

Who Cares?

Building a new relationship
between the not-for-profit
sector and the State 2018





'Who Cares?'

A research report examining the challenges being experienced by some of the key not-for-profit providers of services to people with disabilities in managing their relationship with the State.

The report makes strategic recommendations for the building of a new relationship between not-for-profits and the State, at a time of critical change.

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Preface

The independent not-for-profit sector, which provides vital services for many thousands of people with disabilities across Ireland, faces an uncertain future. This sector has arrived at a crossroads. It is finding it impossible to operate in the no-win environment between the fully funded State sector and the for-profit sector in the health and social care arena. After years of underfunding, a huge growth in regulation and compliance requirements, and having to operate in the absence of a Government strategy for its role and future, the sector will soon be unsustainable.

This research report has been commissioned by the Rehab Group to map the challenges currently being faced by the sector and to make recommendations for a sustainable future, a future where we contribute fully.

The question we are asking is, Who Cares? Who cares about the future of this sector? More importantly, who cares about the many thousands of vulnerable people who use the services we provide every day? Who cares about their, and our, future?

Ostensibly, the key challenges are under-funding, the management of a very significant demand for accountability and compliance, and meeting the requirements of regulation. These challenges are made more difficult by the lack of a policy framework for the current and future role of these organisations, known colloquially as 'Section 39s', a name drawn from their designation under Section 39 of the 2004 Health Act.

This report focuses on the challenges being faced by some of the large providers, whose current combined annual funding is in the region of €430m and who provide residential, respite and day services for more than 20,000 people with disabilities.

We would like to thank the CEOs of these large providers who willingly gave their time to contribute to this research and who, in the process, have provided a valuable insight into the reality of managing in an uncertain environment, while being fully committed to ensuring that those needing their services are fully supported.

This independent, not-for-profit group of providers – while substantially funded by and accountable to the State – is required to fulfil the entire panoply of accountability, compliance and regulatory structures which have grown up in the last decade, without being funded to do so. For-profits are not obliged to fulfil many of them and therefore do not have to carry the cost burden. Hence,

not-for-profit providers live between the fully funded State sector and the for-profit sector; an environment that is currently eroding the ability of this sector to operate effectively and sustainably.

The real victims of this uncertain future are the people who rely on the residential, respite and day services which we provide, people whose needs are often complex, changing and varied and who deserve to live full lives as citizens, and the support to do so.

Historically, this group of not-for-profit providers stepped up when the State did not, to ensure that people with disabilities had the life they wanted; and we want to continue to do so. The State has been happy to allow us to do that but now questions arise about our future.

We believe that the independent not-for-profit sector, having a proud history of stepping up to provide services which the State does not, has a significant contribution to make. However, the current stranglehold in which we operate, caught between the statutory, fully funded sector and the for-profit sector, is unsustainable.

A new vision is needed, a vision which recognises that there is a role for an independent not-for-profit sector. A vision which is recognised in legislation, which allows the sector to continue to do what it has shown itself well capable of: that is, enabling people with disabilities to live the life they want - and deserve - to have.

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Executive Summary

Introduction

The purpose of this report is to explore the evolution of the relationship between the State and not-for-profit organisations involved in the provision of services to people with disabilities. The significance of these organisations cannot be overestimated. In 2017, €1.233bn was allocated to provide disability services in the non-statutory sector, including a total of almost €1.157bn to organisations via Section 38 and Section 39 of the 2004 Health Act.

Clearly, these are not inconsiderable amounts of money and their management requires constant, positive and progressive interaction between not-for-profit organisations and the State. **This report sheds some light on those interactions and shows that while collaboration and partnership were features of past relationships, recent years have seen a turn towards command and control and the growth of the regulatory state.**

The report also captures the growing sense of crisis in this sector, not least the crisis of financial sustainability confronting many not-for-profit organisations. As this research will demonstrate, the underlying causes of this crisis are the underfunding of services, the increased costs of complying with multiple and ever-expanding regulation, pressures on core administrative costs including insurance, and declining capacity to raise and use other sources of income.

The report makes a series of recommendations, not least the need to articulate a renewed collaborative relationship between not-for-profit organisations and the State and the provision of adequate funding to enable the continued provision of services to people with disabilities.

What's in a name?

It was recognised early on in this research that choices around terminology have the potential to communicate particular messages. It can tap into pre-determined assumptions that may not be fully accurate, or capture the changing nature of organisations that deliver services to people with disabilities. The commonly used **'Voluntary and Community'** conveys the strength of a broad sector, with community-based roots, one that is particularly well developed in Ireland, but that hides considerable variation in size, scale and ethos present within such a large number of organisations. It also obscures the scale, size and professionalism of many organisations and a corresponding decline in voluntary input.

The **'Third Sector'** terminology, though not commonly used in Ireland, usefully separates the range of community, voluntary, social enterprises, mutual and

co-operative organisations from the public sector and the private sector, emphasising their independence from government, their particular value and motivational base and their commitment to reinvest surpluses in pursuit of common goals.

Though more commonly used in Ireland, the label **'charity'** sometimes invokes historical and paternalistic notions of charitable giving, dependence on charity, and a reliance on volunteers or poorly paid staff, even if the **'charity'** employs hundreds of staff and has a budget in the millions of euros.

Ultimately, it was decided to use the term **'not-for-profit organisation'**, so as to communicate the social purpose of organisations while avoiding the often limiting connotations of the terms **'voluntary'** or **'charity'**. This is in no way to disconnect the organisations from their civil society, voluntary or charitable base. Instead, it locates them using more contemporary and internationally recognised language that may help to recalibrate the mind-set of some - including the public sector - towards recognising them as highly competent, professional and very necessary organisations in the landscape of policy design and service delivery in Ireland.

Historical context

This chapter positions the research in a brief historical context. From this, it can be seen that the key feature of the provision of services to people with disabilities is the State's persistent reliance on not-for-profit organisations. This may be attributed to the State's early capitulation to the Catholic Church and to pressure from vested interest groups to stay out of certain areas of the care of its citizens; a lack of adequate resources; and to a belief by some decision makers that these functions should not be taken on by government and should instead be best left to **'charity'**. Over the years, this reliance on **'voluntary bodies'** has not only been acknowledged by successive governments but at different times has been actively encouraged by them.

Four approximate phases of reliance are identified:

- **Conceded/abdicated reliance:** from the foundation of the State to the mid-1950s, characterised by the State's absences from the provision of services to people with disabilities;
- **Co-ordinated reliance:** from the mid-1950s to the mid-1980s – during which time the State remained largely absent from service delivery but began to make greater effort to more formally support and co-ordinate with not-for-profit delivery;
- **Collaborative reliance:** from the mid-1980s to the mid-2000s, recognisable by a greater emphasis on partnership, collaboration and co-operation and continued reliance on not-for-profit delivery;
- **Command-and-control reliance:** from the mid-2000s to the present time, representing the application of stronger State control over the activities of not-for-profit organisations through increased regulation and a growing emphasis on input-based accountability.

These different phases are reflected in the body of legislation that has evolved to support the role of not-for-profits in the provision of health and social services. The key persistent feature of this evolution is an outmoded distinction between organisations that provide services 'on behalf of the State' and those that provide services 'similar or ancillary to' the State. While in many instances almost the same services are being delivered, this distinction results in differential funding, pay and pension regimes being applied between broadly similar organisations.

During these four phases the **institutional landscape has also changed considerably**, oscillating between a localist, albeit centrally directed, orientation and a later, more nakedly centralised and controlling approach. More recent years have also seen the stronger emergence of the regulatory State, with the creation of The Health Information and Quality Authority (HIQA), the Charities Regulator and the Department of Public Expenditure and Reform, resulting in lower levels of local discretion and a weakening of collaborative approaches.

The key question raised from this section is, given the continued reliance on not-for-profit organisations to deliver services **what potential is there for a further and substantially different phase of engagement between not-for-profits and the State?**

Evolving approaches to the delivery of public services

Understanding the nature of/influences on public administration is important if we are to develop a clearer understanding of how the State sees the role of

not-for-profit organisations. In Ireland and elsewhere, recent years have seen the gradual spread of New Public Management-informed approaches, manifest in:

- An increase in bureaucratic thinking and an emphasis on rules-centred models of administration
- An expansion of accountability and compliance requirements
- Reduced commitment to partnership
- Treating not-for-profit organisations as service-delivery extensions of the State rather than as distinct mission-and-ethos-driven organisations

Along with these is the apparent assertion of the primacy of the market as the guiding rationale for public policy interventions, as suggested in the Department of Health's 2012 Value for Money and Policy Review of Disability Services in Ireland. This stated that 'in theory', the public sector '*should only intervene when markets are not efficient and when intervention would improve efficiency*'. **Whatever about theory, in the real world the market has never prioritised services for marginalised groups, in Ireland or elsewhere and is unlikely to do so, not least for those with disabilities.** It seems strange therefore to rely on such an ideologically distinct, market-based rationale for public policy intervention. However, it does partly perhaps explain why the public administration system acts the way it does. One consequence of this type of thinking may be an unwillingness to recognise the need for an independent not-for-profit sector and for its broader democratic role.

4. The emerging research themes

Five main themes have emerged from the research:

- **What makes not-for-profit organisations different?**
- **The state of current relationships**
- **Accountability, regulation and compliance**
- **Funding**
- **Pressure on people**

4.1 What makes not-for-profit organisations different?

- **They have unique motivation:** Not-for-profit organisations are most often social-oriented and ethically based as opposed to being motivated by a focus on profits. In the words of one research participant, they are '*advocates, they're the soul, they're the conscience of the country*'.
- **They can deal with difference:** Undoubtedly, not-for-profit organisations have their own systems and

bureaucracies but these are considerably more flexible than those of the State and more open to adjustment than those of the private sector. Whereas the public sector often struggles to meet needs and plan for services that are outside of the mainstream, not-for-profit organisations are the opposite.

- **They have stronger relational capacity:** Many not-for-profit organisations maintain strong connections with the communities they serve, a strength that public sector or for-profit organisations will rarely, if ever, be able to replicate.
- **They are innovative:** In the public sector the capacity for innovation is constrained by bureaucratic controls or by the directions of political leadership. While no organisation is constraint free, not-for-profit organisations, freed from an excess of political control and from the need to create profit, are in the best position to innovate, be flexible and to provide the type of nimble and nuanced responses to the often complex needs of marginalised groups, including those living with a disability.
- **They stick around:** Most not-for-profit organisations display important characteristics of longevity and durability. Even during the recent recession, many continued to maintain their level of service provision and indeed, expand it, despite significant cuts in State funding. While it may be attractive to some to consider a stronger role in service provision for the private sector during times of economic expansion, should the economic cycle of ‘boom and bust’ continue, this may prove vulnerable to future shocks.
- **They are inherently person centred:** Many not-for-profit organisations operate from a ‘naturally person-centred approach’ as opposed to being dominated by the requirements of a system of bureaucracy or the exercise of political control.

There are however threats to this distinctiveness, not least the nature and multiplicity of regulatory requirements and the spread of a more interventionist, managerialist culture within the Irish health sector.

4.2 The state of current relationships

There is a distinct feeling amongst not-for-profit organisations that the State does not value their contribution as much as it did in years gone by. While it wants them to deliver services to people with disabilities, it is less willing to see not-for-profits as partners in this exercise. Relationships with the State have changed, often in a negative way, with evidence of a drive for stronger accountability, compliance and the dominance of narrowly defined efficiency and value-for-money measures. At the heart of the analysis of virtually all of the not-for-profit participants involved in this research is a belief that higher

levels of State control have superseded collaboration; domination has displaced dialogue and closer integration into the State’s service delivery infrastructure has become more important than preserving independence and autonomy.

Inevitably, in any discussion on relationships, the role of the HSE is going to be subjected to considerable scrutiny. On the whole, relationships with the HSE are mixed, seen as stronger at local level but weakened at national level by poor communication and institutional arrangements, leading to a deeply felt loss of autonomy and independence.

4.3 Accountability, regulation and compliance

The stronger focus on accountability, compliance and regulation of recent years is simultaneously embraced by not-for-profits as essential to guarantee the quality of outcomes, but is also criticised for its narrow focus, for the inadequacy of financial provision to meet regulatory requirement, and for the existence of multiple and often competing forms and processes of regulation.

Nobody suggests that accountability is not a good thing. However, the poor and disconnected design of multiple and sometimes competing regulatory regimes runs the risk of undermining the work of not-for-profit organisations. All organisations believe that they must constantly seek to improve their own governance, optimise performance and deliver excellence in everything they do. They are also committed to being fully accountable for public funds and to ensure high levels of quality outcomes. However, there was concern about the ability of organisations to meet the ever-expanding regulatory requirements. **There exists a real fear that the balance and burden of accountability and compliance regimes is hampering the ability of organisations to function effectively and to deliver quality outcomes for people with disabilities.**

A number of key gaps in the implementation of compliance and regulation regimes were named:

- **There is an inadequate focus on bigger picture outcomes. Many not-for-profits want to see more strategically focused performance and outcomes-based accountability, with less time spent on the micro management of individual organisational activities. In short they want to be able to show how they are making a difference in people’s lives;**
- **Regulation and compliance standards are inconsistently applied by different inspectors, across different HSE areas or across different regulatory regimes;**
- **There is an ongoing failure by the State to adequately support the costs of meeting compliance and regulation requirements;**

- There are new compliance pressures on organisational governance, especially in relation to the appointment/retention of board members;
- Dealing with multiple compliance requirements and the duplication and overlapping nature of compliance requirements runs the risk of taking the human out of human-orientated services;
- Competing and changing compliance obligations exist between compliance regimes.

Organisations may also find themselves stretched between multiple accountability obligations. Being connected to community means that not-for-profits need to be accountable to service users and their broader supporters. However, it can be difficult for organisations to manage multiple accountabilities, especially when those demanded by the State are directly linked to an organisation's funding.

4.4 Funding

Given the historical evolution of service provision in Ireland and the absence of any significant philanthropic base, it is not surprising the not-for-profit sector is highly dependent on the State for its funding (Mazars, 2016). This creates vulnerability for organisations and significant uncertainty for the people they serve. Five main funding related issues emerge from the research:

- **The cost of delivery - Paying the full economic cost of delivery**
- **Financial management and sustainability**
- **Value for money**
- **The impact of not-for-profit governance failures**
- **Alternative models of funding**

Paying the full economic cost – One of the most pressing issues raised by interviewees in this research is the unwillingness of the State to fund the actual cost of the delivery of services. All of the not-for-profit organisations interviewed reported their inability to deliver the expected level of service for the resources allocated by the HSE. The current service arrangement does not allow for the inclusion of deficits thereby masking the funding gap being experienced by all of these organisations.

Financial management and sustainability concerns – Apart from the inability to identify funding deficits within the service arrangements, many organisations have expressed concerns about their own financial sustainability and that of other not-for-profit organisations. At the heart of these sustainability concerns lie the underfunding of services; the costs of meeting multiple compliance requirements; the absence of funding for core administrative costs; increasing costs of insurance; high

transport costs and pressure on organisations' abilities to fundraise.

Value for money – In recent times this issue has moved centre stage in the relationships between the State and the not-for-profit sector. Nobody objects to the principle of achieving value for money. However, for many of those interviewed in this research, the experience of value-for-money requirements are at best formulaic, at worst, ill informed. There is a clear belief that approaches to achieving increased efficiency should acknowledge complexity, the expertise of not-for-profit organisations and engage in serious dialogue with them. Simple application of a one-size-fits-all formula is not seen as likely to produce benefits for the users of services.

The impact of not-for-profit governance failures – Not-for-profit representatives recognise the impact of 'scandals' on how they are perceived, both by the public and by the State, and recognise that the not-for-profit sector needs to continue to improve how it does its business. However, they regret that there is often an inability or an unwillingness to distinguish between the many highly effective organisations and the very small number of entities with governance deficiencies.

Alternative funding models – Given the above issues, many contributors to the research have suggested that there needs to be a renewed discussion on alternative models of designing, delivering and funding service provision. One such model is commissioning. The role of commissioning was put firmly on the political and administrative agenda by the Department of Public Expenditure and Reform in 2015 when it undertook a consultation exercise and commissioned the Centre for Effective Services to carry out a Rapid Evidence Review (REA) about approaches to and experiences of commissioning internationally. However, it no longer seems to be a political or administrative priority.

The main conclusion emerging from this research is the clear need for a major and urgent revision of how not-for-profit organisations are funded and how funding agreements are overseen and managed. In the short term, where services are being provided under a Service Level Arrangement, it seems evident that the level of funding needs to match the actual cost of delivery. While there should be space for dialogue about costs and for the HSE to question the cost bases being proposed, not-for-profits cannot be expected to be pushed further into deficit by effectively **subsidising the State's provision of services**. Either the level of funding should be adequate to deliver the required services or the level of services provided needs to be reduced. Ultimately, an alternative model of funding needs to be considered if financial sustainability weaknesses are to be adequately addressed.

4.5 Pressure on people

The final theme emerging from the research is about people. The delivery of services to people with disabilities is a human resource-intensive process requiring highly experienced staff at all levels alongside unpaid board members capable and willing to take on increasingly onerous governance and compliance responsibilities. For the reasons outlined in this research, there can be no complacency that Section 39-funded organisations will be easily able to overcome the many human resource challenges faced by them. There are challenges to retain existing staff and to recruit new personnel. There are challenges to retain and recruit senior managers to oversee the effective operation of organisations. Finally, there are challenges to secure the involvement of a range of board members who can bring different perspectives and skills, not just those demanded by an increasingly professionalised regulatory environment.

5 Conclusions and ways forward

This report has detailed a range of issues that impact on the success and sustainability of the relationship between the State and the not-for-profit sector. A number of ways of moving forward on these issues are proposed.

Changing how public administration operates

The research has shown that over time, there has been a notable and negative shift in the nature of the interaction between the State and not-for-profits. Relationships, once based on loose co-ordination and strong collaboration, have been replaced by not-for-profit organisations being seen largely as contracting bodies, entities to be managed and to be directed, akin to being a 'sub-cost centre' of the HSE.

The key long-term message from this research is the need to renew an ethos of collaboration and co-operation in the relationship between the State and not-for-profit organisations, one where broader public value principles, not just narrowly defined and short-term 'value for money' considerations, inform the choice of operational priorities and the character of relationships.

- In particular, it is recommended the HSE functional units dealing with the disability sector (nationally and regionally) should be designated as a pilot for public value/public governance-orientated reform processes, taking OECD recommendations on capacity building as their starting points (OECD, 2017).
- The issue of how the not-for-profit sector itself operates in the longer term was also raised during this research, the suggestion being that existing models of service delivery may need to change considerably to embrace and reflect a stronger commitment to emancipation, personal autonomy and control. Thus, as well as reform in the public sector, an internal sectoral focus on reform should also be considered.
- It is recommended that the not-for-profit sector itself, via its main representative bodies, convene a process/forum to explore its own longer-term vision of how services might be best provided to people with disabilities and how organisations in the sector can be best configured to deliver such a vision.
- ### Building a new relationship
- While partnership and collaboration have not been the defining elements of the State's recent disposition towards not-for-profit organisations, there is still a widespread desire to work in more collaborative ways. More effective future relationships can be built by:
- Articulating a clear vision of the role not-for-profit organisations both in the design and delivery of services
 - Agreeing principles for interaction, setting out of relevant roles, rights and responsibilities
 - Establishing direct, regular and mutually respectful communications pathways between senior HSE staff and not-for-profit organisations
 - Devolving decision making power to the HSE regions where the experience of and potential for collaboration is stronger.
 - To provide a framework to address these issues it is recommended that the State commit to develop a Compact Agreement governing the relationship between itself and not-for-profit organisations. This should be done in partnership with the not-for-profit sector within a three-year period. If the task of developing a sector-wide agreement is seen as too demanding, a pilot for the disability sector should be developed instead. Models of such state-voluntary sector agreements already exist in Scotland, Northern Ireland, and in England and Wales and would provide a useful starting point.

- It is also recommended that the Government take a decisive step to signal the importance of the not-for-profit sector. To do this it should follow the example of New Zealand and create a junior ministerial portfolio for the community and voluntary/not-for-profit sectors. This should be located as a distinct office/unit within the Department of the Taoiseach. The portfolio would cover the development of strategic relations with the community and voluntary/not-for-profit sectors, including the negotiation, monitoring and review of a Compact Agreement; advancing funding frameworks relevant to organisations involved in substantial service delivery on behalf of the State and the review and revision of legislative frameworks governing these relationships.

Moving to an alternative model of funding

There are real and justifiable fears for the financial sustainability of many not-for-profit organisations. The word 'crisis' has been communicated more than once during this research. If organisations collapse, either the service they provide will have to be picked up by another organisation, it will have to be delivered directly by the State, it may be deliverable by a private sector organisation (most likely at higher cost) or the service may just be lost. An alternative model of funding capable of meeting current and future delivery of services is clearly needed. Commissioning is a key element of this.

- In parallel with the development of the Compact Agreement, it is recommended that a model of commissioning for the provision of services to people with disabilities be developed without further delay. This model should reflect the place of partnership and co-production as well as a distinction between the strategic planning and purchasing/contracting stages. It should also seek to replicate the features of internationally recognised progressive models and avoid the negative impacts of narrow, managerialist and competition-based approaches.

Legislative provision

There is general agreement that the existing Sections 38 and 39 of the 2004 Health Act are not fit for purpose, given that the services provided by organisations through Section 38 are largely indistinguishable from those provided by many of the larger organisations supported under Section 39. However, the legislative distinction means that the State assumes liability for the full costs of services provided by Section 38 organisations, whereas Section 39s, although the services are the same, and costs are similar, are underfunded. As a result, for these organisations at least, the legislative distinctions between

organisations providing services 'on behalf of' the State (Section 38) and 'ancillary to' the State need amending.

- To address this anomaly, it is recommended that the Department of Health acknowledge that a reconfiguration of the legislative provisions governing the relationship between the State and not-for-profit organisations in the disability sector is needed without further delay. It is recognised that there are serious challenges in addressing this anomaly. It is recommended that a new, middle-ground legislative provision is agreed, falling someplace between Section 38 and Section 39. For the moment, this could be called 'Section 38½'. Under section 38½ it would be acknowledged that funded organisations are providing services on behalf of the State, but that for historical reasons that they must be treated differently than those funded under Section 38. This could mean that for instance while their staff would not be counted as public sector employees, their salaries would be set to the protected pay scales applying in state or Section 38-funded organisations and that section 38½ organisations would be funded specifically to meet such salary levels. Equally, pension arrangements for section 38½-funded employees, while not enjoying defined benefit status, should be sufficient to not be the cause of employee attrition.

Dealing with immediate need

Finally, a number of shorter term immediate recommendations are made:

- Paying full economic cost of delivery – It is recommended that State recognise the impact of its underfunding of services and commit to pay the full economic cost of delivery in respect of services delivered on its behalf.
- Addressing current financial sustainability issues – An independent review of the level of financial deficits facing organisations in the disability sector be undertaken. This review should map out the scale of organisational deficits and their causes and should recommend actions to address them. Those appointed to carry out the review should be mandated by and should report to a joint Department of Health/not-for-profit task group.
- Easing immediate financial pressure – To ease some of the short-term financial pressures on organisations some of the big ticket items that increase particular financial stress on organisations should be addressed. In particular, it is recommended that not-for-profit organisations of a particular scale be included under the cover of the State Claims Agency for services they are carrying out on behalf of the State.

- Management of funding in service arrangements
 - The process of completing an annual instead of a multi annual service arrangement places an unnecessary burden on the administrative capacity of many organisations that operate across HSE regional boundaries. It is recommended that moving to a multi annual budgeting cycle be prioritised. This would also enable the development of more meaningful, outcome based reporting processes.
- Dealing with fundraised income – The issue of how fundraised income within not-for-profit organisations is dealt by the HSE needs immediate attention. It is recommended that, as part of the financial sustainability review suggested above, HSE practices on the use of/deployment of fundraised income also be examined.

Regulation and compliance: Finally, there is general agreement that streamlining regulatory and compliance processes is essential. Just as the development of a system of Regulatory Impact Assessment was seen as necessary to enable a conducive business and economic environment in 2005, so too the same principle needs to apply to provision of services to people with disabilities. This requires the development of a better form of more intelligent, integrated and communicative accountability systems, which:

- strike a balance between upward, downward and internal accountabilities
- eliminate duplication within the HSE sphere;
- accommodate the needs and demand of different regulators;
- focus not just on financial and governance compliance but also performative accountability;
- provide the basis for meaningful engagement and communication;
- restore lost confidence within the not-for-profit sector;
- resource the core administrative costs of organisations.

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