How can managers ensure that service users and their families are effectively involved in service planning and avoid accusations of tokenism?

In recent years, one key demand of policy makers has been to involve service users in service planning. To meet this requirement, service managers have mainly used consultations with service users. However, the scope, nature and quality of these consultations vary greatly and sometimes services have attracted the charge of engaging in tokenistic exercises.

While there are various ways of influencing service planning and commissioning, the research evidence for user involvement is quite scant. Of the evidence that is available, a study on learning disability partnership boards found that users had little effective say on service decisions and were often consulted post hoc (Riddington et al., 2008).

As some services undergo organisational change, user involvement in planning new services is thought to be a critical aspect of creating effective support structures. Times of change may also present service users and patients with an ideal opportunity to influence service planning, highlight service gaps and indicate unmet need. Yet again, there is little research on whether users are well-placed to advise on either of these aspects when new services are being planned. Nor is it clear whether users or patients can offer useful advice on these matters to professionals. Last but not least, there is not enough evidence at present on whether users can effectively influence service planning, and how.

What we did
To attempt to address these questions, we undertook some research that examined two learning disabilities services that were co-locating in child development centres in Wales.

Many learning disabilities services operated similar centres in the 1970s but they have failed to function as service hubs over the past few decades, mainly because health and social care professionals developed disparate practices and often moved away from centralised and co-ordinated service delivery. This has changed with the increasing emphasis on service integration in Wales, ushering in a new era of multi-agency co-operation and, in some cases, leading to co-location of health, social care and voluntary support services in child development centres.

Previous research has shown that co-location does little to improve the experiences of users and carers if it does not bring about a sea change in multi-agency work. In our study, both local authorities established new integrated work practices, such as single referral systems, case management, shared assessments, common screening tools, and multi-agency panels to discuss cases. Thus, in our cases, co-location presented professionals with a genuine opportunity to improve multi-agency work for patients and users.
During the period of change, both local authorities engaged parents of children with learning disabilities in the planning process. Steering groups were formed to plan the new services, elicit full commitment from strategic staff to the new processes and harmonise practices across care sectors. While none of the new services aimed to create a fully integrated learning disability service, and professional boundaries remained in place, co-location created an opening to form new multi-agency processes.

In our study we were particularly interested in how both steering groups engaged service users, what service users thought about their participation in planning the new services, and what users knew about the new services taking shape. We designed a mixed method approach that comprised interviews with user representatives on the steering groups in both locations and a survey of a non-probabilistic sample of service users.

The new services in both locations were co-located child disability services, so service users were children and their parents. Both steering groups asked parents of children with learning disabilities to participate in steering group meetings and three parents agreed. We approached all three parents, but one declined to be interviewed.

The other two parents were then asked to consent to be interviewed by phone and called at a time of their convenience. Interviews lasted about 40 minutes and were audio recorded. The recordings were transcribed and analysed by two independent researchers who produced some broad categories of issues raised by the respondents. Since the data set was very small, no in-depth coding was conducted and consequently no detailed qualitative analysis could be carried out.

During the interviews questions were asked about the nature and extent of the respondents’ involvement in steering groups, what they thought the main problems of establishing new services were and whether they thought they could influence the service planning.

As the new services started to operate we designed and piloted a brief questionnaire for parents of children with learning disabilities. We asked service staff in both locations to facilitate the questionnaires with families they visited in a professional capacity. About 100 questionnaires were distributed with self-addressed envelopes that parents could complete and send back to the research team directly.

The questionnaire contained some descriptive questions about the characteristics of their child, what respondents thought the main needs of their child were, and whether or not they had heard of or noticed any changes in the way services operated. The study was conducted over a 10-month period and received ethical approval from the relevant NHS ethics committee. Funding for this study was obtained from the New Ideas Fund of the Welsh Government and the Betsi Cadwaladr University Health Board.

What we found
During the interviews we were particularly interested in whether parents thought that their views were taken into account and how much they thought they could influence plans for the new services. Two themes came through very clearly. First, parents often felt unable to comment on the details of service practices. This was mainly because professionals on both locations were mostly using professional terminology but also because it was not always clear how the specific processes related to outcomes. For example: “[There] were, you know, lots of discussions about the different pathways that they have and... I couldn’t feel qualified to say, well, no, you don’t need that or you do need that. So, yes, there was a lot of that because obviously there was a lot of different therapists and what have you, health people there, and you feel like you know a little bit more about what education and maybe social services, where they’re coming from, because it’s a little bit more in layman’s terms... I don’t want to step on any therapists’ toes by saying you don’t need that, and then the therapist, you know, saying, well, this is what we need and the children need this. I mean, they’re the experts in it. [So] a lot of it went over my head.”

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A second theme was the extent to which parents felt services may have used user involvement as a strategy to justify and strengthen the service change agenda vis-a-vis their strategic leadership. The link between user consultation and genuine service planning was not always clear to the parents:

“You know we went to every meeting and we were on occasion asked what we were thinking... There was an element of paying lip service to having parents at the meeting. It was as if, well, okay, what do we need to get this to go through? We need parents to be involved, so that then becomes something that they can take as a selling point to their respective agencies to say, we need to change, the parents want to change...”

These comments highlight the difficulty of how to involve users effectively in steering groups and service...
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planning. There seem to be significant barriers to effective participation in service planning for users with respect to understanding multi-agency processes, and how to meaningfully link these to improvements in service delivery. While our respondents were fairly confident that they had a view on what the problems of existing learning disabilities services were, they were less clear about how future changes to service structures would affect the quality of them.

Using professional terminology may constitute another significant barrier to understanding new multi-agency processes. Parents may not have the knowledge to make robust assessments of changes to practices and processes. Our respondents seemed to be well aware of these barriers and they articulated clearly that, given the impact of these difficulties, their involvement may have had a tokenistic aspect.

Survey
Following the establishment of the new co-located services, we wanted to know whether users in both locations had noticed changes and, if so, what. To do this we asked local staff to facilitate a brief survey with families in both locations. Forty-eight families responded and we obtained a fascinating picture of the service user perceptions of service changes.

Two issues were particularly striking. Although the number of responses was small, the data allowed us to conduct some simple univariate analysis that demonstrated a correlation between users’ perception of service needs with needs of service improvements. This may not be surprising since it only tells us that parents are well aware of the problems as and when they use local services.

However, what is significant is that parents’ perception of service needs varied considerably depending on their child’s needs. This highlights an additional problem for user involvement in planning services. It seems that parents are likely to demand improvement in those areas that they are currently experiencing. Parental involvement in service planning may therefore be more of a reflection of individual needs rather than an objective assessment of service gaps for the general service population.

The second finding from the survey relates to parents’ knowledge about service changes. The responses clearly showed that there was practically no awareness among service users of the imminent changes. Instead respondents talked mostly about ‘cuts to services’. We contrasted this with our analysis of planned local service changes and it seems that talk about ‘cuts’ was more a reflection of the national debate in the wake of the UK austerity budget since neither service in our study had reduced service capacity or resources at the time of the study.

Once parents were prompted about the exact content of locally-planned changes, they responded positively to plans for co-location of learning disabilities services in a central child development centre. However, given that parents initially knew practically nothing about the new co-located services, important questions about the role and nature of user involvement in, and assessment of, service changes are raised.

Lessons
Our study identified two important issues that need to be addressed to ensure effective involvement of users in service planning. The first relates to the experiential and terminological gap between professionals and parents. For service planning involvement of users to avoid the charge of tokenism, professionals need to ensure that professional language makes sense to parents and users taking part in service planning discussions.

The link between processes and anticipated outcomes also needs to be explained to users for them to make a useful assessment of how service changes may possibly impact on service quality. Given the tight timetable for service changes, this may require important changes in the way in which users can be usefully involved.

The second barrier relates to the potential role and knowledge of users about service practices, structures and planned changes. The study showed that there was little or no knowledge about the changes in either location in the wider service population.

This lack of awareness of changes may restrict the extent to which users can play a meaningful role in assessing service changes. That users may use national debates as a frame of reference in consultation rather than local issues poses a serious challenge to effective involvement of users in service planning on a local level. It indicates that local services need to raise awareness for planned changes to their services prior to consultation exercises.

Consultation and participation of users is an important vehicle to design effective learning disabilities services that are tailored around their clients. However, more research needs to be done to explore how to ensure that users are effectively involved in service planning rather than engaging them in a tokenistic exercise.