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Author: Dyke, Jan Hailstone, Joan

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Abstract

This article looks at the ineffective ways in which information has historically been collected from people with a disability and their families. Five issues raised by people with disabilities and their families in Queensland are discussed with the conclusion being that change needs to be based upon reliable information from people who are living out a lifestyle which is to be affected by change. The article promotes the importance of positive and effective exchanges of information between policy makers and service providers and people with disabilities and their families. **Keyword: Families**

QUALITY LIFESTYLES

FINDING OUT WHAT PEOPLE REALLY WANT

*Jan Dyke
Joan Hailstone*

There are always difficulties in trying to find out what people really want in life. In the past, most information about what people with a disability and their families want has been collected by asking the so-called experts who provide services to them. Now there is much greater recognition that people who are the users of services should be consulted about the types and the quality of the services they receive, rather than having such services thrust upon them, sometimes for life. There is also greater recognition that there is more to life than just services.

In spite of these important changes towards a user rights perspective and the unlocking of a lifestyle for people with a disability from service provision, very little attention has been paid to ways of finding out information from the users of services and their families. On the whole there has been little discussion generated about the problems inherent in the process of collecting and interpreting information from consumers.

The current modes of collection of information from people with a disability and their families tend to be by mass meetings or by expecting individuals to write in or to front up to a committee. In many instances, it is assumed that the service recipients are parents, with very little facilitation given to obtain direct information from the real service consumers, the people with a disability themselves. There are many very obvious problems associated with these methods of finding out information.

During the Quality Lifestyles Project of Queensland Parents of People with a Disability Inc., many concerns about consumer based research were raised by people with a disability, their families and advocates. There were five major issues which were seen to seriously affect the quality and nature of the information received. These were:

- Confidentiality of information
- Who is the user of the service?
- Information used against the consumer
- Perceptions of equity with others
- Something is usually better than nothing

Each of these issues is discussed further.

Confidentiality of Information

Usually information about one's life and personal aspirations is sensitive and private material. Most people do not feel comfortable giving such information in front of a public meeting or to people who have direct influence over one's life. Such influential people might include government officials, service managers and professionals as well as direct assistants and parents.

Information needs to be collected by people who will not divulge its source and who are seen to have sufficient credibility to warrant open and honest discussion. People who usually fit these criteria are either not involved in an influential position in the particular service and are therefore without a vested interest, or peers who have been through similar circumstances.

It is far more likely that people will be prepared to talk about personal and sensitive issues if they are in their own environment rather than in a formal office or meeting room which is someone else's territory. For this reason, the Quality Lifestyles team interviewed people where they felt most comfortable, usually in their own homes.

especially if funding is linked to such information. The consumer is keen to give the impression that they wish to continue as a user of that service, especially if no other service option is available to them.

The situation becomes rather like a mother asking her son or daughter whether she is an appropriate mother or not. If the answer given is yes, then any issues about the quality of the relationship are not addressed. Alternatively, if the answer is no, the relationship may totally disintegrate given that this mother is highly likely to be the only mother the person will ever have, appropriate or not.

This method of information gathering tends to confirm the status quo where alternatives cannot be openly discussed, obligation and gratitude are expected and fear of withdrawal of service can be generated if criticism is levelled.

Perceptions of Equity with Others

It is very easy for users of services to become locked into societal perceptions of what is expected of people. If people are devalued then the types of services they are given are likely to mirror their devaluation. There are many examples of how people with a disability are perceived as second class citizens and as a result have not achieved the rights that other citizens take for granted.

People with a disability and their families have been taught to accept some very inappropriate and poor standard services as their lot in life. Expectations have been equated with what they see other people with a disability and their families receiving, rather than with what other citizens in the community receive. When asked what type of services they need, it is therefore highly likely that the answer will be based upon people's perception of equity with others in similar circumstances.

Such questioning again maintains the status quo. Unless the reference group of people with a disability and their parents is changed to being other citizens rather than themselves, then they are likely to say they are satisfied if they are receiving a service which others in similar circumstances also receive.

The most obvious current example of this phenomenon is the mass migration of people with a disability from a special nursing home into community based supported accommodation. This move followed a small group's successful demonstration of this viable residential alternative. Before such an option was available, few people with a disability or their parents had considered it even feasible. Now many people in a similar situation are considering it not only feasible, but also their right to have a home in the community and are looking towards such a move now for themselves or for their son or daughter.

Something Is Usually Better Than Nothing

When people with a disability and their families have had no support or services and something becomes available, no matter how inappropriate, it is usually accepted with great enthusiasm. This way service provision which does not fulfil needs can be proliferated, with attempts to make the users of the service fit what is on offer and justify its cause.

This form of service provision is reminiscent of the old Procrustean bed where the ancient Greek hotelier stretched his guests or cut off their feet in order for them to fit his standard service. The rather horrific reality remained that the travellers needed a bed, the same way that people with a disability need a service. In some ways the consequences of not having a bed or a service were worse than the consequences of its inappropriateness.

To add to this problem over time, the users of the service don't even question its inappropriateness any more. They have learnt to accept it as their lot in life and can become its greatest defenders. In this role they can be used as pawns by unscrupulous service providers who can easily use emotive and vivid memories of no services to whip up support and fear of change.

Special arrangements often have to be made to ensure that trust and confidentiality are established and maintained.

For example:

- explaining why information is required and how it will be used.
- explaining that personal information will not go back to service providers or to parents in a way that the source would be recognised.
- explaining that the discussion was not part of some assessment for placement elsewhere.
- ensuring mechanisms that return how the information was used back to the people who have provided it.
- becoming familiar with people's usual methods of communication e.g. headpiece or light with a communication board, an electronic communicator, an interpreter, sign language, or speech which is difficult to understand.
- ensuring an advocate is present if a person so wishes.
- modifying the usual complex patterns of speech in order to be understood by people with an intellectual disability.
- doing things with people which gain their confidence e.g. having a cup of coffee, looking at a photograph album etc.

It is useful to be able to have direct contact with people with a disability and families via their own networks rather than having to rely on service providers teeing up consultations on behalf of a team. When service providers are used as the contact, a team can be seen as an arm of that service provision rather than being an independent source. This then can have a negative effect on the information received.

Who is the User of the Service?

Although some moves are being made towards consumers being asked what they want of services, many organisations have taken this to mean asking parents. This move can certainly be seen as a step in the right direction, however this approach does not address the needs of the person who is living out the lifestyle - the person with a disability. When the person is an adult it may be totally inappropriate to ask a parent, especially when the person is well able to put their own view forward for themselves.

There may be other times when both parties will need to be consulted. This situation occurs when the person with a disability has some means of verbal or non-verbal communication, but still requires a parent or an advocate to ensure that their wishes are heard, accurately interpreted and acted upon. In other circumstances only the parent or advocate will need to be consulted. This is especially when the person has such a severe disability that they are unable to communicate their needs to others by themselves or with assistance.

If this three pronged approach to gaining information is followed, then age appropriate services based upon quality information are more likely to be established.

Information Used Against the Consumer

Traditionally information about a service has been collected by the service organisation whose business it is to provide the very service which is under review. Such an approach usually means there is a vested interest on both sides. The service provider is keen to confirm that they are giving appropriate assistance,

CONCLUSION

Change is always a difficult process especially when a vested interested or a power base is involved. The new catch words of consumerism and empowerment assume a readdressing of the balance of power between all players in the service game: that means service providers, policy makers, people with a disability, families and other citizens of the community as well. However change needs to be based upon reliable information from people who are living out a lifestyle which is to be affected by change. Such information can only be elicited if people are freed from the constraints of poor and heavily biased information gathering processes.

The Quality Lifestyle consultations demonstrated that many people with a disability and their families were quite aware of the components which were part of such a change in values and practices. Many said they did not want stereotyping of services, they wanted options and choices. Many knew they had not failed when they were unable to find a service or were terminated from using one. Many knew they did not have to be grateful to a service which did not fulfil their needs. Many realised that assistance was a partnership, not control of one party over another.

Many people also talked about being seen as people first with the same rights and needs as other citizens. They often saw themselves as requiring ordinary services such as housing, work, leisure etc. in the community of their choice with the support they required to be part of that community. Such aspirations are very much in line with the principles and objectives of the Commonwealth Disability Services Act, yet the majority of people interviewed would not have known of that congruence. It was also clear that many people felt a real ambivalence towards their service providers. Often they admitted that they felt they should support them publicly but privately were prepared to voice their real concern about service providers' strong resistance to change.

If policy makers and service providers want reliable and constructive information which will lead towards positive change in lifestyles, then collection of information will need to be:

- consumer based
- where the consumer feels most comfortable
- individualised or in small peer groups
- from a person with a disability and/or their family or advocate
- by an independent source
- having peers interviewing peers
- giving opportunities for informed discussion and choice.

Unless these practices occur, the perception of people with a disability as poor unfortunates will continue, along with the belief that their few special needs are totally being met by charity and government assistance to expert service providers, who, after all, know what is best for them and their families.