

**Post Qualifying Social Work
Research Methods Programme provided by
Ulster University and employer organisations**

**Research and Evaluation Studies Undertaken
2022-2023 as part of the
“Research and Evaluation Methods in
Social Work Module” (SWK 752 Module)
And
“Research and Evaluation Methods to inform
Social Work” (SWK 754)**

**Abstracts
2023**

Preface

Social Work Research Methods Programme

The Research Methods Programme provides two postgraduates, post qualifying modules for social workers approved by the Northern Ireland Social Care Council as part of the Professional in Practice Framework:

- The Evidence–Informed Professional and Organisation (SWK 751)
- Research and Evaluation Methods in Social Work (SWK 752)

The programme provides three modules for users of social care services and their families:

- Using Evidence to Inform Professionals and Organisations (SWK 753)
- Research and Evaluation Methods to Inform Social Work (SWK 754)
- Innovation and Co-production in Social Work Research (SWK 755)

The modules for social workers are accredited by the professional regulatory body, the Northern Ireland Social Care Council, and enable candidates to gain Requirements of the Professional in Practice Framework as detailed below. They require employer support and post-qualifying practice experience for entry. They are designed particularly for Senior Practitioners, training officers and other experienced social workers to gain knowledge and skills in using evidence to inform their practice and service development in their organisation. These modules achieve credit towards the Postgraduate Certificate and Postgraduate Diploma and MSc in *Professional Development in Social Work*.

The modules for service users and carers equip them to carry out roles in developing social care research, such as membership of research committees and grant awarding panels. These modules achieve credit towards the Postgraduate Certificate and Postgraduate Diploma.

All modules are 60-credit Level 7 (postgraduate) modules and are designed to develop knowledge and skills relevant to social work research-related activity and culture in Northern Ireland in support of the *Social Work Research and Continuous Improvement Strategy 2020-2025* (Health & Social Care Board, 2021) updated from the previous 2015-2020 Strategy.

Research and Evaluation Methods in Social Work module (SWK 752)

Research Evaluation Methods to Inform Social Work module (SWK 754)

These modules require the 'Evidence' Module (SWK751 or SWK753 or equivalent) as a pre-requisite for entry. Candidates build on the literature review undertaken during that module (or equivalent) to undertake a work-based research, service evaluation or professional audit project agreed with line management. Candidates develop knowledge and skills in designing and managing a project that will support robust, evidence-based development of professional practice and services. An additional booklet on the outcomes from these modules will be produced and placed on <http://www.ulster.ac.uk/dare>.

Learning Outcomes

- Demonstrate competence, leadership and initiative in negotiating and collaborating with a range of stakeholders and fostering reciprocal relationships in undertaking a research, audit or evaluation project relevant to their role.
- Create a focussed and answerable research, evaluation or audit question which addresses a practice issue, using informed judgement to select an appropriate methodology.
- Negotiate complex ethical and governance arrangements to secure approval for an innovative project and access to data.
- Gather relevant data in accordance with a rigorous research methodology.
- Analyse the data and interpret the findings in the context of current literature and policy by writing a postgraduate dissertation which makes worthwhile recommendations for service improvement in line with organisational and social work principles.

- Influence change through delivering an oral presentation to managers, professionals and service users which critically appraises and applies knowledge from the project to inform practice.

Both modules have identical, joint classroom teaching; require the same academic entry requirements, and require similar assessment. They are designed to contribute to improving our Social Work Services to individuals and families by improving knowledge and skills, service quality and the effectiveness of organisations delivering social care services. The module runs for one academic year from September to September each year.

This document provides full abstracts and contact details for those who undertook research and evaluation module of the post qualifying course between 2020/21. To obtain copies of the research and evaluation studies please contact the individuals directly. Contact details are included on each abstract. Electronic versions of the abstracts are also available on the University website <http://www.ulster.ac.uk/dare>.

[Abstracts from the academic year 2016 onwards are also available in this website. See pages 26-31 of this document for a list of names, project titles and contact details.](#)

This report will also be placed on the Northern Ireland SCIE page under Evidence, Innovation and Quality Improvement. And you can also find it at Northern Ireland Social Care Council Website.

Contents

Title	Researcher or Evaluator	Organisation	Page
Research and Evaluation Methods in Social Work module (SWK 752)			
Who cares? Staff perceptions and experiences of the barriers to identification of informal carers in primary care services	Kate Havern	South Eastern Health and Social Care Trust	6-9
What are Social Workers' Perceptions of Carer Support and Assessment within Adult Services?	Laura Thomson	Southern Health and Social Care Trust	10-14
Alternatives to Acute Admission for Patients with a Primary Diagnosis of Emotionally Unstable Personality Disorder – Staff Perspectives	Carrie Cruikshank	Belfast Health and Social Care Trust	15-19
Research Evaluation Methods to Inform Social Work module (SWK 754)			
Social Resilience: A Transformative Journey for Lonely Young Persons	Noel Wilson	Service User	20-24
Young Onset Dementia – Informal Carers perspectives on formal and professional support post diagnosis	Emily Wilson	Service User	25-29

Research and Evaluation Methods in Social Work module (SWK 752)

Title of Study

**Who cares?
Staff perceptions and experiences
of the barriers to identification of
informal carers in primary care
services**

Abstract

Context

Research suggests that informal carers are more likely to have seen their GP than any other health professional and staff within primary care services may be the first connection to the health service that an informal carer may make while providing care to another individual. For this reason, it is vital that systems and supports are available within primary care services to identify, involve, and subsequently provide support to enable carers to maintain their own health and wellbeing.

Methodology and Methods used

This service evaluation study used a qualitative approach to explore the perceptions and experiences of a range of staff groups within selected GP surgeries to consider the barriers to identification of family or informal carers throughout their day-to-day work. Survey Mechanics online survey tool was used to assist with producing a survey questionnaire. Overall, thirty-one participants with a range of roles including GPs, Practice Managers, Mental Health Practitioners, Social Workers, Pharmacists and Reception/Administration staff participated in the study. The data generated was organised into key themes with the support of the Survey Mechanics tool and then collated using excel software.

Findings

Despite the evaluation being a small-scale study, it provided a valuable insight into the challenges faced by staff based in GP surgeries when identifying

informal carers in order to provide advice or support. This study established that barriers and challenges reported in the survey are well established in previous research around identification of informal carers in primary care services. Research supports the notion that there is a high number of informal carers who do not self-identify for a number of reasons and it is only when they reach crisis point that any support or intervention can take place. The analysis of the findings produced three main themes, identification, impact and response.

Identification

The results highlight a cultural aspect of the caring role; there appears to be little or no change over the years and the same barriers continue to be identified in relation to identification of this group. Many responses included a cultural aspect in their perception of any barriers to identification, and it demonstrates that there continues to be informal carers who will not self-identify as they feel that is their duty as a family member to provide this care or they are unaware that they are indeed in a caring role. Lack of knowledge and understanding from both staff and informal carer's perspectives also appeared frequently within the results with many respondents believing that this proves not only as a barrier to identification but also as a challenge for staff.

Impact

An important and emerging theme from the study involves the impact that pressures and challenges can have on both those with caring roles and on service delivery. Such challenges further hinder identification of informal carers to provide them with appropriate supports depending on individual needs.

Response

The study arrived to establish participant's knowledge of the key issues facing informal carers, what may prevent them from registering, and what may be

available to support them in their local community or from other health trust services. Many respondents highlighted challenges from a practice perspective in identification such as lack of time, resources and knowledge of what is already in place to support informal carers. Partnerships within the community and voluntary sector was identified as an appropriate response to supporting informal carers as it not only provides a user involvement opportunity but allows staff in primary care services to signpost cares for support while they focus on the cared for persons treatment. This would give assurances that informal carers can avail of early intervention supports that will go a long way towards educating, building capacity and therefore the less likelihood of reaching crisis points in their journey.

Conclusions and recommendations

Uncovering carer identities is important not only to validate the work that they carry out every day but to ensure that their needs are recognised. The study evidenced that many participants have a good understanding of the issues facing informal carers, but it does not appear to translate into practice for several reasons. With an increasingly busy workload and many changes in structure for some services it may not be priority at present. However, it is worth considering that if carers were prioritised it will not only benefit the cared for person but may decrease informal carers requiring primary care services for their own wellbeing.

As research around carer issues is limited, further studies or discussions around informal carers would go a long way towards finding and developing a mechanism that could be used in primary care services. This would enable consistent identification, communication with and planning for appropriate supports alongside local communities.

Recommendations from the study include:

- GP practices to consider adopting a culture of carer awareness and provide opportunities for staff training to keep abreast of any changes in relation to carer issues or developments. Regular carer awareness training would keep informal carers on the practice agendas and staff could be updated on any new services or supports.
- Consider early intervention initiatives to provide support to carers before they reach crisis point i.e. create a referral process to social work team with carer consent for an opportunity to discuss their situation and look at their informal networks, social, cultural, and economic aspects of the role.
- Find ways for each GP practice to record their carer population and use this database to assist in providing information to carers in a seamless and effective manner and equally to all. Carer information and a directory of services could be made available and regularly updated on practice websites or social media pages
- Examine ways to make better use of current practice social media, websites, in house communication and community group's support to raise the profile and encourage carers to register.

Build links with community organisations that offer supports to carers and work in partnership with them to signpost informal carers.

Name of Reviewer	Kate Havern
Organisation	South Eastern Health and Social Care Trust
Contact Details	<u>kate.havern@setrust.hscni.net</u>

Title of Study	What are Social Workers' Perceptions of Carer Support and Assessment within Adult Services?
Abstract	
Context <p>Informal carers are individuals who care for another person unpaid, such as for a friend, neighbour or family member, due to illness or disability (Carers Trust, 2023). It is estimated that there are over 290,000 informal carers living in Northern Ireland (Carers UK, 2023). Informal carers provide a substantial contribution to the health and social care system by helping to maintain the safety and well-being of the people that they care for. Consequently, carers frequently report that they are stressed and burnt out but receive inadequate support to maintain their own health and well-being (Carers UK, 2022). Therefore, social workers play a crucial role in supporting and assessing the needs of informal carers to help them continue in their caring roles.</p>	
Methodology and Methods used <p>This study draws upon a small-scale service evaluation within a Health and Social Care Trust, in Northern Ireland. Qualitative methods were used to explore the perspectives of community-based social workers across adult service directorates, on assessing the needs of informal carers and provision of carer support. Purposive sampling resulted in the recruitment of twenty-seven social workers across eight different service areas within adult services. Jisco Online Surveys © tool was used to protect the anonymity of participants and collect the data. The survey consisted of a combination of closed, scaling and open questions. The survey was piloted with a small number of social workers who were not part of the final evaluation, to test for reliability and validity. The data was analysed thematically using Braun and Clarke's (2006) method, Microsoft 365 © was also used to support the analysis.</p>	

Findings

The findings suggest that social workers have a sound understanding of carer's assessment processes, understand the impacts of caring, and provide high quality support for carers. Five main themes emerged from the data: Recognition of the Caring Role; Supporting Carers; Resource Availability; Social Workers' Understanding and Motivation and Organisational Culture.

Discussion of results

The outcomes of this service evaluation have provided insight into the perceptions of community-based social workers across various adult services directorates, on supporting and assessing the needs of informal carers. Numerous challenges were highlighted in terms of carer recognition, capacity to effectively support carers, resource deficits, practitioners' approaches, and organisational priorities.

The findings indicate that there are difficulties with self-identification by carers and acceptance of the caring label. Confusion and misunderstanding about the label were seen as a key factor, as was carers' preferences to be labelled by their familial status. The study highlighted issues with the terminology of assessment which often causes confusion for carers about its purpose and meaning. Updated carers' literature focuses upon a deviation away from using the word assessment, instead using terms such as conversations with carers (SCIE, 2021).

Overall, participants were fairly confident in their abilities of supporting and assessing the needs of carers. Participants demonstrated knowledge of a wide range of statutory, voluntary and community services to support carers. The qualitative data illustrated that workload and staffing pressures were a major barrier in the provision of carer support. This was mainly due to high caseloads, complexity of the work and administrative tasks, which impacted upon the

amount of time, that social workers could allocate to working with carers. The findings suggest that carers were often viewed as an additional and unnecessary aspect of their workload, with some suggesting that carers were not their responsibility.

Resource deficits were seen as another barrier to providing effective support for carers. The main challenges that emerged from the findings were regarding long waiting lists for domiciliary support and respite care, budget constraints and a lack of bespoke carer support services to meet assessed needs.

The findings indicate that most participants possessed a comprehensive understanding of the purpose of carer's assessments and strived to assess carers needs using a person-centred approach. Whilst most social workers offered a safe and private space for carers to discuss their caring duties, for others it was common practice to do this in the presence of the cared for person or during service user-based contacts. This practice is inappropriate and the wider literature evidences that this can be detrimental to the relationship between carers and those that they care for (Forrester-Jones, 2021).

The data suggests that some social workers view current and existing carer's assessment tools, as ineffective and barriers to meaningful therapeutic intervention with carers. Lack of understanding and guidance around carer assessment process was highlighted by a very small minority of participants, suggesting that perhaps training and operational guidance hasn't been effective in developing social workers knowledge. The organisations current training on carer's assessment, places a strong emphasis upon the ethos of carer's assessment in terms of relationship-based practice, therapeutic intervention, and the impacts of caring.

The qualitative data showed that social workers often faced organisational pressure to complete carer's assessments, in a way that did not reflect the ethos or best practice guidance of effective assessment of carers' needs. Participants identified that they were often encouraged to complete assessments at the time of the cared for person's review to fulfil the statistical agenda of the organisation.

Conclusions and Recommendations

The study highlighted areas of good practice, an understanding of the challenges faced by informal carers and barriers in accessing adequate supports. However, there were areas of practice identified, that would benefit from further development to ensure that the rights of carers are upheld, and promotion of best outcomes.

The following recommendations have been proposed;

- 1) There is a significant need for an update to NI legislation and policy for carers, to provide equity of carers' rights in line with their UK counterparts. However, due to the collapse of the NI Executive this will not be feasible until the Executive is fully functioning again.
- 2) Prevention and early intervention support for carers should be a crucial priority throughout the organisation to reduce carer stress and burnout. This should involve timely assessments of need for carers at the right time. Assessments should be undertaken when there is a change in the carer's circumstances and during times of transition for the carer and/or service user.
- 3) HSC training on carer support and assessment should continue to promote the ethos of relationship-based practice, exploration of the impacts of caring and potential resources.
- 4) Future service evaluations capturing a larger sample and wider demographic of social workers across NI, would be beneficial to compare to the current findings and provide a further context to the knowledge of carer's assessment and support.

Future qualitative research with carers across NI, would be beneficial in capturing the experiences of carers on assessment and support. This would reduce the current gap in the existing research and provide a context for practice within NI.

Name of Reviewer	Laura Thomson
Organisation	Southern Health and Social Care Trust
Contact Details	<u>Laura.Thomson@southerntrust.hscni.net</u>

Title of study**Alternatives to Acute Admission for Patients with a Primary Diagnosis of Emotionally Unstable Personality Disorder – Staff Perspectives****Abstract****Context:**

A Quality Improvement initiative was commenced in Acute Mental Health Inpatient Centre in March 2020 at the start of the Covid-19 pandemic to try and assist with discharging people out of acute care in line with government guidelines at the time. A strategy was devised to reduce the numbers of patients who were classed as 'delayed discharges' in the system. While scrutinising these patients' circumstances, a cohort dubbed 'revolving door' admissions were incidentally identified. This prompted a further Quality Improvement initiative to endeavour to understand why these patients had a number of frequent admissions and how community services could be tailored to better meet their needs, and attempt to reduce pressure on demand for acute hospital beds. Inclusion criteria for the project was any patient who had been admitted twice within a 12-month period. Upon scrutiny of these patients it was discovered that a high proportion of them had a primary diagnosis of Emotionally Unstable Personality Disorder.

Crisis services in the Trust for this cohort of patients is limited and previous research demonstrates that an acute hospital admission can be counterproductive. A literature review was undertaken to inform the development of crisis services for Emotionally Unstable Personality Disorder (EUPD) within the Belfast Trust. Following the literature review qualitative research was completed with the staffing group in acute inpatients to elicit their views on providing front line care for this group, and their professional opinions on the planning of care in the future in relation to the Mental Health Strategy.

Methods employed in the research:

Study Design:

Data was collected using a qualitative approach via three focus groups. Focus groups consisted of staff from all patient-facing professionals within the unit. Each group aimed to have a mixed sample of a maximum 8 participants and lasted approximately 2 hours. The first hour was a semi-structured discussion on working with patients with EUPD. The second hour looked at the different interventions identified in the literature review and staff were invited to share their views on each one.

Sampling:

Given that the study is based in one hospital area, convenience sampling was employed. While there are limitations to convenience sampling, steps were taken to ensure improve the credibility (Stratton, 2021). Efforts were made to find a representative sample as possible (Bell, J., 2010). Ward managers were employed to identify relevant staff members and the sampling frame was all staff who provide direct care to patients with EUPD.

Data Collection:

Participants were asked to take part in one focus group session lasting approximately 2 hours. Focus group dialogue was encouraged using semi-structured, open-ended questions. This included an interview schedule with specific questions, however there was flexibility to allow for sub-themes to develop.

Data Analysis:

Qualitative data was analysed by taking a thematic approach. The use of both NVivo and Excel data analysis software were explored by the author, however the themes were well clarified and consistent across the groups making manual analysis an appropriate method. The researcher transcribed the groups with the use of voice recognition software on Microsoft Word. The data was then analysed with different colour highlight being applied to different themes. Once

this was complete, the themes were copied, grouped together onto a separate document and organised under the relevant interview questions. From this separate document, subthemes were identified and also colour coded. This approach facilitated a systematic approach to data analysis (Krueger, 1998). Such was the similarity of data collected across the groups, data saturation was reached by the third group and demonstrated robustness (Marshall & Rossman, 2011). Data was coded and linked with key themes. Findings were then compared with the literature review to interrogate similarities and allow integrative interpretations of the data. Patton (2002) argues that interpretation of the data means making sense of the findings, offering explanations and drawing conclusions based on the findings.

Findings:

Three focus groups were carried out with a total on 22 participants in total. Focus group 1 and Focus group 3 both had eight participants, while Focus Group 2 had six participants, due to two members of staff not being able to make it on the day. All staff had direct involvement in providing care to patients with EUPD and had varying degrees of experience working in mental health. While some clearly had more experience to draw on than others, discussion across all professionals and levels of experience drew out remarkably similar issues.

There were four main themes drawn out and some subthemes became apparent during the analysis:

- 1. Effect on Staff of providing care to patients with EUPD – Hopelessness and Frustration; Lack of Training; Increased Workload.**
- 2. Lack of Service Provision – Focus on Risk, not Illness; Insufficient Community Service Provision; Lack of Collaboration across Acute Services.**
- 3. Stigma / Shame**
- 4. Clinical Suggestions for Treatment**

Conclusion:

The over-arching themes and sub-themes demonstrate the effect that providing care for patients with EUPD has on the staffing group. It demonstrates that while there is good practice and staff are actively seeking out training to help improve their practice, there is clear evidence of an underlying frustration and fatigue of working within the current service. This is due to the perceived difficulties and consensus that what is being provided currently is not the correct pathway for the provision of care.

The study gave a valuable insight into the difficulties of working within the current system, the problems that have been raised and the imaginative ways in which they could be addressed. What is reflected in this study is a need to change the system for the betterment of services users, and those who work with them. Gaps in the current system have been highlighted, along with a fear that the current service being provided may be actually detrimental to patient's individual recovery. It is clear that the staff are working under considerable pressure, without sufficient resource and the lack of the correct treatment pathway for patients with EUPD is increasing this pressure and adding to a sense of frustration and helplessness within the staffing group.

These issues are reflected in the review of the international literature review completed by the author. Within that review it was clear that staff working within systems comparable to Northern Ireland expressed the same frustrations and difficulties. These frustrations and difficulties were felt by the patients within those systems. It could therefore be inferred that patients in Northern Ireland feel these frustrations also. This research lends weight to the evidence that the current system is not working and that there is an opportunity to develop a service that meets the needs of individuals and gives them the right care at the right time.

Name of Reviewer	Carrie Cruikshank
Organisation	Belfast Health and Social Care Trust
Contact Details	<u>Carrie.cruikshank@belfasttrust.hscni.net</u>

Title of study

Social Resilience: A Transformative Journey for Lonely Young Persons

Abstract

Context:

The work of a charitable organisation in addressing the needs of young people is studied. Its twelve-week self-referral, youth-led programme is the focus of the research. Typically, participants:

- are of at least secondary education age and
- include those who have either abandoned their education or
- left school with minimalist qualifications, or
- are unemployed, or
- struggling with the transition to adulthood, or
- have acute personal problems.

The study examined how the programme sought to develop young people's wellbeing, with a particular focus on empowerment, resilience and loneliness. Participants' experiences, opinions and outcomes were solicited as well as their views about how participation in a youth-led approach influenced their domestic and community engagements and employability.

Factors including adversity, dignity, relationship building, resilience, self-worth, social wellness, socio-cultural issues and dealing with traumatic life experiences provided the wider context for the study.

Methods employed in the research:

An inductive thematic method was adopted to obtain an understanding of how critical personal issues were addressed by the programme. Persons

knowledgeable about the programme participated in a qualitative study based on interviews, using a semi-structured survey instrument. Comprehensive piloting of the survey included consultations with other staff familiar with the programme but not associated with its delivery.

Ten participants, seven from the programme's youth management group with oversight of the programme, and three youth leaders participated; four participants were female and all participants were beyond the age of consent. The gender breakdown of the youth management group was representative of a typical programme intake. Their backgrounds varied: some youth were rural and others were urban domiciled, some were now in employment and others had achieved qualifications ranging from Open College Network Level II through to progressing on a primary degree. Varying socio-economic and domestic backgrounds were represented in the cohort who participated.

A thematic analysis was conducted using NVivo®. Emerging themes that were subsequently checked for trustworthiness with the participants are summarised below.

Findings:

Themes that aligned with the research aims and objectives appeared as six major topics, based on a logical clustering of 20 sub-themes. In pursuance of an overall theoretical framework, these major topics fell naturally into two overarching domains: one associated with the programme's ethos and the other with participants' social wellbeing.

A summary of the main topics follows:

a) Professionalism

The professionalism manifest towards participants was evidenced by all interviewees, often citing staffs' empathy and how their needs were

accommodated. Signposting and referrals to other support organisations catered for needs beyond the scope of the staff. Relationships with social workers, mental health services and housing bodies, complemented the programme's core activities.

b) Programme Engagement and Professional Needs

Participants spoke positively about how prospective young people approached the scheme; also, the ability of the programme's youth workers' enthusiasm to devise plans to address their needs.

c) Wellness and Safeguarding

The caring ethos manifest by the programme's staff in addressing anti-social behaviours, cyberbullying, social media misuse, personal barriers and mental-health matters featured prominently.

d) Respect and Dignity

Mutual respect, confidentiality, dignity, emotional and psychological discourse, and pedagogy fell within this heading. Participants empathised the importance of developing competencies to become resilient and empowered to cope with life.

e) Social and Professional Development

A range of developmental activities; career, educational, social, and personal were found. Activities undertaken to inculcate skills, and knowledge formed a nucleus of many interview responses.

f) Identity and Relationships

Self-image, self-esteem, and relationship development featured in various guises. Links within the community, with peer groups, employers and other organisations were key elements.

Conclusions:

Challenges confronted by young people whose early life experiences were thwarted by circumstances for which they lacked ability to address were found. Socio-economic, educational, and domestic factors illustrated the risk of being alienated from opportunities, yet with a deep appreciation and compulsion to change lives, transformative schemes can be established to successfully empower our youth.

From this qualitative study the programme delivered positive results for marginalised youth who now enjoy successful adult lives.

Recommendations:

Recommendations focus on those prominent elements that emerged from the findings. The “voice of the young people”, by expressing their reservations about their life’s challenges, promotes the need to present recommendations considered beneficial to others in similar situations.

- a) At a governmental policy level “The Voice of Young People” should be represented by youth, using engaging methods to achieve their input, for example, Youth Councils or Youth Forums
- b) The “youth justice” concept be widely promulgated within services; education, health, probation, policing, social services, and in apprenticeships and employment opportunities – give young people a chance in life
- c) Recognise “one size doesn’t fit all”, especially in the education sector, promoting technical and vocational opportunities and work-based

experience for those disinterested in academic pursuits

- d) Promote the role of youth work's non-formal education and recognise its contribution to achieving cohesive neighbourhoods
- e) Develop skills for social workers and educators to detect social and other barriers to risking dropping out from education, providing suitable methods to address the risk
- f) Formally involve young people in neighbourhood and community spaces and amenities consultations, prioritising provision for leisure, socialisation, and intergenerational engagement
- g) Provide tailored health care and counselling schemes that address alcohol and drug misuse, exercise and sport, leisure benefits, mental health risks, nutritional wellbeing, and social responsibility
- h) Reinvigorate the heart of deprived communities, providing meaningful employment, housing, security, transport, and attractive community cultural opportunities.

Financial implications are not explicitly referenced however these are acknowledged as a prerequisite for implementing change.

Name of Reviewer	Noel Wilson
Organisation	Service User
Contact Details	e28533@btinternet.com

Title of study	Young Onset Dementia – Informal Carers perspectives on formal and professional support post diagnosis.
Abstract	
Context: Currently (2023) is it estimated that there are 22400 people living with dementia in Northern Ireland. In May 2023, the Northern Ireland Statistics and Research Agency, (NISRA), published that,13635 people in the region were recorded on the region’s Dementia Register, but, it is estimated that 35% of people do not have a diagnosis as demonstrated in the MODEM (<u>Modelling outcome and cost impacts on interventions for Dementia</u>), project. Young Onset Dementia (YOD) is considered as individuals who are displaying the symptoms of dementia below the age of 65. It is estimated that nine percent of people living with dementia are classified as YOD. Therefore, using the above figures, it is estimated that over 2000 people in Northern Ireland are living with YOD. No figures are available on how many informal carers (those providing care without receiving payment) there are in Northern Ireland caring for people with YOD.	
Methods employed in the research: This paper reports on a small qualitative study of 6 informal carers, of people living with YOD and who are in receipt of care from a Health and Social Care Trust in Northern Ireland. It was informed by a Systematic Narrative Review conducted by the author, Wilson (2021). Five face to face interviews were conducted on Trust premises with one interview being conducted via Zoom platform. All interviews had a duration of approximately one hour.	

Before commencement of the study the interview schedule was agreed by the Dementia Improvement Lead of the Trust. Questions contained within the semi structured interview were quality assured by Alzheimer's Society employees from three different directorates.

The findings were analysed using a systematic approach and due to the small scale of the study no computer assistance was used.

Findings:

The main findings from the study were classified into five main themes.

1. Professional awareness of Young Onset Dementia and its management.

YOD does not always present as memory loss which is demonstrated more frequently in Late Onset Set Dementia (over 65's). Often due to their young age their general health and fitness is good and there is a higher probability that the individual is likely to be have one of the rarer forms of dementia. Frequently the person is dismissed as having no health concerns or are diagnosed as having a mental health condition.

2. Professionals not actively listening to informal carers before diagnosis.

In this study informal carers had identified that all was not well with those they later cared for before any diagnosis was received. Many living with YOD had sought advice from medical professionals but the voice of the informal carer was not heard due to the General Data Protection Regulation (GDPR) rules and patient confidentiality.

3. Expectations of Social Care

In four of the six interviews the YOD was in receipt of social care (either domiciliary, residential or nursing care). Domiciliary carers coming into the home were not specialised in dementia care, had received little information on dementia and the rarer aetiologies and the care needs. Informal carers were not made aware of what to expect from the package of social care that had been allocated. In some of the interviews it was evident the provision of domiciliary care did not relieve the burden on the informal carers and in some cases the level of carers burden was increased.

Those admitted to residential or nursing care found the system was more dedicated to those in later life and were few activities suitable for YOD

4. Lack of Support around systems.

The social care system can be difficult to navigate especially after receiving a diagnosis of dementia. Some spoke of being left to 'get on with it'.

Any support given was in written format which informal carers found difficult to fully comprehend or have the time to fully understand the information enclosed.

Although legal and finance advice is available, more signposting where to find the appropriate advice and guidance is required relevant to the age of both the individual living with YOD and their informal carer. This also applies to relevant benefits and the availability of grants to make their home more risk averse and dementia friendly for both the present and the future.

5. Support for Informal YOD Carers

Service provision for carers of people living with YOD is sparse. There are services for dementia informal carers but mostly it is for those caring for people of an older age.

Caring for YOD brings many difficulties. Due to younger ages of the individual with YOD and their informal carer they may have additional caring responsibilities for elderly parents and for their own children.

The informal carer may still be in employment therefore the support currently provided may not be at suitable times during the working week. Support from employers is necessary with the ability to work more flexibility, reduce hours and have time available for clinical appointments.

Conclusions:

This study took place towards the end of 2022 when the United Kingdom was emerging from the Covid Pandemic. A period of Volatility, Uncertainty, Complexity and Ambiguity (VUCA) (Murugan et al 2020). This added to the burden of the informal carers due to the difficulty in arranging medical appointments, and of maintaining social contact.

Although there have been many campaigns to raise awareness of dementia it can still be viewed as an older person's disease. There is less understanding of YOD and how it presents especially as many dementias affecting younger people are rarer and less well identified.

More awareness of YOD is required in clinical settings, social care and the general public. With more awareness of YOD will come earlier diagnosis and better support. This is especially relevant with the development of two new drugs, Lecanemab and Donanemab which can slow down the decline of those living with Alzheimer's Disease but an early diagnosis is necessary.

Recognition that in domiciliary care one size does not fit all. More information and specialised training in dementia and how to deal with various presentations of dementia both in domiciliary care and care homes is crucial.

Informal carers are not looking for services for themselves but appropriate services and support for those they care which in turn will ease the care burden of informal carers.

Name of Reviewer	Emily Wilson
Organisation	Service User
Contact Details	<u>emilywilson1955@icloud.com</u>

Research and Evaluation Studies 2022

Title	Reviewer	Organisation	Email address
"Patience, Persistence, and Proportionality": Probation Officer's Perspectives of Desistance in Practice	Peter Beck	Probation Board for Northern Ireland	peter.beck@probation-ni.gov.uk
A description of inspectors' experiences using the Risk-Adjusted, Dynamic and Responsive (RADaR) scaled assessment tool within the context of the RQIA Care Home's Team	James Laverty	The Regulation and Quality Improvement Authority	James.Laverty@RQIA.org.uk
A Study of Adult Protection Procedures: Threshold Screening of New Referrals by Designated Adult Safeguarding Practitioners.	Scott Fleming	Northern Health & Social Care Trust	Scott.Fleming@northerntrust.hscni.net

Research and Evaluation Studies 2021

Title	Reviewer	Organisation	Email address
What works best to embed a collective style of leadership in social work?	Jillian Morris	South Eastern Health & Social Care Trust	Jillian.morris@setrust.hscni.net
Using retrospective file analysis to explore the role of a Post-Adoption Service in reunifications between adopted adults and their birth relatives.	Donna Elizabeth Shields	Belfast Health and Social Care Trust	donna.shields@belfastrust.hscni.net
Public Protection and Trauma-Informed Practice in the Probation Service: Competing or Complimentary Paradigms? Exploring Practitioners' Perspectives on Trauma-Informed Practice with Service-Users Assessed as Presenting the Highest Risk of Serious Harm to Others	Annie McAnallen	Probation Board for Northern Ireland	annie.mcanallen@probation-ni.gov.uk
Practitioner perspectives on working with young victims of trauma and their experiences of vicarious trauma and vicarious post traumatic growth	Bill Vail	Western Health & Social Care Trust	bill.vail@westerntrust.hscni.net
Has AYE Mentoring impacted on student to social worker transition, for social workers that graduated early during the Covid-19 pandemic?	Bronagh Hamill	Northern Health and Social Care Trust	bronagh.hamill@northerntrust.hscni.net
The profile of human trafficking offenders in Northern Ireland and an exploration into coercive control.	Emma Richmond	Probation Board for Northern Ireland	emma.richmond@probation-ni.gov.uk

Research and Evaluation Studies 2020

Title	Reviewer	Organisation	Email address
'The Hospital Social Work Role: evaluating social workers' perceptions of the impact of an early intervention pilot within an acute hospital.'	Pamela Fillis	South Eastern Health & Social Care Trust	pamela.fillis@setrust.hscni.net
What are the experiences of community social workers supporting those impacted by a non-malignant palliative condition?	Gillian Thomas	Western Health and Social Care Trust	Gillian.Thomas@westerntrust.hscni.net
Enhanced Research Methods Reflection Report for the Proposed The Apex of Involvement? An Evaluation of Mental Health Workers' Experiences of Co-Production in a Recovery College Project	Karen Bester	Service User/ Carer	karen.l.bester@gmail.com

Research and Evaluation Studies 2019

Title	Reviewer	Organisation	Email address
How does the “Heart of Living and Dying” conversation enable people to talk about death and dying and support them to plan ahead?	Deirdre Mc Kenna	Southern Health and Social Care Trust	Deirdre.mckenna@southerntrust.hscni.net
Getting co-production off the ground: The experience of service users and social workers who have tried.	Patricia Burns	Belfast Health and Social Care Trust	Patricia.burns@belfasttrust.hscni.net
Foster Carers' Experiences of the Role of their Personal Support Networks in Helping Develop Resilience.	Laura Butler	Northern Health & Social Care Trust	Laura.butler@northerntrust.hscni.net
Parent perspectives on family based short breaks in The Southern Health and Social Care Trust.	Janet Johnstone	Southern Health & Social Care Trust	Janet.johnstone@southerntrust.hscni.net
Experiences of adoption disruption in Northern Ireland: the parents' perspective.	Elizabeth Lyttle	Service User	Elizabethlyttle65@gmail.com
'My experience of school' – The perspectives of adoptees aged 16-21 years.	Fiona Templeton	Service User	fionatempleton@hotmail.com

Research and Evaluation Studies 2018

Title	Reviewer	Organisation	Email address
What works best when completing Pre-Birth Risk Assessments ? Social Workers' perspective	Jane Hindes	South Eastern HSCT	Jane.hindes@setrust.hscni.net
Does a Practice Learning Opportunity increase a student Social Workers Emotional Intelligence?	Robby Nelson	South Eastern HSCT	robby.nelson@setrust.hscni.net
An evaluation of social work in involving patients with Dementia in decisions related to hospital discharge	Robyn Lennox	Northern HSCT	Robyn.lennox@northertrust.hscni.net
Self-Harm and Adolescence	Elaine Pollock	South Eastern HSCT	Elaine.pollock@setrust.hscni.net
A service evaluation to examine the impact of implementing a new Scaled Inspection Tool (S.I.T) on inspectors	Suzanne Cunningham	RQIA	suzanne.cunningham@rqia.org.uk
Do service user and practitioner training in co-production enable service improvement within health and social care?	Sonia Patton	Service User	sjpatton924@gmail.com

Title	Reviewer	Organisation	Email address
-------	----------	--------------	---------------

Research and Evaluation Studies 2017

perceptions of assessing individuals with a dual sensory loss and learning disability	Tanner		.net
Restorative approaches with families in elder abuse	Carole Kirk	Northern HSCT	carole.kirk@northerntrust.hscni.net
Developing team resilience as a strategy to prevent burnout and compassion fatigue in a statutory residential child setting implementing therapeutic practices	Adrian Graham	South Eastern HSCT	adrian.graham@setrust.hscni.net
Ageing out from foster care, the support and experience of young people	Franz Kavanagh	South Eastern HSCT	francis.kavanagh@yahoo.co.uk
Female care leavers' experience of the staff-child relationship while living in an intensive support children's home in Northern Ireland	Jenni Rice	South Eastern HSCT	jennifer.rice@setrust.hscni.net
Fitness4Survivors: A pilot study examining the impact of a 10-week CrossFit exercise program on fitness and quality of life with teenager and young adult cancer survivors in Northern Ireland	Simon Darby	Belfast HSCT and CLIC Sargent	Simon.Darby@clicsargent.org.uk

Research and Evaluation Methods in Social Work Module (SWK 752)

Research Evaluation Methods to Inform Social Work Module (SWK 753)

Contacts

<p>Course Director Dr Campbell Killick Ulster University C.Killick@ulster.ac.uk</p>	<p>Course Lead Dr Paula McFadden Ulster University P.McFadden@ulster.ac.uk</p>
<p>Programme Support Vanessa Butler pgresearchmethods@ulster.ac.uk</p>	<p>School Office School of Applied Social and Policy Sciences Room MH208 Ulster University, Northland Road, Londonderry BT48 7JL www.ulster.ac.uk</p>

Improving and Safeguarding Social Wellbeing: A Strategy for Social Work 2012-2022 Strategic **Priority 3** adding value, delivering outcomes places a focus on continuous improvement and a focus on demonstrating outcomes and learning from practice.

The Social Work Research and Continuous Improvement Strategy 2015-2020 revised in 2020 and reproduced as The Social Work Research and Continuous Improvement Strategy 2020-2025 places emphasis on the importance of building capacity of social workers and service users and carers

Our vision is that people in Northern Ireland who use our services will have confidence that social work and social care policy, practice and service outcomes are underpinned by a strong research evidence base committed to continual improvement? People will have the confidence that the social work and social care workforce will be sufficiently resourced, motivated, skilled and freed up to engage in research activity.

The Strategy is available at <http://www.hscboard.hscni.net/swresearch/>

The SWK modules support the vision of the: Improving and Safeguarding Social Wellbeing: A Strategy for Social Work in NI 2010 - 2022) available at <https://www.health-ni.gov.uk/publications/improving-and-safeguarding-social-wellbeing-strategy-social-work-northern-ireland>

Notes:
