



Experiences of Social Care in the Health and Care Experience Survey 2015/16: analysis of free-text comments



HEALTH AND SOCIAL CARE

Experiences of Social Care in the Health and Care Experience Survey 2015/16: analysis of free-text comments

Contents

Chapter 1: Introduction	1
Policy Context.....	1
The 2020 Vision.....	1
The Health and Care Experience Survey	2
Methods and Reporting	3
Limitations and caveats	4
Summary of Findings.....	4
Access	4
Coordination and management	4
Delivery	4
Outcomes	5
Unpaid care	5
Chapter 2: Access	6
Information and advice	6
Availability and eligibility	7
Location	8
Time.....	8
Chapter 3: Coordination and Management	10
Care management.....	10
Inter-agency working and communication	11
Discharge planning.....	11
Chapter 4: Delivery	12
Part 1: Relationships with professionals.....	12
Compassionate care.....	12
Continuity.....	13
Employment conditions.....	14
Part 2: Choice and Control	15
Person-centred support	15
Not feeling listened to	15
Time.....	16
Public sector finances and efficiency savings	16
Chapter 5: Outcomes	17
Independence.....	17

Social connectedness.....	18
Stress and anxiety	19
Recovery.....	19
Safety.....	20
Chapter 6: Unpaid care	21
Conclusion	23
Key messages	23
References	25

Acknowledgements

We are grateful to Aisha Macgregor, PhD candidate at the University of Glasgow, who undertook the data analysis as part of an SGSSS internship project.

Chapter 1: Introduction

Policy Context

There are several key social and economic factors impacting on the planning and delivery of social care in Scotland. Since 2006, there has been a 22% rise in the number of people aged between 65 and 75 years old and a 16% increase in over 75s (NRS, 2017). Health and social care services are facing growing demands and reducing numbers of unpaid carers, due to the changing age structure of society, in a context of economic uncertainty, efficiency savings, and welfare reforms.

The 2020 Vision

In 2011, the Scottish Government set out a 2020 Vision for achieving sustainable quality in the delivery of healthcare services across Scotland, in the face of the significant challenges of Scotland's health record, our changing population and the economic environment. All healthcare policy in Scotland drives the delivery of this Vision, which states:

By 2020 everyone is able to live longer healthier lives at home, or in a homely setting and, that we will have a healthcare system where:

- We have integrated health and social care
- There is a focus on prevention, anticipation ('forward planning') and supported self-management
- Hospital treatment is required, and cannot be provided in a community setting, day case treatment will be the norm
- Whatever the setting, care will be provided to the highest standards of quality and safety, with the person at the centre of all decisions
- There will be a focus on ensuring that people get back into their home or community environment as soon as appropriate, with minimal risk of re-admission

(Scottish Government, 2011)

As part of the 2020 Vision, a suite of policies affecting the planning and delivery of health and social care have been implemented in recent years. Together, these

policies aim to fundamentally change the way social care services are delivered in Scotland.

The Social Care (Self-directed Support) (Scotland) Act 2013

The Act introduced fundamental changes to the way social care services are delivered in Scotland. The principles of choice and control are at the heart of self-directed Support (SDS), which aims to provide individuals with more autonomy in relation to care and support. SDS is still in its infancy in Scotland and there is a lack of empirical research about people's experiences of social care under SDS.

The integration of health and social care

Integration aims to provide better joined up care to help improve the quality of health and social care in Scotland, through an emphasis on preventative and anticipatory care (Scottish Government, 2016a). Implementation has taken place at different stages across Scotland, however all 31 partnerships were operational by 1st April 2016.

The Carers (Scotland) Act 2016

This legislation places a duty on local authorities to provide support to unpaid carers, subject to local authority eligibility criteria. The Act will take effect from 1st April 2018 and therefore will not be reflected in these comments.

The Health and Care Experience Survey

The Health and Care Experience Survey (HACE) is our main national source of data for people's self-reported experiences of health and social care in Scotland. HACE is run every two years and the results are published on the Scottish Government website. As part of an internship with the Scottish Government, a student undertook analysis of free-text comments in responses to HACE 2015/16 which related to social care, with the aim of widening our understanding of the factors that affect people's experiences of social care and what matters to them.

Around 110,000 people responded to the HACE survey and just over 4,000 chose to provide comments about their experience of social care, in answer to the question:

“Do you have any other comments to make about the help, care or support that you receive?”

Comments were made by people providing and receiving care, as well as those commenting by proxy on behalf of someone else. This report presents the findings from analysis of this qualitative data and is complementary to the quantitative analysis which makes up the main report for HACE 2015/16 (Scottish Government, 2016b). Taken together, the two reports help to provide a clearer picture of social care experience in Scotland.

HACE 2015/16 results indicate that the majority of people are happy with the care and support they receive. Although there was a slight decrease by three percentage points from the 2013/14 survey, 81 per cent of respondents rated their overall help as excellent or good. People were most positive about being treated with respect (90 per cent) and were least positive about the coordination of health and care services (75 per cent) (Scottish Government, 2016b). This supplementary analysis of the free-text comments people made about social care provides insights into the factors that influence the quantitative data.

Comments covered an extensive range of issues relating to the planning, the coordination and management, and the delivery of social care services in Scotland. The support people described took many forms and was provided by a variety of professionals, as well as friends and families, to those with a wide spectrum of needs ranging from low level to more complex needs.

People were most positive about social care staff and relational aspects of care. This was accompanied by a strong and consistent message about the need for continuity of care, with regular workers who understand individual needs and preferences.

Methods and Reporting

Whilst the quantitative data from HACE provides understanding of the prevalence of particular issues and overall satisfaction levels, it does not provide an in-depth picture of everyday experiences of social care. The HACE survey aims to address this by including a free-text box for participants to elaborate on their answers where they can provide more detail about any specific areas that they feel are important to them. As noted above, 4,000 people chose to repond with additional comments. Irrelevant comments were omitted from the analysis - typically comments stating that no social care was required. Once these had been filtered out, 3,500 comments were left. The comments were thematically analysed using an inductive approach to coding. They were imported into NVivo and coded by theme as well as satisfaction level (positive, negative, neutral, mixed). Although initially a larger number of themes and subthemes were identified, some were merged due to their inter-related nature. Several of the themes are interlinked and transcend individual aspects of social care, but for ease of presentation, findings are structured in relation to five key areas:

- Access
- Coordination and management
- Delivery
- Outcomes
- Unpaid care

Limitations and caveats

It is important to note the methodological limitations associated with free-text comment analysis. Unlike open-ended questions, free-text boxes do not have a specific focus and therefore participants may discuss any issue that they feel is relevant. Whilst this provides flexibility and diversity in the issues that are covered, this can also result in a wide range of variability in the quality, scope, and relevance of the comments, which tend to be more detailed when negative in nature (Garcia et al, 2004). This, coupled with a lack of context or detail, can cause difficulties for the analysis (Garcia et al, 2004; O’Cathain and Thomas, 2004). Indeed, one of the limitations of the analysis is that there is no scope for probing to gain a more in-depth insight into the factors that have shaped people’s views.

Due to issues of representativeness, the comments cannot be inferred to the wider population and therefore reporting frequencies of comments does not provide any meaningful addition to the analysis (Garcia et al, 2004). Nor can it be assumed that the comments presented here are exhaustive and cover all issues relevant to social care experience.

Despite the limitations, the comments provide useful insight into the issues that have an impact on social care experience and what things matter to people. They are therefore a useful tool for improvement purposes. The results should therefore be considered with this in mind and in the context of the 2015/16 quantitative results, alongside existing research into social care experience.

Summary of Findings

Access

A large proportion of comments were concerned with accessing support. Responses highlighted the need for up to date information and advice and the importance of person-centred support planning based on individual need.

Coordination and management

The coordination and management of services was another common theme. Comments emphasised the importance of collaborative working and communication between service providers and service users and their families. Responses also highlighted issues in relation to the coordination of support for people being discharged from hospital.

Delivery

The delivery of care was another recurrent theme. Comments highlighted the need for continuity of care, with regular workers at consistent times, to suit individual need rather than resource priorities. Responses focused on the relationships people had with care workers and how this impacted on the quality of care. Comments were also concerned with choice and control, and whether this was reflected in support packages.

Outcomes

The comments highlight the impact of care on people's everyday lives. They demonstrate how support can improve outcomes, by facilitating independent living, social participation, and recovery. However, this was perceived to be influenced by resources and whether support packages were person-centred.

Unpaid care

Many comments related to experiences of unpaid care and highlighted the interaction between paid and unpaid care and the importance of support for carers.

Chapter 2: Access

Summary

Comments highlight a range of factors that influence access to the support which is needed to meet social care needs and outcomes. Participants expressed the importance of receiving accessible information and advice at the right time. Responses highlighted concerns in relation to eligibility criteria and the availability of services.

Access to care was a prominent theme within the comments. Responses highlight the need for timely, person-centred support as opposed to resource-led assessments and interventions. This section provides an overview of the comments relating to:

- Information and advice
- Availability and eligibility
- Location
- Time

Information and advice

The social care landscape is complex. Public, private, and independent sector organisations provide social care and have different remits, funding arrangements, and eligibility criteria. Information and advice about local supports and referral pathways are therefore important in influencing access to services.

Responses highlighted the need for accurate information and advice to be provided at the right time, in an accessible format. Positive comments demonstrated how signposting to local support organisations helped people to access services, and less positive comments articulated the frustrations some people experienced when trying to access support, particularly when information and advice are absent.

“Have just had a visit from care advisors. Had good advice about where to obtain aids to help with my ability to use my hands.”

“There are a lot of help/care/support services for my condition, yet it is only if you know/ask about them you get referred - so if no one tells you about them, then you are forgotten.”

Responses also demonstrate the requirement for information about symptoms, management options, and supports, following a medical diagnosis. Likewise,

unpaid carers require information and advice about how best to provide care and support. This is important in helping people to cope with everyday adjustments required post-diagnosis. People identified the need for holistic information, which includes a range of support options. The following quote is typical of the types of comments people made in relation to this.

“I cared for my relative, who has dementia, for five years and found the service very poor. No information was given to me about my relative's entitlements - treatments etc. We were told by the consultant she had dementia then hustled out the door with no information on what could or couldn't be done for her. There should be a combined service with doctors and social workers - giving you a complete knowledge of illness care and entitlements.”

Availability and eligibility

Comments demonstrated specific concerns about the availability of services. These focused on differences in expectations between service users and professionals, and restrictions imposed by eligibility criteria. Although a national eligibility framework exists within Scotland, local authorities have the discretion to interpret and determine how needs should be met (Scottish Government, 2014).

Positive comments, like the example below, focused on receiving timely supports that are responsive to need.

“I had excellent care from s/w to access the help I need to get a grant for a disabled shower. I received visits and assistance from them when I needed increased care following a fall. I have a good care package with council care staff who are always helpful.”

Conversely, negative responses focused on specific issues with the assessment process. Comments described resource constraints and bureaucratic processes, which led to people feeling that they had to fit in with service providers rather than addressing individual needs and preferences.

“It was driven by administrative priorities and not patient needs.”

“Asked if I could get shower as problems with health, was given a bath seat that can help me in and out of bath, but doesn't solve my main problems. It all comes down to money.”

The responses reveal differences between the expectations of service users and professionals in relation to support needs.

“When my late spouse was poorly he wanted help to bathe and needed appliances that made it easier to manage. The OT [occupational therapist] who came from a private care firm hired by the Council was not helpful nor was the person on the phone of their office - even said that they didn't consider bathing or showering a priority for an elderly person.”

“I was sent home from hospital without any care or help when I had broken a bone in my back. I was told not to go into the shower until I had help, which was refused as I am under 65.”

Location

Social care is provided at local authority level. This results in differences in the types and quality of service availability. Responses highlighted that geographical location affects access to services and the delivery of care, especially in rural communities. The comments indicate that this is exacerbated by staff shortages, particularly in remote areas, as well as people’s ability to access services.

“Nothing is available for rural areas. All support networks are miles from home and I cannot drive very often. More transport support is needed.”

“The [island removed] staff do their best, but we need someone on [island removed]. If there's no ferry, there's no help, no food.”

Time

A substantial number of comments referred to time. Positive ones focused on quick response times in getting an assessment and the speediness of implementation following assessment. In particular, there was an emphasis on receiving timely installation of equipment to support individuals to remain at home and maintain their independence.

“I have had to access care and support for my relative who lives with me, services were put in place quickly.”

“I got excellent care when I came out of hospital... When I moved here my spouse got in touch with [area removed] Council and they were very helpful. I needed bath aids and hand rails outside. They provided them within 3 days, very good service.”

In contrast, negative comments described a lack of responsiveness and lengthy implementation times, highlighting the impact this has on quality of life and the distressing consequences of slow implementation.

“Spouse seriously ill and the social care offered to her was deplorable. Spouse bed bound and as a "priority" case was told they had to wait weeks to be given an answer as to what care they were entitled to. Spouse died before any help could be given.”

“My elderly relative had a urine infection and it caused them to be unable to stand, therefore unable to go to a toilet or commode. It took several days for

incontinence pads for the bed to arrive. Bed ruined and skin damaged by urine burns. Takes too long for requested help to install a handrail for stairs.”

However, the comments also show that people are often happy with support once it is in place, although they may be dissatisfied with implementation times.

“... it took almost one year to [get] the care support set up. Since it has been in operation it has been good but we could have done with it earlier.”

“When I eventually received physio through [project] it was good, but too little too late. I was left in a crisis situation with no support and difficulties accessing services, for the first crucial stressful 2 weeks after hospital discharge.”

Chapter 3: Coordination and Management

Summary

Several issues emerged in relation to the coordination and management of services. This mirrored the quantitative analysis which positioned coordination and management as the area where survey respondents were least content in relation to social care (Scottish Government, 2016b). The comments highlight the importance of partnership working between agencies, with clear communication across organisations as well as with service users. Responses focused on discharge planning and the need for agencies to work collaboratively at crucial points in people's care trajectories.

The coordination and management of services was a prominent theme within the comments. Only 75 per cent of people responding to HACE reported that the services they received were well coordinated, which is a decrease of four percentage points from the 2013/14 survey (Scottish Government, 2016b). The integration of health and social care addresses some of the issues highlighted in this section, although its potential benefits are not reflected within these comments due to the stage of integration implementation when people were responding to HACE 2015/16.

This section outlines the main factors mentioned in relation to coordination and management, including:

- Care management
- Inter-agency working and communication
- Discharge planning

Care management

Participants highlighted frustrations with having to take on care management roles. The comments demonstrate the need for coordinated services in order to alleviate the burden involved in organising and managing support. This is particularly pertinent during times of adversity when individuals may be struggling to cope. The following quote is typical of comments in relation to this issue.

“Currently caring for parent with dementia. There is no joined up services, you are just constantly referred to different services and given leaflets to read. You have to do all the groundwork yourself, which is very time consuming and difficult when you are dealing with someone who is losing their memory.”

Inter-agency working and communication

Inter-agency working affects access, delivery, and coordination and management. The way organisations communicate with each other, as well as with individuals and families, is an important area of social care experience. Positive comments focused on effective communication and timely partnership working between agencies.

“30 mins out of hospital the equipment I needed was delivered and installed promptly. I have a new found respect for physiotherapists and the job they do.”

“Doctor organised early intervention team to come to my house to help in the care for my mum, who was released from hospital and came to live with me because she was unable to live on her own. Got excellent support from doctor and community nurses.”

In contrast, negative responses, like the one below, provided examples of fragmented care and expressed concerns about communication structures.

“Lack of communication between services provided. Totally disjointed. One did not seem to know what the other was [doing], this led to time wasting and much unnecessary duplication e.g. filling in the same answers to the same questions time after time.”

Discharge planning

Discharge planning was a central focus within coordination and management. The responses provided examples of people being in hospital for longer than required due to a lack of alternative support. There were also examples of people being discharged from hospital without the support they required being in place.

“Social services had a two to three week delay in providing any help with post-operative care. I was bed blocking at hospital but district nurses agreed to come every other day and family help allowed me home (partner ill at time). Bed blocking a major hospital for lack of simple after care at home is economic madness.”

“When discharged from hospital it was assumed as a younger person I wouldn't need help or support but that family would provide. No offer of support for [activities of daily living] offered other than commode.”

“After my stroke which hospitalised me for months, I required my bathroom converted to a wet room, the provision of a ramp for wheelchair access and the installation of a stair lift. Although I needed all these as soon as I was discharged and brought home, it took many months before this happened. I seriously struggled in the intervening period and was greatly distressed and inconvenienced. The time interval was far too long!”

Chapter 4: Delivery

Summary

Comments demonstrate how various factors influence satisfaction levels with social care. There was a strong message about the need for consistent care, with regular workers who understand personal needs and preferences. On the whole, participants were positive about staff, focusing on the quality of relationships, interpersonal skills, and compassionate care. However, there was also recognition of the difficult employment conditions facing the social care workforce. Responses also emphasised the importance of having choice and control over care, and suggested that this could be limited by budget constraints and efficiency savings.

Due to the breadth of issues covered in relation to delivery, this section is split into two parts. The first section focuses on relationships with professionals, including experiences of compassionate care, continuity in services, and employment conditions. The second section examines comments relating to choice and control, including experiences of person-centred support, and the impact of cuts and efficiency savings in response to public sector budgetary constraints.

Part 1: Relationships with professionals

A number of comments referred to the relationships people had with care workers. Although there were some negative comments about relationships with workers, there were substantially more positive comments. Positive comments provided examples of highly skilled, professional staff delivering valued compassionate care.

Compassionate care

The quantitative results from HACE show that 87 per cent of participants felt they were treated with compassion and understanding (Scottish Government, 2016b). This was echoed in the comments, which showed how compassion and understanding shaped care experience. Responses described the role of kindness and compassion in helping people to cope during times of adversity, and particularly in relation to palliative care.

“Having fell out of bed recently and unable to get up, I activated my community alarm. They took over and got a key and had me back into bed within the hour. The compassion, consideration, and efficiency the team showed was greatly appreciated and renewed my confidence in my safety in my home, even if I have a wee accident. Thank you all.”

“A dear friend came to live with us for his last few days as he didn't want to die in a hospice or hospital. Once his GP was notified that he was with us a really good care package was put together giving him the care he needed and us the support

that we also required sometimes. Thanks to care staff he had a pain-free peaceful and dignified death that was such a comfort to all who loved him.”

Responses also highlighted the importance of interpersonal skills in delivering compassionate care. Care workers who were warm and friendly, respectful, good listeners, and made the effort to get to know the individual were valued. This is reflected in the quantitative results from HACE 2015/16 where 90 per cent of participants felt they were treated with respect. Notably, this was the area with the highest levels of HACE respondent satisfaction in relation to social care.

“I am very impressed with the gentle and thorough care the carers provide. They are confident in their work and very professional. I am very grateful for what they do and even in the short time they have been coming, the difference they have made.”

“I have an excellent carer called [name removed] who is truly excellent helping me with my health, independence. I can talk to [name removed] about anything, she has the highest respect. I am grateful for her loyalty, patience, kindness and overall support helping me through a very difficult time.”

However, some responses described negative relationships and poor quality care. These comments emphasise the need for people to be treated with compassion, dignity, and respect.

“The home care service is supposed to provide the same carers, but inevitably we find we see strange faces with no warning and a lack of dignity then ensues when asked to go into the bathroom to remove all clothing, so embarrassing!”

“Some people are patronising, I call it 'the poor old dear' syndrome.”

“They need to be more aware that they're in a person's home and domain! And not to be giving people who are seriously ill orders or have bad manners and be disrespectful to the patient! And for more compassion shown to a person recovering from major operation, full stop!”

Continuity

A recurrent message within the data is the need for continuity of care. The comments describe the value placed on having consistent carers at regular times, alongside the need for any changes to be communicated to service users. Participants described frequent changes to support staff and support times, without any prior indication of this.

“There are too many different carers from the care agency every week, this week there are 8 different ones.”

“I receive support from [agency removed]. I regularly don't get rotas, times of support are not always the same as my support plan. [agency removed] don't contact with changes to times of the carers.”

The comments illustrate the intersection between continuity of care, relationship building, and quality. Establishing relationships with care workers is important in ensuring that the care provided is responsive to need, taking into account personal likes, dislikes and preferences (Boltz and Galvin, 2016).

“My support staff have supported me for a long time and know me really well and I know them well too. As I am not able to vocalise on most matters, but people around me know me well and interpret my facial expressions etc.”

“I have been receiving help for over five years, I was very happy with the carers that were allocated to me. But now I do not get my regular carers. I do not like this, and neither do they (the carers). New people turn up, they are not used to the house, and I do not like the change. I know a lot of people who feel the same, including the carers. It must be very confusing to dementia patients, and it is enough to send a 'normal' elderly person demented.”

“Inconsistent carers provided by agency leads to poor service, not knowing me or what to do. No management of resources. In last three months have had 15 different female carers, and nine different males.”

Having consistent support staff is particularly pertinent for those with specific conditions, including mental distress, dementia, and other cognitive impairments. Building and maintaining relationships allows workers to gain a deeper understanding of the individual and how best to meet care needs. The following quote is typical of the types of comments people made in relation to this issue.

“I have a carer that attends me five times a week - same carer. Next year that is going to change - our carer informed us that I could get a different carer every day, that's totally wrong (because they are putting all carers on shift work). With my cognitive and memory problems this won't help me at all. I am not looking forward to the change.”

Employment conditions

Comments were mainly positive about individual workers, but people felt workers were hindered by wider structures and organisational procedures. Comments described staff working in a context of poor employment conditions, including low wages, and high workloads. Participants commented on the negative impact this has on continuity of care.

“The actual carers were generally fabulous but their management are squeezing them too tightly to allow quality in their care provision. The organisation's culture appears to have become about quantity led targets rather than quality led care. This is becoming evident in staff ability and morale.”

“[S]trongly feel support workers and care workers are undervalued, underpaid and overworked. They willingly go the extra mile and forego some of their own scheduled free time to help out workmates and make sure service users are safe and get the help needed, but their own needs are often ignored or belittled.”

Some people who receive social care services expressed concerns about the amount of time assigned to complete tasks specified in the support plan. Responses described care workers not having enough time to travel between clients, with consequences for the amount of time allocated to each person.

“Time allocated for carers is not sufficient. It is important to have consistency in carers to build up a safe and secure relationship.”

“Does depend on which carer comes (some are moved from other areas). Time slot is very tight for someone who doesn't know the routine! Otherwise usual carers excellent!”

Part 2: Choice and Control

The principles of choice and control are fundamental to social care policy in Scotland, emphasising the importance of co-production in the planning and delivery of support (Scottish Government, 2010) and are at the heart of self-directed support which is being embedded as the mainstream approach for social care in Scotland (COSLA and Scottish Government 2016).

Person-centred support

A key theme that emerged within the comments was the importance of choice and control for social care satisfaction. Positive comments focused on increased levels of choice which enables flexible, responsive support to meet needs and improve personal outcomes.

“This funding [direct payment] has allowed me to once again be in charge of how and when I receive care and WHO my Personal Assistants are. I am hugely thankful for this.”

“I have a self directed support package, I feel it allows me to be a human being and do things I was able to do when I was able bodied. I try to live my life as normally as I can.”

Not feeling listened to

Some people raised specific concerns about not feeling listened to and not having their choices acted upon. Instead of choice and control directing support plans to meet identified outcomes, in some cases wider administrative priorities shaped available support.

“[P]eople did not pay attention to what was important to my parents but instead gave them what they thought they needed.”

“I would like to have the ability to choose what I want to enable me to care for my relative, not ‘this is what you are getting’, which didn't suit us as a family, disjointed care which led to my relative feeling unsafe and care package didn't work. So rather than taking pressure off me, it increased it.”

Time

Comments also revealed a lack of choice and control over support times in some cases. Receiving support at inappropriate or inconvenient times could disrupt daily routines and practices.

“My parent would like earlier visits in morning from their care package as she's lying down 15 hours a night.”

“As I need help with dressing and undressing, the time that they come in the evening makes me unable to have any social evenings with friends, even just for special times.”

Public sector finances and efficiency savings

A prominent theme was the impact of public sector budgetary constraints and services being under-resourced. Comments demonstrated concerns about increasing efficiency savings and fears about further cutbacks and closures.

“It seems to be getting taken off me due to cut backs, I have to pay for treatments.”

“I go to a class weekly, locally in [area removed]. It is aimed at elderly people and gives gentle exercise classes to help keep you active and avoid falls, which can cost NHS a lot of time and money. It is very popular, gets lonely people together and yet is threatened by closure through lack of funds. We would not like to see it closed.”

Chapter 5: Outcomes

Summary

The comments demonstrate the impact that care and support has on personal outcomes and wider quality of life. Support influences independent living, social participation, and recovery, and the extent to which this is achieved depends on a range of issues relating to access, coordination and management, and the delivery of safe and appropriate services.

This section focuses on the extent to which people felt that care and support helped to improve personal outcomes in relation to:

- Independence
- Social connectedness
- Stress and anxiety
- Recovery
- Safety

Independence

Independence was one of the areas that people were more positive about. Positive comments focused on how care and support has enabled people to live independently in the community. Participants described various types of support and the ways in which this facilitated independent living, including the provision of aids and adaptations to enable people to stay at home for longer and prevent hospitalisation.

“The service is excellent, absolutely essential and most valued; without it, myself and my spouse would have been in hospital.”

“Having a grant from the council to make adaptations to our home has meant we can stay here and I can still have some level of independence.”

“I get help from the [name removed] who take me out twice a week, and I get housing support from [name removed], which helps me live independently, this gives me a good feeling and I don't need to rely on my elderly parents so much!”

However, some responses revealed that a lack of adequate care and support has led to negative outcomes. Some comments described people being housebound due to lengthy waiting times for adaptations to be installed. Others described

people being admitted to residential care as a result of not receiving the required supports.

“If help/support had been provided whilst I had been in my own home I would not have needed to go into a residential nursing home when I did. My family struggled to care for me, my mobility failed and I suffered an injury resulting in my hospitalisation. I never got to return home and could not express my wishes regarding my care. The choice was not made by family but via social workers.”

“Having seen my care and support dwindle away - now less than three hours each week, I'm really struggling in trying to maintain my independence. Whereas before I had home-helps, social (and hospital) support, I now only have one visit with food and medication each week meaning that I'm very isolated as a result. I cannot afford private care and feel very much a burden and abandoned by those who should be assisting me.”

Social connectedness

Responses highlight the importance of social support. For some people, contact with support workers is their only form of regular social interaction, and for others the provision of support facilitates their wider social participation in the community.

“My personal carer makes a huge difference to my life, she makes me smile, laugh and feel young. She does a lot of housework and helps me collect prescriptions, re-orders for me, helps cut my nails, keep my feet clean and moisturised. Most of all her company means a huge amount to me.”

“Independent living has made me free to follow my inclinations regarding my attitudes in society, government elections, awareness and above all my worship in local and other church buildings.”

There were also responses from people who did not have the support they felt they needed, which described feelings of loneliness and isolation. This further highlights the importance of care and support in maintaining or establishing social connectedness.

“Overall care provider left me without warning and had then been left isolated for months until another new system and care support could be found and is still on-going.”

“There is no care in the community, the only help I receive is from my mum. I'm in my house 24 hours a day with no visits apart from mum. Nobody cares about what happens to me. I'm [age removed] and my life is over.”

“I don't feel I get much support from any outside parties except my own GP and my [age removed] son. I am very isolated and spend a lot of time upstairs in my bedroom as I can't get up and down stairs most days as I am very breathless.”

Stress and anxiety

Whilst many responses demonstrated the benefits of care and support in relation to health and wellbeing, other responses revealed the negative impact of delays and difficulties in accessing and coordinating support. Comments described experiences of stress and anxiety associated with availability, fragmented services, and lengthy waiting times.

“The main problem is the daily battle to get the services that are required. Information is not passed between agencies in a timely manner (if at all), and the time between requests for services and the execution of said services is too long. This is an incredible source of stress and adds to the suffering and discomfort of the patient and the carer.”

“Difficult to get care quickly. It took 7 weeks to get care package from social services, even though doctor stated it was urgent. Spouse collapsed through stress. Had to threaten council with [correspondence removed] and care was arranged within one hour! Disgusting.”

Recovery

Several comments made reference to receiving good quality care and the positive impact this had on the recovery process. This was particularly evident in mental health care where social and psychological forms of support were viewed as important in supporting recovery journeys.

“This last few years has made a remarkable difference to both of us and I reckon that my [family member removed] would not be alive today due to the excellent care, especially in our home.”

“I have found all my carers very helpful and supportive and I look forward to them coming as I have been very seriously ill and they are helping my recovery.”

Other comments described how not receiving support at the right time could be detrimental to recovery. Responses also described the impact when families had to take on additional responsibility to provide support.

“I received no aftercare support whatsoever. My CPN [Community Psychiatric Nurse] did not contact me. I was very vulnerable and definitely took longer to recover as a result. I felt totally abandoned by the NHS. It took the care of my relative who came to stay with me upon my discharge to take all this upon their shoulders to pull me through. It was too much for them. I feel quite angry no aftercare was in place.”

“This is speaking about the care of my mother in law. We initially had choices, treated very well and then closures happened. When moved hospitals we were not given information/choices and her care and well-being has greatly been effected.”

Safety

Comments demonstrated the role played by support workers and equipment in generating feelings of safety. In particular, responses described how community alarms and e-health technologies help to make people feel safe and secure in their own home and within the wider community.

“The alarm from the council I wear gives me such a lot of confidence.”

“I moved to sheltered house, which I have found to be a great help for me. I am a widow, therefore I feel safe in my sheltered home. The care is marvellous.”

“Being profoundly deaf, I get great support and all helpful equipment needed to help me feel safe and secure.”

Other comments showed that people had concerns about their safety. Some people had concerns about being alone and not having anyone around to assist in the event of an accident or in their health deteriorating, whilst others felt vulnerable because of constant changes of support workers.

“Well sometimes I've fell a few times and hurt my head, it is very scary when you're on your own. Also, I've knocked myself out. Also I've took epilepsy fits as well.”

“Home care in the evening has been inconsistent and this does not make me feel safe. Too many different workers at night.”

Chapter 6: Unpaid care

Summary

The comments highlight the importance of support to enable unpaid carers to continue in their caring role. The provision of care and support from formal services can help to reduce the responsibilities placed on unpaid carers. Responses reinforce the need for formal support, including respite, to address the balance between unpaid care and other activities.

Responses from people who were providing or receiving unpaid care were a mixture of positive and negative experiences which focused on the intersection between paid and unpaid care. The quantitative results from the 2015/16 survey show that unpaid carers report lower satisfaction scores compared with those receiving care (Scottish Government, 2016b). Only 41 per cent of carers felt supported to continue in their caring role, 42 per cent felt that local services were well coordinated, and 40 per cent felt that caring did not have a negative impact on their health and wellbeing.

Positive responses focused on services which supported people to continue in their caring role. The provision of formal care services can help to address the needs of people who require support and can also alleviate the pressure placed on informal carers by enabling them to balance caring with other activities. In the quantitative analysis, this was the area carers were most positive about, and 68 per cent of carers felt they had a good balance between caring and other activities (Scottish Government, 2016b). The free-text comments describe how formal support has helped people to cope, with many suggesting they would be unable to continue in their caring role without such provision.

“I received excellent support and help from local services while I was caring for my dying partner at home. During the final six weeks leading to their death, I was also supported by overnight services - without the help of these dedicated nurses I could not have cared for them until the end.”

“I am answering this on behalf of my relative and I certainly could not cope without help given to [their] everyday care in the morning and evening and in emergencies, with community care and community alarm! These people deserve a medal!”

“As a carer, the help I get for my father by having someone coming to the house once a week to shower and shave him is a god send.”

“The help I received is on behalf of my husband. The help has allowed me to continue in my full time employment and aided a better quality of life.”

Nevertheless, participants also described increasing responsibility on families to provide care and support for their loved ones. The issues discussed previously in relation to access, coordination and management contribute towards this. This can impact upon carers' health and wellbeing, and comments highlighted the importance of respite.

“My [age removed] [family member removed] is caring single-handedly for my relative with advance dementia and it has proved impossible to get any home-help with daily personal care... There are not enough support services to go round and my relative has in the past ended up in hospital because the support he needed was not available at home. The NHS is inefficient and does not offer holistic personalised care and is not joined up with other care services.”

“Having suffered a stroke in [date removed], I am now cared for by my family. As far as providing physical aids, speech therapy and physiotherapy, the service has been first class. However their request for some respite from their caring for me, has had a very different response. After an initial enquiry, they are still awaiting news of what respite care they are entitled to. So after praising the social work department. I would exclude the unit [name removed] from that praise.”

“I care for a family member, every time we ask for any help or support from the council we (myself and the other two 24hr carers) are pushed to the side. We have failed to receive any of our entitled respite this year! This causes stress throughout family.”

With effect from April 2018, the Carers (Scotland) Act 2016 will place a duty on local authorities in Scotland to provide support for carers.

Conclusion

“Do you have any other comments to make about the help, care or support that you receive?”

Analysis of the free-text social care comments in response to the above question from the Health and Care Experience Survey 2015/16 provides insight into the issues that shape people’s social care experience. The wide ranging spread of comments illustrates both positive and negative experiences in relation to accessing support, having choice and control, the planning and delivery of services, and the subsequent influence on outcomes. The comments and quantitative analysis taken together provide a fuller picture of the issues that have an impact on service users and their families.

The quantitative analysis shows that people were most positive about being treated with respect, compassion and understanding. This was reflected in the free-text comments, with a focus on the relationships people have with social care workers. Many people received compassionate care and described the difference this made to their day to day lives. People were most negative about the coordination of services in the quantitative analysis, which again was echoed in free-text comments around service access, coordination and management, and delivery. These comments highlight the importance of partnership working between agencies, with clear communication across organisations as well as with service users.

Key messages

- The comments reinforced the need for person-centred, outcomes-focused support plans, with people having choice and control over how and when support is provided, and by whom.
- Clear and responsive communication at all stages of the social care process is key to good care and support. Greater communication and collaborative working is also required between agencies, and people who use services and their families to prevent fragmented care.
- The comments provided a powerful and consistent message about the need for continuity of care. Responses emphasised the value of relationships and the importance of regular workers in building up trust and knowledge. People described receiving compassionate care, despite the challenges facing the social care workforce.

- Good quality support can improve outcomes and wider quality of life. However, support must be adequately resourced and be responsive to individual needs. This can shape various outcomes including: independence, social connectedness, and recovery.
- Formal support can help with the balance of care for unpaid carers and is important in enabling people to continue in their caring role and balance this with other activities.
- Whilst there are methodological limitations in relation to the analysis of free-text comments, the findings of this report provide insight into the issues that have an impact on social care experience and what matter to them. The analysis of such data is, therefore, a useful contribution to the evidence base for improvement.

References

- Boltz, M; Galvin, J.E. (2016). "Dementia Care: an Evidence Based Approach" Springer (ebook) <http://www.springer.com/gb/book/9783319183763> [last accessed: 24/01/2018].
- COSLA and Scottish Government (2016). "The Implementation Plan 2016-18, for the Self-directed Support Strategy 2010-2020." <http://www.gov.scot/Resource/0051/00510921.pdf> [last accessed 05/02/2018].
- Garcia, J., Evans, J, Reshaw, M. (2004). "Is there Anything Else you Would Like to Tell us?' Methodological Issues in the use of Free-text Comments from Postal Surveys", *Quality and Quantity* 38, pp.115-125.
- National Records of Scotland (2017). "High Level Summary of Statistics: Population and Migration." <https://www.nrscotland.gov.uk/files/statistics/high-level-summary/j11198/j1119802.htm> [last accessed: 09/01/2018].
- O'Cathain, A., Thomas, K.J. (2004). "Any Other Comments?" Open Questions on Questionnaires - a Bane or a Bonus to Research? *BMC Medical Research Methodology* (4), p.25.
- Scottish Government. (2010). "A 10 Year Strategy for Self-directed Support in Scotland which Aims to Set Out and Drive a Cultural Shift Around the Delivery of Support that Views People as Equal Citizens with Rights and Responsibilities." <http://www.gov.scot/Publications/2010/11/05120810/0> [last accessed: 24/01/2018].
- Scottish Government (2011). "2020 Vision." <http://www.gov.scot/Topics/Health/Policy/2020-Vision> [last accessed: 12/01/2018].
- Scottish Government. (2014). "Self-directed Support: Practitioners Guidance." www.gov.scot/Publications/2014/08/5212/6 [last accessed: 24/01/2018].
- Scottish Government. (2016a). "Guidance: Guidance for Health and Social Care Integration Partnerships." <http://www.gov.scot/Resource/0049/00498038.pdf> [last accessed: 24/01/2018].
- Scottish Government. (2016b). "Health and Care Experience Survey 2015/16 Volume 1: National Results." <http://www.gov.scot/Resource/0050/00500340.pdf> [last accessed: 24/01/2018].

How to access background or source data

The data collected for this social research publication:

- are available in more detail through Scottish Neighbourhood Statistics
- are available via an alternative route <specify or delete this text>
- may be made available on request, subject to consideration of legal and ethical factors. Please contact patientexperience@gov.scot for further information.
- cannot be made available by Scottish Government for further analysis as Scottish Government is not the data controller.



© Crown copyright 2018

You may re-use this information (excluding logos and images) free of charge in any format or medium, under the terms of the Open Government Licence. To view this licence, visit <http://www.nationalarchives.gov.uk/doc/open-government-licence/> or e-mail: psi@nationalarchives.gsi.gov.uk. Where we have identified any third party copyright information you will need to obtain permission from the copyright holders concerned.

The views expressed in this report are those of the researcher and do not necessarily represent those of the Scottish Government or Scottish Ministers.

This document is also available from our website at www.gov.scot.
ISBN: 978-1-78851-678-5

The Scottish Government
St Andrew's House
Edinburgh
EH1 3DG

Produced for
the Scottish Government
by APS Group Scotland
PPDAS376186 (03/18)
Published by
the Scottish Government,
March 2018



Social Research series
ISSN 2045-6964
ISBN 978-1-78851-678-5

Web and Print Publication
www.gov.scot/socialresearch

PPDAS376186 (03/18)