

Review of evidence on personal outcomes relevant to the Carers (Scotland) Act 2016

Dr. Emma Miller, Senior Research Associate, University of Strathclyde, March 2017

Executive Summary

Review of international outcomes programmes

This review identified several long-term programmes on outcomes focused planning, some specific to carers, based in England, Wales, Canada, Sweden and Scotland.

Key features of early work by the Social Policy Research Unit (SPRU) at York University influenced later work in Scotland and include adoption of similar frameworks for service users and carers, the inclusion of both process and quality of life outcomes, and the exchange model of assessment, which incorporates the views of service users, carers, practitioners and agencies in negotiating and agreeing outcomes.

The SPRU programme adopted ‘whole systems thinking’ to reflect awareness that resolution of many health and social problems, and achievement of outcomes for people, lie beyond the ability of any one practitioner or agency. It was acknowledged that systems are complex networks of inter-relationships, which links to the recent emphasis on complex adaptive systems highlighted in the implementation paper that sits alongside this paper. A ‘paradigmatic leap’ in service designed and delivery is required.

Literature on outcomes for young carers is more limited but growing and identifies long-term impacts of substantial caring on development and opportunities into adulthood. Separate work is underway focusing on young carers relating to the Act.

Evidence about outcomes in practice

This section covers evidence and learning about three practice related themes: conversations, recording of outcomes and measuring and tracking outcomes. The Scottish based Meaningful and Measurable project is key here (Miller and Barrie 2016).

Outcomes focused practice shares many principles with person centred and strengths based practice. All three require a focus on environmental resources (friends, family, community) that can assist with pursuing goals/outcomes. Lessons from challenges with embedding person centred practice are relevant. This includes the unhelpfulness of ‘measurable but not meaningful goals’.

The key shift in outcomes focused practice involves moving from identifying deficits and matching them to services to engaging with the person in the context of their whole life. The exchange model specifies a move from a question and answer format to a conversational exchange. It involves practitioners, people using services and carers working together to build outcomes into individual narratives. Rather than people being viewed as consumers of services, they are co-producers of collaborative plans.

Outcomes focused conversations take time but can be an effective intervention in their own right, restoring self-identity and instilling hope. Conversations are only one component of an outcomes approach however, along with recording of the outcomes in a plan, and use of the information for decision-making. Where resources are limited, it may not be possible to work towards all identified outcomes. However, investing the time in such conversations achieves more effective resource use, through ensuring the

relevance of any interventions as compared to standardised service led approaches. Such conversations require culture change in the whole organisation.

Research consistently identifies that recording outcomes requires specific attention. The Meaningful and Measurable project identified five simple criteria were agreed as indicators of outcomes recording; outcomes not just outputs, personalised outcomes; a role for the person/family, inclusion of the person's voice, and an action orientation.

The review process is an important opportunity to track progress with outcomes and check if the plan needs to change. It also enables capture of information that can be used for planning and improvement.

Regarding measurement, there is a view that tracking outcomes is a helpful concept in allowing for inclusion of narrative data, and fluctuations over time. There are concerns about the validity of all outcomes measurement data, if viewed in isolation. Understanding is required that interventions are delivered in complex systems which are influenced in unpredictable ways by internal and external factors.

The project called into question the implicit measurement assumption that a 'higher score' is necessarily better and that all aspects of wellbeing should improve. Further, as aspects of human existence, wellbeing dimensions cannot be 'achieved' once and for all. It is therefore more appropriate to describe 'pursuing' or 'improving' wellbeing, or 'realising' an aspect of a wellbeing dimension.

Evidence about context

Work on embedding outcomes has shown that most challenges are associated with measurement and attribution, and that there is a need to articulate distinctions between personal, programme and population outcomes.

The need to embrace complexity and accept the unpredictable nature of outcomes is reflected in principle by the Scottish Approach to Government. With regard to the Carers Act, it is recognised that more prescriptive top down measures would not be welcome, particularly given that different frameworks have already been adopted across localities. However there are opportunities to test out more bottom up approaches to measurement. This would require prioritising personal outcomes and linking these upwards towards strategic outcomes. It would also require a shift in focus away from viewing outcomes as items to be measured in predictable, linear ways to encountering complexity. This would need to be linked to an improvement approach, tying review of recording to quality assurance to practice development. There is work like this underway in some localities including East Renfrewshire and Midlothian.

A further area requiring consideration, of particular relevance to integration authorities, is eligibility criteria, based on the Fair Access to Care Services criteria which include four bands - critical, substantial, moderate and low.

The requirement made of practitioners to balance user-defined need against fixed eligibility criteria in framing decisions about support has been highlighted for some time as representing tensions in practice. Evidence shows that they don't always support preventative work, and tend towards a deficit focus. There is work underway in Wales considering eligibility at a later stage, and early stage development work in Scotland.

Conclusion

An existing body of evidence can support effective implementation of outcomes focused support planning. There are also opportunities to test out means of addressing tensions in the context of the Act. Areas which emerge include more bottom up approaches to measurement, more sympathetic approaches to eligibility, specific efforts to work with health partners, and use of qualitative data, building on existing progress.

Introduction and background

This literature review was commissioned by the Carers Branch of the Scottish Government, to support implementation of the Carers (Scotland) Act 2016 (the Act). As the Act contains provisions that the adult carer support plan and young carer statement must set out the carer's identified personal outcomes, this review focuses on personal outcomes in practice. The review prioritised peer reviewed journal articles, in most cases including 'carers' and 'outcomes' in the titles, with preference given to papers which also focused on assessment or support planning. These were identified through a snowballing approach, whereby relevant references within well-known papers were followed up. Other sources include research and practice reports and policy documents.

The review found several international longstanding bodies of work on outcomes focused carers assessment, all extending over the past ten to twenty years. The evidence is mainly qualitative, with particular emphasis on the difference made by focusing on outcomes in practice, from service user, carer and practitioner perspectives. Most programmes produced evidence about the importance of organisational and policy contributions to supporting this work. It includes limited evidence on measurement of outcomes. There were close links between the researchers included here, as identified through the references used. The programmes, whose main outputs include research reports and journal articles were led:

In England by the Social Policy Research Unit (SPRU) at York University (more recently also at the Personal Social Services Research Unit (PSSRU)

In Wales by Diane Seddon and colleagues

In Sweden by Elizabeth Hanson and colleagues

In Canada by Nancy Guberman and colleagues

In Scotland initially by the Joint Improvement Team, researchers and local organisations
The latter programme began in 2007, and many of the outputs can be found [here](#).

It is notable that these long term programmes all involve interaction between research, policy and practice, offering learning on sticking points which need to be addressed and successful strategies in this challenging area of practice. The context is defined by the Scottish Approach to Government. The Christie Commission on reforming public services set out four pillars underlying the Scottish approach: empowering people; promoting partnerships for service provision; preventive strategies; and more efficient public services. These principles have been reinforced by government statements on engaging with citizens, open government and the empowerment of individuals and communities (Coutts and Brotchie 2017). The recent report from the Office of the Chief Social Policy Adviser (OCSPA 2016) highlights links between practice improvement and approaches to measurement compatible with co-production. A separate paper by Ailsa Cook, also commissioned by the Carers Branch of the Scottish Government provides a comprehensive overview of how evidence on implementation can inform next steps. This paper includes consideration about how approaches to implementing the Act might contribute to the emerging Scottish approach.

This review incorporates an executive review and three sections:
Review of outcomes programmes

Evidence about outcomes in practice
Evidence about context

Section One: Review of international outcomes programmes

This section provides a brief overview of selected literature from relevant programmes on outcomes focused carer assessment/planning. First, attention will be paid to underpinning assessment frameworks, because these reflect perceptions and values about carers, and therefore influence how carers are responded to by systems. A long established challenge is that carers have occupied an ambiguous position within health and social care systems. Twigg and Atkin (1994) proposed four conceptualisations; carers as resources, co-workers, clients or superseded carer, whereby the focus is on maximising independence for the cared for person. Nolan et al (1996) promoted a fifth alternative of the 'carer as expert', arguing that service providers should build partnerships with carers which recognise the carer's expertise throughout the caring journey. While carers are increasingly identified as partners and as experts in policy, there can be tensions in practice. In resource and time limited contexts, there can be a concern to focus resources on those deemed most immediately in need of support. However lack of preventative support to families can result in unmanageable demands on all involved, as well as to the health and care system. Such tensions manifest themselves in ambiguity towards carers in practice (Miller 2012). While the existence of the Act provides signals as to the value of carers and of preventative support, the tensions need to be acknowledged and therefore approaches to implementation are key.

Early work on embedding outcomes in the UK promoted the expertise of carers and was largely progressed by the Social Policy Research Unit (SPRU) at York University, from 1996 to 2010. The aim of the earliest programme was to find practical ways in which the outcomes valued by older people, disabled adults and their carers could become central to services. Regarding carers specifically, Nicholas (2001) argued that services not only needed to focus on outcomes relevant to carers but also consider the views of practitioners and managers (Nicholas, 2003) a theme reiterated in later programmes.

Three important features of the SPRU programme have permeated subsequent work, particularly in Scotland. The first is that the programme adopted a similar approach to both people deemed as service users, and carers. Secondly, although categories of outcomes differ, both quality of life and process outcomes were common to both. The focus on process outcomes, reflecting relational practice, has proven fundamental, as reflected below. Thirdly, the exchange model of assessment, initially devised by Smale et al (1993) underpinned the work. In Scotland it has proven to be a powerful motif in representing the importance of negotiating different perspectives in agreeing outcomes and associated actions. The exchange model affords opportunities to build on the strengths of each participant, acknowledging different contributions to identified outcomes and any perceived barriers (adapted by Miller and Barrie 2016).



The SPRU programme adopted 'whole systems thinking' to reflect awareness that resolution of many health and social problems, and achievement of outcomes for people, lie beyond the ability of any one practitioner or agency. There is recognition of the need to develop systems for provision of 'seamless care' for patients within and between agencies. It was acknowledged that systems however are complex networks of inter-relationships (Iles and Sutherland, 2001). This links to the recent emphasis on complex adaptive systems highlighted in the implementation paper. SPRU identified at an early stage that enactment would be complex and may require a 'paradigmatic leap' in service designed and delivery (Qureshi et al 2000).

In Wales, work on carers assessment has been underway for over twenty years, led by Diane Seddon. Despite a policy and legislative context affording increased recognition and rights for carers, the work has consistently reported practitioner ambivalence about carer assessment. They recently re-emphasised the need for outcomes focused rather than problem oriented assessment tools which embrace the diversity of caring relationships, including reciprocal caring, and recognise the tensions and competing priorities that may arise (Seddon and Robinson 2015).

The work in Sweden, starting twenty years ago, was influenced by SPRU, and resulted in a distinct Carers Outcomes Assessment Tool (COAT) (Hanson et al 2008). They found that few municipalities were conducting systematic assessments, and those that did tended to operate a procedural model (Smale, et al., 1993) whereby services were allocated largely on the basis of pre-determined criteria, effectively a 'one-size fits all' approach. They found that COAT enabled partnerships to be developed between carers and practitioners, recognising the expertise of both parties (Hanson et al 2007).

Three relevant Canadian studies with health and social care practitioners took place between 1999 and 2006, linked to the programmes identified above. This work pointed to the following as preconditions for successful implementation: clarification of carer status within policy and practice; making explicit agency philosophy with regard to the role and responsibilities of families in care and conceptions of carer assessment; and agency buy-in at all levels. Four themes emerged as issues for implementation: integration of the carer assessment tool with existing tools; ensuring training and ongoing supervision; human and material resources required for carer assessment and agency responses; and logistical questions around who should be assessed at what point and by whom (Guberman et al 2003, Guberman 2007)

A large-scale outcomes knowledge exchange programme began in 2006 in Scotland, supported by the Joint Improvement Team. This followed research at the University of

Glasgow, on the outcomes important to people who use services provided in partnership between health and social care (Petch et al 2007). The programme continues, supported by diverse agencies (Cook and Miller 2012). A more recent research project helped to clarify practice support needs, to be outlined below (Miller and Barrie 2016). The work is progressing at different rates across sectors, and sustained effort is required to address longstanding barriers. In social work/care, the aspiration to balance personal outcomes with eligibility criteria, which can focus attention on risk and critical need can create tension and will be discussed below. In health, further work is required to progress beyond functional and treatment goals to include broader quality of life concerns (Barrie 2013). More recent emphases on shared decision-making and realistic medicine, as promoted by the Chief Medical Officer (NHS Scotland 2017) should support this. In both cases further work is required to support and recognise the contribution of the individual and their own resources in achieving outcomes, consistent with co-production principles (Barrie 2013, OCSA 2016).

Across research programmes concern is evident as to the links between assessment for the carer and for the cared for person. There are sound and justifiable reasons why it is argued that the carers assessment should be distinct from that of the cared for person. However, their separation can also create tensions. When the assessments sit apart in systems, this can result in a disjointed view of how outcomes can be achieved within a family. Challenges are amplified when there is conflict between the needs and outcomes of each person. It is argued that policy guidance needs to clarify the links between assessments (Rand and O'Malley 2014, Seddon and Robinson 2015).

Considering outcomes for young carers

The programmes identified above have tended not to focus explicitly on young carers. In general, evidence about young carers is limited but growing, with implications for support planning. Research finds that being a young carer can have a significant impact on a young person's life that extends well into adulthood (Szafran et al 2016). Young carers report disruption in many aspects of their lives: their emotional and psychological development, relationships, and financial stability (Gelman and Rhames 2016). Despite such disruptions, and limited resources tailored to their needs, some affected young carers demonstrate remarkable resilience (Gelman and Rhames 2016) with one study finding that female young carers valued the relational skills they developed including empathy and understanding (Szafran et al 2016). A major challenge is a tendency for young carers to keep their situation private, for fear of external interference into the family, and of being bullied (Szafran et al 2016) pointing to the need for proactive support. Tailored support from professionals is important in contributing to positive experiences (Gelman and Rhames 2016). An Australian study found that social support from the young person's social network was the most consistent predictor of adjustment (Pakenham et al 2007). In Scotland, any approach to identifying outcomes with young carers would need to be consistent with relevant policy principles which include the SHANARRI indicators (safe, healthy, active, nurtured, achieving, respected, responsible, included).

Section Two: Evidence about outcomes practice

This section covers evidence and learning about three practice related themes; conversations, recording of outcomes and measuring and tracking outcomes.

Conversations

We've done the respite, we've looked at people's benefits, we've made sure that people get throughout, you know, help with maintaining the house or picking up medications, what we haven't looked at is what's the emotional impact this has put on you (Practitioner, Wales, Seddon et al 2015)

... [A]nd one woman started to cry when I informed her about the study we were doing ... 'Oh dear, how wonderful, forgive me for crying, but at last someone is willing to listen to me' (Practitioner, Sweden, Guberman et al 2003)

Before nobody seemed to notice. I just seemed to be the person who was there all the time and nobody cared ... I just felt like I were you know, nothing (Carer, UK, Nicholas 2003)

I think it's good that you do actually...listen to us seriously... it's brilliant, because we know what we're talking about with our particular situation (Carer, Scotland, Tsegai and Gamiz 2014)

The key shift involved in outcomes focused practice involves moving from identifying deficits and matching them to services to engaging with the person in the context of their whole life. The model promoted by Smale et al (1993), specifies a move from a question and answer format to a conversational exchange. It involves practitioners, people using services and carers working together to build outcomes into individual narratives. Rather than people being viewed as consumers of health and social care, they are involved as co-producers of collaborative plans (de Silva 2014, Miller 2014). A further key component is the strengths approach articulated in the 1980s (Rapp and Chamberlain, 1985). As with person centred practice, this seeks to identify the person's competencies and their environmental resources (friends, family, community resources) which might assist with pursuing outcomes. It means that services are not the starting point, and requires engaging with people rather than processing them.

Lessons from person-centred planning are worth considering here, with a considerable way to go before person centred care is the norm (de Silva 2014). At an earlier stage in the US, Smull and Lakin (2002) identified how good intentions with person centered planning were derailed by a concern to pass quality assurance reviews, driven by external criteria. Requirements for goals to be measurable and for data to document progress resulted in recording of 'measurable, but not meaningful' goals (Smull & Lakin, 2002, p. 383). Recently Taylor and Taylor (2013) highlight the limitations of identifying pre-determined outcomes as contradicting the principles of person-centered planning, because many will become apparent during the planning process itself. In the context of outcomes focused practice, this suggests that tools need to support fluidity and measures need to flow from rather than direct the conversation.

Despite the challenges, there is significant evidence of benefits. While further evidence is available from literature on person-centred planning, the focus here is on benefits of outcomes focused practice, with examples selected from the programmes above.

The opportunity for reflection, release from bottled up feelings, gaining new insights into the caring role and opportunities for honest discussion about challenges and hopes were identified in relation to outcomes focused assessment for carers (Nicholas 2003).

Research involving Canada, Sweden and the UK found that focusing on outcomes facilitated more comprehensive, in-depth and carer-focused assessments. Such approaches were found to transform the relationship between carers, and the health and social care system. Giving carers a voice, acknowledging their perspective and expertise accorded them status as active partners, and as individuals with their own needs and aspirations, rather than seeing them as resources (Guberman et al 2003).

The benefits of COAT in Sweden included a comprehensive understanding of each unique situation, to build a relationship and provide emotional support. Data from interviews indicated that carers were overwhelmingly positive about the COAT interview, as it enabled them to play an active role and then decide together with the assessor what support should be provided. In-depth discussion about the caring situation was seen as therapeutic in itself (Hanson et al 2007).

Welsh research emphasises the benefits of narrative approaches to engaging with carers that capture the emotional aspects of care-giving (Seddon and Robinson 2015).

Most recently the Meaningful and Measurable project in Scotland set out to progress use of personal outcomes information collected by organisations. The project confirmed the role of the conversation within the context of relationship building, as a key contribution and an effective intervention in its own right. There was also evidence about improved individual involvement in decision-making, greater clarity of purpose and more enabling practice. However, an outcomes approach does not just consist of good conversations. The conversations are intended to have a purpose, which is not only to identify intended outcomes, but to record them in a plan and to acknowledge who is responsible for working towards each outcome (Miller and Barrie 2016). This is why the outcomes approach in Scotland identifies three components; conversations, recording and use of information (Cook and Miller 2012). The main use of information by participating organisations was for practice and service improvements and planning, with additional learning about use of information for performance and commissioning.

Across the programmes, consistent barriers for practitioners are identified as lack of time for conversations, concern about difficult issues arising and fear of raising expectations. The Meaningful and Measurable project confirmed that in parallel to the conversations having to change at the frontline, the conversation needed to change in the organisation. Factors to support this include supervision, sharing good practice and storytelling, supporting practitioners so that they feel valued and listened to, and a feedback loop to practitioners about how outcomes data is used (Miller and Barrie 2016). In addition, a range of tools and resources to support this type of conversation have recently been produced by different agencies in Scotland.

Recording outcomes

Research on outcomes focused practice has consistently identified that recording outcomes needs attention in its own right. Earlier work by SPRU found that recording tended to cluster round a relatively limited number of outcomes, and that there was limited evidence of innovative solutions. The research identified opportunities for using routine practitioner documentation to highlight areas of organisational and professional change and learning (Foster et al 2008). The Meaningful and Measurable project in Scotland paid detailed attention to the quality of recording, similarly identifying opportunities for linking recording practice to quality assurance and supervision within organisations. Five criteria were agreed as indicators of outcomes recording:

- a clear distinction between outcomes and outputs
- the outcome should be personalised
- the person/family should have a role
- the person's own language should be used as appropriate (including non-verbal communication where appropriate),
- and the plan should be action oriented (Miller and Barrie 2016)

When these criteria are met, the record can positively influence the person's self-perception, further restoring a sense of identity in face of a disrupted life narrative, and acknowledging the role of the person in contributing to their own outcomes. It also influences how practitioners view the person.

The review of the outcomes plan provides opportunities for checking whether there has been progress with the outcomes which were identified in the plan; whether actions agreed in the plan have been undertaken; whether new outcomes have emerged; whether particular factors are identified as contributing towards achieved outcomes explore and also for unintended impacts on outcomes (positive and negative) to be captured and understood. The review process is an important opportunity to capture information that can be used by the organisation for improvement purposes (see recorded example below which is referred to again in use of information).

Recorded outcome example (based on real story)

BACKGROUND
Clare has identified that she is 'burnt out and constantly on the verge of tears' after a recent event involving her sister Sarah, who has long-term mental health problems. Sarah was found unconscious in her flat three weeks ago after taking an overdose of her anti-psychotic medication for the first time. Clare was caught up in home visits and meetings involving the hospital, police and crisis team and phonecalls with family members who live over 80 miles away. Clare, who is a single parent, feels she is neglecting her children and her job by constant demands relating to Sarah, who is now in recovery in hospital. Clare has always been available for her sister, but the recent trauma has left her feeling overwhelmed and she is anxious about her sister's safety
BASELINE OUTCOME: physical and mental wellbeing
Clare is aware that her own wellbeing needs attention. She wants to 'be able to breathe again' and although she previously felt able to cope on her own, needs to feel that she has some support and someone to talk to about how she feels
ACTION
Clare doesn't like to bother him but is going to phone her brother and ask him to stay for a few days, to take on all interactions with services relating to Sarah Clare is taking her children out to the cinema so they know she is there for them A mental health charity has offered Clare a home visit to talk through her worries about her sister's safety
REVIEW OUTCOME: physical and mental wellbeing
Clare is still 'struggling a bit' to balance parenting, work and caring. However she says that she might feel 'ready to cope again' after her brother's visit. As well as the visit taking the heat off, she felt that talking about their family history brought them closer. The visit from the support worker made Clare realise she was blaming herself for her sister's actions and she is trying not to give herself a hard time. She is still tearful but

feels ‘much less alone.’
ACTION
Clare wants another meeting with the support worker with her brother there too, so that they can talk in more depth about what has happened and how they can manage their anxieties and continue to support their sister and each other

Measuring and tracking outcomes

Although outcomes have been prevalent in Scottish policy for some time, and evidence of benefits is accumulating, challenges remain with regard to their measurement. In this section, consideration is given to measurement of outcomes at the individual level. More strategic influences will be considered below. This section will focus on learning from the Meaningful and Measurable project, because of its focus in Scotland. Most of this section is from the summary report from the project. While consideration is given to ‘measuring’ outcomes, it can also be helpful to think of tracking outcomes, which allows for inclusion of narrative data and with the concept of a caring journey.

Five of eight practice partners involved in the project were using a scale measure as part of their outcomes approach. These included both numeric wellbeing measures and simple improvement measurement scales. Most partners adopted an agnostic view about the adoption of associated tools, with a view that measurement should be tailored to different populations or conditions (Miller and Barrie 2016). There was discussion around the validity of the data generated by all of the approaches. A key concern was that percentage outcomes scores can give an artificial sense of accuracy and mask important differences. Further, mismatches between quantitative and qualitative recording reinforced the importance of viewing percentage outcomes in the context of other data. What mattered was consistency within systems, promoted by collaborative learning, to generate valid and useable data. While standardised benchmarking across agencies was not feasible, broad comparison and exchange of learning across organisations was valuable, and supported consistency.

The project generated useful learning about distinctions between wellbeing and personal outcomes measures. Two partners were working with wellbeing measures (Angus wellbeing web used with children and families and Penumbra’s I.ROC (the Individual Recovery Outcomes Counter) (developed with adults in recovery) while three had adopted personal outcomes scales. The first distinction was that wellbeing dimensions are incommensurable and irreducible, and each has intrinsic value (Alkire, 2002). As they also exist in balance with each other, there is a need to attend to and visualise all wellbeing dimensions in the round. In contrast, with personal outcomes, it is possible to focus on selected outcomes relevant to the individual. A second point worth noting is that where wellbeing measures are employed, additional efforts are required to link the measures to the planning process (Miller and Barrie 2016).

The notion of aspects of wellbeing existing in balance also suggests the possibility of imbalance. This calls into question the implicit measurement assumption that a ‘higher score’ is necessarily better and that all aspects of wellbeing should improve (or even be maintained at the same level). This is illustrated poignantly through the Angus Council project and the reported experiences of young carers who had assumed too much responsibility for their age and whose ‘responsible scores’ would have to decrease in order for improvements in other aspects of wellbeing to be achieved. This has significant implications for the approach to wellbeing and personal outcomes measurement, highlighting the need to contextualise scale ratings through supporting

text. To consider the case of Clare in the recorded outcome example; there was a further traumatic incident when Sarah disappeared from the hospital for 24 hours, a week after this outcome was recorded. While Clare reported a negative impact on her wellbeing as a result, she reported that she felt better able to recover because she had a lifeline through the support worker, and with her brother phoning every day for moral support. The mental and physical health score might decrease, but the narrative puts this in context and demonstrates contributory factors to being more able to recover.

Further, as aspects of human existence, wellbeing dimensions cannot be ‘achieved’ once and for all (Alkire, 2002). It is therefore more appropriate to describe ‘pursuing’ or ‘improving’ wellbeing, or ‘realising’ an aspect of a wellbeing dimension. This also has significant implications for measurement of both wellbeing and personal outcomes, with scales such as ‘unmet / met’ not making sense, and use of scale points based on fixed assumptions rejected. Further, it was identified in relation to the latter type of scale that practitioners tend to identify that outcomes are partially met. They do not like the term unmet as this can be discouraging to people. They have reservations about saying that an outcome is fully met in case the service is removed (Miller and Barrie 2016).

A further issue at a slight tangent to measuring outcomes is the analysis and use of qualitative data. This was identified by all partners as necessary to sense check scale measurement data, and to increase *understanding* of outcomes in context. Through tracking qualitative outcomes data through review processes, opportunities arise to explore factors such as those described in Clare’s case.

This learning matters because measurement practice is a longstanding barrier to embedding outcomes in practice. The next section will consider measurement at the strategic level, along with other areas for attention.

Section Three: Evidence about context

A recent review of international evidence on outcomes confirms that the majority of challenges are associated with measurement and attribution and that there is a need to articulate the distinctions between personal, programme and population outcomes (Cook 2017). Perhaps most influential has been the tendency of predominant approaches to performance management (associated with new public management) to reduce measurement to a limited set of centrally determined, statistical targets and indicators. This is illustrated most starkly by the Francis review of mid-Staffordshire NHS Trust, which highlighted that although the hospital concerned was ticking the boxes for external reporting purposes, hundreds of people died due to unsafe and poor care (Francis 2013). With regard to personal outcomes specifically, the need to distinguish between measures for internal improvement and those for external judgement is emphasised (Miller 2012). Evidence from the programmes above confirms that focusing internally is essential to embedding the changes required over time.

Regarding the challenge of attribution in particular, the recent review has identified that two different sets of assumptions are in operation about the relationship between cause and effect (Cook 2017):

1. The system in which the intervention is being delivered is closed and not influenced by external factors, or influenced in predictable ways.
2. The intervention is being delivered in a complex, adaptive system which is influenced in unpredictable ways by internal and external factors.

The recently articulated Scottish approach to government is aligned to the second set of assumptions. In contrast to a traditional ‘linear’ model of delivering outcomes for

people and communities it espouses a cyclical and relational model (OCSPA 2016). It acknowledges a need to progress understanding of how asset-based approaches could be expected to contribute to achieving National Outcomes, and that there is a need to think beyond established, readily available, easily measured and quantifiable data. With regard to the Carers Act, it is recognized that more prescriptive top down measures would not be welcome, particularly given that different frameworks have already been adopted across localities. However there are opportunities here to test out how more bottom up approaches to measurement. This would require prioritising personal outcomes and linking these upwards towards programme and national outcomes. It would also require a shift in focus away from viewing outcomes as items to be measured in predictable, linear ways towards encountering complexity. This would need to be linked to an improvement approach, tying review of recording to quality assurance to practice development. There is work like this underway in some localities including East Renfrewshire and Midlothian, and in some carer organisations in their work with commissioners. In East Renfrewshire, there is an explicit focus on tracking personal outcomes in diverse service areas, as evidenced in their [website](#).

A further area requiring consideration, of particular relevance to integration authorities, is eligibility criteria. With regard to decision-making about allocation of services, the Fair Access to Care Services (FACS) Guidelines were initially implemented in England and Wales around 2003. The FACS criteria are based on individuals' needs and associated risks to independence, and include four eligibility bands - critical, substantial, moderate and low. When placing individuals in these bands, councils identify immediate needs and needs that would worsen without help. Scotland introduced eligibility criteria for local authorities in relation to older people, prompted by the Sutherland Review, now extended more broadly to other care groups (Miller 2010).

The requirement made of practitioners to balance user-defined need against fixed eligibility criteria in framing decisions about support has long been highlighted as representing an issue of real conflict in practice (Abendstern *et al.*, 2008). Eligibility criteria have also been cited as creating confusion relating to carers assessment in Wales (Seddon *et al* 2007). Evidence shows that while FACS criteria may support standardisation, they are likely to lead to people not receiving the support they need with cost implications for all concerned (CSCI, 2009). They encourage a focus on what the person is unable to do, to focus on deficits and commensurate risks, to establish a sufficiently high band to access services, at odds with outcomes focused and preventative practice (Miller 2010).

The Institute of Public Care (2009) argues that developing outcomes-based eligibility criteria need not necessarily call for a major overhaul of the system but rather refinement and improved application. They identify three hurdles:

- By tightly linking needs with resources the eligibility process discourages other forms of help being brought into the package;
 - Eligibility tests discourage a preventative approach because if people do not cross the threshold at the time of assessment they are not eligible for resources even though the acquisition of help now may prevent poor outcomes later;
 - By making the eligibility threshold increasingly hard to cross it encourages people to hold onto resources once obtained and hence provides no incentives for improvement either by the service user or the provider.
- (IPC, 2009, p.23)

Again, as with outcomes measurement, although the issue of eligibility is of broader relevance than carers, there is an intention to test out supportive approaches to eligibility criteria in the context of the lead up to commencement of the Act.

Conclusion

Situating the personal outcomes work in Scotland in context of longstanding international programmes is intended to clarify the gains to be made, common barriers, strategies for overcoming these and continued sticking points. A frequent theme in the literature is the need for clear policy signals as to the value and importance of caring, and the Act supports this. However, as suggested by the commissioning of this review and the associated review on implementation, there is recognition that how the Act is progressed and implemented will be critical to its success. There is significant learning to draw on about embedding outcomes in general. With regard to the challenges involved, the Meaningful and Measurable project progressed some issues, but there are opportunities to test out novel means of addressing tensions, including how best to achieve outcomes in face of resource and time constraints, in the context of the Act. Novel approaches to community led support are being tested in Scotland and may prove informative here. Existing and possible further areas for testing include more bottom up approaches to measurement, analysis and use of qualitative data and multi-agency collaboration around outcomes, building on existing patches of progress. There is also potential to exchange knowledge with partners in Wales where they have adopted an approach to eligibility which explicitly aims to enable preventative work with families. In relation to young carers there is also potential to test the salience and interpretation of the SHANARRI indicators, within the context of Getting it Right for Every Child (GIRFEC) and to further develop the evidence base.

In broader terms there is potential to contribute to the development of the Scottish Approach to Government, which includes emphasis on relational practice, co-produced outcomes and assets based approaches. A variety of multi-media materials and a wealth of good practice examples are available to provide stimuli for learning. As suggested by the review on implementation in general, and the evidence from embedding of outcomes presented here, collaborative approaches are required to make use of these stimuli for progressing practice development, finding pragmatic solutions and supporting consistency across agencies.

References

Abendstern, M., Clarkson, P., Challis, D.J., Hughes, J. & Sutcliffe, C.L. (2008) Implementing the single assessment process for older people in England: lessons from the literature, *Research, Policy and Planning*, 26(1),15-32

Alkire, S. (2002), Dimensions of Human Development, *World Development*, 30(2), 181-205

Barrie, K. (2013) *We've Got to Talk about Outcomes*, Glasgow: The Alliance

Barrie, K. and Miller, E. (2015) Measuring Personal Outcomes in Service Settings: Collected Briefings from the Meaningful and Measurable Project, https://meaningfulandmeasurable.files.wordpress.com/2015/04/mm_projectreport_measuringpersonaloutcomesinservicesettings.pdf

Cook, A. and Miller, E. (2012) *Talking Points personal outcomes approach: A practical guide*, Edinburgh: Joint Improvement Team

Cook, A. (2017) *What Works Scotland position paper: Outcomes based approaches in Public Service Reform*, Edinburgh: WWS

Coutts, P. and Brotchie, J. (2017) *The Scottish Approach to Government: A Discussion paper*, Alliance for Useful Evidence and the Carnegie Trust, <http://www.alliance4usefulevidence.org/assets/AfUE-The-Scottish-Approach-to-Evidence-v7.pdf>

De Silva, D. (2014) *Helping measure person-centred care*, London: The Health Foundation

Francis, R. (2013) *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry*, London: The Stationery Office

Gelman, C.R. and Rhames, K. (2016) In their own words: The experience and needs of children in younger-onset Alzheimer's disease and other dementias families, *Dementia*, 0(0) 1-22

Glendinning, C., Hirst, M. and Harris, J. (2005) *Understanding and Measuring Personal Social Service Outputs Relating to Disabled Adults and Carers*, Social Policy Research Unit, University of York

Guberman, N., Nicholas, E., Nolan, M., Rembicki, D., Lundh, U. and Keefe, J. (2003) Impacts on practitioners of using research-based carer assessment tools: experiences from the UK, Canada and Sweden, with insights from Australia, *Health and Social Care in the Community*, 11(4), 345–355

Guberman, N., Keefe, J., Fancey, P. and Barylak, L. (2007) 'Not another form!': lessons for implementing carer assessment in health and social service agencies, *Health and Social Care in the Community* (2007) 15(6), 577–587

Hanson, E. (2007) *The emergence of family caregiver assessment – the Swedish perspective*, Invited International Symposium Presentation, Caregivers: Essential Partners in Care Conference, 17–19 June 2007, Toronto, Canada

Hanson, E., Magnusson, L., and Nolan, J. (2008) Swedish experiences of a negotiated approach to carer assessment: the Carers Outcome Agreement Tool, *Journal of Research In Nursing*, 13(5) 391-407

Iles, V. and Sutherland, L. (2001) *Managing Change in the NHS: Organisational change, a review for health care managers, professionals and researchers*, London: NHS SDO

Institute of Public Care (2009) *Transforming the Market for Social Care: Changing the Currency of Commissioning from Outputs to Outcomes*, accessed at https://ipc.brookes.ac.uk/publications/market_facilitation_paper4.pdf

Miller, E. (2010) Can the shift from needs-led to outcomes-focused assessment in health and social care deliver on policy priorities? *Research, Policy and Planning* 28(2), 115-127

Miller, E. (2012) *Measuring outcomes: Challenges and strategies*, Glasgow:IRISS

Miller, E. (2014) Considering two outcomes paradigms: the improving (person-centred) and the proving (managerialist) agendas, Chapter 5 in *Human Rights and Social Equality: Challenges for Social Work*, Surrey, Ashgate

Miller, E. and Barrie, K. (2016) *Learning from the Meaningful and Measurable project: Strengthening links between identity, action and decision-making*, Glasgow: Health Improvement Scotland

NHS Scotland (2017) *Realising Realistic Medicine: CMO report 2015-16*, Edinburgh: SG

Nicholas, E (2001) Implementing an Outcomes Approach in Carer Assessment and Review, In: Qureshi, H (ed), *Outcomes in Social Care Practice*, University of York, SPRU, pp. 65–119.

Nicholas, E (2003) An outcomes focus in carer assessment and review: value and challenge, *British Journal of Social Work*, 33: 31–47.

Nolan, M., Grant, G., and Keady, J. (1996) *Understanding Family Care*, Buckingham: Open University Press.

Office of the Chief Social Policy Advisor (2016) *The Scottish Approach to Government: How should we measure and evaluate impact?* Edinburgh: OCSPA

Pakenham, K.I., Chiu, J., Bursnall, S., and Cannon, T. (2007) Relations between Social Support, Appraisal and Coping and Both Positive and Negative Outcomes in Young Carers, *Journal of Health Psychology*, 12 (1) 89 -102

Petch, A., Cook, A., Miller, E., Alexander, H. E., Cooper, A., Hubbard, G. and Morrison, J. (2007) *Users and Carers Define Effective Partnerships in Health and Social Care* https://www.researchgate.net/publication/255648896_Users_and_carers_define_effective_partnerships_in_health_and_social_care

Qureshi, H., Bamford, C., Nicholas, E., Patmore, C., & Harris, J.C. (2000) *Outcomes in social care practice: Developing an outcome focus in care management and use surveys*. York: Social Policy Research Unit, University of York.

Rand, S. and O'Malley, J. (2014) Carers' quality of life and experiences of adult social care support in England, *Health and Social Care in the Community* (2014) 22(4), 375–385

Rapp, C.A. and Chamberlain, R. (1985) Case managers services to the chronically mentally ill, *Social Work*, 30(5), 417-422

Seddon, D., Robinson, C., Reeves, C., Tommis, Y., Woods, B., and Russell, I. (2006) In their Own Right: Translating the Policy of Carer Assessment into Practice, *British Journal of Social Work*, 37(8): 1335-1352

Seddon, D. and Robinson, C. (2015) Carer assessment: continuing tensions and dilemmas for social care practice, *Health and Social Care in the Community* 23(1), 14–22

SG (2015) *Scotland's Carers: An official statistics publication for Scotland*, Edinburgh: Scottish Government

SG (2016) *Carers (Scotland) Act*, Edinburgh: Scottish Government

Smale, G, Tilson, G, Biehal, N, Mars, P (1993) Empowerment, Assessment, Care Management and the Skilled Worker. National Institute for Social Work Practice and Development Exchange. London: HMSO.

Smull, M., & Lakin, K. C. (2002). Public policy and person-centered planning. In S. Holburn & P. M. Vietze (Eds.), *Person-centered planning: Research, practice and future directions* (pp. 379–398). Baltimore, MD: Brookes.

Szafran, O., Torti, J. Waugh, E. and Duerksen, K. (2016) Former Young Carers Reflect on Their Caregiving Experience, *Canadian Journal of Family and Youth*, 8(1),129-151

Taylor, J.E., and Taylor, J.A. (2013) Person-Centered Planning: Evidence-Based Practice, Challenges, and Potential for the 21st Century, *Journal of Social Work in Disability & Rehabilitation*, 12:3, 213-235

Tsegai, A. and Gamiz, R. (2014) Messages for integration from working with carers, *Journal of Integrated Care*, 22(3) 99-107

Twigg, J. and Atkin, K. (1994) *Carers Perceived, Policy and Practice in Informal Care*, London: Open University Press