Development and satisfaction with individual programme planning in a disability service

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Abstract
A consumer survey of a preschool disability service identified parents who did not feel their concerns were fully understood by professionals, nor felt involved or in agreement with treatment decisions, nor that services were provided in a coordinated way. A system of individual programme planning (IPP) was introduced in order to address these issues and other shortfalls of the existing service. Information was obtained from 96% of parents and 87% of professionals who attended IPP meetings over a four month period. Overall satisfaction was high (92% of parents: 96% of professionals). Parents now felt fully involved in decision making, 80% felt their views were understood and 100% agreed with treatment goals. Dissatisfaction was expressed with meeting attendance, the marginalisation of parents, and the timing and chairing of meetings. Consumer satisfaction surveys are recommended for use in highlighting areas of service shortfall, to direct and evaluate service change, and to monitor quality.

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The evaluation of health services is an important objective of both purchasers and providers. However, it is difficult to specify appropriate outcome measures for disability, terminal illness, and mental health services as health gain is often difficult to quantify.1 2 Interventions are often multiple, provided by a range of professionals over a period of time, with benefits often being cumulative, long term, and diffuse.

The problem of objectively quantifying health gain has led to increased interest in consumer satisfaction as a measure of outcome and a way of assessing and monitoring service quality.2 4 Government reports have repeatedly advocated increased involvement of consumers in both determining the nature of health care and the evaluation of its delivery.5-7

There have been a number of consumer surveys assessing satisfaction with paediatric disability services.18 9 While these provide useful baseline information about the quality of individual services, significant methodological variations prevent comparisons between studies. Typically, surveys tend to be one off events using locally constructed questionnaires with no information offered on changes in service delivery arising from the data. It is therefore unclear whether paediatric disability services use consumer views to direct and shape service delivery and whether consequent changes result in increased satisfaction.

The purpose of the current paper is to described how a preschool disability service responded to consumer views and the effect of the resulting change in service delivery upon both parental and professional satisfaction.

Bath disability services in 1990
Disability services were organised and coordinated via five children's handicap coordinating committees, each covering a geographical patch of the health district. These committees had two functions. Firstly, monitoring and evaluating overall service provision within their locality, and secondly reviewing plans for individual children. This second task was usually accomplished during half day meetings where up to 12 children would be discussed. These meetings were primarily professional reviews and parents were rarely invited.

Consumer satisfaction in 1990
A survey of parents of preschool children with disabilities was undertaken in the Bath health district in 1990. The survey was designed to determine parents' satisfaction with the services they received and their views as to how these could be improved.10 11 The parents of approximately one in three of all identified preschool children with disabilities were interviewed using a specially constructed questionnaire. High overall rates of satisfaction were obtained to general questions, although specific areas of dissatisfaction clearly emerged. In particular, 41% of parents had received differing advice from professionals, 73% felt their concerns were not fully understood, 45% felt that professionals did not know who else was involved with their child, 37% did not feel involved in the decisions made about their child with 21% not agreeing with them.

It was evident that many parents of preschool children with special needs felt neither understood by professionals nor involved in deciding their child's treatment programme, and that services were uncoordinated, providing differing and, on occasions, conflicting advice.

Service change
The consumer survey formed part of a wider review of services for preschool children with
disabilities. Comments were also received from other parents attending opportunity playgroups and parent support groups. Professional views were obtained from individual and group discussions, with issue papers and draft documents being widely circulated and discussed. These views culminated in a report endorsed by the district child health policy group identifying key issues, a series of recommendations, and a proposed action plan for improving disability services for preschool children. In 1992, a decision was taken to abolish the children’s handicap coordinating committees and to manage the service and individual treatment planning functions in new ways.

(1) SERVICE EVALUATION
Three children’s disability service evaluation committees were established. These were geographically based upon the three social service districts that overlap the Bath health district, namely Avon, Somerset, and Wiltshire. They monitor and evaluate local provision of disability services and are like the disability equivalent of area child protection committees.

(2) INDIVIDUAL PROGRAMME PLANNING (IPP)
Individual programme plans (IPPs) have been used as a way of organising and delivering services to adults with learning disabilities for the past decade. The IPP process has three key aims: (i) To identify and meet the needs of people with learning disabilities and ensure their involvement in decision making. (ii) To provide a forum for professionals and agencies to coordinate their activities and tailor service provision to individual needs. (iii) To monitor the effectiveness of services in meeting client needs.

The IPP process appeared a useful way of addressing the service shortfalls identified in the previous survey and was therefore introduced throughout the district in January 1993. IPPs were offered to preschool children with severe or profound disability for whom three or more different disciplines were providing services. In adapting the system to preschool children, it was necessary to modify the first aim in order to emphasise the central role of parents and thus maximise their involvement in the decision making process.

The IPP process adopts a positive, structured framework. A form is completed by both parents and professionals before each meeting focusing upon the strengths and needs of the individual child. Strengths are those things the child can do, or nearly do, and also the things they enjoy. Needs are the tasks, skills, and activities the children need to be able to achieve over the coming year. These are then discussed at the IPP meeting and result in the formulation of an agreed action plan in which a maximum of six goals are clearly identified. For each goal the time span, person responsible, and the method and resources required to achieve it are stated. A review date is agreed, usually 12 months later and the meeting is then summarised and circulated to all those invited on one side of A4. The review meeting evaluates the achievement of the action plan, unachieved goals are discussed, service shortfalls identified, and unmet need fed back to the local children’s disability service evaluation committee.

The central principle is to empower parents and involve them in all aspects of decision making. Parents therefore decide who to invite, and occasionally choose not to invite professionals who otherwise might have assumed a right to attend. Health visitors have a key role in facilitating the IPP process and help parents complete the strengths and needs form, prepare for the meeting and decide who to invite. Both health visitors and senior clinical medical officers who chair the meetings received training in facilitation and chairing skills before starting the system.

Methodology
Standardised questions were designed to obtain both quantitative and qualitative data about the IPP process. Question areas were selected on the basis of previous research, direct observation of four IPP meetings, and talking with the parents and professionals involved in those meetings about important aspects of the process. A questionnaire was constructed and piloted on three families. This formed the basis of a postal questionnaire for professionals and a standard interview for parents, administered in the child’s home by an independent researcher seconded to the project. The questions, similar for both parents and professionals, asked about preparing for the IPP meeting, the meeting process, the goals and action plan, overall satisfaction, and areas for change.

The study was prospective and the sample consisted of all children having IPPs between 1 January and 30 April 1994. The professionals attending these IPP meetings were sent the questionnaire accompanied by an explanatory letter. In order to avoid the results being biased by the views of multiple attendees, only one questionnaire was sent to each professional regardless of how many IPPs they attended.

The IPP summaries detailing the action plan agreed at the meeting were analysed. Information was obtained about the location of the meeting, number of people attending, number of strengths, needs, and goals identified, and the duration of the meeting. In the case of review rather than initial IPPs a specific monitoring sheet was used to ascertain whether previous goals had been achieved.

Results
(1) RESPONSE RATE
Twenty-six children had IPP meetings during the study period and parents of 25 agreed to be interviewed at home (96% response rate). Seventy-five different professionals attended these meetings. All were sent the questionnaire and 65 were returned (87% response rate). The response rates are such that it is
reasonable to assume that the views obtained are representative of those involved in the process.

(2) MEETINGS
Altogether 68% of IPP meetings were conducted at opportunity playgroups. These are multiagency funded and represent the major local community resource for preschool children with disabilities. A further 20% were conducted in the parents’ own homes, and 12% at either a specialist therapy nursery, general practitioner surgery, or social services respite home.

The meetings were fairly small, with an average of seven people present including mothers and, on 11 occasions, fathers. The meetings were usually chaired by a senior clinical medical officer and consisted of a common nucleus of professionals including health visitor, opportunity playgroup representative, portage tutor, speech therapist, and physiotherapist.

(3) GOAL ATTAINMENT
An average of 18 strengths, 10 needs, and five goals were identified at each meeting. Of the 10 review IPPs, information on the attainment of previous goals was obtained for nine. Of the 47 goals identified, 41 were achieved (87%). Of the remainder, two were achieved later than planned, one was partially achieved. Two were not achieved due to lack of staff and one due to lack of equipment.

(4) OVERALL SATISFACTION
The IPP process has been very favourably evaluated by both parents and professionals with overall satisfaction being very high (table).

Quantitative data suggest that the strengths and needs framework is seen as useful, the right number of goals are selected, and that these are considered to be clearly specified and achievable. Both parents and professionals were less certain whether necessary resources are available to achieve these targets, although they were optimistic.

(5) SPECIFIC AREAS OF SATISFACTION
Parents and professionals were asked to identify one aspect of the process with which they were more than satisfied. All parents, and 31 professionals, responded to this question with an analysis of the qualitative data indicating four key areas.

Greater coordination of professional inputs was identified in 18 responses (eight parents, 10 professionals), increased parental involvement by a further 17 (six parents, 11 professionals). Thirteen referred to the IPP meetings being a positive, empowering experience (five parents, eight professionals), with nine referring to the clarity and specification of the treatment goals (five parents, four professionals).

(6) SPECIFIC AREAS OF DISSATISFACTION
Parents and professionals were asked to identify one aspect of the IPP with which they were less than satisfied.

(A) Shared views
The following two areas were identified by both groups as a shared source of dissatisfaction:

(i) Meeting attendance – One or more invited professionals had not attended at 60% of meetings. Six parents and 13 professionals commented upon their absence, with some parents feeling let down and unable to learn about and challenge professional opinions. This view was shared by 10 professionals with three feeling that important people had not been invited to the meeting.

(ii) Meeting process/chairing – Four parents and eight professionals commented about the chairing of the meeting. They were concerned about minor issues being laboured, important issues remaining unaddressed, and professional views dominating.

(B) Mixed views
A further two areas were identified where parents and professionals expressed contrasting opinions.

(i) Time – Eleven professionals made comments about either the timing of meetings or the amount of time involved. Of these, four wanted more advanced notification of meetings, four felt that IPPs were time consuming, two that meetings were too short, and one felt the meeting time was inconvenient. This view was not shared by parents, as only one expressed dissatisfaction in this area, feeling that the IPP meeting was too short.

An analysis of quantitative data indicates that on average, professionals were spending 49 minutes preparing for the meeting and parents 35 minutes, with the meeting itself lasting 54 minutes. Although this does not include travelling time, professionals appear to spend less than two hours per child each year in the IPP process.

(ii) Parent marginalisation – Professionals were sensitive about the experience of parents at the meeting. Four felt it was a daunting experience, two commented that the use of jargon excluded parents, and two felt that parents were confused and unsure of the meeting’s purpose.
Once again this view was not shared by parents, as only one expressed feelings of being undervalued. Ninety six per cent reported saying everything they wanted at the meeting and 80% felt their view was well understood.

(7) SUGGESTIONS FOR IMPROVEMENT
Parents and professionals were asked how the IPP process could be improved. Two key areas emerged. Firstly, 11 comments were made about the timing of meetings (four parents, seven professionals). Professionals wanted more advanced notice of meetings, whereas parents wanted longer meetings. One parent wanted them at a more convenient time (after work), and one wanted them more frequently.

Secondly, 11 people (four parents, seven professionals) felt that better preparation for the meeting was required. Of these eight felt that more general information about the IPP process and its purpose would be useful. Two felt a checklist of professionals to invite would be helpful. One felt that families should be routinely encouraged to bring a friend/advocate.

Discussion
Individual programme planning was introduced as a response to dissatisfaction expressed by parents in the previous consumer survey. In particular, a significant number of parents did not feel understood, involved in their child’s treatment programme, or that services were provided in a coordinated way. Significant improvements in all these areas have now occurred, with 80% of parents feeling that their views are well understood compared with only 27% in 1990. The parents’ central role for their child has now been emphasised, as they determine who is to be invited to the meeting, provide their assessment of their child’s strengths and needs, and prioritise and agree the treatment goals. This has resulted in parents being fully involved in all planning meetings. There is very high agreement and satisfaction with treatment plans, with this increased involvement being identified as one of the most important sources of satisfaction for both parents and professionals. This compares favourably with the previous survey, where 37% of parents did not feel involved in decisions about their child and 21% did not agree with them. Finally, a number of parents and professionals identified the coordination of therapeutic inputs, advice, and planning as one aspect of the IPP process with which they were most satisfied.

The satisfaction surveys we have contrasted have used different research methodology. Reported improvements in satisfaction may not be directly or exclusively attributable to the introduction of IPP. Furthermore it is acknowledged that while the response rate in this present study is good, the sample size is small. The results should therefore be interpreted with some caution. The very high rates of satisfaction nevertheless suggest that IPP has met with widespread approval from both parents and professionals and has gone some way to rectify previous shortfalls in service delivery. There is further scope for improvement, particularly in terms of increasing meeting attendance thereby improving service coordination. A number of professionals did not attend meetings to which they had been invited, particularly hospital paediatricians and general practitioners who provide a substantial proportion of care for this client group. Educational psychologists did not attend any IPP meetings, although issues to do with future schooling figure prominently. These particular professionals tend to have clinical timetables which make it difficult for them to attend these meetings. Their absence does not prevent them contributing to the IPP process, as they are invited to provide a written summary of the child’s strengths and needs. Active discussion of contentious issues and the resolution of differences of opinion are prevented by their absence, although it may be more realistic for these to be resolved with the relevant professional outside the planning meeting. Parental disappointment could be reduced were it made clear that some contributions would be written. Professionals have suggested that more advanced notice would enable rescheduling of prior commitments and this will be explored further. However, the development of such a procedure would still require professionals to allocate attendance at IPP meetings as a priority. This is a problem which has been identified in previous studies.14

The chairing of IPP meetings is a challenging task requiring a range of skills to ensure that everyone feels comfortable, fully involved and able to contribute their views, while working within a limited time span to arrive at a clear action plan. Parents generally feel comfortable and able to contribute to the meetings and professionals appear sensitive to their needs. Dissatisfaction with the process has been expressed, indicating a need to train chairs to be more effective. They must ensure that all views are heard, parents feel empowered, and pertinent issues are fully addressed. The possibility of peer review will also be explored whereby chairs sit in on each other’s meetings in order to provide constructive feedback regarding the management skills of their colleagues.

The third area of dissatisfaction focused upon the need for parents to receive better preparation and more general information about IPPs. Information currently provided to parents will therefore be reviewed and updated and an information pack containing a checklist of professionals will be developed and included in the parent held record.

One positive effect of the IPP process is the strengthening of the health visitors’ role, and thus the primary care support for families of disabled children. Health visitors often stated there was little they could offer in view of the involvement of many specialist therapists and frequent hospital appointments. They now have a task which draws them into contact with the family, and this provides an opportunity to consider the needs of all the family not just those of the disabled child.
Although satisfaction with the IPP process is high, a more comprehensive evaluation would include data on outcome and cost. Specifying appropriate outcomes for disability services is difficult, although the successful achievement of specified goals would be one such measure. The system is comparatively new so that most children had their first meeting during the study period. Preliminary information from nine review meetings is encouraging, and indicated that 87% of the goals selected had been successfully achieved. The process appears inexpensive, involving each of six professionals in approximately two hours work per child per year at an estimated cost of £600 including the cost of administration and travelling. Further evaluative work is obviously required, although these preliminary findings would suggest that IPP meetings are a cost effective method of planning and coordinating services for preschool children with disabilities.

Finally, this study has demonstrated how services can be responsive to consumer views. Repeated evaluation of satisfaction can be a useful way of monitoring quality and quantifying the effects of service change.

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10. Stallard P, Lenton S. How satisfied are parents of preschool children who have special needs with the services they have received? A consumer survey. Child Care Health Dev 1992; 18:197-205.