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“Experts by Experience”: the involvement of Service Users and Families in designing and implementing innovations in Family Justice

Gabriela Misca, Janet Walker, Carole Kaplan

Abstract

Drawing on international research, policy, and practice, this paper explores what is meant by service user involvement, how it has developed and how it has been implemented across different areas of practice. Using examples from across the health and social care fields, it reflects on how the learning from other areas of practice where service user involvement has been successful may be applied to the family justice field. The arguments presented highlight the value of taking a bottom-up approach in designing and implementing innovations in family justice, which would embrace the views of family members including children, as “service users”. It is important, however, to balance both the challenges and the opportunities offered by involving those who are ‘experts by experience’ in the Family Justice processes, in order to lead to improved services and experiences.

Keywords: Service users’ involvement; Experts by experience; Collaborative System Design; Family Justice.

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PART 1: INTRODUCTION - What is "service user involvement", how it has developed and how is practiced across areas?

In order to consider how service users and families can be used appropriately and effectively in developing family justice programmes and interventions, it is helpful to understand how service users have contributed to developments in other sectors. In this section, we provide a brief overview of what service user involvement means, how it has developed and how it has been implemented in practice. It explores the theoretical underpinnings and some of the political drivers that, historically, made the service user involvement movement possible. Dilemmas, challenges, and barriers in practice towards achieving effective and meaningful service user involvement are highlighted throughout.

It is widely accepted that most people will need and use some form of public service(s) at some point in their lives. However, service users *having a say* in the provision of such services is a less widely accepted practice. Indeed, service user involvement is a relatively recent, international phenomenon, emerging through developments from different countries: for example, in the UK, with its drive to move away from the paternalistic state; in the USA with its tradition of civil rights; with the Netherland's legislative move towards patients and patient organisations having opportunities to be active in decision-making about treatment and service provision; and with several Nordic countries, using local democratic mechanisms to involve patients and the public in the health service.

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It has been argued that *service user involvement* is “poorly defined and carelessly used” (Beresford, 2013, p.21). The confusion(s) surrounding service user involvement is undoubtedly augmented by the plethora of terms used to identify individuals or groups who are in receipt of public services: *‘client’, ‘customer’, ‘consumer’, ‘service user’, ‘service survivor(s)’, and ‘expert(s) by experience’* are among the terms often used interchangeably, although they convey different nuances. At the heart of service user involvement is the recognition that people are experts in their own lives, and thus service users are referred to as *expert(s) by experience*, suggesting a relationship of equals (McLaughlin, 2009), a term also common in user involvement in research. In the context of the “psychiatric survivor movement” which originated in the USA, the users of mental health services have defined themselves as ‘*survivors of services*’ (Walcraft et al, 2003), a term which intrinsically speaks to their involvement in the service. In social work contexts, the term “service user” is seen as problematic, with connotations of people being passive recipients of services and the term ‘client’ is often preferred as being more individualised (Misca and Unwin, 2017, 2018).

In respect of the health sector, service user involvement was initially defined as involving service users in decisions about their care (Hickey & Kipping, 1998). Over the past two decades, its scope has been expanded beyond users participating in the decision-making process about their own care into the realm of users participating in decisions about the broader service(s) planning and delivery. For example, in the context of the National Health Service (NHS) in the UK, the service user involvement is currently defined as the process by which people who are using or have used a service become involved in the *planning, development, and delivery* of that service (NHS England, 2015). It is noteworthy that this definition considers user involvement across the wide spectrum of a service's life-cycle: from planning, through development, to delivery, and improvement/reviewing plans.

Patient-led health services, *parent power* in education, involving *experts by experience* in research, *empowering service users* in social care, are some of the many facets of how service user involvement manifests itself in various areas of public services. In the UK, service user movements began to emerge in the 1970s, and the political drivers which paved the way for service user involvement can be traced to the move away from the paternalistic state that had characterised the British post-World War 2 public services, further supported by policy shifts in the 1990s aimed at modernising health and social services. For example, the involvement of users in the transformation and improvement plans in the National Health Service (NHS) has required a considerable cultural shift: however, this has become well embedded, in a variety of forms, and nowadays it is accepted as 'the right thing to do'. In the USA, America's War on Poverty in the 1960s, paved the way for similar developments: for example, the Head Start programme is a classic exemplar of parent involvement in classroom and educational policymaking, helping pre-school children from disadvantaged families get a 'head start', and which continues today (Seden and Ross, 2007).

Models of service user involvement: from participation to co-production

The ideology of user involvement in services is rooted in notions of *citizenship*, *participation*, '*handing power back to the people'* and *partnership* between agencies and users of their services. An initial theoretical underpinning for service user involvement was provided by the ‘*ladder of citizen participation*’, a model put forward by Arnstein (1969) which offers a typology of participation taking into account the power dimension (see Figure 1).

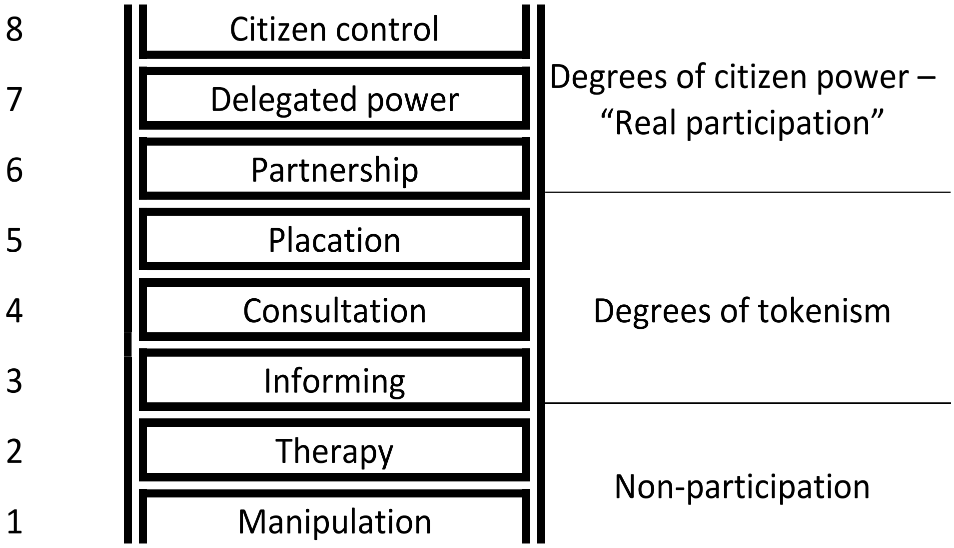

Figure 1 The ladder of citizen participation (adapted from Arnstein, 1969)

Although this model was put forward in the context of “participation of the governed in their government” (Arnstein, 1969, p. 216), the model is pertinent to user involvement in public services. By seeing service users as *citizens* who have rights and, importantly, by including the ‘power’ dimension which increases with each rung on the ladder, it provides a useful framework for exploring the challenges and barriers to effective user involvement in services.

The model is helpful as it allows a distinction to be made between *real* participation, which is based on a partnership between service users and the agencies providing the services; and those which represent degrees of *tokenistic* participation. For example, *consultation*, with its ubiquitous presence in the practice of most service providers, is often cited as evidence of service user involvement; however, while consultation provides the opportunity for service users to be heard, it offers no guarantee that their views will be acted on, thus rendering it a ‘tokenistic’ form of participation.

Building on the model of the ladder of participation, it has been proposed that service user involvement is best viewed as a continuum (Seden & Ross, 2008). Such a continuum (see Figure 2) provides a framework through which the concept of user involvement can be explored, and against which practice can be assessed (Hickey & Kipping, 1998). On the involvement continuum, service user involvement starts with offering information/explanation, moves through consultation and participation, and ultimately leads to user-managed or user-controlled service provisions, such as those set up by survivors of mental health services.

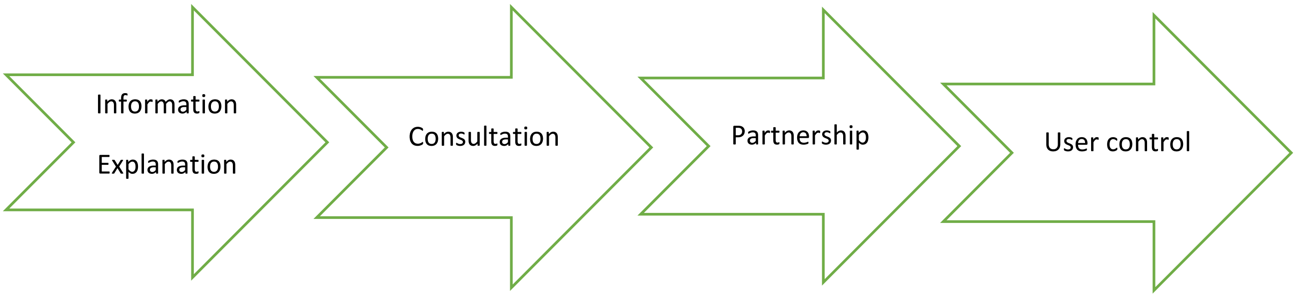

Figure 2 – A participation continuum (adapted from Hickey & Kippin, 1998)

The contemporary discourse around service user involvement has advanced user involvement into *co-production*, the process through which agencies and service users *share power* to plan and deliver support services together. The notion of co-production is accepted as a high level of user involvement and has been widely explored within mental health services and research. Slay and Stephens (2013) have adapted the original Arnstein ladder of participation into a *progressive pathway*, with 3 stages illustrating how co-production builds on user(s)/professional(s) dynamics. These are:

> Stage 1: “*Doing to*” - by coercing, educating, and informing and represent traditional services intended to educate and cure the users.
>
> Stage 2: “*Doing for*” - encompasses the tokenistic participation in Arnstein’s ladder such as consulting, engaging the service users but within the parameters set by professionals.

Stage 3: “*Doing with*” - recognises that best outcomes can be achieved through equal and reciprocal relationships, deeper level of service user involvement that shifts power towards people and require a fundamental change in how services work with service users.

It has been argued that co-production enables people to play active roles in delivering the services that they have designed, and these roles can range from peer support, mentoring, through to running everyday activities and making decisions about how the organisation is run (Slay and Stephens, 2013).

Challenges and dilemmas in effective service user involvement

Despite becoming an established mantra in public services and seen by governments as a valuable contribution towards shaping the availability of services, as well as a driver in the push for accountability in public services, when it comes to its effective implementation in practice, user involvement presents a unique set of dilemmas and challenges. The prerequisites of effective user involvement are, at a very basic level, access and support for both individual service users and service user organizations. Service users have identified problems of access and mobility as obstacles, as well as a lack of resources to support the effort needed for being actively involved (Branfield et al, 2006).

Views of the service user(s) as expert(s), although increasingly accepted, all too often translate in practice as an *add-on* or tick box exercise, lacking any meaningful participation and remaining at a tokenistic level. Moreover, taking into account the power (in)balance, which is of great importance in effective service user involvement, even when the views of people most affected by a service are heard, as in the process of consultation, there are no assurances that they are given the same importance as the views of those who work or lead the services provided. Such "*devaluing of service user knowledge*" (Branfield et al, 2006) is reported by users who feel that their knowledge is not valued or taken seriously by professionals and services, resulting in a (further) disempowering experience.

Concerns have also been expressed regarding the input and views of service users who may not be representative of that particular service user population and, at times, seen as being those who are more vocal and/or who often complain about the service and fail to provide a balanced view or consider its positive aspects. While this may be true to some extent, it is also difficult to find service users willing to engage in involvement processes without them having a strong motivation to make things better.

Does it make a difference? The impact of service user involvement on service planning, delivery and policy

Service providers have begun to question if service user involvement is actually beneficial and if it is improving services. At the same time, service users and their organisations have begun to question the usefulness of getting involved, and what is actually achieved through their involvement. It has been argued that even if involvement is seen as a right and as such holds an inherent value irrespective of its impact, it does not mean that the user involvement should not be evaluated (Staley, 2015).

When researchers asked the same questions, the overall conclusion is that the evidence base for service user involvement is scarce, the impact of service user involvement being often unevaluated and, even when it is, the methods of evaluation are not always robust enough to enable firm conclusions to be drawn about its impact. For example, in a systematic review examining the effects of involving patients in the planning and development of health care (Crawford et al., 2002) 337 studies (reported between 1966 and 2000) were identified from a variety of countries including the UK, USA, Australia, Canada, and Sweden. However, on inspection, the vast majority (87%) of the studies had to be excluded from analysis because they failed to describe the actual effects of involvement. The remaining studies described the effects of 40 initiatives involving patients, of which, 31 were case reports, five were the results of surveys, three examined records of meetings, and three described the findings of action research. These observations on the pool of available evaluation studies are concerning for two main reasons: not only there are very few studies assessing the impact of service user involvement on the planning and development of services but, when they do, they do not employ a robust methodology to enable valid, replicable results. These design limitations significantly limit the generalisability of the conclusions that can be drawn.

Even when more robust methods of evaluating the impact of service user involvement have been employed, conclusions remain limited. For example, a systematic review of the effects of involving users in the delivery and evaluation of mental health services (Simpson & House, 2002), identified five randomised controlled trials and seven other comparative studies (1996-2001) from across the USA, UK, Canada, and Australia. Although employing more robust methods of evaluation, the conclusion of this systematic review is also limited in scope, indicating merely that involving users as employees, trainers, or researchers *has no negative effect* on services and that *it may be of benefit*.

Regarding the evidence for public involvement in health care policy, the results are not much more optimistic. A systematic scoping review (Conklin et al., 2012) of studies undertaken (between mid-1990s and mid-2000) in England, Canada, the USA, Northern Ireland, France, the Netherlands, Italy and Israel, echoed concerns about the lack of sound empirical evidence of the outcomes of public involvement activities in health care, highlighting the often poor fit between evaluation aims, the study design and indicators of impact employed.

A systematic review of UK studies (from 1997 to 2009) which focussed on the impact of service user involvement in NHS healthcare services (Mockford et al, 2012) found that many and varied patient involvement activities in the UK NHS healthcare services are taking place, but the studies did not provide robust evidence of their impact and almost no evidence of its cost.

The collective conclusions that can be drawn from this diverse body of evidence on the impact of service user involvement are threefold:

1. Despite the growing body of work on public involvement in health-care policy and practice, evidence of its impact remains scarce: thus, firm conclusions about involvement activities that are appropriate and effective are difficult to draw (Conklin et al., 2012).
2. It is important to note that the absence of evidence does not indicate an absence of impact: rather it indicates inadequate reporting with a lack of valid and reliable tools to capture the impact of service user involvement (Mockford et al., 2012).

3. There is an urgent need to develop clear concepts and robust forms/tools of measurement/evaluation to enhance an understanding of the impact of service user involvement, alongside clearer economic evaluation (Mockford et al., 2012).

Service users involvement in professionals' training and research

An area where service user involvement has burgeoned in recent years, is involvement, in research and professionals' training, particularly across the health and social care fields.

Service user involvement in research has been slow to develop, but the potential benefits of bridging the researcher-researched gap are self-evident. On one hand, it allows the users' experience to shape research, arguably the researchers '*don't know what they don't know*' until they involve patients/the public (Staley, 2015). On the other hand, it allows researchers to acquire a different kind of knowledge about the issues which are the focus of their enquiry, namely '*experiential knowledge*' gained through direct experience of working with patients/the public.

Similar to the evidence for the impact of user involvement in services, current debates on the impact of patient/public involvement on research focus on the lack of empirical data and/or evidence being anecdotal and/or lacking robustness (Sheppee et al., 2013). These debates, however, are not without their limitations. It has been argued that applying methods of evidence-based medicine to evaluate the impact of involvement may not yield meaningful results, as the impact of involvement is highly context dependent. Thus more can be achieved by focusing efforts on understanding ‘how it works’ rather than ‘what it achieves’ (Staley, 2015).

Active involvement of people who use health and social services in the training and education of the workforce/professionals who provide the care has developed as a natural consequence of patient and public participation in health care and health research and has expanded greatly over the past 20 years (Towle et al., 2011). Examples of wide-ranging and nationally supported ‘*patient-as-educator*’ initiatives come from the UK, where service user and carer involvement in education has become enshrined in the standards of the statutory bodies responsible for the accreditation of educational programs in health and social care professions (Unwin et al, 2017) and more recently, medicine. Service user involvement in education can materialise in a broad range of educational activities, including the selection of students, teaching including assessment and providing feedback, and curriculum development (Unwin et al., 2017). It is acknowledged that it provides valuable opportunities for trainees to develop their communication skills, empathic understanding, overall professional attitudes including an individualized approach to the client/patient (Towle et al., 2011, 2016). In recognition of the importance of these issues, an international and multidisciplinary group gathered at an international conference “Where’s the Patient’s Voice in Health Professional Education?” in November 2015, developed a statement – consequently known as the “The Vancouver Statement” (Towle et al., 2016) - setting specific priorities for action to embed the involvement of patients in the education of health and social care professionals internationally.

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PART 2: LEARNING FROM USER-PARTICIPATION IN SERVICE DELIVERY IN FAMILY JUSTICE

In promoting service-user involvement in family justice processes it is helpful to consider the learning from other sectors which can be usefully applied to family justice. As highlighted above, service user involvement in health care services and delivery has been at the forefront of developments in this field worldwide. Thus, the provision of healthcare in England offers some useful learning.

The National Health Service (NHS), which was established as long ago as 1948, is the publicly funded national healthcare system for England and the largest single-payer and provider healthcare system in the world. Thus, it offers a significant platform for learning about the effectiveness of user participation. Primarily funded by the government through general taxation and overseen by the government Department of Health. NHS England provides healthcare to all legal English residents, with most services free at the point of delivery/receipt by users. Some services, such as emergency treatment and treatment of infectious diseases, are free for everyone, including visitors.

The NHS provides the majority of healthcare in England, including primary care, in-patient care, long-term healthcare, ophthalmology, and dentistry. The NHS, then, provides an end-to-end service from the cradle to the grave. It is an enormous delivery system, unlike family justice which is delivered by different organisations in England and is typically split between services delivered in the community and those delivered by the court system and spans a number of voluntary, statutory and private providers. Although private health care has

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continued in parallel to the NHS, paid for largely by private insurance, it is used by only about eight per cent of the population, generally as an add-on to NHS services. In its seventy-year history the NHS has undergone several major changes and extensive transformations. Inevitably, as medicine advances, health needs and priorities change as society itself changes so that it is essential for the NHS to continually move forward to ensure that the service remains fit for purpose.

A whole system approach to change

The NHS has been involving service users, carers and families in the improvement of its services for the last decades. Experience shows that this is of enormous value, and the most effective involvement is within a structured approach to service improvement. In such a large system it is not surprising that a key message from the experience of user engagement is that the delivery of healthcare must be based on an understanding of the whole system not just on small sections of it. While a patient might need to receive treatment for a minor ailment from their primary practitioner (in England, most people are registered with a local doctor, their general practitioner or GP) it is likely that other health professionals might be involved in undertaking medical checks, perhaps at the local hospital. If a patient needs secondary care from a specialist, other parts of the health service subsequently become involved. Thus, if the patient experience is to be understood and continually monitored and improved, the working of the whole system must be considered and not just the input by the patient’s local doctor. To improve the quality and effectiveness of health care delivery, therefore, all the individual parts of the system must complement the whole.

Similarly, in family justice processes, improvements/changes in one part of the family justice system need to be considered within the whole system, including with reference to out-of-court services as well as in-court services. This is a fairly new recognition and, in the past, the various services have been disjointed. To this end, in recent years in England and Wales, there has been increased emphasis on joining up the out-of-court pathways with the in-court pathways. The extensive review of family justice headed by David Norgrove (2011) argued that the family justice system was not a recognisable system at all. The current emphasis is to improve the client journey such that a family law client experiences a seamless set of services and processes from the start of a family law case through to its conclusion.

Service users are well-placed to contribute to the improvements of any system since they have first-hand experience of what works and which elements need to be changed. The use of a well tried and validated approach to a system change has proved to be helpful in the NHS by enabling a more accurate and holistic understanding of how services are delivered and received. An added bonus of this approach appears to be that service users in the NHS regard themselves as part of a joint enterprise, not simply as passive receivers of services over which they have little or no control.

Who are the service users in family justice and what are their views?

A structured approach to user involvement first requires reliable knowledge about the population being serviced, the “service users”. Therefore, in the family justice context, an understanding of the diverse population of users and their needs are essential prerequisites. In recent decades many research studies of various family justice processes in England have captured the first-hand experiences of users (both parents and children and young people), and what they find helpful and unhelpful is well-documented (see, for example, Walker et al., 1994; 2001; 2004; 2007; 2010). These studies included users of mediation services, counselling support, family law practices, and court processes. In a review of a number of research studies that have reported the lived experiences of people in family law processes in England the over-riding message was:

> *greater attention needs to be paid to the needs of parents caught up in court proceedings, and most particularly to the needs of especially vulnerable groups such as parents with learning difficulties or mental health problems, women who have experienced domestic violence, and parents from minority ethnic communities […] parents want a less intimidating, more personal, and participatory process (Hunt, 2010, p119).*

All these research studies provide a comprehensive picture of the problems that have been identified by users of the family law system. Hunt (2010) concluded her review by urging policy-makers and practitioners to take account of the experiences of users if their voices in research studies are not to be regarded purely as tokenistic.

'Know the business' and 'know the problem'

Taking learning from the NHS example, it is essential to *'know the business'* and *'know the problem'*. What is the family justice system wanting to achieve and where are the difficulties that should be addressed? The Norgrove review (2011) identified a raft of problems which needed to be addressed. The conclusion reached was that the family justice system was in urgent need of major reform. The review cited incoherence across the court system, unacceptable delays in dealing with cases and delivering justice, distrust, a lack of leadership, unequal application of resources between cases, and a total disregard for the voices of children and young people in processes which were designed to make life-changing decisions about their futures.

Service users shaping the delivery of services

The Norgrove review led to an extensive and exciting programme of reform, spearheaded by a number of task groups looking at the delivery of mediation, for example, and ways to ensure that the voices of children are routinely heard and listened to. Sir Ernest Ryder, now the Senior President of Tribunals and Lord Justice of Appeal in England, led a court modernisation programme, resulting amongst other things in the introduction of a unified family court. These reforms were informed by a body of research which had involved service users and highlighted their needs, and young people were centrally involved in shaping recommendations about how their voices could be heard in future (Walker and Lake-Carroll, 2015). These reforms are discussed in other articles in this Special Issue (see, Walker and Misca; Ryder).

The transformations in health provision in England were similarly informed by service users. Patients felt that they had been listened to and they felt valued, just as the young people had done when talking about their experiences in the family court in both private and family law. There is increasing interest in asking users of services to describe what ‘good’ looks like for them and using this information to monitor change and make continuous improvement. Keeping systems under review is essential if the views of users are to be useful and valued.

There is now considerable evidence that services can be more effective and efficient if service users are involved in shaping delivery. It is very easy for pathways to become complicated if different elements are added to them as a result of different players in the system working in isolation. A common complaint by the users of family justice processes in the past has been the number of times they have had to repeat their stories as practitioners in different parts of the system have become involved. Tracking the client journey and looking to streamline the move from one service/step to another presents a constant challenge but one that might be assisted by the increased use of digitisation (see Hodson, this issue).

A recent pilot of an online dispute resolution platform developed by Relate in England in conjunction with colleagues from the Netherlands and the USA provided invaluable feedback from users about the aspects that worked well and those that needed improvement in order to develop the platform for more general use (Walker and Sherwood, 2017). The platform had been constructed after a similar platform had been evaluated in the Netherlands (Bickel et al., 2015). The international collaboration in this project demonstrates the enormous value of partnership working which allows a body of evidence to be built up. Without this kind of information, it is unlikely that processes in family justice will meet the needs of users as well as they should. Of course, an important determinant of whether suggested changes will be implemented is the willingness of policy-makers and practitioners to change from the traditional cultures which have tended to ignore the views of users. A true acceptance that a service exists to serve, that delay is not acceptable and that causing distress is the opposite of what should be desired, does not happen easily. The invaluable contribution of those who have used, and possibly suffered from a system that is not user-friendly, cannot be overestimated.

A considerable amount of change has occurred in family justice in England since the Norgrove review. It is important to recognise that incorporating different perspectives is key to collating knowledge of how the current system works. The view of the applicant may be very different to that of the lawyer or the judge. An approach similar to the one used in the NHS will combine the concerns and experiences of users of the system with detailed data about system functioning. The approach of bringing many different voices together to understand how well the family justice system is functioning is one which can ensure that it continues to meet the needs of its users. Users of any system are often the best custodians of the principles of service delivery and, as such, can hold people and systems to account. Constructive critical scrutiny is an integral part of the work.

Conclusion

The involvement of people who use a service and have to deal with the results that a system produces can provide a rich picture of how a service is functioning. They are the experts on how it does or does not meet their needs. Consequently, if they are involved from the start of a project or new programme the design and delivery of better service is more likely. Family justice systems have traditionally been devised and operated by the professionals that administer the systems and deliver the services. In recent years, however, there has been a considerable shift and the value of user participation in designing a smarter, less bureaucratic and more accessible family law system has been increasingly recognised. Changing culture is challenging and takes time, and it has often been said that the law is slow to adapt to changes in society, but there are exciting developments, particularly in new digitalisation programmes. It is noteworthy that some of the biggest champions of these changes have been senior members of the judiciary. They have recognised that the law is a blunt instrument with which to intervene in the complexities of family life and to resolve disputes which impact on the outcomes for children and their parents when parents separate or are unable to offer adequate care for their children. Their leadership is an important factor in increased user involvement.

Despite the increasing involvement of service users in providing valuable feedback about the family law system in England, there is still a considerable way to go. The adversarial system of divorce is deeply divisive and outdated and the removal of fault-based facts has long been the subject of campaigns. Moreover, the removal of legal aid has resulted in a vast increase in litigants-in-person. Sir James Munby, immediate past President of the Family Division in England and Wales, has pointed out that practices and procedures in family law still assume a family justice system where most litigants have legal representation when the reality is that this is no longer the case and the procedures and rules are largely unintelligible to litigants-in-person (Munby, 2019). Wisely, he has suggested that the rules need a radical review and rewrite using the language of 'ordinary people' and in a way which is comprehensible by non-lawyers. This would be a perfect opportunity to involve court users in the process.

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