

An audit of disabled children's services – what value is MPOC-SP?

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Introduction: Achieving high standards of health care provision with children and young people with a disability requires a focus on family-centered care. There are a range of tools available to audit this type of provision. The Measure of the Processes of Care for Service Providers (MPOC-SP) is a questionnaire, which enables evaluation of family-centered care. The aim of this study was to explore staff and parental experiences of family-centered care.

Method: The study utilized a mixed methodology. Quantitative data was gathered from administration of the questionnaire with staff. A series of interviews and focus groups based around the themes from the questionnaire were also conducted with staff and parents of disabled children. The questionnaire data were analyzed with SPSS v.16 for descriptive statistics. Interview and focus group data were analyzed using a template and editing approach.

Results and conclusions: The mean of 'interpersonal sensitivity' was 5.35 and 'respect' 5.74 compared to 'providing general information' 4.34 and 'communicating' 4.96. Staff commented on the value of the questionnaire as a self-reflective tool. The qualitative data provided deeper insight into this area of practice. The questionnaire alone would provide limited data as part of an audit of disabled children's services.

Keywords: childhood, disability, measurement of family-centered care

Introduction

In the UK, the need to demonstrate quality in health care has become a higher priority since the advent of clinical governance in 1998.¹ The four elements of clinical governance are professional management, resource use, risk management, and satisfaction of patients with the service provided.² The need to establish standards that are monitored by performance indicators at a local level requires investment of time and energy from all staff. This is to ensure that the patient's episodes of care are delivered to the highest professional standards and changes to service delivery made in response to timely feedback. The use of clinical audit to measure service delivery and drive up the standards of health care requires staff to identify areas where they consider improvements could be made.³ Chambers et al suggest that quality of care is everyone's business and, by giving both health care professionals and patients a voice, both parties can contribute to the improvements of the National Health Service (NHS) culture.⁴

Services for disabled children in the UK are provided by the NHS in partnerships with various agencies, including social services and the voluntary sector. Staff members in these services have a role in evaluating parental satisfaction as well as reviewing their own performance. In the context of patient-centered health care, the services for

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families with disabled children have been proposed to work best if they are “family-centered”.⁵ There are differences of opinion as to what family-centered care means in practice. One definition of family-centered care is that “families are supported in their decision-making roles in an equal partnership with professionals, ensuring optimal quality of health care”.⁶ MacKean et al have suggested that family-centered care needs to move to more collaborative working with parents.⁷ Using a grounded theory, the authors developed a conceptual framework making treatment decisions and implementing a care plan that will work best for the child and family, rather than shifting the care management and advocacy responsibilities to the families.

As part of the clinical governance framework, National Service Frameworks have been developed. In England, the National Service Framework for children and young people with disabilities and complex health needs recommends minimum standards for care of the disabled child. Information provision is one of the services most valued by parents of children with a disability.^{8,9} In Wales, the National Service Framework for Children, Young People and Maternity Services has developed standards relating to this quality of care.¹⁰ These standards provide a basis for good practice but require auditing to evaluate level of performance. Services are advocated to be child- and family-centered, with provision of clear and accurate information to empower parents and children to make informed choices. Standards also include enabling the child and family to be active partners in goal-setting. The “team around the child” has been suggested as a way forward to achieve this goal.^{11,12}

To achieve a family-centered approach, staff members need training opportunities to raise their awareness of the issues that are important to parents and their children. This includes wider issues than just professional service provision, because the emotional support required by such families is often outside the experience of novice practitioners. To enable children with a disability to achieve their potential, staff members working in these services needs to develop specific communication skills. This is to deal with both children who are developing their communication strategies and parents who are distressed.¹³ In the NHS staff members are expected to perform in six areas of the Knowledge and Skills Framework, and one of these is communication.¹⁴ At the highest level of performance (Level 4) staff are expected to show the ability to communicate with people on complex matters, issues, and ideas in complex situations. Demonstrating evidence of this as a practitioner is challenging and there is

little evidence of training opportunities in specific family-centered care.

In order to measure family-centered care, we did a pilot study designed to explore the factors that influence service delivery and families’ experiences of service delivery. The research question was “how do ‘family centered’ staff and parents perceive their work with disabled children and young people?” This study had four objectives. The first was to determine staff self-evaluation of “family-centered” service provision in organizations that provide services to disabled children, young people and their families, by completing the questionnaire Measure of Processes of Care for Service Providers (MPOC-SP). The staff could be employed in one of several organizations, namely the NHS, Social Services or the voluntary sector. The second was to explore staff members’ views on their own family-centered care through discussion in a focus group, using the themes from the MPOC-SP. In terms of clinical audit, aspects of information and caregiving as well as interpersonal sensitivity were to be explored. The third was to explore parental views of family-centered provision for their disabled child or young person by interview individually or in a focus group. Parents of disabled children or young people needed to be receiving services currently. The fourth objective was to identify any areas where staff felt they would benefit from further training to improve their “family-centered” service provision.

This study was approved by the Cardiff University School of Healthcare Studies Research ethics subcommittee in December 2006. It was considered a “service evaluation” that did not require ethical review by an NHS Research Committee (Ref: 07/WSE04/35). This project received trust research and development approval from three Welsh NHS Trusts, and honorary contracts were set in place for one year. The information sheet was translated into Welsh for parents.

Methods

A literature search was carried out using the databases of Assia, Amed, Cinahl, DARE, Embase, and PubMed for the period 1989–2006. The earliest definition of family-centered care was in 1989 and the year the research began was 2006. The key words used were “childhood”, “disability”, measurement of family-centred (UK spelling)/centered (US spelling) care. A total of 125 abstracts were found and the search was refined to exclude acutely ill and dying children. This resulted in 26 papers of direct relevance to childhood disability in the community and to family-centered care.

A variety of measurement tools were documented that related to outcomes of treatment with children, but the aspect

of caregiving that the author wished to measure revealed only two specific measures. From a parental perspective, the MPOC measures attributes of information exchange, respectful and supportive care and enabling, and partnership.⁵ It has been developed into a 20-item questionnaire which uses a 7-point Likert scale from its original 56 items.¹⁵ The construct of this questionnaire was tested in Canada initially, where validity and test–retest reliability were measured. The intraclass correlation coefficients (ICCs) ranged between 0.81, 0.99, 0.79, and 0.99 in the four scales of caregiving. The MPOC has also been shown to demonstrate reliability and validity in different countries, ie, Holland and Sweden.^{16,17} Van Schie et al demonstrated ICCs ranging from 0.79 to 0.94 when translated into Dutch for parents.¹⁶ Bjerre et al found the MPOC to be reliable in a Swedish context, but some parents reported that it was difficult to answer some of the questions with a specific answer. This suggests that the nature of the questions expected more closed answers, but parents wished to express more open replies to describe what they meant. The MPOC does require a certain level of education and literacy to complete without assistance. Due to parental literacy difficulties, the author had previously used themes from the MPOC as the basis for focus group questions when doing research with parents, rather than getting the parents to complete the questionnaire.¹⁸

The MPOC-SP is a further development of the MPOC, which enables staff to reflect on their caregiving under headings of showing interpersonal sensitivity, providing general information, communicating specific information and treating people respectfully.^{19–22} It is a staff self-assessment 27-item questionnaire that provides a baseline measurement on a 7-point Likert scale and indicates strengths and weaknesses in caregiving. It does not measure actual staff behavior, rather it measures staff members' perceptions of their own behavior. It has been tested both for validity and test–retest reliability. Woodside et al showed test–retest reliability, when staff completed the MPOC-SP with a five-week interval, to have ICCs of 0.81, 0.99, 0.79, and 0.97, respectively, for the four scales of caregiving. Additionally, the authors were concerned there could be a social desirability bias where staff might overestimate their performance. To establish if this was the case, test–retest reliability was carried out with a three- to six-week interval, where staff initially scored their own performance then scored it again as to what the ideal FCC should be. The differences were calculated with a *t*-test and found to be significant in all four scales $P > 0.001$.¹⁹

Dyke et al carried out a study using both measures for parents and staff and concluded that the tools were useful in facilitating service providers to identify areas for improvement.²² Both the MPOC and the MPOC-SP have been shown to be sensitive, valid, and reliable measures to enable services to move towards more family-centered care.^{20,22}

The author came from a background of practice in physiotherapy with children and considered that the questionnaire data alone would not give enough insight into this complex area of practice. The questionnaire would provide numerical data, which could only show trends in staff performance. The study, being a pilot, would produce small numbers that were unlikely to reach statistical significance. Therefore interviews and focus groups were also used, to increase the rigor of data collection for the topic under exploration.²³ The idea of combining the two designs enabled the researcher to explore the experiences of family-centered care in more depth, to gain deeper insight into issues that a questionnaire design alone cannot capture. This triangulation of data collection strengthened the trustworthiness of the information gathered.²⁴

Three children's services were approached within a one-hour traveling distance from the researcher's base at the university. Approval was sought from the South East Wales Central Office for Research and Ethics Committee which suggested that this research was service evaluation that did not require ethical approval. Applications were made to the three NHS Trusts' research and development committees for approval to collect data in these three children's services. Approval was granted and honorary contracts set in place for one year. The inclusion criteria for health and social care professionals were that they were currently providing an "information or caregiving role" to families of disabled children and young people and were employed at one of the three centers in Wales. The three centers that agreed to be involved included one medical model (Center 1) and 2 interagency projects (Centers 2 and 3); the researcher had previously worked in Center 2 as a physiotherapy manager.

Purposive nonrandom sampling was used to recruit study participants. Letters for permission to approach staff members were sent to the managers of the three children's services. Once they had agreed, staff members were sent an information sheet about the study with an invitation letter to attend a specific focus group at their center. After staff members had had the opportunity to ask further questions about the study, they signed the consent form at the beginning of the focus group appointment. This assured them of anonymity and confidentiality. The MPOC-SP questionnaire was com-

pleted individually at the beginning of this appointment. The focus group then commenced with a discussion around the impression of the questionnaire which was recorded with a dictaphone.

At the completion of the focus group the staff members were asked if they could think of any parents who might be willing to participate in the study. Parents who had young children receiving services from one of the three centers were given an information sheet about the research study by these health or social care professionals. Parents then had to contact the researcher to agree to take part on a voluntary basis; this ensured that the researcher was not given any direct access to patient records.

The MPOC-SP questionnaire was introduced to the staff and completed at the beginning of the focus group. This was to ensure that all staff members had the same amount of time to consider the questionnaire that was previously unfamiliar to all participants. A brief explanation was given as to how to complete the 7-point Likert scale. The MPOC-SP questionnaire was used as the basis to design the interview, and focus group questions for staff and the MPOC questionnaire was used as the basis to design interview questions for parental interviews. Data collection began in July 2007 and was completed in June 2008.

The quantitative data was gathered from the staff's completion of the MPOC-SP questionnaire. These were analyzed by descriptive statistics using SPSS software (v.16; SPSS Inc., Chicago, IL). Qualitative data were gathered from focus groups (with health and social care professionals) and semistructured interviews (with parents/service users). The use of semistructured interviews with parents allowed appropriate, indepth exploration of this sensitive topic.^{25,26} The data obtained were analyzed by an editing approach, starting with the template of themes from the MPOC-SP and MPOC. The computer program Inspiration™ was used to create mind maps of the themes.

Results

Twenty-nine staff members were recruited for the study and took part in one of five focus groups or two individual interviews. Professionals included two information officers, a key worker, a nurse, a nursery nurse, an occupational therapist, 11 physiotherapists, six portage workers, a psychologist, two social workers, and three speech and language therapists. A pilot focus group was held with five MSc students, all of whom were physiotherapists who did not work in any of the three centers. Two focus groups took place in Center 1, the first comprising five portage workers and a psychologist; the

second comprising two physiotherapists, a play specialist, and two speech and language therapists. One individual interview took place with a nurse. One focus group took place in Center 2 comprising one information officer, one social worker, a speech and language therapist, a physiotherapist, a portage worker, and a key worker. An individual interview took place with a different information officer. Center 3 held one focus group, which included an occupational therapist, a speech and language therapist, and three physiotherapists. The data collected represented all the staff who responded to the invitation letter within the time period for the honorary contracts. Due to the researcher being a physiotherapist, there was a bias in the recruitment. However, physiotherapists do provide a significant proportion of care and advice for children with a disability. The representation of wider staff groups in Center 2 reflects that this is a multiagency partnership who were using key working as a model of service delivery. The researcher aimed to cover all themes identified from the MPOC-SP and so made a deliberate effort to include wider staff perspectives.

The eight parental interviews included a foster parent, an adoptive parent, two fathers and eight mothers. Ten parents took part altogether. A father of a child with Down syndrome was recruited from Center 1. Staff at Center 2 recruited a mother of a child with spina bifida and a mother of a child with Weaver's syndrome, a foster mother of a child with cerebral palsy, and a mother and father of a child with Down syndrome who did a joint interview. Staff at Center 3 invited a mother of a child with cri-du-chat syndrome, a mother of a child with mucopolidosis Type II, and an adoptive mother of a child with cerebral palsy who did a joint interview with a mother of a child with unconfirmed cerebral palsy. The children were aged between 11 months and six years. The range of disabilities reflects the types of children seen by the range of professionals interviewed, that includes learning as well as physical disabilities. Although more physiotherapists took part than other staff, the parents who volunteered represented the wider service provision.

Data was collected at Center 1 with staff first, then parents who had contacted the researcher were interviewed. When this was completed, Centers 2 and 3 followed chronologically. Although recruitment was lower than hoped, no attempt was made to coerce staff or parents to take part. The bias inherent in the researcher being a physiotherapist may have influenced the uptake of participants from a staff perspective. The importance of audit and service evaluation seemed to be a higher priority for Centers 2 and 3, where staff had more links with other agencies. The parental response

was determined by the staff handling the letter to the parent and the parent considering it important enough to give time to talk to a researcher with no financial incentive.

It may have been more rigorous to carry out interim analyses of each focus group and amend the questions according to the findings. However, in reality, a limitation of the study was that the researcher was only able to do this research on a part time basis. The honorary contracts only lasted for a year, and clearly there was time pressure to collect the data in this window. In retrospect, this meant that the focus group and interview questions were kept similar to ensure consistency. In hindsight, an iterative approach where each focus group or interview are analyzed and changes made in response to these preliminary findings could have generated richer data.

The quantitative data were analyzed with SPSS 16 for descriptive statistics. Overall, staff scored themselves higher in the “interpersonal sensitivity and respect” aspects of caregiving, ranking themselves 7 (to a very great extent) and 6 (to a great extent) compared with the “information giving” which they scored at 4 (to a moderate extent) and 3 (a small extent). The mean of the “interpersonal sensitivity” was 5.35 and the mean of “respect” was 5.74, compared with “providing general information” 4.34 and “communicating” 4.96.

These data gave limited information about the quality of staff behavior in family-centered care because it was a record of staff members' perception of their own behavior. However, the questionnaire provided a stimulus for staff discussion at the start of the focus groups. The staff felt that the MPOC-SP questionnaire was a useful tool for self-evaluation; for some it made them feel good about their practice, for others it highlighted areas of practice they had not considered before. Staff became aware of their limitations in providing support information to parents and the oversight in the needs of siblings, raising their awareness of the need to include them.

Physiotherapist: “... you don't perhaps realize how much you do or don't do, I found it quite nice to think 'oh yes I do, do that'. That's nice. But then there are things that you don't actually think about ... perhaps telling them about what other facilities are around that would enable their siblings to be involved for example ...” [S1]

Occupational therapist: “... because I think sometimes we overlook the unaffected siblings, that did make me think. I mean we try and include them obviously but it ... is something we could do a bit more of I think ...” [S3]

The interviews and focus groups were transcribed by an independent person. The transcripts were then verified

by the researcher and sent back to each participant for confirmation of the data. The design of the focus group and interview questions was based on the themes of interpersonal sensitivity, respect, and information-giving from the MPOC and MPOC-SP questionnaires. These qualitative data was analyzed using an editing approach based upon the template of the original three themes. This generated new themes and subthemes, which are shown in Table 1.

The new themes included staff development, parental styles, quality of life, “team around the child”, and child protection. If the questionnaire had been used alone, these richer data would not have added to our understanding of staff and parental views. These wider issues need further consideration regarding their impact on service delivery in a family-centered way. These themes were illustrated with quotes to highlight areas of good practice and open up areas for consideration in service evaluation.

The challenge of involving some families was brought out by staff members who recognized that some parents need more support and are not able to function in an empowered way.

Key worker: “*But what it (MPOC-SP questionnaire) was asking was 'do we involve the families?' and that's something we are quite critical of ourselves at the moment ...*”

Speech therapist: “*It's more with some, as the families that we work with are so diverse that with some you can tick every box and think I'm a fantastic practitioner. But sometimes with the parents and the child where you've got*

Table 1 Themes of the focus groups and interviews

Themes	Subthemes
Questionnaire	†Staff self-evaluation
Interpersonal sensitivity and respect	Valued staff attributes; †challenges to achieve; ‡unhelpful staff behaviors
Information-giving	†Modelling; verbal, †demonstration; †feedback; written, photo, video, goal-setting; †timing
Staff development	†KSF; support, training, and service evaluation
Parental style	†Expectations and issues
Quality of life	‡Wider family; siblings; †future planning, respite, financial, and coping strategies; social opportunities; †ethical dilemmas
Team around the child	Multidisciplinary team-working, key worker
Child protection	†Working in partnership in child's best interests

Key: †Staff only; ‡parents only; grey screen, main themes from MPOC-SP.
Abbreviation: KFS, Knowledge and Skills Framework.

the more challenging of the families then it's perhaps, no, you're not doing all those lovely things ..." [S4]

Indeed, further discussion opened up areas of practice where other factors affected some parents' ability to engage in partnership working:

Question: Do you think you are able to work with parents as partners?

Portage worker 1: *"Yes, we do we leave activities for the child and they work on them."*

Portage worker 2: *"By going every week the family ask you about a range of things. If they are sometimes having hassles or stress then you accept that you can't work with them that week, they may discuss other issues and I refer them on ..."* [S2]

Social worker: *"... I would have thought that it is easier to actually be setting goals on a clinical basis as a therapist, whereas from a social point of view from our service with things like respite it's not an easy goal to achieve. But then also there may be six other goals which might be achieved within that. Where a therapist may say this is the goal we aim to achieve and that's what you work to ..."*

Speech therapist: *"But what it (MPOC-SP questionnaire) was asking was do we involve the families and that's something we are quite critical of ourselves at the moment because to make it work you want to have the families setting the goals as you're more likely to achieve them but when you come across a family that is unable to set goals and therefore you're doing it for them."*

Social worker: *"Yes."*

Speech therapist: *"Then are you actually delivering what you want to do? When the family have got their own ideas ..."*

Speech therapist: *"It comes back to every family is different ..."* [S3]

Sometimes staff became aware that their agenda was not always as important as the family's needs, and flexibility was required to address new parental concerns. However, sometimes a lack of parental confidence can lead to a more staff-directed service than a family-centered one, as illustrated by a nurse working with hemophiliac patients:

Nurse: *"... I can remember going to their house because I was actually quite involved in teaching this family and I went to the house and they did it fine (giving the child injections) but then they lost their confidence and they wanted ... and they chose to come back to the hospital. The parents often did it ... sometimes they don't get it very well the first time and they try two or three times and then the child gets distressed. You know it is quite a responsibility (teaching parents to do an injection on their child) ..."* [S3]

Professional practice across the staff represented in the focus groups focused on child protection concerns. The MPOC-SP questionnaire did not ask about such concerns or ask staff to consider their behavior in this aspect. Sometimes the parental issues were not clearcut as to whether it was a lack of compliance or lack of knowledge that raised the child protection concerns for the staff.

Social worker: *"... If the parent is right emotionally, psychologically then she will get on or they will get on and do the job they have to do in order to enable the child to develop ... there is this issue of this family not being compliant, that their standards are not as they should be. But coming from a social work background you can look at that in several ways – that could be an indication of depression, that the home standards have slipped and there's this issue about good enough parenting. We shouldn't be going down child protection routes because a situation isn't what we think it should be ... as long as you know and you make that judgment that the child is safe, it's about the rights of the child and the rights of the family and the child's needs are paramount ... you know its quite complicated, not really straightforward ..."* [S5]

The priority must always be for the child's safety. Sometimes, if the parents were not following through on advice, concerns were expressed about the child not achieving their full potential in the longer term.

Physiotherapist: *"... yes, I think it's very difficult when you've got children with severe complex needs, for example, who requires a particular way of handling the child. I think we have moved away over the last perhaps two decades, from hands-on exercising to making it about how you hold the child, how you move the child and position the child so that they can access activities but they can do more function, but it's still very difficult if you have a parent who thinks they may well do it for five minutes or 10 minutes and think they have done a 'physio' program. 'We have to do your physio today' but actually the rest of the other 23 hours of the day they're not putting it into place because they will still pick them up how they want to pick them up and they'll still do what they want to do. In fact it ends up as you said (looks at another participant) being quite a negative experience in that the child might not only not progress, but might actually get worse. And then again it's that situation of having to try and reiterate it and reinforce it and be reassuring you've got to keep going and you try this and at the end of the day you do somehow still have to come down on the side of if you don't do this, this is going to happen it's going to have quite a serious implication. So you do have to come down quite tough sometimes ..."* [S2]

A variety of parenting styles was described in the focus groups, including parents from different ethnic backgrounds as well as academic ability. A specific point was noted about parents preferring learning styles being a factor to consider when giving information in both written and verbal formats. Sometimes pictures or videos were used to enhance the recall of specific exercises.

Speech therapist: "... *If a parent I had had learning difficulties, perhaps not understanding what I was saying, then I wouldn't give them a standard thing, you know, you'd have to adapt that and they might need taking through something more practical. 'Well, okay, lets take turns at doing this' actually having a bit of a demonstration and talking to the special needs health visitor; sometimes they have a key worker and we can say this is what we've been working on and you might sort of mention this, you know, and get some reinforcement from different people. One can try and give them another format of something written or sometimes I would give them some specific pictures to work on so they work on a specific activity rather than perhaps trying to give them activities (and I'm the biggest culprit) that can be hard to do. 'This is just the picture this is what you are doing, just remember this is what you are doing, this game' ...*" [S1]

The concept of "team around the child" was referred to by all three centers, but some had a more formal structure to manage this process as described below by the key worker in Center 2.

Key worker: "... *the referrals come sometimes through the Child Development Team, other ones come in a bit later. All professionals get involved straight away and my criteria is that they have three or more professionals involved and that includes the pediatrician and then I'll get involved to go out and bring all that information together for the family. As very often they're going to two different hospitals seeing 15 million different professionals, they quite often know what's happening, but don't really know how they got there in the dark. So, to bring that information together and bring that back to the team of professionals that are going to be working with that child and family as they don't always coordinate before they go out. Some of it can be done in a way that doesn't overwhelm the family but also involves them in some way saying this is what this person is going to be doing and you're going to be working with that person and this person will be doing that. And then we bring that back then at three-monthly, six-monthly at 'team around the child' meetings to feed that back to each other with the family present so they can kind of hear it all ...*" [S2]

The role of a key worker was only described by Center 2 and therefore this is a role that needs wider evidence to justify its use in family-centered care with disabled children and their families. The parents who received the key working service spoke highly of it, but it was not a model of service provision that Centers 1 and 3 followed. In the original construct of the MPOC for parents, the concept of care coordination was measured more specifically, but it was found not to be consistent in all services and so was dropped in later versions.

In terms of staff showing evidence of high-level communication skills to demonstrate their competence on the Knowledge and Skills Framework, there was a mixed response to this question. Some had not considered how to find written evidence, feeling that verbal evidence was enough. Others had been quite strategic, with minutes of meetings and case notes collating written evidence for their portfolios.

Speech therapist: "*I think that if you take part and you're a key person in a diagnostic clinic or you're having to sit at the end with the parent and the child and discuss and provide a diagnosis I think that's got to show you've got good communication skills ... I think if you've documented it in a file, that you know, gave this diagnosis and spoke to parents about blah blah blah blah, that'd have to be evidence ...*" [S6]

The MPOC-SP did not consider the Knowledge and Skills Framework at all. This is a specific UK staff development and performance indicator that relates to career pathways. If the questionnaire alone had been used this additional perspective would have been overlooked.

The consideration of quality of life issues was more evident from parental feedback, because this area was more relevant from their perspective. There were different areas highlighted concerning good practice and a few areas where concerns were raised which required followup. Parents were positive about most of the staff who worked with them. If they had a concern they were not always clear about how to complain or who to report these concerns to. During one interview, the author explained to the parent that the profession in question was regulated by the Health Professions Council to which she could report her concerns about unprofessional behavior. In Center 2, there was a parents' council that had a reporting mechanism for concerns through the chairperson of this council, who took part in the research study. He explains his role:

Father: "*We're hoping that although we said we'd set it up (complaints process) we haven't done it for a couple of years, we were hoping to set something up where if there*

was any problems with parents to come and see me about it ... Well, we were trying to do a suggestion thing as well so because there are people that could be unhappy but can't say anything and they will just put up with it and so we were hoping we could do an anonymous suggestion box whereas if they had that and they have got a problem, they can sort of let us know anonymously so something can be done about it ..." [P5]

It was evident for the majority of parents they had no need to complain, but the complaints procedure was not clear in Centers 1 and 3.

On a positive note, many parents reported feeling the whole family was included, even the siblings, which is contrary to what the staff had reported from the MPOC-SP questionnaire. One mother with five children was delighted with how her 11-year-old had been included in the playgroup with her three-year-old child with a disability.

Mother: "My children come with me to physio sessions, they all came to Bobath (specialist children's therapy center) with me as well, and Kerry (physiotherapist) comes out to the house and they do a session, with my oldest daughter Alys, and Jack and I go out of the room. She's 11, she's done quite a lot of joint work with Rebecca (speech therapist) as well. Alys did, she's come down so she knows a lot because Jack is so sensitive with his mouth, he's unbelievably sensitive, so things like, Alys knows how to 'dab', they've taught her to 'dab' his mouth with a wipe and things like that. Alys does sessions with Michelle (portage worker) as well, if she's off school. The children are very involved and it's encouraged. On a day off, Alys will come down with me and go to the playgroup for the day and help out with the other children as well ..." [P5]

Overall the qualitative data added to the quantitative data that the MPOC-SP questionnaire had provided. This gave a deeper insight into the findings and answered the research question from different perspectives.

Discussion

The scores on the MPOC-SP questionnaire for interpersonal sensitivity and respect were higher than for information-giving, supporting the evidence given by parents who felt supported in a partnership of decision-making but sometimes felt the information was not available for them. Sometimes the information is not available for staff to give to the parents at the time when they feel they need it. These findings are echoed in previous studies using MPOC-SP questionnaire. Woodside et al suggested that this measurement tool would be useful

in professional development as well as service evaluation.¹⁹ The questions can enable staff members to distinguish their own performance in terms of showing interpersonal sensitivity and respect, communicating specific information or general information in order to identify their strengths and weaknesses. More generally, staff feedback can facilitate the manager's service evaluation to consider amendments to their provision of disabled children services.

To enhance a service evaluation, the MPOC questionnaire carried out with parents could strengthen such a review. Knox and Menzies carried out a study using this tool and suggested that the results of parental feedback can promote positive staff reflection.²⁷ Additionally, the exploration of what skills and training might be needed to enable the delivery of family-centered care needed further consideration. Law et al did a study to develop and evaluate educational materials about family-centered care.²⁸ The educational materials developed were used for service providers, parents, and health care students. These results showed that this educational material was suited to the three target groups, which is contrary to the current literature suggesting information needs to be different for different target groups.

The new themes identified, which included staff development, parental styles, quality of life, "team around the child", and child protection, need further consideration concerning the need to include them in a service evaluation. If the questionnaire had been used alone, these richer data would not have added to our understanding of staff and parental views. These additional themes require a stronger evidence base to show their impact on service delivery in a family-centered way.

In terms of auditing children's disability services, a questionnaire alone would provide limited quantitative data that might indicate trends in performance, such as being better at interpersonal sensitivity and respect than information-giving. How one can show improvement in these qualities has a degree of subjectivity in terms of preferences of individual staff and families. The parental interviews gave a wider view and enabled these opinions and feelings to be expressed concerning the services they received for their disabled child in Wales. It was clear that the teamwork that parents experienced supported them in their decisions. Their stories and examples allow parents to articulate what is important to them in caregiving. A designed questionnaire will not extract such rich data, which the researcher was interested in finding out. The two dimensions of staff and parental views have enhanced the trends indicated by the quantitative data.

Study limitations

This was a small pilot study collecting data from three Welsh children's community services and the findings need to be considered with caution. The author's previous employment at Center 2 could have introduced some bias in the interview questions. Additionally, the author's background as a children's physiotherapist could have influenced the staff recruitment, which led to a higher proportion of physiotherapists than other professionals participating in the study. The quantitative data generated from the questionnaire provided limited information about family-centered care. The time constraints of honorary contracts can lead to rushing data collection and reducing its rigor.

Recommendations

The MPOC questionnaire for service providers has value for practitioners in the measurement of their own performance of family-centered care as part of service evaluation. Staff may choose to use it for their own reflection, and managers may wish to use these data to inform service improvements over time. As a stand-alone audit tool it provides limited data that can show trends in performance rather than giving specific results. It needs to be used in conjunction with parental feedback whether by use of the MPOC questionnaire or parental forums for feedback. The majority of parents considered they were treated as equal partners in the decision-making processes and this should continue. Parents valued the team-working experience in all three sites. However, parental feedback suggested that there needed to be a clearer complaints procedure to enable parents to voice their concerns if necessary.

To increase understanding of family-centered care, the author considers that the development of this topic could be explored by a closer ethnographic study in this context. It is the intention to develop this further by seeking ethical approval to carry out an observational study of staff working with disabled children. This deeper insight could lead to clearer pathways for service evaluation and staff development.

Conclusion

The research question was answered from the two different perspectives of staff and parents of children with a disability. The MPOC-SP questionnaire highlighted areas of staff performance that broadened their view of family-centered care. The consideration of wider family needs, particularly those of siblings, increased staff members' awareness of their oversights. However in some areas, parents felt their

whole family was included so it was not an issue for them. The added value of focus group discussion and interviews with parents give deeper insight into family-centered care and has provided further understanding of this in a Welsh context. Larger studies in other areas would need to be carried out before such findings could be generalized to the service provision of disabled children's services in the UK in general. Further research should explore the factors that impact on the quality of service provision for children with disability, including staff development opportunities and parental involvement of service evaluation.

Disclosure

The author reports no conflict of interest in this work.

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