime. Where disabled people's right to live independently is violated, then they should have the opportunity to complain to the UN Committee through the ratification of the UNCRPD Optional Protocol.



## Guarantee sustainable services for family carers by funding voluntary organisations delivering Service Level Agreements on behalf of Government on a full cost recovery basis.

Voluntary organisations play an essential role in the delivery of health, social and community services and are a critical component of Ireland's public health and social care system. However, the sector has reached breaking point with many organisations struggling to stay afloat amid rising costs and deepening disparities in pay and conditions between the public and voluntary sector leading to an escalating crisis in the recruitment and retention of staff. The situation has deteriorated to the extent that service delivery and continuance are being jeopardised due to chronic staff shortages. While public sector employees have benefited from pay restoration agreements that rolled back the cuts implemented after the financial crisis, these agreements have, until recently, excluded Section 39 employees, despite the fact they are delivering services contracted by the State. Notwithstanding the pay proposal agreed for Section 39 workers in November 2023, an effective pay indexation process has yet to be achieved, with voluntary organisations continuing to struggle to meet the full cost of services provided, including associated pension and employer PRSI costs. Additionally, the failure to incorporate appropriate indexation in Grant Aid and Service Level Agreements in line with public sector cost increases has left voluntary organisations to bear the brunt of inflation and inevitable increases in the cost of service delivery. In line with the 2023 ruling of the Workplace Relations Commission, FCI is calling for the indexation of Grant Aid and Service Level Agreements and for funding to be provided on a full cost recovery basis, beginning with an immediate 10% uplift across all Section 39 organisations to provide for core costs.







For more information about FCI's General Election campaign and information on how to get involved, please see www.familycarers.ie/generalelection2024

familycarers.ie
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