

# Choice for People with Learning Disabilities and High Support Needs

## SUMMARY

*Some severely disabled people get no choices - about where to go, what to do, what to wear, when to go to bed...All those things are decided for them, without consulting them.*

Lloyd Page, Mencap volunteer<sup>1</sup>

The Choice Initiative, a programme of five innovative projects, explored how people with severe, profound and multiple learning disabilities, (to be referred to hereafter as people with high support needs) can express choices and take more control over their own lives. This initiative highlighted the crucial role of support staff in enabling people with high support needs to make choices. Staff in the projects established relationships of trust with participants and 'communication partnerships'. They in turn have required support and training.

For the people with high support needs in these projects, making choices was a very positive experience. If this is to happen more widely, there needs to be a culture in services and in society, of listening to people with high support needs. Furthermore, resources need to be allocated to facilitate choice.

## BACKGROUND

In 1997, the Foundation for People with Learning Disabilities funded the Choice Initiative. The Choice Initiative had its roots in *Building Expectations*, the Inquiry report into opportunities and services for adults with a learning disability. The Inquiry established the importance of choice. However, it was not possible to analyse to the same extent the additional needs of people with profound and multiple disabilities. Therefore, the Foundation invited applications that would explore how people with high support needs who used few or no words, could be listened to and supported to make choices in the area of daytime activities, friendships and housing.

## THE PROJECTS

**Pathways to Advocacy, based at the British Institute of Learning Disabilities, Kidderminster.** A part-time worker was funded to research and write a training resource for citizen advocates.

<sup>1</sup> All quotations are taken from the report of the Choice Initiative, *Everyday Lives, Everyday Choices*, due to be published by the Foundation for People with Learning Disabilities. Participants names have been changed.

**Choices at the Markfield Project, London.** A part-time project worker, sessional workers and volunteers were funded to enable people with high support needs to choose and access community activities.

**The Friendship Train at People to People, London.** Two facilitators were funded to support people to choose friends and access community activities.

**The Future Project at Choice Support, London.** A part-time worker enabled 10 young people to express their wishes about their futures during the transition process.

**The Step Out Project at L'Arche, Liverpool.** Two job trainers were funded to enable eight people with high support needs to choose work.

The work of the projects was monitored and evaluated in relation to the following issues:

- How participants expressed their wishes
- How choices were presented
- Whether options appeared to be meaningful
- How choices were supported
- The impact of choice on people's lives
- The nature of obstacles to choice.

## THE FINDINGS

*A key message...is that people with high support needs can make choices and can have control over their lives.*

- For many people choice is very limited. In most cases, participants chose to join the projects and saw them as an opportunity to extend their experiences.
- Establishing choices was time consuming. It was important to first build up a communication partnership and establish trust. It is helpful if people can be supported to record their preferences.
- Choices had to be presented in meaningful ways. For example, if someone was not used to making choices it was important to start with the familiar, such as choosing what to cook or for them to watch others doing things first.
- Other people close to the participant could support choices. They could suggest areas of interest and enable people to become involved. Choices sometimes had to be explored to see if they were valid and people had to be able to change their minds.

*Peter's first placement was as a handyman doing maintenance work at a training centre, but after two weeks he ran away, saying he did not want to go back. His next job [at a store] was a very different experience.*

- It was important that the choices were those of the person. Even if choices were difficult to hear, they had to be honoured. For example, in one project, an advocate realised that a move from a hostel to a new bungalow for the person was not working out. The individual became depressed. When he returned to the hostel he reverted to his normal and friendly self.

- Choice can involve risk. Many of the risks can be emotional ones. New experiences can prove daunting and open emotional doors. Risks need to be addressed sensitively and appropriately.
- Advocacy services are vulnerable and fragmentary, and many people are unable to have an advocacy partner. Yet they could play such an important role in supporting choice.
- The most difficult area in which to bring about change was in the area of facilitating friendship. As one worker said:  
*They have more structures around them...they need more people to work with them and support them... but it means that it is often hard to reach people.*
- Choices for most people were very positive.  
*Tina has relished the change in her life by enjoying local parks, cafes, pubs, swimming pools, museums and social events. Tina's mother has told us that she is laughing and smiling a lot now...*
- There are many obstacles to choice. Transport may not be available. People may not have much money for social activities. Residential staff may not be supportive. Family carers may understandably be worried about big changes in their sons' or daughters' lives.
- Good support, training and management structures were crucial. As John O'Brien writes:  
*These projects demonstrate that many people with substantial disabilities respond to project workers' interest in knowing them, accepting direction from them, and walking with them to open new possibilities. Over time, a number of people responded to project workers with trust and generosity, finding ways to share their interests and preferences with workers as they tried new things together.*

## THE IMPLICATIONS

*The policy for heightened community involvement is already solid. What remains is the really hard work of re-allocating existing resources and demonstrating one person at a time that providing inclusive community options for every person is possible and a means of achieving the national ideal of full citizenship.*

Barbara McIntosh

- People with learning disabilities and high support needs can become more independent and be part of their communities, as long as there are sufficient staff to enable them to lead fuller lives.
- Services should have procedures in place which enable them to listen to individuals.
- Voluntary organisations that support people to increase choices, including independent advocacy services, need more secure funding.
- Those commissioning and providing services need to ensure that there is a culture that promotes choice and values the friendships and relationships of people with high support needs.

- Services should operate risk policies and procedures that both keep people safe and provide for opportunities.
- Training and good management for frontline staff is crucial and needs to encompass values and attitudes, as well as skills and knowledge.
- Those who choose to access Direct Payments may have more choices. The benefits system needs to enhance rather than inhibit opportunities.

### Further reading:

Alaszewski, A., Alaszewski, H. & Parker, A. (1999) *Empowerment and Protection: The development of policies and practices in risk assessment and management in services for adults with learning disabilities* London: The Mental Health Foundation.

The Foundation for People with Learning Disabilities (2000) *Everyday Lives, Everyday Choices* London: The Mental Health Foundation

The Mental Health Foundation (1996) *Building Expectations: Opportunities and Services for People with a Learning Disability* London: The Mental Health Foundation

Series editor: Lisa Bird

For further information on *Everyday Lives, Everyday Choices*, for those commissioning and providing services, and a training resource, *Choice Discovered*, for frontline staff, please send an SAE to the Publications Department at the Foundation for People with Learning Disabilities.

***This Update was written by Hazel Morgan, Programmes Manager of the Foundation for People with Learning Disabilities.***

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