

User Led Organisation/ Centre of Independent Living in Telford and Wrekin

A Briefing Paper

Introduction

This paper aims to brief colleagues who are involved in the development of a User Led Organisation (ULO) and a Centre of Independent Living (CIL) for disabled people in Telford and Wrekin.

Improving the Life Chances of Disabled People

In January 2005, the Prime Ministers Strategy Unit published its report "Improving the Life Chances of Disabled People", aimed at achieving full equality for disabled peoples by 2025 in a long term strategy to be implemented as future government policy.

Recommendation 4.3 in this report states;

By 2010, each locality should have a user led organisation, modelled on existing Centres for Independent Living.

Local Background

Locally, The Physical and Sensory Disabilities Partnership Board members discussed both the implications and impact this recommendation will undoubtedly have. Recognising that this will have an impact on all client groups with disabilities, a report presented to the Adult Health & Well Being Partnership highlighted this recommendation and brought it to the attention of a wider audience.

The outcome of this presentation was a partnership project between the Council/Primary Care Trust (PCT) and the Council for Voluntary Service (CVS) to commission a feasibility study looking at the development of a user led organisation in Telford that leads on a centre of independent living.

The Aim of the Project

To undertake a Feasibility Study looking at the development of a user Led Organisation /Centre for Independent Living for all Disabled People in Telford and Wrekin and to recommend the most effective approach to achieve this.

Transformation of Adult Social Care

The Governments intention and vision to transform adult social care was set out in the Department of Health's Green Paper, "Independence wellbeing and choice" and further reinforced in "Our Health Our Care Our Say"(2006).

This document argues for change recognising that sometimes the design and delivery of services can lead to disabled people having less control creating dependence rather than independence.

Recently, the approach was confirmed in the Putting People First agreement which highlighted the need for agencies to work together to achieve transformation in the way services are delivered.

Therefore, the values and aspirations of the Putting People First program and the philosophy of a User Led Organisation driving independence and social inclusion through a Centre of Independent Living are working towards the same outcomes of greater choice and control for disabled people.

Definition of User – Led Organisations

User - led organisations are run and controlled by disabled people and will be a vital part of the implementation of a new approach to supporting social inclusion and independent living.

User - led organisations are those where the people who the organisation represents or provides a service to, **have a majority on the management board or committee**, and where there is clear accountability to members and/or service users (Morris 2006).

This means that more than half of the management committee must be disabled people, carers and other people who use the service.

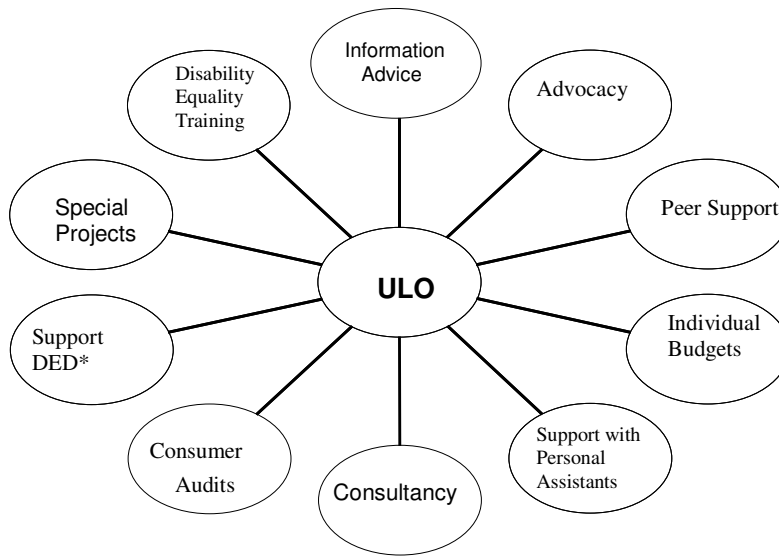
Centres of Independent Living (CIL)

Centres of independent living are grass roots organisations run and controlled by disabled people. Their aims are that disabled people should have control over their lives and achieve full participation in society. They work towards these aims by representing disabled peoples views both nationally and locally, and by providing services which promote independent living. (Morris 2006)

The exact natures of the services provided by these local centres of independent living will vary according to local circumstances but, at a minimum, the organisation should provide;

- information and Advice
- advocacy with peer support
- support in using individual budgets (including cash payments) to meet needs
- support to recruit and employ personal assistants
- disability equality training
- consumer audits of local services and support the implementation of the disability equality duty by public sector organisations in the locality.

A User Led Organisation leading on a CIL could look like this



* Disability Equality Duty

National Research

National research has concluded that many disabled people feel it is not possible for one Single organisation to cover all the activities a centre of independent living need to have, or that one organisation covers all the different “groups of users” (ie; people with a learning disability, sensory and visionary impairment, mental health etc).

Disabled people thought a network of local organisations in each area could fulfil the requirements for a Centre of Independent living and connect together through a partnership of local groups meeting common aims and objectives.

This can take different formats including;

- a federation or consortium of organisations, or an organisation in its own right.
- it could be building based “one stop shop” or could be a “virtual centre” ie a website acting as a “contact centre”

Examples of National Centre of Independent Living

1. Disability Connects is a network of disability related organisations that aim to work together across the different impairment related boundaries to create change for disabled people.
2. Breakthrough UK was set up to provide training, employment and business opportunities for disabled people. Run by disabled people as a User Led Organisation it was initially funded by Manchester City Council , then became a limited company and now has contracts in Manchester and Liverpool to provide employment, training and independent living opportunities for disabled people.

Local Research

It is recognised locally, that to achieve the vision behind the Life Chances recommendation there is no single model that can be applied everywhere.

Local environmental factors and the availability of resources will determine to some extent determine how an organisation is developed and run.

In Telford the foundations of a formal network already exists through the joint work done by organisations representing different service user groups.

Examples of this include;

- The Councils Disability Forum that has a Steering Group made up of local Voluntary and Community Sector disability groups and individuals who have led on developing and monitoring the Councils Disability Equality Scheme and action plan.
- Advocacy Forum who are local Voluntary and Community Sector groups who are identifying gaps in service and looking at funding opportunities.

These are all functions of many of the Centres of Independent Living led by disabled people.

What happens next

An event is taking place for the 9th January 2009 9.30 – 13.00 at the Park Inn Telford.

The Corporate Director of Adult and Consumer Care Richard Webb and Deputy Leader and Cabinet Member for Adult and Consumer Care Jacqui Seymour will be leading on a workshop style event to listen and collect your views on your vision for a User Led Organisation and Centre of Independent Living in Telford and Wrekin.

At the event, different models based on national policy and research will be presented. You can contribute by looking at the strengths and weaknesses of each model and discussing how local Voluntary and Community Sector organisations can further contribute to the independence of local disabled people and move this agenda forward.

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Reference

Morris J (2006) Centres for Independent Living /Local User Led Organisations; A discussion paper