



Towards a Participation Income for Family Carers

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Summary of recommendations

The following recommendations arise from the findings of the literature review, qualitative interviews, Merging of Knowledge Workshop and policy analysis that was undertaken as part of the research. They focus on what needs to be done to advance a new income support for family care – Family Carer’s Income Support (FCIS). We note the dominant concern that underinvestment in, and lack of adequacy of, services is also a clear priority for family carers, and our recommendations need to be understood in this context: parallel investment in comprehensive services is essential.

- 1. Introduce a Participation Income (PI) based non-means tested Family Carer’s Income Support (FCIS)** for all family carers who fulfil the assessment criteria. This should be fully implemented by January 2027 and paid initially at no less than the contemporary CA rate. As the department with most administrative efficacy in income support, this scheme should be administered by the Department of Social Protection.
- 2. Establish a PI FCIS Implementation Group.** This should begin in 2024 and work to ensure all aspects of legislation, costing, administrative feasibility, communication and eligibility criteria are clearly planned and in place before Budget 2027. The Group should follow co-production principles and include participants reflecting relevant aspects of public administration, family carers and representatives of people in need of additional care. This should begin in 2024 and conclude by 2026.
- 3. Ensure adequacy of PI FCIS by benchmarking and indexing** the payment in line with Commission on Tax and Welfare recommendations. We acknowledge this is complex and requires consideration of both the carer and person in need of additional care as well as (non)availability of services. In progressing this, it is crucial to determine adequacy ‘for who’ and adequacy for ‘what’. We recommend to continue the principle of socially valuing care by maintaining the half rate CA for eligible applicants and by paying 1.5 payments to carers providing care for more than one person.
- 4. Establish a Navigational Operations Group to improve navigational processes** related to applying for and proving eligibility for a new FCIS and for existing payments. This group should follow co-production principles to make practical changes including in communication, training, and processes to review eligibility. Focus needs to be on improving the process of evaluating carers’ time and reviewing eligibility. Membership should include Department of Social Protection (DSP) and HSE officials, Family Carers Ireland (FCI) and other carers’ representative organisations, people in need of additional care, the DSP Chief Medical Officer and GP’s working with people in need of additional care. This should begin in 2023 and conclude in 2024.

Removing (or maintaining) a means test on family income has broad impacts across different equality grounds and particularly gender. These recommendations should be underpinned by gender and equality impact proofing. Campaigns are needed to advance more equal sharing of care across genders, as are work sharing policies to enable care sharing within a gender care parity framework. FCIS should also be underpinned by a social contract between the carer, the person in need of additional care and state institutions. Central to all this is the voice of the person in need of additional care, and the needs of the carer. More social support institutions (linked to HSE and local social services) and access to public employment services and paid labour market institutions, can both maximise social and economic inclusion.



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Section 1

Progressing Policy

Our conclusion on foot of this review is that Carer's Allowance (CA), first introduced in 1990, is in need of fundamental reform. A means tested and taxable weekly payment much like other working aged social assistance payments, CA, rather than a payment that socially values care, is more understood as an antipoverty measure. This research builds upon and progresses initial efforts by the State to acknowledge care and moves policy towards an income support that socially values care. This is an already accepted principle of some family care related payments, for example, the half rate carer's allowance, a unique payment that is paid to persons already in receipt of certain social protection payments¹, the payment of 150% of CA when a carer is caring for more than one person that requires additional care, and other payments including the Carer's Support Grant, Carer's Benefit, or Domiciliary Care Allowance. The recent Commission on Pensions (2022) acknowledged the principle of socially valuing care in recommending that care should be treated as work in respect of pensions provision. Its proposal for enhanced provision for long-term carers (caring in excess of 20 years) to attribute contributions for gaps in their record to the contributory old age pension is due to be introduced in January 2024².

The proposal at the centre of this report is for an adequate income support that recognises the economic and social value of care, and, where appropriate, allows carers to maintain a connection to the paid labour force. However, this significant step change cannot, in our view, be achieved by simply changing or tweaking the CA means test. Instead, this report proposes a fundamental transformation of CA to a **Family Carer's Income Support** as a form of Participation Income (outlined later in the report).

The research informing this transformative proposal examined the challenges experienced by family

carers in accessing CA and in providing care when in receipt of CA. The focus was on developing a proposal for a new form of income support that socially values and rewards family care. The project involved:

- (1) a scoping literature review on socially valuing care, standards of living of family carers and income supports for family carers;
- (2) semi-structured interviews with 19 family carers across Ireland carried out online using the MS Teams platform;
- (3) a merging of knowledge workshop with family carers, experts on income supports for carers, policy makers and civil servants to discuss alternatives to CA and the challenges that would be presented by the development and implementation of a Family Carer's Income Support proposal.

The report reinforces previous reviews that have examined the CA, many of which have acknowledged the significant issues with the means test³. Oireachtas Committee reviews, including the Oireachtas Committee on Gender Equality (2022), have recommended that the means test be abolished or that a new system, based on Participation Income (PI), be introduced. Official departmental reports tend to acknowledge demands for abolition of the means test for CA, while also frequently citing the rationale and purpose of CA as an income support as the primary reason to retain the means test. These reports clearly fear that a more fundamental reform of CA from a means testing perspective may lead to demands for means testing to be abolished across the social protection system (Department of Employment Affairs and Social Protection, 2019; Department of Social and Family Affairs, 2007; Department of Social, Community and Family Affairs, 1998).

1 You are not eligible for the half rate carer's allowance if you are in receipt of the following payments: Basic Supplementary Welfare Allowance (SWA) and SWA Increase for a Qualified Adult; Jobseeker's Benefit; Benefit for people who retire at 65; Jobseeker's Allowance; Jobseeker's Transitional payment; Working Family Payment; Back to Education Allowance; Carer's Benefit.

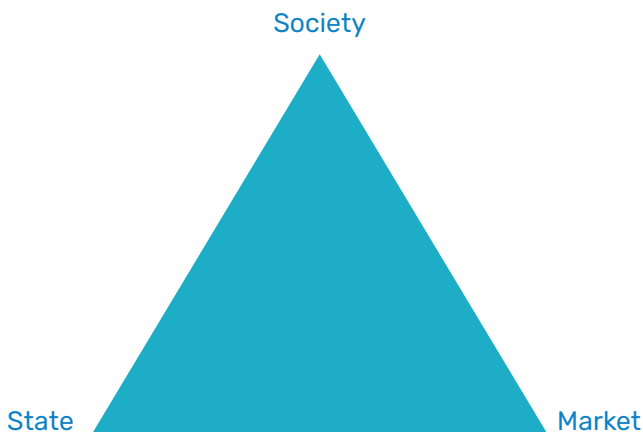
2 http://merrionstreet.ie/en/news-room/releases/minister_humphreys_announces_landmark_reform_of_state_pension_system_in_ireland.html.

3 Joint Committee on Gender Equality, 2022. Annual Carer's Forum 2022, see <https://www.gov.ie/pdf/?file=https://assets.gov.ie/230053/1317e69e-5904-4fc9-a850-a52e729d2b45.pdf#page=null>.

We believe a different approach can ease such fears; breaking the link between CA and working age income support logics including maintenance of incentives to work and replacement ratios.

While this report is focussed on income, it is important to acknowledge that the solution more centrally requires significant investment in services. Recognising the centrality of services, however, this report aims to move beyond debates on reforming the means test for CA to build a new approach, based on PI, that can both socially value care and meet the income support needs of family carers. It does this by recommending a new category of Family Carer's Income Support that clearly sits 'outside the box' of working age income supports.

Figure 1:
State, market, society



The figure above shows the present understanding of Ireland's care economy dominated by state, market and societal institutions, and with a relative lack of visibility of both family and family carers, as well as a lack of focus on people in need of additional care. It sets the scene for understanding how little Irish social policy supported or valued family-based care up to 1990. CA was first introduced in Ireland in 1990 as a payment to address deficiencies in, and eventually replace, the existing problematic Prescribed Relatives Allowance (Department of Employment Affairs and Social Protection, 2019). The 1986 Commission on the Status of Women had recommended that single women working as family carers should have an income in their own right⁴. CA subsequently evolved as a means tested and taxable payment much like other working aged social assistance payments. The 1998 Departmental Review of CA identified one of the objectives of CA was to "recognise and support the valuable role of carers" (Department of Social, Community and Family Affairs, 1998). However, it is now understood as an antipoverty measure rather than a payment to value and reward care. The means test impacts in two ways: the payment is

inaccessible to many and inadequate for most, with significant restrictions that limit capacity to advance in life. In summary, there are growing concerns in relation to coverage, adequacy and impact on paid labour market participation (MacMahon et al, 2022; Harkin, 2023). CA is ill-equipped as an income support for family carers and there is a need for a new income support that socially values and rewards the work of family carers.

The report

- a) Sets the context for progressing abolition of CA means test and development of a new approach to income support for family carers (building on PI).
- b) Reviews relevant literature concerning social valuation of care and family carer's income support.
- c) Centres, through qualitative research, the experiences and views of family carers about income support and CA.
- d) Develops an alternative PI based proposal for a family carer's income support.
- e) Discusses assessment of this proposal in a Merging of Knowledge approach.
- f) Outlines a specific proposal for a PI based **Family Carer's Income Support**.
- g) Makes specific recommendations and time lines for implementation.

Context

How care is provided is of increasing strategic importance in Ireland and elsewhere (European Commission, 2021). The role and practice of family care is presently undervalued in Irish society. The Slaintecare strategy provides a blueprint for a non-institutional approach to supporting care in Ireland, with a focus on community and family-based care (Committee on the Future of Healthcare, 2017). Recent policy processes including the Commission on Tax and Welfare (2022) and the Commission on Pensions (The Pensions Commission, 2021) explored how demographic changes and societal choices will fundamentally reorientate how we imagine the provision of care in the future. Increases in age dependency ratios (Carroll and Barnes, 2023) and other needs, including those of people with disabilities, will be such that community-based rather than institutional care provision will be the primary vehicle for meeting the significant increase in care needs. Census 2022 shows a massive increase in the number of people providing unpaid care in Ireland, increasing by almost 53% to 300,000

4 A social insurance-based Carer's Benefit was also introduced for those leaving employment to provide family care.



Values

As society (correctly) moves from institutional care to a focus on provision of care in the community and/or at home, the role of family carers becomes ever more strategically important as does the ethical and practical need to socially value family care work. Key policy recommendations, detailed in this report, draw on the framework of PI to value care and on the need, as set out by the Commission on Tax and Welfare, to enhance Ireland's capacity to meet the need for public financing of services and income supports, consistent with the principles of **Sustainability, Reciprocity, Adequacy, Equity** and **Efficiency**.

with 87,000 providing at least 43 hours of care per week (up 111% on 2016 figures). Carers are predominantly women, with people in their 50s most likely to be providing care. The Census also found that more than 1.1 million people have some form of disability with 407,342 experiencing a long-lasting condition of difficulty (CSO, 2023). Socially valuing family care is therefore of strategic importance.

The issue of socially valuing care is recognised in the proposed forthcoming referendum on Article 41.2⁵, Irish society is undergoing a re-examination of how it can better socially value, recognise and reward care including family-based care. The recent Citizens' Assembly on Gender Equality acknowledged the risk of poverty experienced by many family carers and the inadequacy of existing social welfare measures (CA, 2021). The Oireachtas Committee on Gender Equality recommended the replacement of Article 41.2, with a focus on the needs of family carers with respect to services and financial support including the introduction of a PI for family carers (Joint Committee on Gender Equality, 2022). The IHREC #CareAboutEquality campaign⁶ and civil society and trade union campaigns also aim to value care. This research is therefore timely and policy relevant.

(Commission on Tax and Welfare, 2022). We examine how a new approach to income support for family care might better support such care work, promote gender equality and the social inclusion of both people requiring additional care and those caring for others.

We also ground the research in feminist care ethics that aim to socially value care by focusing on recognising, rewarding and redistributing care work and that seeks to dismantle the current gendered patterns of care (Klostermann et al, 2022; Daly, 2021). This ethic of care values gender equality and (re)distributing care work more equally between women and men. This can require creative use of time-related policy including shorter working days/weeks, and family-friendly policies. The autonomy, voice and rights of the person requiring additional care must be respected alongside the voice and rights of the carer. A care ethical approach values our mutual interdependence and the centrality of care in all our lives. Our collective interdependence means our needs are most sustainably met through the provision of collectively shared universal basic services and income supports that are adequate to meeting our needs.

5 At the time of writing, the wording for the forthcoming referendum to replace Article 41.2 is pending.

6 <https://www.ihrec.ie/careaboutequality/>.

Section 2

Literature Review

The literature review engages with research that has mapped and theorised caring as relational, a social practice and as a set of policies to situate our analysis of family carers' experiences of accessing services and supports to care (Daly, 2021). It defines care and explores how care ethics can inform research into mechanisms to socially value care. The focus then shifts to what the literature says about the social and personal costs of caring. Particular attention is paid to analysis of the ideas found to lie behind care policies that privatise care, making individuals, especially women, responsible for care. Alternative approaches that view care more as a societal responsibility and public good are also examined. Feminist analysis of care offers a critical lens to excavate inequalities that arise in the social organisation of care and offer alternative frameworks that value care and support carers. Comparative assessments of care systems and models of income support for care are also reviewed and aligned with the Irish policy context. Academic and policy literature related to income support is examined in the practical policy proposal for a Family Carer's Income Support based on a PI.

Care ethics and family care

Debates about care raise questions as to how care infrastructures are being reorganised and the implications of shifts in relations between markets, communities, carers, and states for how care costs and contributions are distributed (Dowling, 2020). Carers are understood as "embodying the values of caring labour that have no assigned value and low political voice. The result is that the carer and those who depend on care are under cared for" (Lynch, 2021:55). As such the disadvantages of providing care are individualised, while the benefits of caregiving extend beyond the parties involved in care relationships to society. In economic terms, caregiving creates social externalities (that is, 'spillovers and side effects') which cannot be completely measured in terms of the immediate or direct benefits of this service (Folbre, 2021:49–51).

"the reason caregivers are exploited is not simply that caregiving is undervalued, but also that caregivers operate in an unjust social structure in which the quantity of care provided is in inverse proportion to the benefits accrued by caregivers, as these benefits go to others" (Lynch, 2021:57).

The social valuation of care requires an acknowledgement of what "good" care involves in all of its relational, affective and physical forms. For this to happen, a caring state that builds and maintains a sustainable infrastructure of care is required alongside a transformation of cultural norms including how welfare states operationalise care, enable and facilitate autonomy and recognise and value interdependence (Folbre, 2021).

The hidden costs of care to the carer

Caring intensively over a long period without support or recognition negatively affects a carer's health, financial status, and social integration (Family Carers Ireland et al, 2019; DePasquale et al, 2016; Cheshire-Allen and Calder, 2022; Kim, 2022). Care is also stratified according to socio-economic status. In the richest economies, the poor are disproportionately likely to be carers and carers are disproportionately likely to be poor (Cheshire-Allen and Calder, 2022:51). Family carers are often viewed as fulfilling a 'natural' aspect of their familial role (particularly for women). The position of family carers is an increasingly prominent policy issue (Eurocarers, 2022). However, Daly (2021) suggests there is still a lack of evidence regarding the complex but real costs to unpaid carers of non-recognition and lack of support. Analysis from a wide range of disciplines underline how COVID-19 has had a negative impact on family caregivers (Parmer et al, 2021; Cheshire-Allen and Calder, 2022).

Comparing care policy across the EU

The value of care is recognised in EU policy in the European Pillar of Social Rights and the Charter of Fundamental Rights. The European Care Strategy (European Commission, 2022) calls on states to improve the **adequacy, accessibility and affordability** of long-term care to protect care givers and persons requiring additional care from poverty. States should provide a “balanced mix of long-term care services” and a quality framework for long-term care (LTC), as well as addressing challenges of vulnerable workers and projected labour shortages. For family carers, it emphasises that support should be provided through training, and psychological and financial support (European Commission, 2022). A key measure in the strategy relates to support for family carers, suggesting informal care should be formalised through a service contract with local or public authorities.

Family carers in Ireland provide the second highest number of hours of care in the EU per week (European Commission, 2021:80). Care in Ireland is “regarded more or less as a private matter and to get public assistance one is forced into a situation of relative low income and caring on a full-time basis. The ‘choice’ is a very constrained one in Ireland” (Daly, 2018:10). Ireland has been described as a “careless” welfare State in other contexts (Murphy, 2023).

A comparison of long-term care systems across Europe and New Zealand revealed that information and comparative data on informal care allowances is fragmented due to differences in the way in which care is structured (Ecorys, 2021). Approaches and reforms to LTC systems in Finland, Austria and New Zealand show recent efforts to better socially value care, and move in the direction of a PI-type approach to family care.

In Finland, support is provided by the State agency Kela and informal care allowance determined and paid by the municipality⁷. From January 2023, LTC is administered by 21 newly established “well-being” counties in a bid to improve access and control rising costs.

In Austria, a 2019 pilot program in the Laendar of Burgenland has established family carers as direct employees of a publicly owned, not-for-profit company with a monthly net income of between €1,022 to €1,750 depending on the intensity of the care required. As direct employees, family carers are entitled to paid holidays, employment-related welfare entitlements, and a public pension.

In New Zealand, financial support for carers is paid under the supported living payment scheme, which provides support for people with health conditions, injuries, or disabilities that restrict them from working, and those caring for such individuals. The payment is concurrent for both the carer and the person being cared for, and the average income support is higher than the minimum wage level.

Placing a focus on access to income support alongside an account of the realities of the ongoing enactment of care – by family carers – allows us to understand what might be required for care to be enabled, supported, managed, and matched to needs (Fine and Tronto, 2020).

⁷ <https://www.espoo.fi/en/care-allowance-informal-carers-and-substitute-carers-1-january-2022>

Section 3

Qualitative Interviews

The qualitative research aimed to better understand family carers' experiences of becoming a carer, resources required to sustain the care they give and the role of income support in enabling them to provide decent and dignified care. Family carers⁸ were asked to reflect on their own care journey: how becoming a carer shaped their life plans, the implications for their labour force participation and how they balance the provision of care with their capacity to engage in meaningful activities including recreation. The researcher drew from previous research that established the costs of providing care and the gaps between what carers have access to and resources required to deliver care (MacMahon et al, 2022). The specific focus of the research was carers' individual and therefore subjective experiences of accessing CA. The data was analysed using a thematic approach in which common themes were identified to build a profile of the lived experience of caring, including the costs and the rewards of care; themes included depletion, devaluation, misrecognition, low status, loss of autonomy, stigma, suppression of family income, precarity, strain, navigation, intrusion and administrative overload.

Research participants emphasised the personal and social impacts of care which include loss of employment and recreational pursuits that result in a lack of economic autonomy and social integration. These costs are compounded by inadequacy of income supports and deficits in services experienced by carers, as a devaluation of their care and those they care for. Family carers interviewed experienced depletion of material resources and their emotional and psychological wellbeing as they aimed to meet the additional costs of care and compensate for the paucity of services while maintaining dignified and appropriate care. Poor

services and low income support underlined in their view the misrecognition of the complexity of and skill required to care.

As well as the pressures of system navigation (see box on page 9) the system of **means testing** was characterized by carers as embedded in metrics that failed to take adequate account of the carers wellbeing, the number of hours of actual care work, and the loss of income and care-related expenses. Carers recounted a formulaic approach that lacked the flexibility to take the reality of caring into account, exemplified in the lack of consideration given to care-related expenses in the means test. Means testing based on gross family income was considered as especially problematic. Carers described how these processes made them feel "like you're begging for something you're entitled to. I worked all my life and paid tax all my life." Some carers were in a position to enter the paid labour market on a part time basis, however, eligibility requirements meant this was not a feasible option as the family's income would have reduced as a result. This interviewee commented that they "would be willing to work anywhere if Carer's Allowance would facilitate it". **Means testing** was a direct source of **devaluation** for carers:

"it's the only job that you are means tested to do ... If I were a nurse looking after someone, is the government going to say to me, you know, we're going to means test you?"

All interviewees felt that the means test should be abolished, or the limit substantially increased:

"A child who needs 24/7 care and [the carer] is working so hard and because their husband earns more than €800 or €900 [per week], they don't get Carer's Allowance at all. Like it's so wrong."⁹

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- 8 Participants included 17 female and two male family carers located across Ireland. They were interviewed on MSTeams and interviews lasted an average of 70 minutes. Family carer participants were predominantly carers who are parents (one interviewee was an adult child caring for parents, one spouse was caring for spouse with dementia. Two carers who are parents were caring for adult children).
- 9 While eligibility criteria for CA would suggest that a carer with this level of income would not be disqualified from accessing CA, it is clear that there is a miscommunication around income thresholds and eligibility that may deter carers from applying for CA and/or in seeking additional paid work.



Another interviewee spoke about the archaic nature of the system:

"you're basically getting awarded on what your husband's earnings are like, how 1960s is that really? ... Like he's out doing his job, whereas I'm here 24/7 for the two girls. ... But you'll get penalized on what he does, but he's not at home caring."

Interview data suggest that family carers, who are already depleted and devalued, experience administrative burden and fatigue associated with seeking services and accessing income supports (see system navigation box on page 9). Means testing was understood to reinforce the low status of care, reproduce stigmas associated with other means tested payments and operate eligibility criteria and a payment structure in ways that often suppressed family income. When awarded even at higher rates CA was still inadequate and did not substantially defray the significant costs of care that include plugging the gaps where services are poor meaning that family carers experienced economic stress. Family carers value the care they provide, yet when they become carers, they often experience loss of economic and social status compounded by the low value accorded to care. The process of applying for and the adequacy of CA can reinforce this devaluation and undermine the capacity of family carers to provide good care.

System navigation

The literature review highlights the degree to which system navigation is a specific problem for welfare recipients generally and family carers in particular. Incomplete and ungenerous care policies create incentives and gaps that family carers must respond to as they attempt to secure resources and manage care responsibilities (Kodate and Timonen, 2017). Family carers devote significant investment and emotional energy in seeking access to supports, this navigation includes the work that carers do to access income supports, monitor formal services, advocate with providers, and coordinate informal support (Funk et al, 2019). Studies in the Canadian context found significant structural burdens on family carers in their efforts at this 'system navigation' (Taylor and Quesnel-Vallée, 2017), service rationing, user-fees, means-testing, and an increasing reliance on for-profit models of care exacerbate stress associated with navigational work (Duncan et al, 2020). This navigational work was a source of structural burden in systems that were excessively bureaucratic, fragmented and where supports did not match needs. This analysis aligns with the experiences of carers in this research in the Irish context.

System navigation: carer strain

Qualitative interviews found that managing the administrative processes required to access services and income support to provide care, is a significant source of strain, and experienced as onerous, invasive and time consuming. The administrative assessment of family income through the means test was described as often intrusive and at times humiliating and “degrading”. The means test compounds carers’ sense of low status and loss of autonomy, while contributing in a substantial way to a suppression of family income by eliminating the opportunity to earn additional income from overtime or part time work.

Interviewees spoke about how time and resources spent navigating the system narrowed their options to take on part time work while their children were in school:

“[you can work] up to 18 1/2 hours a week and the [children], they’re in school but you feel that you can’t take on any part time work or morning work because you’re dealing with services and you just need to focus on that.”

Getting to and from, and arranging, appointments was “like a full-time job” in itself. Accessing services and income support was often the most challenging part of caring:

“[You’re] fighting, fighting for everything, for speech and language, for occupational therapy, for physiotherapy, for school places. You’re fighting for everything all the time. That’s the most challenging.”

The **administrative burden** placed on carers accessing income support is significant. The nature of the information sought, fragmentation across government departments and the high bar (in their view) required to be met for eligibility were significant obstacles. The intense scrutiny of finances and family arrangements as well as at times the technocratic nature of the bureaucratic systems left already depleted family carers emotionally vulnerable: the application process for CA, which can include processes of appeal and subsequent review, was summed up by carers as often “degrading.” The length of the application form and details sought causes significant stress to carers. Some of the comments related to the application included:

*“There is a really long **soul destroying** form”;*

“filling out the forms is depressing.”

This burden was reinforced by bureaucratic fragmentation reflected in experiences of information supplied to one office, often not shared across systems, resulting in considerable labour in meeting requirements:

“it was like a book. And you’re repeating yourself over and over again.”

Having to document the disability of their children, parent or spouse was also traumatic:

“I’m so depressed when filling in these forms because it really spells out to you what [the person being cared for] cannot do”.

Carers agreed overall that the **application process** for CA was experienced as invasive and intrusive, particularly with respect to their income and expenditure.

“The application form is very invasive and intrusive. They want to know everything. I mean everything. About you. About your partner.”

In this sense, the means test in itself created stress and feelings of stigmatisation associated with having to prove eligibility. The cumulative effects of such navigational labour were to compound the suffering and exhaustion of carers and increase their feelings of precarity and vulnerability in accessing support.

Section 4

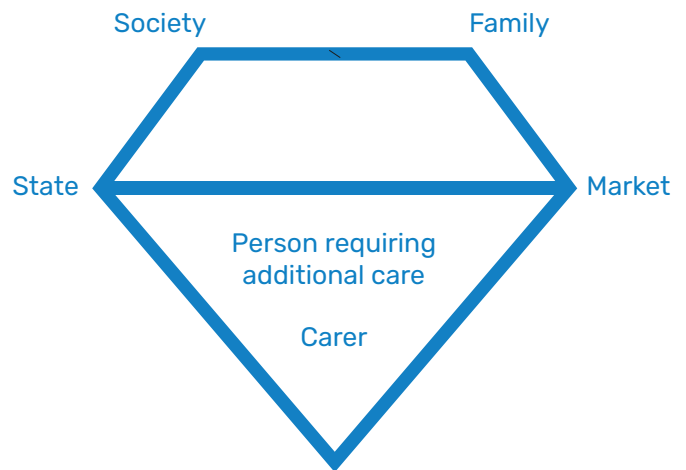
Proposal for a Family Carer's Income Support

The importance of investing in services

The first step in proposing a family carer's income support payment that socially values family care is to stress the relationship between income support and services. Both the literature review and the qualitative interviews affirmed the primary importance of a **service-led approach** to meeting care needs. Carers' time, lives and emotional energy are in deficit in the context of a continual fight for services, fights that are often lost and where families are often forced to purchase vital services in the private market, at considerable expense.

Any recommendation for income support must be understood as part of a wider recommendation for **universal basic care services**, accessible to all and ideally free at the point of use. Investment in such services is essential to ensure the capacity of State and society to meet their reciprocal obligation to support family carers. Fig 2 advances Fig 1 to illustrate how the provision of family care needs greater visibility in the wider political economy. In giving greater recognition to the role of family care, and carers, it is also important to make visible and to centre the needs and voice of people requiring additional care.

Figure 2: State, society, market, family, carer and person requiring additional care



Making visible, recognising and socially valuing care

Building on the **discussion** in the literature review and insights generated in the interviews with carers, it is clear that tweaking or reforming the present system of means tested CA will not be sufficient. What is required is far more transformative: taking income support out of the spectrum of working age social assistance payments that are limited by concerns about maintaining incentives to work, where adequacy is framed by replacement rates and family payments are limited by working age social assistance legislative requirements. This means imaginative thinking about an income support that economically and socially values, recognises and supports family care work, meets requirements of gender equality, greater universality and enables needs to be met through more generous payments.

Figure 3:
Reimagining Family Carer’s Income Support as a Participation Income



Income supports can value care

As well as the need for universal basic care services to meet care needs, income support policy and practice needs to be reformed to socially value care and recognise and reward varieties of participation. Policy can better recognise and support reciprocal interdependent family-based care relationships throughout the life cycle (as reflected in the new 2024 carer’s pension credits). Income supports differ according to a number of criteria: eligibility (whether they are targeted or means tested); entitlement (who can access the payment: age, gender, disability); and conduct (the levels and types of conditions or behaviours required to maintain access to the income support) (Bohnenberger, 2020). We can distinguish between very targeted, conditional versions like CA and versions of income support with no targeting or conditions.

Figure 4:
A spectrum of income supports



This spectrum runs from means tested/conditional payments to fully universal/non conditional payments. Participation Income (PI) is mid-way on such a spectrum in that it can have conditional requirements and can require some level of income testing (for example to screen out high earners).

In this research we rule out contemporary approaches to social assistance as too targeted, conditional and employment-oriented, while fully universal approaches are costly and lack a direct relationship with care. PI is an income support

system that enables and values other forms of work, including social and ecological work such as providing care, democratic participation and sustaining the environment. PI is the starting point for our recommendation for a new **Family Carer’s Income Support**. We discuss later whether it should be income tested.

Participation income

This report builds on previous recommendations by NESC (2020) and the Oireachtas Committee on Gender Equality (2022) which proposed that a PI be established for care work. PI was a policy idea first introduced by the British economist Anthony Atkinson (1996), ‘where people are paid, not for doing nothing, but in exchange for an activity that is useful for the society’. A PI is linked to a broadly defined activity requirement to do socially useful work (Murphy, 2023). It can be either permanent/long term or transitional/limited to a short-term period, but is neither universal nor unconditional (Bohnenberger, 2020:596). PI, as the qualitative data showed, aligns with family carers

who participated in this research and favoured abolition of the CA means test.

PI retains a commitment to the principle of reciprocity or obligation, but only for socially

valued activities, including family care. PI is, at least in the short to medium term, a necessary institution to encourage, incentivise and enable activity and forms of social reproduction such as family care work. Enabling reciprocal mutual aid offers an opportunity for creating substantive social value as well as vehicles for social inclusion and solidarity.

PI shifts the focus away from paid employment, and enables care and interdependence, while widening participation requirements away from narrow conceptions of paid ‘work.’ It offers capacity to redistribute care work. PI, therefore, offers the

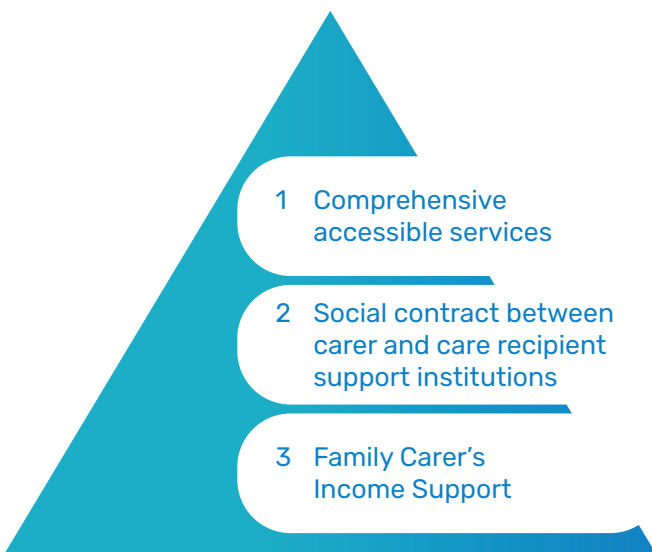
greatest scope to socially value care in a manner that meets principles of individualisation, income adequacy and near universality.

Participation Income (PI) is a near-universal payment with broad reciprocal activity requirements including care. Flexible, and somewhat targeted, the payment is clearly linked to support of care.

Practical proposal for Family Carer’s Income Support (FCIS) based on PI

We propose a FCIS that is complementary to services, which places the person requiring additional care at the centre of care policy, that socially values care enabling family carers to access an income support which is linked to broader social and economic inclusion mechanisms¹⁰. The income support is outlined in diagrammatic form below in Figure 5 with services highlighted as necessary and fundamental alongside a social income for those who engage in socially useful activity, in this case, family care. This option includes full contributory pension entitlement (as recommended by the Pensions Commission (2021)) which should also be supported by a range of social and economic institutions (many existing, some new).

Figure 5: Family Carer’s Income Support



- 1 **Comprehensive accessible services** as universal basic care services – the literature review, and our qualitative findings stress the primacy of a **service-oriented policy** to meeting the needs of both the person requiring additional care and of family carers.
- 2 **The implicit social contract between the carer and the person requiring additional care needs to be drawn out.** The provision of Family Carer’s Income Support needs to ensure a process of meeting the needs of the person requiring additional care while also valuing the full range of care work undertaken by family carers. The voice and dignity of the person requiring additional care are paramount and need to be respected though a process of social contracting to agree care packages including income support for carers, and supported by key local institutions (for example access to respite services, advocacy, mediation).
- 3 A universal income support called **‘Family Carer’s Income Support’** should be paid directly to the carer. Social institutions need to ensure inclusion and support for family carers and the person requiring additional care (as above), with full entitlement to contributory pension as recommended by the Pensions Commission (2021).

Merging of knowledge

On April 19, 2023, 16 people came together in a Merging of Knowledge (MOK) event to unpack, assess pros and cons and identify what is needed in research and information terms to further develop a proposal for an alternative to the means tested CA (the FCIS as outlined above). The participants, who were tasked with teasing out a strawman proposal and were not asked to directly support any specific reform or recommendation, were guaranteed anonymity, and included three academics, five NGO executives, three family carers, two Department of Social Protection officials and one retired senior civil service manager. Two Maynooth University lecturers and one research assistant facilitated the half-day session which focused on policy and practical considerations concerning a Carer’s Participation Income. These considerations, and related debates in the academic and policy literature, are briefly sketched before specific policy recommendations for an alternative Family Carer’s Income Support are outlined.

¹⁰ We recognise that some family carers may prefer a family care **wage** as an explicit recognition payment for their care work which should be linked to a range of supports that enable them to retain a presence in and progression through the paid labour market. This is not developed in this proposal. Present labour market institutions could form the basis for a family care specific ‘family care wage’ income option. Ireland already has a range of active labour market measures which support, reward and value socially useful work (Community Employment, TUS, Rural Social Scheme), and offer a structured labour market progression route; they also break social exclusion.

The issues are complex and while they primarily need to be considered from social and economic perspectives, there are also ethical, technical, administrative and political considerations that are important in determining policy direction. The following section includes a focus on:



Of particular importance are issues of adequacy, recognition, values, links to the paid labour market, and equality impacts on specific groups, particularly women supported by equality proofing and impact assessment.

Entitlement criteria

The main focus of the recommendation is to move CA 'out of the box' of a means-tested and anti-poverty working age payment into a family carer's income support with no means-test. This is in line with the Oireachtas Committee on Gender Equality (2022) recommendation to prepare "a report on the potential introduction of a participation income as an income support that acknowledges the contribution given by carers to society".

In making this recommendation we acknowledge that entitlement criteria will remain to limit or restrict access to Family Carer's Income Support. Overall, such assessment of entitlement should remain based on hours of care work; we do not recommend a two-band system at this time. In order to qualify for CA, carers are restricted to a maximum of 18.5 hours spent on paid work or education. We acknowledge that this is a source of frustration for many family carers who may be in a position to engage in more than this. However, we recommend keeping this under review and incorporating digital assessment mechanisms where possible. Medical assessment of the person requiring additional care should remain based on a GP assessment and efforts should be made to streamline this process as much as possible in co-production with the Chief Medical Officer of the Department of Social Protection.

Entitlement reviews are always stressful, but are necessary to maintain public confidence in the payment and to avoid fraud. However, much can be done to avoid unnecessary repetitive requests for data which is a source of distress for many family carers.

The Public Service Data Strategy provides guidance on the collection and use of data across the civil service. The strategy states that "Implementing the **Once-Only principle**, by ensuring that citizens and businesses supply the same information only once, and reducing the number of independent copies of data held in the Public Service, will promote sharing and reuse of data and common services **to improve service provision and decision making**" (Chief Information Officer, 2019:12). In cases where no change is deemed medically likely, more use should be made of 'Do Not Review' instructions as a way of limiting unnecessary intrusion and stress.

Eligibility

Universality is a key principle of a human rights-based approach and already a feature of some Irish income supports including child benefit and household benefit packages. It avoids 'claims stigma' related to poor treatment of claimants (Coote, 2022), lack of privacy and ultimately low benefit take up (Baumberg, 2015:183). However, while we advocate for no means test it is still the case that PI is not fully universal as there is still a principle of reciprocity, requiring the recipient to participate in socially useful care work. The artist's basic income pilot offers another payment mechanism of a universal (non-means tested) income support for socially useful work. Some might argue that there may be a benefit in screening out the small number of very high income earners, this is explored later.

Adequacy

The issue of adequacy of social welfare payments is core to academic, policy and political debate, see, for example, proposals of the Commission on Tax and Welfare (2022) to re-examine social protection indexation and benchmarking mechanisms. The issue of adequacy of family care-related payments is particularly complex. Both the carer and person requiring additional care, as adults, have income needs in their own right. It is not always clear what payments are being made in respect of, so it is very difficult to determine adequacy 'for who' and adequacy for 'what'. The dearth of services adds to this dilemma as income supports are stretched to cover services that should be available for all.

Even by minimal standards carer's payments fall short and do not incorporate the cost of care (or housing). Cost of living increases in 2022/23 highlight the need to increase the real value of social payments. In Ireland, the cost of care can only be understood in the context of the deficit of care services, a deficit that forces many families to purchase essential care-related services (including, but not limited to, physiotherapy, speech and language therapy, counselling, critical infrastructure, equipment, respite, personal sundries, and clothing) in the private market, putting more pressure on family income. In the absence of basic services, families have no choice but to purchase them, making income support stretch all the more.

In the context of inadequate services it is impossible to make a clear recommendation on adequacy. The question of 'adequate for what' depends on what services are available to whom, when and where. The approach taken here is to assess adequacy for the everyday life of the carer not including in the payment the real 'costs of caring' or replacing what should be available as a service. Some participants in the MOK indicated that the present full rate of CA is the minimum level that is acceptable even if it is a universal payment. Other possible benchmarks include existing state payments including the Artist's Basic Income, new Pay Related Benefit thresholds, and the Foster Carer's Allowance. More long-term proposals focus on benchmarking the payment to a more adequate level and indexing it to the cost of living and inflation. The Oireachtas Committee on Gender Equality (2022) recommends bringing "social protection rates for carers in line with a minimum essential standard of living (MESL)." The principle of socially valuing care work requires the continuation of the half rate Carer's Allowance and additional payments in the case of caring for more than one person.

Gender and equality

Means-testing applied at a household level penalises women (Atkinson, 1996). Individualisation of payments is an essential feature of progressive welfare reform and an essential prerequisite for economic independence for women. Abolition of the means test opens up entitlement and is the most effective way to guarantee individual access and so facilitate recognition and valuing of a wide range of care activities and women's social reproduction work. Such income support must be paralleled by a range of other working time policy initiatives that promote and support paternal care work if it is not to reinforce gender care inequalities, shared care work should therefore be a principle of the payment reinforcing socially valuing work that is useful and vital.

The effects of any changes and also of maintaining the status quo (e.g. no change in current arrangements) has broad impacts across different equality grounds and particularly gender. The policy proposal to advance FCIS should be fully poverty and equality proofed.

Reciprocal conditions and political feasibility

MOK participants felt it was relatively unproblematic to socially and politically justify the requirement for reciprocal obligations of care. Such requirements appear relatively publicly acceptable in the context of care. Reciprocal requirements also open opportunities to stress the reciprocal obligation of the State to support care, to define and monitor obligations regarding standards of care, and to safeguard the person requiring additional care. All of this requires training, follow up, oversight and support. It does not require auditing or supervising, unnecessary surveillance, state intrusion, or stereotypes of good carer/bad carer. In placing emphasis on supporting and facilitating care work it is crucial to avoid stigmatising claimants and to practically administer payments consistent with personal autonomy and agency.

Reciprocity enables political feasibility. Cost was understood as a major political deterrent with an obvious trade-off between enhanced eligibility to an adequate payment and the fear of increased numbers applying for a more accessible payment. The proposed Commission on Care, commitments in the Programme for Government, the forthcoming Referendum on Art. 41.2 and the Oireachtas Cross Party Interest Group on Family Carers are all vehicles to enhance the political feasibility of the proposal.

Institutional capacity

Absence of a means test lightens administrative work but greater focus on screening eligibility through 'care work assessment' may mean greater administrative complexity and some new risk. Demand for the new payment would in part depend on the degree to which it was used as a gateway or passport to other care-related supports. The question of institutional capacity is somewhat a red herring, as the system is generally responsive to policy or political imperatives. Capacity for implementation, including reassessment and review could be enhanced through real time administrative systems. Co-production with carers and those in need of additional care offers a valuable methodology to enhance payment design and administration, politicians should be included in such policy dialogue.

Legislation

There is a need to develop a legislative basis to remove family carer's payments from working age social assistance payments legislative framework. It may be possible to build on the seeds of Participation Income evident in contemporary welfare policy that values different types of care work.

Practical proposal for reform

The remainder of this report focuses on practical recommendations for an income support. It first discusses the difficulty of establishing a base line of information that can inform likely costings for a **Family Carer's Income Support** in order to advance the discussion. Following this, recommendations are set out, with a possible timeline for implementation.

FCI (2021) discuss the difficulty of establishing base line data regarding carer prevalence. They found for example that Census 2016 records 195,263 carers (4.1% of the population), whereas the Irish Health Survey (2019) finds 12.5 per cent of the Irish population aged over 15 years provide care (499,904 family carers). Regarding hours spent caring Census 2016 finds carers provide an average of 38.7 hours of care each week with a median of 15 hours per week (Census 2016), suggesting many carers would not meet the rigorous definition of full time established in contemporary eligibility criteria for CA. New data in Census 2022, while highlighting the growth in the number of family carers to 300,000, find 87,000 provide full time care (at least 43 hours per week). Given the above, and the reality that a) take up and b) changes in labour market behaviour to meet eligibility requirements, of a new PI based family carer's income support are both difficult to assess, it is challenging to provide a comprehensive cost analysis of FCIS.

FCI's State of Caring report (2022) estimated gross household income based on a convenience sample of 1,484 carers within FCI networks and found less than 4% earned over €100,000pa. This correlates with carers and employment data from the Central Statistics Office showing deprivation quintiles for carers (2019 Irish Health Survey), and also correlates with 2023 Parliamentary Budget Office (PBO) analysis of SILC data. This triangulation enables us to conclude that there is little to be gained by restricting any new family carer's income support to those under an income threshold (e.g.€100,000). We therefore recommend complete abolition of the means test for a Family Carer's Income Support.

The cost of a universal family carer's income support based on Participation Income

This proposal is for a non-means tested FCIS that is well targeted and politically feasible. The full costs are complex to determine as the cost will be impacted by payment design.

Most families with significant full time care commitments are in the lower to medium income deciles. This is logical given the care pressure on such families. This means there is little policy rationale, other than political nuancing and messaging, to restrict the payment to those earning under €100,000. As PBO observe not all newly eligible recipients will avail of the new payment due to a lack of awareness regarding eligibility (i.e., take-up rates could be lower than assumed), although this may be balanced out by some families reconsidering paid labour market participation in order to qualify for a new PI based income support for family carers.

Table 1: Estimate of annual cost – Baseline

Policy 1: Removal of the means-test for CA

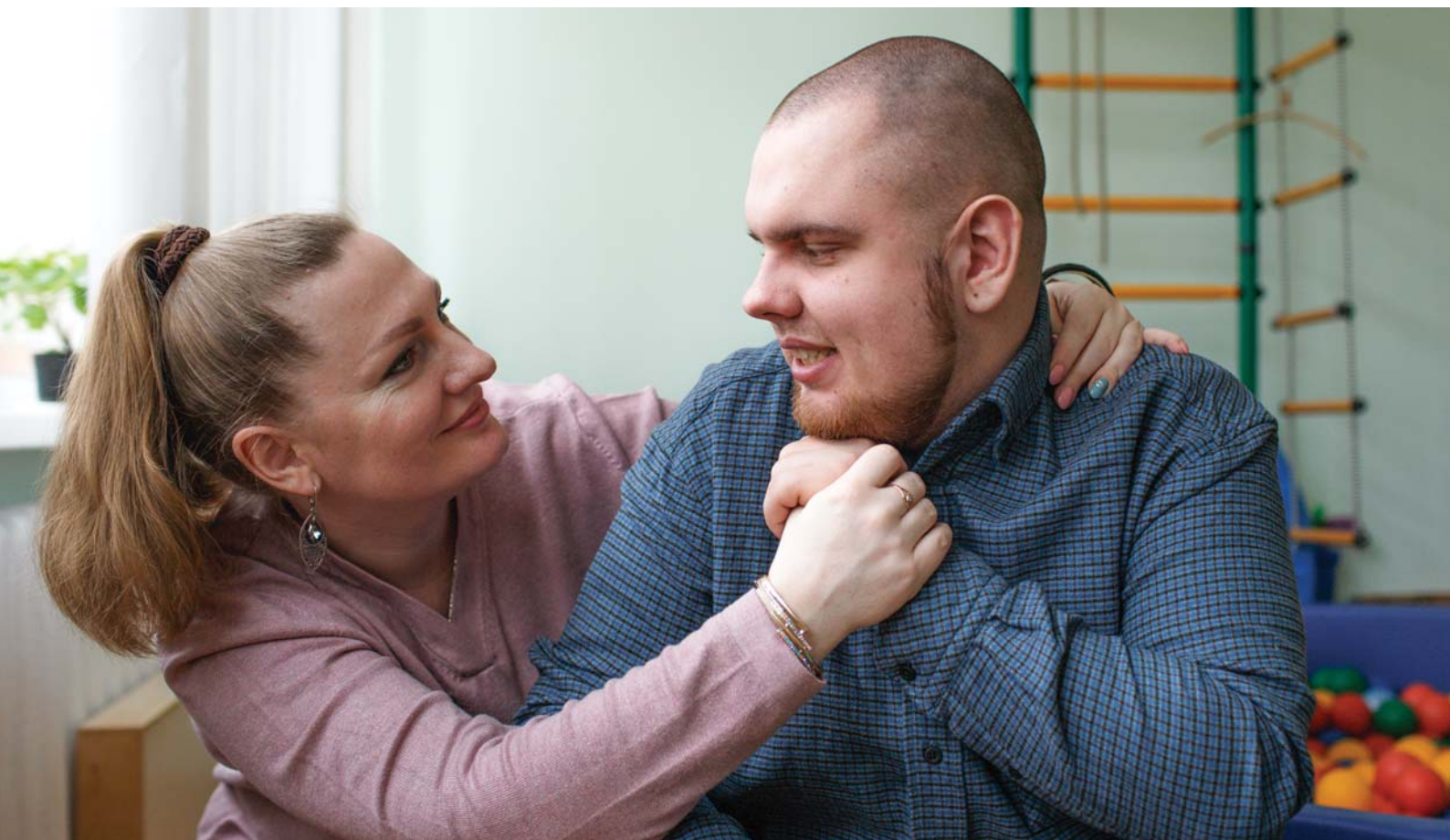
Policy 2: Raising the income threshold so that all households earning under €100,000 would qualify for CA

Policy	Estimate of weekly cost	Estimate of annual cost	Additional cost relative to baseline
Baseline	€17.5 million	€910 million	–
Policy 1	€25.14 million	€1,307 million	€397 million
Policy 2	€24.94 million	€1,297 million	€387 million

Source: Source: PBO's own modelling using DSP data, and SILC 2021. Estimate of annual cost based on annualised weekly cost. Rounding may affect totals. Data available from https://data.oireachtas.ie/ie/oireachtas/parliamentaryBudgetOffice/2023/2023-05-30_costing-analysis-on-abolishing-the-means-test-for-the-carer-s-allowance_en.pdf. This includes a detailed breakdown of methodology and scope of costing.

Previous calculations of the cost of abolishing the means test for CA have incorrectly¹¹ assumed that all carers (Census 2016 definition) would automatically qualify for the new payment and so estimated a very high cost. However, as argued above not all family carers would satisfy the exacting and still existing and necessary eligibility criteria associated with a new non-means tested Family Carer's Income Support¹². The PBO, on the request of Deputy Pauline Tully, has calculated the cost in similar terms. The PBO estimates the cost of increasing the threshold of the means test so that all families with an income of less than €100,000 pa at €387 million per year and at €397 million per year to abolish the means test¹³.

This does not include additional costs for secondary benefits (Carer's Support Grant, the Carer's GP Visit Card, Free Travel Scheme and the Household Benefits Package), or for services. The estimated costs cannot anticipate extra demand due to the availability of a new PI based FCIS. The estimated costs do however include all carers who qualify for the Carer's Support Grant as a standalone payment, and parents or guardians of children currently in receipt of Domiciliary Care Allowance. These are a proxy for increased take up as they represent carers presently ineligible for CA but who may be eligible for and be likely to apply for the new PI based FCIS. We recommend retention of payment of a Half Rate Carer's Allowance, and also retaining the practice of paying 150% in the context of a second care recipient, both are practices that socially value such additional care work.



- 11 In response to a Parliamentary Question, the Minister for Social Protection stated that it would cost approx. €1.2bn per annum to abolish the means test for CA and provide a universal payment to all carers (PQ50414/22 available at https://www.oireachtas.ie/en/debates/question/2022-10-13/17/#spk_289 [Accessed 31 May 2023]). This calculation was based on the number of carers identified in Census 2016 i.e., 195,263 and assumes all would both qualify and take up the payment – suggesting an additional 104,263 carers would become eligible for a universal payment $104,263 \times €224 \text{ (CA)} \times 52 \text{ weeks} = €1.2\text{bn}$.
- 12 Including the medical assessment undertaken by a GP and medical assessors in the Department that determines care needs which are at the centre of qualification for family carer's income support, the requirement to provide at least 35 hours of care each week (related to an 18.5 hour ceiling on work and study) and domiciliary requirements for carers to live relatively close to the person in need of additional care and the Habitual Residence Condition (HRC).
- 13 FCI analysis estimates the total cost of abolishing the Carer's Allowance means test would be in the range of €400 million per year (with an alternative option of increasing income thresholds to €100,000 pa, decreasing the cost by only an estimated €10m). The estimated costs are in addition to current expenditure on carer schemes (Carer's Allowance (€1.2b), Carer's Benefit, DCA, and the Carer's Support Grant) which the Department estimate will be €1.6bn in 2023.

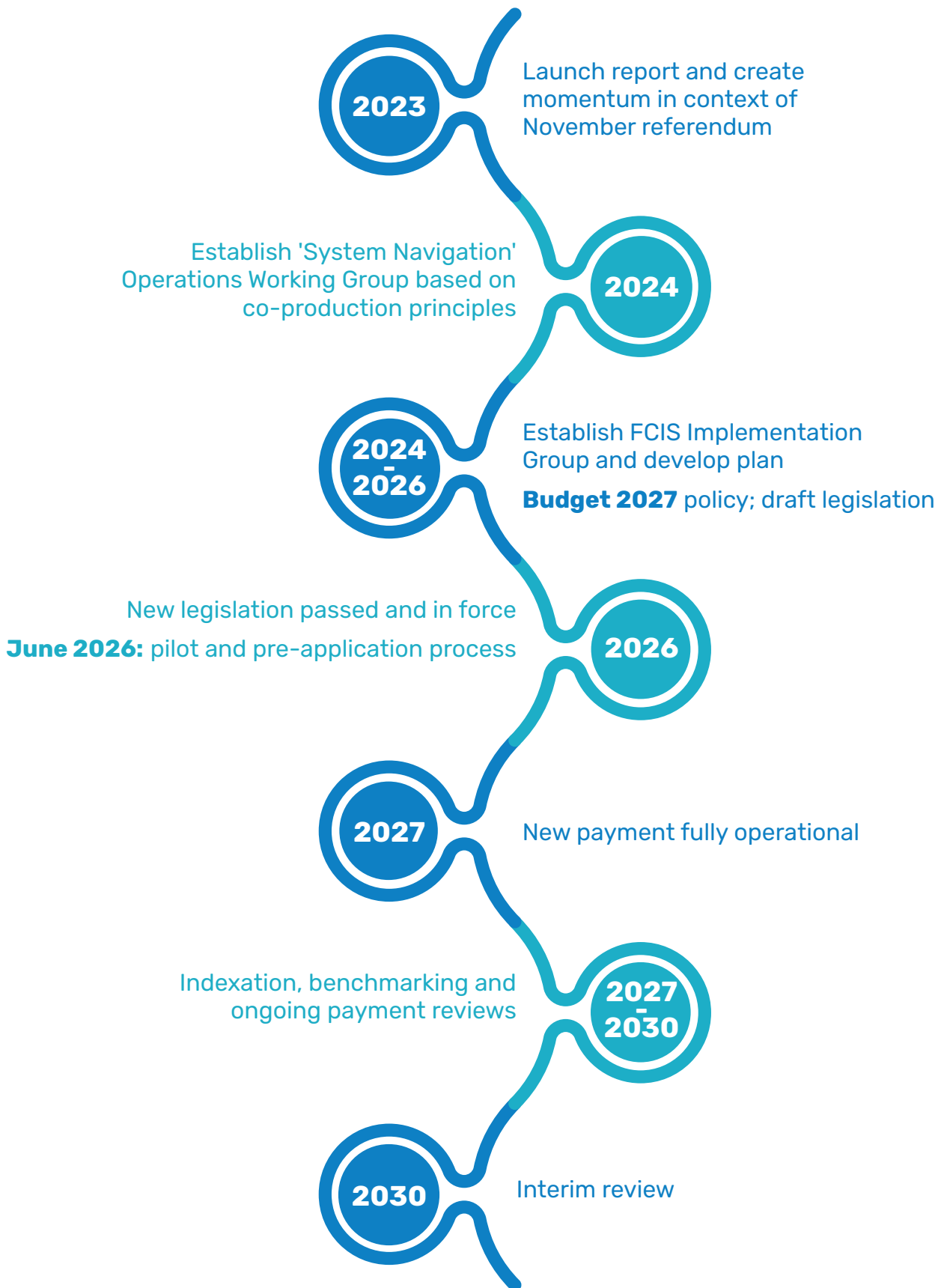
Summary of recommendations

The following recommendations arise from the findings of the literature review, qualitative interviews, Merging of Knowledge Workshop and policy analysis that was undertaken as part of the research. They focus on what needs to be done to advance a new income support for family care – Family Carer’s Income Support (FCIS). We note the dominant concern that underinvestment in, and lack of adequacy of, services is also a clear priority for family carers, and our recommendations need to be understood in this context: parallel investment in comprehensive services is essential.

1. **Introduce a Participation Income (PI) based non-means tested Family Carer’s Income Support (FCIS)** for all family carers who fulfil the assessment criteria. This should be fully implemented by January 2027 and paid initially at no less than the contemporary CA rate. As the department with most administrative efficacy in income support, this scheme should be administered by the Department of Social Protection.
2. **Establish a PI FCIS Implementation Group.** This should begin in 2024 and work to ensure all aspects of legislation, costing, administrative feasibility, communication and eligibility criteria are clearly planned and in place before Budget 2027. The Group should follow co-production principles and include participants reflecting relevant aspects of public administration, family carers and representatives of people in need of additional care. This should begin in 2024 and conclude by 2026.
3. **Ensure adequacy of PI FCIS by benchmarking and indexing** the payment in line with Commission on Tax and Welfare recommendations. We acknowledge this is complex and requires consideration of both the carer and person in need of additional care as well as (non)availability of services. In progressing this, it is crucial to determine adequacy ‘for who’ and adequacy for ‘what’. We recommend to continue the principle of socially valuing care by maintaining the half rate CA for eligible applicants and by paying 1.5 payments to carers providing care for more than one person.
4. **Establish a Navigational Operations Group to improve navigational processes** related to applying for and proving eligibility for a new FCIS and for existing payments. This group should follow co-production principles to make practical changes including in communication, training, and processes to review eligibility. Focus needs to be on improving the process of evaluating carers’ time and reviewing eligibility. Membership should include Department of Social Protection (DSP) and HSE officials, Family Carers Ireland (FCI) and other carers’ representative organisations, people in need of additional care, the DSP Chief Medical Officer and GP’s working with people in need of additional care. This should begin in 2023 and conclude in 2024.

Removing (or maintaining) a means test on family income has broad impacts across different equality grounds and particularly gender. These recommendations should be underpinned by gender and equality impact proofing. Campaigns are needed to advance more equal sharing of care across genders, as are work sharing policies to enable care sharing within a gender care parity framework. FCIS should also be underpinned by a social contract between the carer, the person in need of additional care and state institutions. Central to all this is the voice of the person in need of additional care, and the needs of the carer. More social support institutions (linked to HSE and local social services) and access to public employment services and paid labour market institutions, can both maximise social and economic inclusion.

Figure 6:
Timeline for introduction of new FCIS based on Participation Income 2023-2030



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**“Our definition of work must change,
must evolve and widen, to incorporate
the important role of caring and carers
as essential workers; workers far too
long undervalued by society”**

President Michael D. Higgins, 2021



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Coimisiún na hÉireann
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