Key Issues in the process of implementing shared decision-making in mental health practice

Abstract

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Key Issues in the process of implementing shared decision-making (SDM) in mental health practice

Abstract

Although SDM is seen as a favourable approach in mental health settings, its routine use in everyday practice is low. Implementation is judged to be the test of the intention to use SDM because of its value base and its potential to improve mental health practice, across medical, psychological and social interventions carried out by multidisciplinary providers, including peer support workers. Successful implementation is achieved by enhancing the incorporation of understanding SDM as based on different types of knowledge (scientific and experiential) and leading to decisions more acceptable to service users than only to clinicians, thus enabling a more genuine working partnership between the key stakeholders in mental health services.

Purpose: This review article will look at internationally existing publications in the English language on mental health SDM implementation of a variety of interventions, including different methodologies and research methods, age groups and countries. We will aim to provide an overview of: process, degree, and outcomes of implementation; barriers and facilitators; perspectives on implementation by different stakeholders; analysis of the process of implementation in mental health services through the lenses of the Normalisation Process Theory (NPT)

Design: Following a targeted literature search the data was analysed in order to provide an overview of methodologies and methods applied in the articles, as well as of the variables listed above. Three different types of information were included: a content analysis of key issues, reflective understanding coming out of participating in implementation of an SDM project in the form of two narratives written by two key participants in an SDM pilot project, and an NPT analysis of the process of implementation.

Findings: Only a minority of mental health SDM research focuses on implementation in everyday practice. It is possible and often desirable to achieve SDM in mental health services; it requires a low level of technology, it can save time once routinized, and it is based on enhancing therapeutic alliance, as well as service users’ motivation. Implementation requires an explicit policy decision, a clear procedure, and regular adherence to the aims and methods of implementation by all participants. These necessary and sufficient conditions are rarely met, due to the different levels of commitment to SDM and its process by the different key stakeholders, as well as due to competing providers’ objectives and the time allocated to achieving them.

Implications: The review indicates both the need to take into account the complexity of SDM, as well as future strategies for enhancing its implementation in everyday mental health practice. Perhaps because applying SDM reflects a major cultural change in mental health practice, current value attached to SDM among clinicians and service managers would need to be more positive, prominent, and enduring to enable a greater degree of implementation.

Key words: implementation, shared decision-making, mental health, review.
Introduction

This review article focuses on the implementation of shared decision making (SDM) in mental health, an issue that has arisen only recently at the stage in which some of the pilot projects on SDM have led to this strategy becoming accepted policy in some mental health services, while the majority of such projects have not moved to the implementation stage. Implementation is defined here as the routinization of SDM as a process applied in everyday practice by multidisciplinary providers across the range of key interventions, to include medical, psychological and social interventions.
Mental Health Review Journal

SDM is defined as the process by which intervention options are looked at in a two-way exchange of information and knowledge (formal and experiential) by a patient and a clinician, who together decide on a course of action (Charles, Gafni & Whealan, 1999). This collaborative process is based on mutual respect, open communication, and consideration of individual preferences and values, usually entailing:

1. the inclusion of at least two people, patient and clinician
2. who share information
3. take steps to build a consensus about preferred intervention
4. reach agreement on the intervention to be implemented

Based on a systematic literature review of journals that centre on implementation of SDM, this paper looks at key themes highlighted in the relevant articles thus identified, followed by a reflective section, leading to an overall analysis from the perspective of NPT (normalisation theory process). NPT is a sociological theory developed to support the work of implementing and embedding complex interventions in healthcare and other institutional settings (May et al, 2007). NPT constructs were used as sensitizing concepts whilst designing and undertaking the review, and as a heuristic framework for analysing and synthesizing the literature.

Two reflective narratives based on experiencing implementation work are included, as ways of illuminating issues raised in the key content section, and of highlighting the experiential reflective perspective alongside a scientific one. Such a perspective is all too often missing in formal research, while it is a key element in enabling shared decision making, which is based on understanding coming from both scientific and experiential knowledge. The first narrative was written by a senior nurse who has been involved in a UK SDM project introducing a SDM intervention during its experimental phase (see Stead, Morant and Ramon, 2017), as well as during the first two years of its implementation, playing an even more central role in the latter phase. The second narrative was provided by a service user trainer and researcher, who has been involved in the project since its inception.

Shared decision making in mental health is perceived as a necessary and useful process especially in the promotion of the new meaning of recovery in mental health (Davidson, 2003 Ramon, Healy and Renouf, 2007, Slade, 2009) which is defined as leading a meaningful life, even if symptoms of mental ill health have not disappeared.

The analysis of the articles, the key themes and the reflective narratives from the Normalisation Process theory (NPT) perspective provides an in-depth overview of what is meant by the process of implementation and its components. This connects the text to an emerging conceptual framework focused on both outcomes and processes of change in mental health services which impacts on all stakeholders of these services, be they service users, clinicians, peer support workers, managers, or researchers.

Methods

Literature Search Strategy

The aim of the search was to identify articles on the implementation of shared decision-making within mental health services. Given the relatively recent interest in the topic under consideration, and our own knowledge of the mental health SDM literature, we did not anticipate that traditional database searches would yield relevant articles. We therefore opted for a targeted search, using
articles known to the authors on SDM and searching further on the basis of the identified themes and authors within these articles. The authors compiled a list of journals related to implementation and SDM, which were searched for relevant papers (appendix 1). Reference lists of included papers were also searched to identify further papers of relevance.

Inclusion criteria were: studies published between 2000 and 2016 and those pertaining to mental health services on the subject of the implementation of shared decision making written in English. Exclusion criteria were: studies focusing on SDM in mental health but not on implementation, studies not published in English.

73 articles were thus identified, of which 46 were looked at in full, ending up with 28 articles for a more detailed analysis. SR and HB reviewed search results to agree on whether articles should be included or excluded based on this agreed criteria.

The literature included review papers, commentaries, letters to editors, quantitative and qualitative studies as well as those utilising mixed methods. There was little documented service user or carer involvement in the papers reviewed with the exception of Deegan et al., 2008; 2010, MacDonald-Wilson et al., 2016, Bonfile et al, 2016, Stead et al, 2016. Other relevant articles which did not conform to the search criteria, but were considered important for contextual reasons are also included within the manuscript.

A thematic synthesis approach informed by Normalisation Process Theory was undertaken collaboratively by SR and HB in a manual method applied to the analysis of the studies included in the review (Thomas & Harden, 2008). To ensure themes were grounded in the data, a constant comparison method was used during the synthesis process. Authors SR and HB met regularly to discuss emergent themes before agreeing a final list of themes, which were considered representative of the articles included in the review.

The reflective data is based on the subjective perspectives of two key actors in a UK piloted and evaluated project on SDM in the context of psychiatric medication management (Morant et al, 2015, Stead et al, 2017) which was implemented after the experimental phase in the mental health trust it originated from for 36 months. The writers were asked to provide a narrative reflection on key aspects of their experience of being actively involved in this project in both shared and individualised capacities, which they wrote independently of each other.

Results

Key content issues

The following sub-headings are aimed to highlight the differential key issues related to implementation of SDM in mental health which have emerged in the data analysis.

From experimentation to implementation

This important issue is illustrated by focusing on the series of articles on the CommonGround approach to SDM (Deegan, 2005;2010;2014, Deegan et al., 2008, Drake and Deegan, 2009, Drake et al., 2009, MacDonald-Wilson et al., 2016, Stein et al., 2013). CommonGround is focusing on implementing a specific shared decision making computerised tool in US community mental health services.

Respect for experiential knowledge, as well as the ethical aspect of respect towards people with the lived experience of mental ill health underlie the values of this approach, alongside a person centred
focus. Shared decision making is advocated as a tool with which to implement these values in
practice, perceived also as effective in improving therapeutic relationships and all mental health
interventions, alongside the value of activating service users to take control of their lives.

Deegan (2005) has developed the concept of personal medicine, defined as the whole non-medical
repertoire each of us has of dealing effectively with mental ill health, ranging from professional
interventions in the form of medication or psychotherapy, to being in the company of people we
trust and listening to the music we like. She does connect this concept to SDM, especially around the
wellbeing agenda, in that when medication leads to outcomes contrary to the logic of personal
medication, people are likely not to adhere to the medication regime (ibid).

The approach assumes that SDM is a tool for improving wellbeing, rather than focusing on any
specific intervention, such as medication. It perceives of service users as inherently capable of
making decisions and of sharing in decision making with clinicians. Furthermore, it allocates trained
peer workers a central role in the support of service users within the process of SDM, rather than to
a group of mental health professionals.

The areas included in the CommonGround format are any psychiatric intervention and any area of
wellbeing the person wishes to discuss, though it has been developed primarily in the context of
SDM about medication. Its components include power statement (recovery goals), health report,
personal medicine, custom questions (specific to the person filling in the form), SDM and
information RX (prescriptions which include wellbeing facilities, and not necessarily medication).

In conceptualising and implementing the process, the approach focuses on both service users and
professionals preparing themselves for joint meetings, though more work is allocated to the service
users in asking them to note their priorities and issues they wish to raise in advance of a meeting,
while the professionals are asked only to read the information provided by the service users at the
initial stage. Decisions made during the joint meeting are put in writing, but it is unclear whose task
this is, how it is to be carried out, and where the record is stored. Peer support workers are allocated
to provide both technical and non-technical advice throughout the process. A considerable part of
the communication is taking place electronically, using a special format and touch responding
mechanism, rather than typing.

Intervention Methodology

The approach began as a pilot project in Kansas in 2003 and in 2008 was also practised in Threshold,
a large private service organisation practising in Chicago (Drake et al, 2009). Working in Chicago,
which has a wide range of ethnic minorities, highlighted the need for culturally sensitive SDM
process.

By 2013 fifty-two community mental health centres self-selected themselves to be involved in
implementing a decision aid toolkit, in learning collaborative activities specific to this project, and
adding a quality improvement team (QIT) in each centre to monitor the project which included also
one service user (Stein et al., 2013, Deegan, 2014, MacDonald-Wilson et al., 2016).

By 2014, 4,870 service users have followed the CommonGround process. It is not stated how many
people did not do so due to difficulties in accessing the electronic component. A recent paper by
Bonfils et al (2016) highlights lack of most service users’ routine application of the CommonGround,
attributed in part to technological difficulty, but mainly to insufficient staff involvement. Thus
although beneficial outcomes of this process beyond adherence to the procedure were identified,
such as improved engagement in treatment and availability of peer support workers, these are judged by the authors as insufficient.

The development of the project over the years reflects a move from focusing on training only service users, to recognition that support to providers is necessary too in the move to implementing SDM, alongside that of peer support workers.

**Research methodology**

Throughout the stages of this intervention development, a research evaluation was taking place. This has been provided mainly by the Department of Psychiatry at Dartmouth, led by Prof. R. Drake (Drake *et al.*, 2009), but also by other universities such as Kansas and Pittsburgh (MacDonald-Wilson *et al.*, 2016).

The collaboration between the Dartmouth team and Threshold is described in details by Drake *et al*. 2009 paper, and was wider than focusing only on SDM, to include regular conferences and seminars in addition to evaluation of new, practice oriented, interventions. The evaluation methodology often included quantitative and qualitative mixed methods.

Specific components, such as the electronic application of the SDM aids, which is of central importance in the implementation of the approach, are highlighted in some of the papers (e.g. Deegan, 2010, Stein *et al.*, 2013). The question asked was whether use of the electronic version of the tool would lead to increased adherence of using medication, where adherence was defined as continuing beyond 180 days.

It is a curious jump from the empowerment agenda of this approach to the assumption that empowerment through SDM would lead to greater adherence of medication taking, perhaps connected by the assumption that the approach increases therapeutic alliance, and hence would lead to greater acceptance of suggestions made by prescribers. Our knowledge of service users’ views to medication taking is that these are much more varied and also depend on the stages of wellbeing and ill being, as well as their use of personal medicine strategies (Clarke *et al.*, 2015).

By 2013 fifty-two community mental health centres self-selected themselves to be involved in implementing a decision aid toolkit, in learning collaborative activities specific to this project, and adding a quality improvement team (QIT) in each centre to monitor the project which included also one service user (Stein *et al.*, 2013, Deegan, 2014, MacDonald-Wilson *et al.*, 2016).

The findings related to this aspect are mixed, in highlighting that certain sub groups (older people, white, without recent hospitalisation, Medicaid eligible) have higher rates of adherence to medication than most of the outpatient population. The findings were arrived at through statistical linear regressions models, and do not seem to have a qualitative element to them.

In contrast, the evaluation of the effectiveness of engaging a small group of professionals as SDM champions in the community mental health centres was primarily qualitative (MacDonald-Wilson *et al.*, 2016). In this project community mental health teams were asked to support the implementation of a decision support kit, and were themselves supported by learning collaborative activities that follow the Breakthrough Model. The results were positive in terms of a high level of participation of staff in the learning activities, as expressed in posters and presentations by the participants.

The results related to improvement in implementation were more mixed. 60% showed improvement, 15% were steady in their outcomes, and 25% evidenced decline. The decline was
explained in the qualitative comments made by participants as pertaining to the need to relate their SDM work with the other routine daily activities they are expected to undertake.

Nowhere is the involvement in research of service users and/or peer support workers mentioned, despite the value set which would call for such an involvement.

In summary, the development of the CommonGround projects has moved from focusing on individual service users to encouraging the engagement of professionals too, and to a greater focus on organisational support of the move to SDM. Quantitative and qualitative methodologies co-exist in this project, though their usefulness depends on their degree of fit to respond to the specific research question. No attempt is made to create a unifying methodological approach that would fit SDM. Little has been stated about the actual encounter between the client and the clinician, following the first preparatory phase of filling in the CommonGround form and sending it to the clinician.

Reflective narratives on SDM implementation

1. [anonymised] (qualified mental health nurse, advanced clinical lead)

This section reflects on my involvement in implementing SDM across the Trust.

The importance of a policy....and how to use it

Producing the Trust SDM policy was my first important implementation task. Being able to go to teams and tell them that senior managers, nurses and psychiatrists had signed up to SDM as a way of working gave authority to the training sessions we delivered. Of course in a large organisation with numerous policies, the challenge is to make staff aware of the policy and see it as relevant to their practice: this doesn’t happen automatically. To make it meaningful, we wrote the policy so that it presented seven components of SDM and used these as the basis of training sessions.

Defining what we are implementing

There was a tension between the desire to promote SDM via the use of SDM forms (which prompted service users to identify their preferences and priorities and give feedback on their experiences of medication, and for clinicians to summarise decisions taken jointly) versus a desire to win the “hearts and minds” of staff over to greater SDM without increasing the administrative burden. This tension remains unresolved.

Reaching large numbers of staff

The scope of implementation was broad: across a large multi-centre Trust. This led to a dilemma as to whether to visit as many teams as possible or to focus on fewer teams with repeated visits. During the initial follow up phase, repeat sessions with teams petered out after a few sessions, with some of these sessions having been quite uncomfortable. This led to a desire to try something different; hence one off sessions for all the adult community teams in the Trust were arranged. Obviously the advantage of this was that large numbers of staff were exposed to the developments around SDM. On the other hand, it was a one off exposure. Most of these sessions were 30-60 minutes long with no formal evaluation. The themes of “we already practice SDM” and “we can’t engage certain services users in SDM (e.g. due to lack of insight)” occurred in most sessions; teams varied in their capacity to challenge these assumptions. I tended to finish each session with an invitation to staff to identify something that they could alter in their practice to promote SDM.
On reflection, given that my time was limited, the aim of promoting SDM to large numbers of staff, may have been more sustainably achieved by working more closely with Trust Learning and Development (L&D) staff at an earlier stage to incorporate SDM into mandatory training, which is now just starting to happen.

The value of team training

Four of the five teams that participated in the project had separate training for care coordinators and psychiatrists, with approximately half of care coordinators attending. The fifth team was trained as a whole team; doctors, care co-ordinators together, in a whole day session with nearly all team members attending. The follow up sessions with this team felt more constructive, with more discussion around how to implement SDM with particular service users and how to develop team practice. This team’s leader challenged colleagues’ statements that ‘we already do SDM’ suggesting that they could do it better which led to fruitful discussion. In contrast, in the other four teams, staff appeared less able to challenge each other and discussions focused on staff concerns about feeling overloaded with work. On reflection, the root of this may have been the difficulties the teams were experiencing at the time around staff turnover and reorganisation.

One reason for my devoting time to visiting teams was the hope that training a team together could promote discussions among the team about SDM and enable team members to support each other in developing SDM. This hope partly arose from our experience of team training during the project.

Training teams versus disciplines

Non-medical prescribers (NMPs), and peer workers received training separately as discipline-specific groups. NMPs and peer workers gave written feedback, which was generally positive. Although the positive commitment to SDM was evident during the training sessions with peer workers and NMPs, what has not been evaluated is the impact this had on their practice. The project team was concerned that peer workers may feel isolated in their teams if their team colleagues did not support their commitment to SDM. This is yet to be evaluated, though there have been a few anecdotal reports of positive and negative experiences of promoting SDM by peer workers.

Evaluating the implementation of SDM

One of the challenges throughout has been how to evaluate whether the amount of SDM being practised is increasing. We do not yet know whether SDM is increasing, and have not yet identified a way to evaluate this.

Personal reflections: being flexible versus being strategic

From a personal perspective, as a nurse who has worked for over twenty years as part of a team with a shared caseload, working on implementing SDM was a new and different style of working. I had freedom to choose how to organise my time and where to focus my efforts (albeit with support and advice from clinical leaders in the Trust). The initial list of potential implementation tasks was daunting. It was easy to feel isolated and overwhelmed at the scope of what needed be done. In retrospect, it is not surprising that some of the implementation tasks were not completed in the time available. I noticed in myself was a tendency to focus on the clearly defined tasks (producing a policy, folders and leaflets) rather than the less well defined tasks such as meeting with staff teams to promote SDM. There was some benefit to visiting lots of teams myself, as I met with a lot of enthusiasm, knowledge and experience around SDM; certainly lots of conversations were started. However, I was left wondering whether these conversations would be continued once I left the room.
Personally, I preferred visiting the teams with SRT (service user trainer). I welcomed the support of a familiar co-trainer. Also, delivering training as a staff-service user pair fits with the ethos of SDM.

One of the advantages to being flexible was that new developments were added in. As we went along, we started to promote the culture of writing letters to service users (and copying them to the GP) rather than the other way round. The SDM policy stated that this should be the norm, and we started to include this, along with examples of letters to service users, in training sessions. Whereas some clinicians already write to service users, others resisted. Concerns voiced included that GPs wanted technical language, which service users would not appreciate, that service users might not want this type of letter, and that it would take longer to write such letters. One consultant embraced the practice and encouraged others to do so via supervision sessions (with varying degrees of success).

Identifying implementation tasks gave some structure to an otherwise daunting challenge. However, two underlying issues that these tasks did not necessarily address were the ongoing tension among clinicians around “we already practice SDM” versus “we can’t do it with certain client groups” plus the need to target our time resources strategically in order to promote a sustainable increase in SDM in practice.

Whilst writing this article, it became apparent that our implementation approach was shaped by the difficulties we encountered during the project follow up. Initial experiences of resistance from four teams led us adopt a broader approach; one consequence is that it is difficult to evaluate whether SDM is increasing. However, our L&D team is now starting to deliver some sustainable SDM training to all new non-psychiatrists staff.

2. [anonymised] service user trainer and researcher

In this write up I will reflect on my involvement in implementing Shared Decision Making (SDM) within an NHS (national health service, UK) mental health trust in the East of England during 2014 – 2015. As a service user trainer my role was to co-facilitate the training sessions with a Community Psychiatric Nurse (anonymised). The aim was to embed SDM more widely across the Trust. In addition, I have also contributed to the training in SDM to junior doctors, Non-Medical Prescribers and the Peer Support Workers. I have interviewed the co-facilitators of the Hearing Voices Network in Cambridge and Peterborough, as part of the evaluation of the establishment of this network. The network was initiated in the not-for-profit sector as a result of the conference on this theme (January 2015), organised as part of the project implementation, with the financial and professional support of the Trust.

I was involved in the SDM study during 2011 – 2014, and worked as a co-facilitator in delivering SDM training to Care Coordinators in three trust locations. Myself and the professional co-trainer have already established a good working relationship and were practiced at giving presentations together. This stood us in good stead during the implementation phase because the teams still required training in the process of SDM. The information we provided was adapted to reflect the emphasis on implementation in these stand-alone sessions. In addition, we were able to draw on the findings from the project to give further support to the existing research evidence. The remit had also widened as we were promoting SDM across the all the adult community teams and across all areas of care rather just focusing on psychiatric medication management. The aspiration for this wider dissemination was to embed SDM into existing systems, such as policy, clinical effectiveness, the trust reporting system (RIO), and the Care Programme Approach (CPA).
We had also given presentations to the directorate and there was buy in at a senior level. Unfortunately, the SDM leaflets, which have been circulated across the trust, could only be produced after the trust policy had been signed off. It would have been helpful to have had these to hand out at meetings to demonstrate that this was part of a wider movement to involve service users in SDM.

We always tried to ensure that these single sessions were interactive although it was difficult to allow time for lengthy discussions when the sessions only lasted for 30 – 60 minutes. My presence as a service user didn’t seem to inhibit the open and honest discussions that took place, as the participants felt it was a safe environment.

Apart from the time constraints and the fact that each team only received one training session there were other challenges. The trust had been through an exceptionally difficult period and had been in ‘turn around’ preceding the implementation phase. Staff were feeling stretched and undervalued as they were having to do more for less. I imagine this is the reason why some staff were unreceptive and not open to new ways of working. Another factor was the ongoing organisational change and pathway redesign, which had an unsettling effect. This may explain why we sensed that some of the staff felt we didn’t understand how hard their jobs were.

During the training phase of the study there had been considerable resistance to using the forms, which had been developed to provide a clear framework for staff. The forms also enabled services users to express their preferences and priorities and identify any medication issues, which facilitated the decision making process. This was because it was seen as extra paperwork and because clinicians felt that services users would always prioritise application forms and resist any additional form filling. There were also administrative difficulties and forms were not routinely sent out to service users in advance of their appointments and printers were not always readily accessible to prescribers. In addition, because this was a research project it wasn’t perceived as mainstream or ‘business as usual’, staff were reluctant to persevere with forms which they regarded as onerous.

To try and reduce resistance, the forms were shortened and amended during the project to reflect the feedback we’d received from the teams. However, despite making these changes the revised forms were not well received. The advantage of using forms was that they could be audited and evaluated to evidence the extent to which SDM was being implemented. However, for the reasons stated above it was decided not to pursue the use of the forms during the implementation phase. Instead the emphasis was on providing seven memorable steps to guide clinicians through the process of SDM.

The scepticism we encountered from clinicians re the introduction of additional paperwork had made some of the initial training sessions during the project rather tense and slightly confrontational. We felt that at times we were walking a very fine line and this may have tempered the way we presented the information during the implementation phase, as it had impacted on our confidence. Although there were clinicians in the training working group, with hindsight it might have been worth consulting a staff advisory group re the development of the forms as this would have helped to ensure that they were tailored to the needs of staff as well as service users. By the time the revisions were made the tide had already turned and psychiatrists had mostly made up their minds about not wanting to use the forms.

It was important that the training sessions focused on the key messages because of time constraints. To effect change in an organisation the size of the Trust was a huge challenge, especially with limitations on the time and the fact that there were only two of us delivering the training. Without
the forms it is difficult to assess the impact that the training had and whether any resulting changes in practice have been sustained. In some ways the training that we did felt like a drop in the ocean and without continued reinforcement I’m not sure to what extent it has influenced practice.

During the study we had to counteract the ‘we do it anyway’ response which may have been because staff were scared to admit that they could have been doing their job better. We also encountered this attitude during the implementation phase. This belief had to be handled sensitively to prevent staff becoming defensive. In addition, there were a small minority of staff who felt that a percentage of service users would never be able to engage in SDM.

There is a move to encourage prescribers to write directly to service users instead of letters going directly to the GP and the service user being copied in. This work which is being spearheaded by the Clinical Director for Acute Care is on-going although again time remains the biggest constraint. There is also some resistance from prescribers who have expressed uncertainties regarding this approach and who are concerned that this will be more time consuming. As this initiative expands, it is hoped that a tool will be developed to evaluate the extent to which SDM is evidenced in these letters.

Working with the mental health nurse as a co-trainer both during the initial project and during its implementation phase has been a richly rewarding experience. The relationship was one of equals, and hence new boundaries have been crossed. I think it was important for staff to see how we worked together as a team and that coproduction was central to our ethos. From a personal point of view I have gained enormously from the experience and it has also taught me about the challenges of trying to change practice across the Trust. The size of the organisation meant that the message we were trying to communicate became diluted and it’s difficult to know whether other methods might have been more successful, such as a train the trainer approach.

These narratives will be discussed in more detail in the following section on the Normalisation Process Theory (NPT).

**Facilitators and barriers to SDM – A review informed by Normalisation Process Theory (NPT)**

NPT is a tool which supports the implementation of complex interventions such as SDM by focussing on the work required by stakeholders to ensure an intervention is routinized into everyday practice (May et al, 2007). It has been used previously with some success in the mental health field (Brooks et al., 2015, Coupe et al., 2014). This section will focus on the facilitators and barriers to the implementation of SDM within mental health services informed by the Normalisation Process Theory (NPT). The NPT comprises four components: coherence, cognitive participation, collective action and reflexive monitoring, emphasising the importance of evaluating complex interventions both within care contexts and the broader social and organisational context (May and Finch, 2009, May et al., 2007). As a theory, it allows for temporality and focuses on the work required at multiple levels within the system for an intervention to be successfully integrated and embedded into practice. Findings from the studies included in the review will be synthesised and presented under the four NPT headings (figure 1).

*Figure 1: Normalisation Process Theory (May et al., 2007, Brooks et al., 2015)*

Studies included in the review demonstrate service user and professional preference for, and support of, SDM (Deegan, 2010, Hamann et al., 2011, Hetrick et al., 2008, Park et al., 2014, Shepherd et al., 2014, Simmons et al., 2010). The mental health context was considered particularly suited to SDM given the uncertainty of treatment highlighting a role for service user/care preference (Deegan, 2008). This support was facilitated by the promotion of SDM in governmental policies, good practice guidelines, initiatives designed to shape clinical practice and professional directed educational programmes (MacDonald-Wilson et al., 2016, Morant et al., 2015). However, professionals need to be aware of these policies, guidelines and programmes and see their relevance for their own practice (see the reflections on SDM section, O’Sullivan).

For SDM to be successfully implemented all stakeholders must be clear on what SDM is and be able to differentiate it from current practices. Coherence was confounded by the perception of SDM as a complicated, multi-faceted process, which varied across clinical contexts (Drake et al., 2009, Simmons et al., 2010, De las Cuevas et al., 2013). Through its incorporation of patient preference, SDM was considered to not always reflect the ‘best clinical choice’ (Drake et al., 2009, Simmons et al., 2010). Confusion between SDM and other concepts of patient centeredness (Matthias et al., 2012) along with the required shift in roles from more traditional, paternalistic ones were also barriers to SDM (De las Cuevas et al., 2013, Shepherd et al., 2014).

The lack of a universal definition of SDM led to assumptions being made on the part of different stakeholders, which did not always reflect the values enshrined in SDM (Eliacin et al., 2015). There was some disagreement in terms of what constituted true SDM with stakeholders seeing a difference between being involved in the decision making process itself and actively contributing to the final decision (Quirk et al., 2012, Simmons et al., 2010). Some service users felt that SDM was a process of services making decisions for them (Eliacin et al., 2015) whilst others wanted to be asked their opinion and offered options, but preferred providers to make the final decision (Park et al., 2014). These preferences varied according to ethnicity, employment status, education levels and diagnosis (Park et al., 2014). Some professionals could not see a difference between SDM and current practices and felt that they were already implementing SDM sufficiently (Hamann and Heres, 2015, Smebye et al., 2012, see also the reflections on SDM section, O’Sullivan). Of those that could
differentiate SDM from current practices, some were concerned about the potential risk of SDM (Abrines-Jaume et al., 2014), did not consider SDM relevant to some of their clinical situations or to service users with particular characteristics (Simmons et al., 2010). For example, there were assumptions amongst some clinicians that young people were too immature to take part in SDM (Simmons et al., 2011), that those considered by professionals to be lacking insight could not be involved, and that some decisions were entirely outside the remit of SDM (Deegan, 2014).

Differences also existed in what constituted pre-requisites for SDM with professionals reporting that adherence and insight were necessary in order to undertake SDM. Deegan (2014) challenged this potentially circular argument (e.g. SDM being seen as a virtue until there was disagreement and then it reverting to an issue of insight and SDM then becoming a risk) by citing the CATIE trial and the capacity of individuals within it to process complicated information and detailing the legal statutes which exist to guide proxy decisions in the rare circumstance that SDM cannot be utilised (Drake and Deegan, 2009). There is a risk that by falling back on traditional decision making models in situations where insight is deemed to be lacking, will lead only to reinforcing paternalism within services (Deegan, 2014).

Cognitive participation – The centrality of trusting and accepting relationships

The majority of factors categorised within the cognitive participation component involved enrolment (‘buy-in’) and legitimation. The work associated with implementing SDM is unlikely to simply be about individual commitment but also about building the relationships between stakeholders to enable SDM to be delivered successfully.

The relationships between service users and professionals were considered critical to successful SDM (Abrines-Jaume et al., 2014, Eliacin et al., 2015). A trusting relationship built on empathy, partnership, compromise and mutual understanding was considered a prerequisite to SDM but also a necessary component of the context in which SDM occurred (Abrines-Jaume et al., 2014, Eliacin et al., 2015). Relationships were considered easier to develop if service users saw the professionals as ‘being like them’ in terms of gender and ethnicity, which facilitated connections on a personal level (Eliacin et al., 2015). Generally, longer and more sustained relationships, were associated with improved SDM (Matthias et al., 2014). This relationship could serve to protect against future feelings of alienation associated with enforced treatment (Morant et al., 2015).

Involving carers in SDM was considered a facilitator to building the relationship between service user and professional required for SDM (Smebye et al., 2012). However, carers reported low levels of involvement including being restricted to practical tasks and not being involved in treatment decisions (Morant et al., 2015, Simmons et al., 2011) implicating an untapped resource in the implementation of SDM.

Specific elements of the mental health context including coercive and legislative frameworks eroded trust between professional and service user, which made the required relationships difficult to initiate and sustain (Shepherd et al., 2014). Studies also detailed the pervasive paternalistic culture inherent in mental health services reflected in prevalent norms about surveillance and control, which was a direct barrier to the required relationships described here and often not acknowledged by professionals within services (Drake and Deegan, 2009).

The value placed on different types of knowledge within health services contributed to the perceived legitimation of involvement by service users in SDM. A conceptual review documented a gap in the significance placed on the experiential knowledge of service users and carers and the scientific knowledge attributed to professionals perpetuating the hierarchical nature of health
services (Morant et al., 2015). This gap was most pronounced in the service user/psychiatrist dyad indicating a role for other types of workers such as care co-ordinators, peer workers and social workers which was supported by other studies (Deegan, 2010, Ramon et al., 2016). In one study, technological interventions were found to assist communication for those who were acutely unwell by organising accounts of illness that service users were unable to do themselves (Deegan et al., 2008).

Collective action – The importance of contextual integration and challenging prevailing norms

Information sharing was considered a key facilitator to SDM (Shepherd et al., 2014, Smebye et al., 2012) particularly given that medication prescribing was considered to be a trial and error process (Shepherd et al., 2014) and that needs changed over time (Tlach et al., 2015). This Information provision should be tailored to individual needs and preferences (Fukui et al., 2015). However, studies demonstrated that this was not occurring consistently. Inpatient settings, in particular, found such sharing difficult to enact (De las Cuevas et al., 2013, Simmons et al., 2011). Service users reported not being informed of diagnoses, there were consistencies in the type of information being shared and a documented lack of choice offered by professionals (Simmons et al., 2010, Smebye et al., 2012). One study found that information sharing represented a point in which professionals could exert coercion over service users and actually reinforce paternalism (Shepherd et al., 2014). Professionals sometimes withheld information about the potential adverse effects of medication and did not acknowledge that sharing decision making also involved sharing responsibility and risk with the service users they were treating (Baker et al., 2013). SDM models were criticised for failing to capture the complicated nature and conflicting processes (e.g. risk agendas, biomedical models and professional pessimism) inherent within mental health contexts (Morant et al., 2015).

Whilst invitations from professionals to engage in SDM encouraged involvement (Fukui et al., 2015), service user initiation was more likely to lead to increased satisfaction with SDM (Matthias et al., 2012, see the reflections on SDM section by Rae). Mental health advocates could support the SDM process (Simmons et al., 2011).

The studies included in this review implicated SDM training needs for both service users and professionals (Abrines-Jaume et al., 2014, Park et al., 2014, Simmons et al., 2010, Stead et al., forthcoming, see also the two reflective sections on SDM implementation). A number of studies documented the effectiveness of decision support tools to support the work required to implement SDM by encouraging wider consideration of side effects (Deegan et al. 2008). However, the tools needed to be adapted along with procedures to the needs of service users and not be assumed to work universally (Abrines-Jaume et al., 2014).

Pressures from the clinical environment and the informal norms within health services impeded the contextual integration of SDM. These pressures included limited flexibility, lack of management support, pressure to discharge and associated financial pressures (Abrines-Jaume et al., 2014, Simmons et al., 2011, Morant et al., 2015, Thompson-Leduc et al., 2014) indicating the training alone was insufficient. Wider contextual support including support from the host organisation and high level management were facilitators to implementing SDM. Utilising a multi-pronged approach, which extends beyond the micro social, traditional training approach was key to successful implementation. Examples of this include embedding SDM into strategic plans, as well as policy and practice documentation and incorporating evaluation into any implementation plan (MacDonald-Wilson et al., 2016).
There was no evidence about the role of accountability on the part of health professionals and services in relation to the implementation of SDM, leading to severe consequences for service users. For example, if service users refused to take medication, they could be made to do this through Community Treatment Orders or detention under the Mental Health Act. This is likely to impact on relational integration as this lack of balance in relation to accountability is likely to increase service user and carers’ lack of confidence in SDM (Simmons et al., 2010).

There is limited research on understanding the de-implementation of existing practices which is likely to be crucial to the implementation of SDM given the role of historical, economic, political and social contexts identified previously (Montini and Graham, 2015) which are likely to become further complicated in the specific context of mental health services (Brooks et al., 2015).

Reflexive monitoring – An underexplored component of the implementation of SDM.

Reflexive monitoring refers to how people assess and understand the ways that SDM affects them and others around them. This work can range from formal systematization (randomised controlled trials RCTs) to more anecdotal and informal evidence of systematization.

RCTs demonstrate the effectiveness of SDM for a number of outcomes including improved health, engagement, safety, empowerment and satisfaction (Abrines-Jaume et al., 2014, Deegan, 2010, Dixon et al., 2014, Simmons et al., 2011, Stovell et al., 2016) as well as the effectiveness of interventions designed to improve SDM and promote recovery-focused cultures (MacDonald-Wilson et al., 2016). Studies document improvements in clinician and user rated involvement in decision making with associated improvements in satisfaction without increasing consultation time (Hetrick et al., 2008) or shifting service users perceptions of medication significantly (Ramon et al., 2016). Involving carers in the SDM process was also beneficial (Dixon et al., 2014). These findings are likely to be key to shifting professional resistance related to concerns about SDM increasing workload and consultation time (Deegan, 2010, see the reflections on SDM section by O’Sullivan), seeing those service users who initiate SDM as ‘difficult’ (Hamann et al., 2011) or assumptions that service users will be more likely to refuse medication during SDM. Research also indicates that SDM should be revisited at each appointment and not be a one-off decision (Matthias et al., 2012). This consistency of approach was also advocated for any training to support SDM (see the reflections on SDM section by O’Sullivan).

Evidence-based guidelines about the best way to mobilise this knowledge to the services delivering mental health care and support the successful implementation of SDM are lacking at present. A recent study demonstrated the value of a collaborative approach (between researchers, service users and practitioners) to training development and delivery (Ramon et al., 2016). Providing training at a team level could enable team members to support each other in developing SDM and challenging existing practices (see the reflections on SDM section by O’Sullivan). Opportunities such as professional or peer-to-peer supervision sessions could also facilitate communal appraisal but the ways in which to do this warrant further investigation. Furthermore, Trust Learning and Development staff could be incorporated at an early stage to achieve sustainability by incorporating SDM training into mandatory timetables (see also the two reflective sections on SDM implementation). More attention should also be focussed on how individuals appraise the effects of SDM on them and the contexts in which they are based. This information is likely to be crucial to the future successful implementation of SDM.

Conclusion
This article has highlighted the facilitators and barriers associated with the implementation of SDM firstly by outlining the key issues entailed in implementation; secondly by illustrating the experiential perspectives of participants in the process of implementation, and thirdly by using the components of NPT as a sensitizing and illuminating framework. Through each of these components, a number of areas were identified which are currently neglected in the literature. For example, there is limited understanding of the de-implementation of existing practices as well as understanding the role of reflexive monitoring and how to mobilise SDM research to the professionals being tasked with delivering SDM. A thorough consideration of these potential intervention areas may improve the implementation SDM and guide future policy, practice, and research agendas.

This review advocates for future implementation research to consider micro, meso and macro level interventions to gain a more complete understanding of the complex processes at work when implementing SDM with a view to shifting the culture in mental health provision towards SDM. The advantages of engaging in SDM practice – increased therapeutic alliance, enhanced shared knowledge and understanding of key intervention issues, saving time in review meetings, increased commitment to implementing decisions jointly taken – would need to be clearly communicated and evidenced to clinicians and managers for the implementation of SDM to be given the prioritisation it requires and deserves in mental health services. In order for wholesale buy-in to the decision making process within services, favourable attitudes towards SDM would be needed across each layer of the service provision system, interactive and collaborative training delivered by service user trainers and professionals that enables a good understanding of the process, a shared simple and mandatory, form of recording achievements and problem areas, for both service users and providers to become fully engaged in SDM.
References


De las Cuevas, C., Penate, W., Perestelo-Perez, L. and Serrano-Aguilar, P. (2013), “Shared decision making in psychiatric practice and the primary care setting is unique, as measured using a 9-item Shared Decision Making questionnaire (SDM-Q-9)”, Neuropsychiatric Disease and Treatment, Vol. 9, pp. 1045-1052.


Morant, N., Kaminskiy E. and Ramon, S. (2015), “Shared decision making for psychiatric medication management: beyond the microsocial”, *Health Expectations*, first published online, 10th August 2015. DOI: 10.1111/hex.12392,


Appendix 1 Sources used in the review and example search terms

Title of journal:

Administrative Policy Mental Health
Advances in Psychiatric Treatment
Australasian Psychiatry
Biomed Central
BMC Health Services Research
BMC Paediatrics
BMC Psychiatry
British Journal of Psychiatry
Clinical child psychology and psychiatry
Health Expectations
Implementation Science
Psychiatric Rehabilitation Journal
Psychiatric Services Review

Search terms – Implementation of shared decision making in mental health

Provisional question – Implementation of Shared Decision Making (SDM) in Mental Health

Inclusion criteria:

1. Studies on the implementation of any type of SDM in mental health (medication management, care planning, family interventions, psychotherapy, hearing voices, housing, employment, leisure activities)
2. Quantitative studies
3. Qualitative studies
4. “Grey” literature (i.e. narratives written by service users, carers, and providers)
5. International studies in the English language
7. All mental health diagnoses
8. All age groups (children and adolescents, adults of working age (up to 65 y) and older people (post 65).
9. Mixed methods of data collection and data analysis
10. Relevant normalisation theory process studies
## Appendix 2:

### Table 1: Key articles

<table>
<thead>
<tr>
<th>Author/Date</th>
<th>Paper type</th>
<th>Country</th>
<th>Setting</th>
<th>Method</th>
<th>Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abrines-Jaume, N et al., 2014</td>
<td>Clinical child psychology and psychiatry - journal article.</td>
<td>UK</td>
<td>CAMHS (one outpatient, one community and one forensic).</td>
<td>Qualitative - analysis of PDSA log books.</td>
<td>Framework analysis</td>
</tr>
<tr>
<td>Baker et al., 2013</td>
<td>Advances in psychiatric treatment - journal article.</td>
<td>UK</td>
<td>Acute mental health settings.</td>
<td>Qualitative – semi-structured interviews</td>
<td>Thematic content analysis</td>
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<tr>
<td>De las Cuevas et al., 2013</td>
<td>Neuropsychiatric disease and treatment - journal article.</td>
<td>Spain</td>
<td>Comparison of SDM implementation in psychiatric outpatient and primary care from SU perspective.</td>
<td>Quantitative - 9 item SDM questionnaire</td>
<td>MANCOVA t-test and pearson’s correlations</td>
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<td>Deegan, P.E., 2014</td>
<td>Psychiatric services - letter</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
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<td>Deegan P.E. et al., 2008</td>
<td>Psychiatric services – journal article</td>
<td>USA</td>
<td>Outpatients</td>
<td>Qualitative focus groups.</td>
<td>Thematic analysis</td>
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<tr>
<td>Deegan, P.E., 2005</td>
<td>Psychiatric rehabilitation - journal article</td>
<td>USA</td>
<td>N/A - Description and early use of Common ground.</td>
<td>N/A</td>
<td>N/A</td>
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<td>Dixon et al., 2014</td>
<td>Psychiatric services – journal article</td>
<td>USA</td>
<td>Outpatient mental health programs at three medical centres in two veteran services.</td>
<td>Quantitative - RCT</td>
<td>Range of quantitative methods</td>
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<td>Drake, R.E and Deegan, P.E., 2009.</td>
<td>Psychiatric services - letter</td>
<td>USA</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
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<td>Drake, R.E. et al., 2009.</td>
<td>Psychiatric services – journal article</td>
<td>USA</td>
<td>Community mental health setting</td>
<td>N/A – description of experience</td>
<td>N/A</td>
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<tr>
<td>Eliacin, J. et al., 2015</td>
<td>Qualitative health research - journal article</td>
<td>USA</td>
<td>Depart of veterans affairs medical centre.</td>
<td>Qualitative - semi-structured interviews</td>
<td>Thematic analysis</td>
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<tr>
<td>Fukui, S. et al., 2015</td>
<td>Adm Policy in Mental Health - journal article</td>
<td>USA</td>
<td>Community mental health centre, VA medical centre.</td>
<td>Secondary data analysis</td>
<td>Quantitative - factor analysis.</td>
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<td>Hamann, J. &amp; Heres, S., 2015</td>
<td>Psychiatric services - letter to editor</td>
<td>N/A</td>
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<tr>
<td>Hamann, J. et al., 2011</td>
<td>Psychiatric services – journal article</td>
<td>Germany</td>
<td>Inpatients</td>
<td>Quantitative - pilot RCT.</td>
<td>Quantitative - t test and chi squared.</td>
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<td>Hetrick, S., Simmons, M., and Merry, S., 2008</td>
<td>Australasian Psychiatry - journal article</td>
<td>Australia</td>
<td>N/A - commentary</td>
<td>N/A</td>
<td>N/A</td>
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<td>USA</td>
<td>Community mental health centre.</td>
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<td>Emergent thematic analysis.</td>
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<td>Matthias, M.S. et al., 2014</td>
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<td>USA</td>
<td>Psychiatric.</td>
<td>Qualitative – survey and recording appointments, which were coded for SDM.</td>
<td>Correlation analysis</td>
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<tr>
<td>Quirk, A. et al., 2012</td>
<td>Sociology of health and illness –journal article</td>
<td>UK</td>
<td>Outpatients.</td>
<td>Qual – transcribed outpatient consultants</td>
<td>Conversation analysis</td>
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<td>Shepherd, A., Shorthouse, O and Gask, L., 2014.</td>
<td>BMC psychiatry - journal article</td>
<td>UK</td>
<td>Consultant Psychiatrists from a range of services.</td>
<td>Qualitative - semi-structured interviews</td>
<td>Framework analysis</td>
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<td>Simmons, M., Hetrick, S.E. and Jorm, A.F. 2011</td>
<td>BMC psychiatry - Journal article</td>
<td>Australia</td>
<td>Specialist mental health services for young people aged 15-24.</td>
<td>Qualitative - semi-structured interviews</td>
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<td>Smebye, K.L., Kirkevold, M and Engedal, K. 2012</td>
<td>BMC Health Services Research - Journal article</td>
<td>Norway</td>
<td>Dementia services</td>
<td>Qualitative - semi-structured interviews</td>
<td>Framework analysis combined with a hermeneutical interpretive approach</td>
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