

FAMILY CARERS' OPINIONS ON LEARNING DISABILITY SERVICES

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ABSTRACT Sardi, I. et al (2008) Family carers' opinions on learning disability services. *Nursing Times*; 104: 11, 30–31. This study explored the views of parents and family carers regarding current and future learning disability service developments. Twenty-nine participants took part in focus groups, while a further four took part in semi-structured interviews. Participants highlighted a lack of information, the need to be proactive and having to fight for service provision. Further development is needed if services are to meet the needs of parents and family carers. Developing effective mechanisms for seeking their views is central to this.

Changes in service delivery for people with learning disabilities affect how they are planned, developed and implemented. Examples of such changes include the introduction of person-centred planning and direct payments.

The Learning Disability Implementation Advisory Group (2006) has stressed the importance of involving parents and carers in strategic planning to ensure that the end results reflect their needs and priorities.

In 2005 a parent forum alliance in a unitary authority in South Wales commissioned the Unit for Development in Intellectual Disabilities at the University of Glamorgan's School of Care Sciences to undertake this study. A literature review was carried out – for details see nursingtimes.net.

IMPLICATIONS FOR PRACTICE

- Mechanisms for providing information to parents and carers should be reviewed. These should include how to provide timely, accessible and accurate information in a proactive manner and in a variety of formats.
- Ways of involving parents and family carers in strategic planning should be reviewed. There needs to be a variety of

routes to allow for the different demands placed on parents and family carers and the time they have available. Most importantly, there should also be mechanisms so parents and carers can receive feedback about the outcomes of any consultation.

- Disability awareness training should be promoted for healthcare staff.

AIM

The aims were:

- To gather information that could be used to inform service planning and development;
- To address the question: 'What are the views of parents and other family carers in the unitary authority regarding current and future service developments?'

METHOD

A qualitative approach was used, to allow views to be explored in greater depth and concerns to be raised. Data was gathered mainly via focus group interviews conducted by two university-based researchers, with provision for individual interviews.

The topic guide for the focus groups and interviews was developed through discussion with members of the community services division and the parent forum alliance. We also took account of issues in the literature. The guide was then refined following a pilot focus group, held to test both its comprehensiveness and its acceptability to participants.

Four focus groups were held with 13, seven, three and six participants. In addition, three interviews took place with four participants (one interview was undertaken with both parents of one client). The sample included parents and family carers of those in the transition period, as well as those who were older. It also included those caring for people with

varying degrees of learning disability. Seven participants were male and 26 female.

All focus groups and interviews were tape-recorded, transcribed and imported for coding and analysis into a software package. Emerging themes were identified.

RESULTS

Lack of information and the need to be proactive

Lack of information is related to knowledge of services and other issues. The amount of knowledge that participants had regarding services varied a great deal. Some had little knowledge of any services other than those they used, while others had heard of terms such as direct payments but had no information about what they meant.

On direct payments, some participants felt they were given insufficient information. Others indicated they knew nothing about the payments.

Professionals were identified as the main source of information on services, and support from a good professional greatly enhanced access. However, participants relayed stories of parents and relatives who had no access to professional support, or stories indicating that the professional was ineffectual. Some differences in access to support related to age.

Participants' awareness of planned developments was limited and they felt that it could be difficult to access information



about them. Lack of information was closely related to the need to be proactive. Participants in three focus groups and two interviews stressed the need to be proactive about securing appropriate services.

Having to fight for service provision

The theme that seems to recur most often in the literature on parents' and carers' experiences is the view that parents have to fight for service provision (Redmond and Richardson, 2003; Swain and Walker, 2003).

Participants in this study expressed similar views. Those in two focus groups said that parents and family carers had to 'fight'.

Some participants expressed discomfort at having to fight for involvement in their children's care, and for services such as respite care and direct payments.

Participants in three focus groups said those who received services were often those who shouted the loudest. Similar views have been expressed elsewhere (Bogues, 2004).

Hopes and fears

Discussion about hopes was limited, with comments made in only two focus groups and one interview.

The main desire expressed was for services to be built around individuals' wishes and needs. In many instances, carers expressed fears that their hopes would not be realised. One participant spoke of his 'dark hopes', indicating concerns for the future.

A feeling was expressed that the caring role would last a lifetime. Participants expressed fears about what might happen when parents die and the implications for other family members. In addition, there were concerns regarding the potential for abuse of their relatives.

The fact that the need for support would extend beyond their lifetime and the implications for siblings of the person with a learning disability worried older parents.

Involving parents and carers

Communication was a major issue. Views on the role of parent forums were mixed. Most participants were aware that there was a forum but not all received information on its work. There was doubt about how much impact it could have in effecting change.

There was a feeling that communication with social services should be improved, and some suggestions about how this could be achieved. Some strong statements suggested that social services were a barrier to people with learning disabilities receiving services. Participants reported that their and their children's needs were neither listened to nor addressed. However, there was acknowledgement that social services were seeking to consult with parents and carers.

It was also noted that involvement in consultation processes had time implications for parents. Participants also suggested that some attempts to involve parents and carers amounted to tokenism.

Health services

There was a mixed response about both the knowledge and experience of health services received by participants and family members. There was a feeling that children received a comprehensive health service but that this stopped at transition.

Lack of awareness by healthcare staff was also commented on and is reflected in the wider literature (Learning Disability Implementation Advisory Group, 2006).

DISCUSSION

Comments on how parents and family carers felt about service provision were mixed. In general, these depended on the level of the learning disability, and the age of the person concerned and that of their carers. Parents and carers of family members who were younger and had fewer disabilities tended to have better experiences of service provision and appeared less stressed and dissatisfied. Negative comments about specific aspects were often reflected in the wider research.

Both researchers who facilitated the focus groups made sure all participants were aware of services available. The discussions were mainly concerned with social services.

The two-way nature of communication and the impact of its failure were evident. Parents and carers frequently complained about the lack of accessible, timely and

REFERENCES

Bogues, S. (2004) *Focus on Families: Messages from Family Carers. Review of Mental Health and Learning Disability. Northern Ireland.* www.rmhdni.gov.uk/pubs/focus_on_families.pdf

Learning Disability Implementation Advisory Group (2006) *Proposed Statement on Policy and Practice for Adults with a Learning Disability.* Cardiff: Welsh Assembly Government.

Redmond, B., Richardson, V. (2003) Just getting on with it: exploring the service needs of mothers who care for young children with severe/profound and life threatening intellectual disability. *Journal of Applied Research in Intellectual Disabilities*; 16: 205–218.

Swain, J., Walker, C. (2003) Parent-professional power relations: parent and professional perspectives. *Disability and Society*; 18: 5, 547–560.

appropriate information, saying they often had to be proactive in seeking it out. The second aspect of communication is the extent to which views of parents and carers are sought, listened to and acted on. Some positive comments were received but generally participants felt channels of communication were not working as effectively as they should to involve them in strategic planning.

Some parents expressed concerns about having to fight for services. Fears focused on what would happen when they were no longer able to support their relative. Such fears are a source of much concern, and need to be explored in more depth. Very few hopes, if any, were expressed for the future.

Even though some positive opinions were expressed about health services, most participants were less positive, suggesting they often had to deal with unprofessional behaviours and inappropriate care.

CONCLUSION

While some progress is evident, further development is needed for services to meet the needs of parents and family carers of people with learning disabilities. Developing effective mechanisms for seeking their views must be central to this process. ■

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