Social Care in Scotland: learning from the real life experiences of service users, carers and social work students

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# FINDINGS SUMMARY

## Impact on Carers and Service Users

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<td><strong>1.</strong> Carers* and service users want social workers to develop better relationships with them.</td>
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<td><strong>2.</strong> Poor communication and limited involvement in decision making is disempowering carers and service users.</td>
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<td><strong>3.</strong> Carers and service users would like opportunities to share their experience and knowledge with others.</td>
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<td><strong>4.</strong> Carers and service users need more services (especially for post 16 year olds/young adults) and are concerned that current services are being targeted by budget cuts.</td>
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<td><strong>5.</strong> There is a need for greater consistency in the provision of services.</td>
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<td><strong>6.</strong> Carers would benefit from more support groups, especially in rural areas.</td>
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<td><strong>7.</strong> Carers and service users require more information to enable them to exercise choice over services and support.</td>
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<td><strong>8.</strong> More carers need an assessment of their needs.</td>
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<td><strong>9.</strong> Carers/service users’ need for support and information varies over time. The initial transition to becoming a carer/service user and moving from child to adult services being times of high demand for information and support.</td>
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<td><strong>10.</strong> Service users and carers are feeling lonely and isolated.</td>
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## Impact on Workforce Development

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<td><strong>1.</strong> Social workers need to be spending more time developing a relationship with service users and carers.</td>
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<td><strong>7.</strong> More attention needs to be paid to the health and wellbeing of carers through the provision of more respite care and support groups.</td>
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<td><strong>9.</strong> Social workers should not promise services they can’t deliver.</td>
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<td><strong>10.</strong> Services and support need to be responsive to transitions in the lives of service users and carers.</td>
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* Unless otherwise stated references to carers refers to informal carers (family and friends).
1. INTRODUCTION

Over recent years key policy changes in social care in Scotland have introduced fundamental shifts in how social care should be practised and experienced by service users and informal carers. Central to these changes are co-production and person centred practice, requiring practitioners to listen to and respond to individual needs through working collaboratively with service users and carers. The Social Care (Self-directed Support) (Scotland) Act 2013 further consolidates these developments by embedding in legislation the requirement for social workers to work collaboratively with service users and carers to identify the support individuals need to lead a full and meaningful life.

Another key change that is impacting on social care is the growing recognition of the number and heterogeneity of informal carers. For too long informal carers have remained hidden and silent, especially non-traditional carers (children, males, older and disabled people). Recent legislation and policy, for example, the Caring Together: The Carers Strategy for Scotland 2010 – 2015 (Scottish Government, 2010) along with the development of the Equal Partners in Care (EPiC): Core Principles for working with carers and young carers (NHS Education for Scotland (NES) and Scottish Social Services Council (SSSC), 2013) are contributing to highlighting the responsibility people have in identifying carers and for carers needs to be assessed and met, including their social and emotional needs.

Community Care and the Caring Experience Module, University of Dundee

To prepare social workers of the future to work in this changing social care environment students on the MSc Social Work qualifying programme at the University of Dundee study the Community Care and Caring Experience module during the first year of their two year programme. The module consists of campus based lectures covering social care policy, legislation, theory and communication. The campus based learning is complemented with students spending a minimum of fifteen hours with a service user and/or carer (host family). Students work in pairs with each pair being allocated a host family. Arrangements are made between the students and hosts for meetings over a period of three months. Whilst the students are with their host their role as a student social worker differs from when they are on a placement visit. During the time students spend with their host they observe, experience and learn from their host what life can be like for a carer and/or a disabled person. During their fifteen hours the students learn to value their host’s experiences and acquired knowledge of social care.

This report presents the findings from data collected in 2013 for one part of the assignment for the Community Care and Caring Experience module. Data were collected from the responses to the following questions that students discussed with their host. The questions were developed by the University of Dundee’s Carers and Users (CU) Group.

Qu. 1: If your host family could give a message to policy makers in your local authority/health board about the services and supports they require, what would that message be?

Qu. 2: As practitioners of tomorrow and after having experienced this module, are there issues or concerns that you or your host family would like to see highlighted for future practice development?

Carers and Users (CU) Group, University of Dundee

The Carers and User Group (CU Group), established in 2003, is made of people with a range of experience and knowledge gained over many years of living with a disability and/or being a carer. The group is actively involved in the qualifying social work programmes at the University of Dundee. Their involvement includes admissions, teaching and chairing the Programme Board. The Community Care and Caring Experience module is an important aspect of their involvement and enables group members to work directly with students helping to prepare them to become the
‘practitioners of tomorrow’. They support the students to not only ‘hear our individual, and collective stories’ but demonstrate that they can ‘listen to and act on our concerns, and our real life experiences’.

During a World Café event hosted by the CU group in 2012, a senior local authority manager suggested that the students’ learning from the Community Care and Caring Experience module should be used to inform practice. The CU group took this suggestion forward and as a result formulated the two questions used for this report (see above for the two questions). It was agreed by the CU group that the report would be presented to organisations involved in the delivery of social care and that members of the CU group, a few months after the dissemination of the report, would return to the organisations to enquire how they had acted on the findings presented in the report.

2. METHODOLOGY

The findings presented in this report are derived from the responses to the two questions (see above) that first year MSc Social Work students submitted in April 2013 as a requirement for the Community Care and Caring Experience module. Students discussed each question with their host; therefore the findings in this report represent the views and experiences of service users, carers and social work students. Hosts were given the opportunity (if they wanted) to comment on their students’ written responses to the questions. Twenty one responses were received for each question and were analysed by members of the CU group and the module leader. Thematic analysis was used to draw out key themes from across the data.

The responses to the two questions were combined in the analysis of the data. Six key themes emerged from the analysis and are discussed below:

- Communication
- Information
- Services
- Support
- Choice
- Transitions

Whilst the themes are explored separately each of the themes are linked to and present challenges and/or suggestions for ways that co-production and a person-centred approach can work effectively to achieve positive outcomes for carers and service users.

3. FINDINGS

Communication

Effective communication is a key social work skill and fundamental to ensuring that practitioners work collaboratively with service users and carers. Yet the need for better communication was a dominant and recurring theme emerging from the data, as one host states,

... all involved with working with carers and service users need to communicate more and improve their communication skills.

In particular, for social workers to be practicing within current policy frameworks they need to be listening to, responding to and involving service users and carers much more.
The unique aspect of the *Community Care and Caring Experience* module is that students have the time and space to begin to understand some of the complexities and challenges of their host’s life. Facilitating for professionals to have more time to spend with service users and carers came across clearly in the responses to the questions. However, it was highlighted that this shouldn’t be restricted to practitioners but also apply to senior management who were perceived to be ‘too removed’ from the lives of service users and carers.

> ... professionals need to invest the time in order to gain knowledge and more importantly an understanding of each individual’s unique situation. This therefore highlights the importance of professionals working in partnership with users of services and carers in order to allow experiences to be shared and to allow for a deeper, perhaps, more emotional understanding of an individual’s needs.

> Those who have the power to make decisions within local authorities should spend time with families and service users in their homes to gain a realistic experience of their lives and their needs.

**Information**

A key message that came out of the responses to the questions was the need for service users/carers to have access to more information on the provision of services and available support. It was noted that providing this information should be the responsibility of social workers. Hosts stated that they would appreciate and/or needed more information on the following:

- assessments
- services
- illnesses and disabilities, including mental health
- benefits.

In relation to assessments, students highlighted that many of their hosts who were carers hadn’t been assessed and nor did they know anything about the carer assessment, even though social workers were involved with the person they were caring for. On a more positive note, the introduction of joint assessments was seen as a much needed change and the hope was that further integration of health and social care would reduce the amount of times carers and service users were required to provide the same information to different professionals.

Having access to information or being directed to sources of information on relevant services, support groups or a newly diagnosed disability was highlighted as one less thing to worry about and one more thing that would make challenging lives a little more manageable. As one host noted, it’s often the small things that are overlooked but can have a significant impact on people’s lives.

> Carers must be given all information, no matter how trivial this may seem.

Finally, hosts expressed an interest in sharing their experience and knowledge of being disabled and/or a carer with other families adapting to change in their life.
...families already managing direct payments are an untapped resource that local authorities could be using to support interested parties during the decision making process.

Services

The study reveals that carers and service users want social workers who are open, honest and proactive in accessing resources and services. However, it was evident that this wasn’t always the experience of the students’ hosts, as a recurring message in the data was the lack of services and a fear of losing existing services as a consequence of budget cuts.

I’m aware that there are many people who are ‘falling through the cracks’ between services and are not receiving nearly the levels of support and care that they require and are entitled to. Why is nobody enforcing the legislation that is in place to support and protect carers and service users?

...services are being cut back to a point where the lives of the service users and carers are being negatively affected.

Consistency in the provision of services featured across the responses in relation to:

- mental health provision receiving the same attention and range of services and support that is available for people with physical disabilities
- high turnover of formal carers.

With regard to the latter, the lack of consistency of caring staff was leading not only to difficulties in building trusting and meaningful relationships between formal carers and service users, but also resulted in formal carers not fully understanding the needs of the people they care for.

The main issue identified by my host family was the lack of continuity of carers going into the home. The primary difficulty lies in forming relationships and feeling comfortable with the service when so many carers are involved. This causes various difficulties and further negatively impacts upon people’s situations.

This may result in carers not recognising what is ‘normal’ for their client and if they don’t know this how can they tell if something is abnormal? This is how things get missed and the quality of care is diminished.

The second quote in the above box provides an insight into the experience, knowledge and understanding that informal carers can build up over long periods of caring for a loved one. Unlike formal carers who have limited time with a service user, informal carers spend hours and hours caring for the same person, the result being that they can identify the ‘abnormal’. However, our data reveal that too often professionals exclude carers from discussions and decision making about the person they care for. Yet acknowledging and valuing the knowledge base of carers and service users is central to the success of co-production and social workers working collaboratively with service users and carers.

The role of day centres in 21st century community care was raised in the responses with some hosts being critical of the redesign of day services for adults with disabilities. Others pointed to the valuable role day centres play in the lives of the people they cared for and went on to argue that the
concept of integration into the community shouldn’t lead to extensive closures of day centres. Such a scenario was seen as potentially having a negative impact on the lives of both service users and carers.

Two recent changes in social care legislation led to productive discussions between hosts and students. In relation to the Social Care (Self-directed Support) (Scotland) Act 2013 and direct payments concerns were raised over:

- lack of regulation of personal assistants
- risk of financial abuse
- provision of adequate support for carers and service users to administer their direct payments.

The integration of health and social care (Public Bodies (Joint Working) (Scotland) Act 2014) also received attention and amongst other things multi-agency training involving service users and carers was proposed.

An improvement in planning and commissioning of care is needed so that health and social care services complement each other instead of conflicting. We should be aiming to ensure the maximum quality of life and independence of children and adults by working holistically across agencies and by using a whole systems approach.

Support

The current emphasis on person-centred practice opens up opportunities for independent living and greater choice. However, there is also the potential to focus solely on the individual to the exclusion of the broader community and the social context within which they live. The risk of further isolating service users and carers should be noted by practitioners as our findings indicate that a number of hosts were feeling lonely and isolated with little sense of care happening ‘in the community’. Furthermore, it was highlighted that the opportunities for people who decide to manage their own budget and plan their own independent lives through the use of direct payments are further restricted by the limited availability of accessible and inclusive activities. (It should be noted that the data for this study were collected in April 2013 prior to the implementation of the Social Care (Self-directed Support) (Scotland) Act 2013 in April 2014. It is hoped that as the uptake of direct payments increases over time new and innovative opportunities for service users will emerge along with existing services and activities becoming more accessible and inclusive).

It is lonely when you are doing self-support and you are in a minority as most people use day centres, there’s not as much to do or emotional support for them as there is for people who use day centres.

Recent policy developments and legislation including the Caring Together: The Carers Strategy for Scotland 2010 – 2015 (Scottish Government, 2010) along with the Equal Partners in Care (EPiC) Core Principles for working with carers and young carers (NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC), 2013) are transforming our understanding of carers and the significant contribution they make to social care in Scotland. As a consequence of these changes it is hoped that fewer carers will remain hidden, more carers will be assessed and more carers will receive the support they need to enable them to lead a fulfilling life alongside their caring responsibilities. The demand for these changes is reinforced by our findings that point to the need for more support for carers and in particular there is a need for social work to:
• identify hidden carers and offer relevant support
• set up more local support groups for carers, especially in rural areas.

The health and wellbeing of carers was also an area of concern with calls for greater investment in the provision of respite care as well as opportunities for carers to meet up with other carers to socialise, share experiences and support each other, especially in rural areas.

Support groups don’t cost much, but they would be exceptionally beneficial to the carers, having a place to go where there are other carers that understand the situation they are in and how hard it can be at times to care for someone. Therefore the message to the local authority would be to remember that carers also need to be cared for, acknowledgement of their needs are just as important.

Choice

Since the introduction of the NHS and Community Care Act 1990 choice has been a fundamental policy driver in the context of social care. Subsequent legislation has continued to shift the balance of power in the relationships between professionals and service users/carers to empower the latter and facilitate for more choice and control in their lives. The Social Care (Self-directed Support) (Scotland) Act 2013 should further enable service users and carers to exercise more choice in their everyday lives. In many of the responses provided by the students and their hosts there was optimism that the new legislation would make a difference to the lives of service users and carers. However, there were also significant issues that emerged in the data that need to be addressed before real choice is available to service users and carers that would mean practitioners were working within an approach that is person-centred and based on co-production.

... as she (carer) was unaware of such an assessment and services she was unable to ask for them and no-one suggested it.

It is felt that the rural nature of the area is being disregarded in an attempt to make the service provision fit into a pre-developed model, rather than creating a new model that fits the service user and carer requirements.

Transitions

Certain transitions are an inevitable part of life, moving through childhood, adulthood and into old age. Other transitions are less predictable, the birth of a disabled child, becoming disabled at a later stage of life or assuming responsibility as an informal carer. Each of these transitions can be complex and multi-layered and it is at these times of uncertainty, of entering an unfamiliar phase in life, that support and information is paramount for all involved.

When a family member is diagnosed with a psychiatric condition it is extremely distressing for the rest of the family, as well as for the patient himself. Often family members will not have any prior knowledge what the diagnosis will entail and what symptoms will manifest or what medication will be needed and why. It is a difficult time for the entire family, the professionals should therefore ensure to explain the illness and the situation carefully to the family and make sure they feel comfortable.
The transition from child to adult services emerged as a particularly challenging and potentially stressful time for families in relation to accessing support and services. A reduction in the availability of services was highlighted and specifically the limited availability of services for young adults.

There are no services available for those in their late teens/early 20s. Although there are services available to support adults with learning difficulties, the son of my host family does not fit into this ‘category’... They would also like to see more investment within the Post 16 Autism Support Strategy to allow for multi-agency planning to assist adolescents in a successful transition from Secondary School to College, as they feel that this is an opportunity their son has missed out on.

Associated with the challenges of children transitioning into adulthood are the expectations of parents, young people and practitioners in terms of independence verses dependence in adulthood.

Practitioners should acknowledge that parents of disabled children have the same expectations for their children as they would for a non-disabled child, for example, people expect their child to leave the family home in their adult life.

4. RECOMMENDATIONS

The key recommendations emerging from this report will help to respond to the issues raised by the service users, carers and students involved in this study. Rather than create a list of recommendations the authors decided to highlight the saliency of the following concepts: support and relationships, information and knowledge, inclusion and integration, and health and wellbeing. Each of which, we argue, should be more embedded in social work to achieve co-production and personalisation in practice.
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