ARK Policy Brief

Self Directed Support and Adult Social Care in Northern Ireland

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This policy brief presents research evidence and key themes discussed at an ARK policy roundtable event in November 2024. The roundtable was conducted under the Chatham House Rule, bringing together people with lived experience of self directed support, family carers and representatives from policy, statutory, academic and third sectors.

Introduction

Since 2011, a number of reviews and consultations regarding adult social care in Northern Ireland have proposed greater service user choice and control through a 'self directed support' approach. Despite being practised across Northern Ireland for over a decade, there has been no progress in defining this approach in policy. The experience of self directed support for service users is not widely researched or understood, but existing evidence indicates systemic barriers to the success of the approach. These barriers include a social gradient, workforce issues, low awareness, and a lack of advocacy and support services. While personalisation has been legislated for in other parts of the UK, adult social care in Northern Ireland has failed to gain the same policy attention or traction. Evidence provided by Hughes (2024) shows that efforts to embed self directed support have not just stalled but are in need of immediate attention. Following a two-year period of collapse, the Northern Ireland Executive returned in February 2024. This policy brief examines the issues and argues that the current reform of adult social care provides an opportunity to advance self directed support policy.

Background

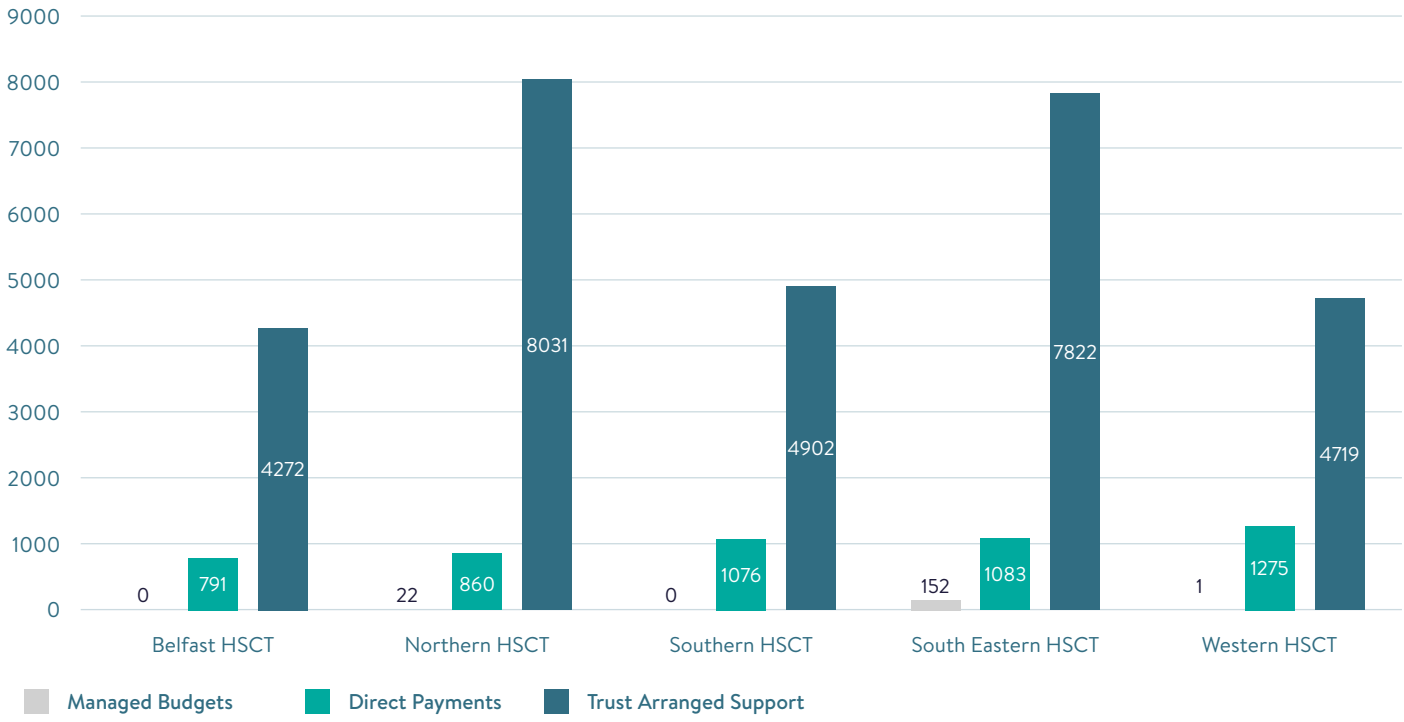
Personalisation represents a major shift in adult social care delivery. The approach offers individuals choice and control over their own social care, choosing how their support could best be arranged so that they can live the life they wish to live (Dunér et al., 2019; Baxter et al., 2020). It was developed as a way to transform social care from a "one size fits all" model to a more person-centred system, underpinned by ideologies of independence, autonomy and freedom for disabled people and other individuals accessing care and support (Duffy, 2018). This approach evolved following the introduction of direct payments, which were conceived as a result of pressure from the independent living movement and disabled activists in the 1980s (Riddell et al., 2005).

The concept of personalisation, called self directed support in Northern Ireland, gained significant traction across the UK in the early 2000s. However, implementation has differed across the four nations (Needham and Hall, 2023), with England, Wales, and Scotland all legislating for this approach to social care while Northern Ireland has lagged behind (Chapman, 2018; Chapman, 2020).

Northern Ireland Policy Context

Ongoing political instability in Northern Ireland has resulted in six collapses of the Assembly since devolution was restored in 1998. As a result, there has been a stark policy vacuum and lack of strategic direction regarding social care, including self directed support (Gray and Horgan, 2010; Chapman 2018; Chapman, 2020). This is despite numerous expert reviews highlighting the need for social care reform to enhance user choice, control, and independence (Department for Health, Social Services and Public Safety, 2011; 2013; 2014; 2016; Department of Health NI, 2017; 2022). The Transforming Your Care consultation in 2011 first proposed self directed support as part of wider efforts to shift care into community settings (Department for Health, Social Services and Public Safety, 2011). Subsequent consultations have reiterated calls for implementation of self directed support (Department for Health, Social Services and Public Safety, 2013; Department of Health NI, 2022). However, these proposals have not translated into policy or an implementation roadmap. Self directed support remains undefined in policy and is still often misunderstood or conflated with the direct payments scheme in Northern Ireland. According to data from a Freedom of Information request made to Health and Social Care (HSC) Trusts in 2023, uptake of Direct Payments in Northern Ireland has been comparatively low and Managed Budgets (a managed budget allows the recipient to have flexibility and choice over their care without becoming an employer) are yet to be fully implemented (Hughes, 2024). Despite the challenges, research indicates that self directed support can be an important step in improving adult social care in Northern Ireland.

Use of SDS by HSC Trusts 2023



Use of SDS by HSC Trusts in 2023 established through FOI requests

Policy Roundtable

The policy roundtable focused on recently completed PhD research findings on self directed support and adult social care in Northern Ireland. To commence the event, Dr Susan Hughes presented the current policy context as well as the key research findings. The PowerPoint slides for this event are available on the ARK website alongside this policy brief.

There is a need for more research on self directed support and adult social care in Northern Ireland. Previous work by Gray and Horgan (2010), Gray and Birrell (2013), COPNI (Duffy et al., 2015) and Chapman (2018) has provided insights into a range of social care issues while Hughes's study looks in more depth at the lived experience of self directed support in Northern Ireland. This research identified the need to further explore workforce issues and organisational culture, experiences of systemic prejudice and inequality, public expectations of self directed support and the potential impact of fully implemented managed budgets (Hughes, 2024).

The following is a summary of the research presented at the roundtable event. The data are based on a review of literature, analysis of policy in UK jurisdictions and interviews with individuals with lived experience, social workers and policymakers in Northern Ireland.

Policy

The absence of a policy framework has resulted in no clear definition, objectives or plan for self directed support. The research found that this contributed to a lack of understanding on the part of service users about what to expect from social care. The term 'self directed support' is not well understood by service users and practitioners and is often conflated with Direct Payments. The lack of explicit underpinning ideology and values has contributed to self directed support being seen as a transactional process rather than a person-centred approach to social work and social care. Attempts to implement some form of self directed support amidst continued austerity has led to ever-increasing eligibility criteria, making preventative work and consideration of wider social needs unfeasible. Initial plans for personalisation in most UK jurisdictions outlined the potential for this approach to shape a diverse and responsive market from which service users could build their ideal support plan. Existing research backs up the findings that privatisation of social care has facilitated a 'race to the bottom', incentivising care providers to 'cream-skim' and prioritise profit over service user preference (Le Grand, 1991; Miller, 2019). The Northern Irish social care market in its current form may be unable to facilitate personalised social care due to a lack of choice and flexibility for service users.

Health and Social Care Trust Arranged Support

Many people are satisfied with their Health and Social Care (HSC) Trust arranged support and are grateful to have a free service that assists them to continue to live in their own home. However, the evidence suggests this form of care remains 'task and time' oriented and inflexible to service users' needs and preferences (Hudson, 2021). The research findings indicate that much domiciliary care can be experienced as rushed and inconsistent. A shortage of care providers and workers has exacerbated the level of control exercised by the private sector over individuals and the HSC Trusts. The comment by one service user that HSC Trust arranged care made them feel they were 'just a number' is indicative of more general views. The research suggests this form of support is not associated with a sense of choice, control or consistency. Furthermore, there was a marked reluctance to report unsatisfactory or unsafe care for fear of losing necessary support.

Direct Payments

Pre-dating self directed support (introduced in 1992), Direct Payments offer service users control of their own social care budget to directly purchase services or employ a Personal Assistant (PA). Direct payments have helped many people access transformative support; delivering freedom, flexibility, and autonomy. Some of those interviewed with experience of using Direct Payments said that they had facilitated the meeting of both physical and social needs simultaneously and cost-effectively. One service user spoke of how Direct Payments had changed his life, supporting the development of working relationships with the PAs he recruited, a return to education and the flexibility to go out in his own car. Direct Payments were also associated with the recovery of family relationships through the reduction of caring responsibilities. They are, however, highly bureaucratic and complex for individuals and keyworkers, making them somewhat inaccessible and impractical for many, a point raised by research participants and widely supported by research across the UK (Lymbery, 2014; Manthorpe et al., 2015; Velzke, 2017; Jepson et al., 2016; Carey et al., 2019). Overall, the research found that self directed support in Northern Ireland is yet to move personalisation of adult social care beyond Direct Payments. The positive experiences of Direct Payments captured in the research promote the value of implementing a model of self directed support capable of offering choice and control through all support mechanisms.

Managed Budgets

Managed budgets were conceived as one such alternative mechanism, bridging the gap between HSC Trust arranged support and Direct Payments. This option was designed to offer full control over budget expenditure without the responsibility of becoming an employer and administering payments. Many policymakers identify Managed Budgets as the solution to fair and accessible self directed support, however, these have not been rolled out across Northern Ireland due to structural barriers, including within contracting and procurement departments. These have been receiving more attention and interest recently as researchers and practitioners seek to understand and overcome the barriers to implementation.

Social Work

Social workers across Northern Ireland recognise the benefits of working in a person-centred and co-productive way and are motivated to practice in this way. Evidence indicates that leadership is pivotal to the success of self directed support. Enthusiasm from leaders can drive implementation of self directed support in all aspects of daily practice. A culture of trust can support social workers to engage in innovative and creative practices, partnering with service users to develop support plans that will meet their individual needs in a way that suits them.

Policy Implications

The research made five policy recommendations developed directly from the data and research findings.

- Northern Ireland needs up-to-date social care legislation and self directed support policy which outlines a legal minimum standard of care and clear expectations.
- Northern Ireland should adopt a Citizenship model of self directed support, as first conceived by Duffy (2018). This means the approach should be underpinned by Human Rights, autonomy, and freedom.
- Self directed support requires a change in culture and leadership. Keyworkers and service users should be trusted to think innovatively and resourced to work preventatively.
- The market must be managed and shaped by local government, with an emphasis on ethical commissioning (Hudson, 2021). Building localised services, grassroots initiatives, and third-sector micro-providers will develop the capacity to offer fair and flexible support.
- Workforce reform is high on the agenda and must continue to be prioritised. Care should be valued, safe and of high quality. Improved working conditions will help to address recruitment and retention issues across social care and social work.

What is self directed support in Northern Ireland?

Data indicate much of what is described as self directed support in Northern Ireland falls outside of the definitions outlined in the literature - for example, the 17 human rights- and evidence-based global standards of self directed support developed by the Self-Directed Support Network (2024). Whilst some experiences of self directed support are transformative, these are not fairly available to everyone. Some people are unable or unwilling to take on the responsibility of direct payments, an issue exacerbated by the lack of advocacy services in Northern Ireland. The vibrant and competitive market envisaged by governments at the conception of personalisation has not yet been realised. There is a recognised lack of real choice for individuals and limited control over support plans.

Interview data identify enthusiasm amongst service users, social workers and policymakers for change and passion for person-centred practices, accessible support and good outcomes for disabled and older people in Northern Ireland.

Roundtable Discussion

In advance of the roundtable, participants received a briefing paper and were invited to reflect on the following questions:

- Is self directed support the right direction for social care in Northern Ireland?
- Is self directed support, as it is currently rolled out across Northern Ireland, achieving the envisaged outcomes?
- Is it possible to implement self directed support successfully with the existing policy and level of resources?
- Is the current context and infrastructure favourable for Managed Budgets?
- What is required in the reform of adult social care to ensure progress for self directed support?

The following themes capture the discussion.

Implementation Gap

Roundtable participants identified a stark difference between the vision of self directed support and practice experienced on the ground, with divergent approaches taken across each HSC Trust. This presents challenges for expectations and delivery of self directed support, particularly for organisations who wish to provide equitable support for people across the whole of Northern Ireland. Differing and contradictory approaches to self directed support are also evident across HSC directorates. Participants recognised a tendency for statutory bodies to target the "largest social care user groups first". They highlighted a sense that the needs of the learning disabled community are considered last, with older people's and physical disability services taking precedence at the point of policymaking and systems design. This perception was also highlighted when discussing current day centre and short breaks provisions which participants felt were lacking in diversity. There was a consensus that social care lacks real choice due to provider and workforce shortages.

One participant indicated that self directed support should not be considered a 'direction' for social care but one 'tool in the tool box' which can be utilised to support individuals in achieving good outcomes. The question was then posed: What is the main priority within social care in Northern Ireland, and where does self directed support fit?

Policy

Legislative issues were raised throughout the discussion, particularly in light of a local television documentary focusing on ongoing issues with Direct Payments and delegated healthcare tasks (Jordan, 2024). This refers to the process of authorising social care workers to carry out specific, necessary health care tasks as part of their role, without which some families would be unable to access Direct Payments and social care support. There is considerable variation in practice with regard to delegated healthcare tasks across Northern Ireland, leading to public discourse and significant media interest. Participants again

raised the differing approaches taken across HSC Trusts when developing support plans for people with complex health and social care needs. It was recognised that the reluctance of HSC Trusts to delegate health care tasks to personal assistants (PAs) was associated with a fear of liability.

The consequences of the absence of up-to-date adult social care legislation generally, along with the lack of a self-directed support policy, were discussed by participants. They noted the absence of minimum entitlement or standards of care and highlighted how the lack of legislation can hinder the implementation of new practices. Participants expressed the view that health care issues have dominated media and policy agendas, with waiting lists for acute services and delayed hospital discharges receiving particular attention. However, this was countered by evidence indicating that personalisation legislation exists across Great Britain, yet issues remain regarding service delivery, equality, and standards. Participants agreed that there is a general lack of awareness and understanding of self directed support, and that the absence of a clear policy definition may contribute to this. Some participants felt there are opportunities for Northern Ireland to learn from other regions in the UK. For instance, one participant believed that the Northern Irish system would benefit from a transparent resource allocation system. Attention was drawn to examples of good practice showcased by local authorities across Great Britain.

Reflecting on existing legislation, one participant highlighted that while Direct Payments can facilitate transformative outcomes for some individuals, they had concerns that the 'spirit' of the scheme had been lost over time. The sense was that the innovation and freedom imagined for Direct Payments have been stifled by strict governance and a lack of trust that people can spend their money in a 'good way' or in a 'sensible' way that will meet the assessed needs. Some comparison was made to the social security system and its contrasting lack of authority over spending, demonstrating it is possible for funding systems to operate very differently.

Components of the existing self directed support model were perceived to require improvement. Participants agreed that HSC Trust arranged support options have suffered as a result of protracted focus on cost-saving measures. This option relies upon a 'time and task' approach, which the group strongly agreed is outdated and contradictory to the objectives of personalisation. The demand for domiciliary care places a high level of market control with service providers and participants raised concerns about the impact this has on service users. One participant indicated that the 'Support Plan' element of self directed support is not functioning as envisaged, limiting the capacity for individuals to exercise choice and control over their care. The development of independent brokerage systems was suggested as a means to encourage greater diversity of support options.

Participants highlighted the limitations on self directed support posed by procurement, contracting and governance. An argument was made that the persistence of these barriers may be related to a lack of top-down leadership and support for self directed support from the Department of Health. Some participants felt these issues are not insurmountable but may provide a smokescreen for a reluctance to embrace innovation, change and managed risk. There was a sense of optimism that these issues are currently receiving more attention and debate, which may result in progress for Managed Budgets implementation.

Values

There was a consensus in the room that the values underpinning self directed support are vital to its success. The point was made that the only way to ensure the success of this approach is to focus primarily on the individual, rather than the needs of the system or services – the objective has to be genuine person-centred planning. The view was expressed that the capacity for social workers to engage in meaningful co-production has been diminished by the introduction of care management and the impact of neoliberal agendas.

There was agreement that self directed support necessitates a level of bottom-up policymaking, as the top-down approach to personalisation across the UK has undermined the critical ideologies central to self directed support.

The pressure on budgets was recognised, and the importance of ensuring existing budgets are used effectively to deliver the best outcomes was emphasised. The point was made that, while not a primary rationale for self directed support, such an approach, if planned well and with the appropriate value base, could prove cost-effective. An example was provided of individuals with Direct Payments returning unspent budgets when given the freedom to spend flexibly. The importance of trust was a key theme of the roundtable event. In the room there was a strong conviction that people know how their own budgets can best be spent. Participants recognised that trusting people and their family members to develop the most appropriate support plan should not be framed as an option but as a human right.

Workforce

The roundtable participants acknowledged the growing workforce crisis in Northern Ireland, which has a direct impact on the success of self directed support. In particular, they saw that the benefits of Direct Payments can be countered by difficulties recruiting PAs and that such problems can be more challenging for those living in rural areas. One participant expressed their aspiration for the development of a record of available PAs to assist with recruitment. Participants reiterated the importance of addressing the range of social care workforce issues; pay and conditions, recruitment and retention and training. Associated with this, participants wanted clarification on the role of social care workers – for example, the debate regarding delegated healthcare tasks raises significant important questions for social care. Workforce concerns are not limited to care and support workers, and it was also understood that social workers are under increased pressure, with growing caseloads, unfilled job vacancies and an increasingly bureaucratic role.

Final Point

When asked for closing remarks, participants felt it was important to draw a line under the concerns and issues that were raised throughout the discussion, focusing instead on hopes and ideas for the future. It was agreed that Northern Ireland needs a social care system that is fair and equitable, flexible and responsive to users' needs. Greater flexibility around budgets was considered to be one important way to achieve person-centred practice. Some participants recommended the introduction of self directed support champions who could share positive examples of practice that have contributed to life-changing and transformative outcomes. This would help to inspire those working in the social care arena to embed values of co-production, empowerment and trust in their day-to-day practice.

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