



reading about

Introduction

With the increasing emphasis on mental health promotion through the National Service Framework (NSF) for Mental Health, the publication of a series of articles on self-help resources and information is both topical and relevant.

The Department of Health recently (2001) issued a report, *Making It Happen*, that provides a range of information to support those people working locally to promote mental health, with a specific focus on delivering Standard One of the NSF. This report reminds us that Jorm *et al* (1997) found a clear gulf between public and professional beliefs about mental health problems but argues that an improvement in mental health literacy will be an important contributor to the success of prevention, early intervention, self-help and support for people with mental health problems in the community (Jorm *et al*, 2000).

Historically the emergence of many self-help organisations was a welcome response to what many people saw as 'medical paternalism' and lack of information and support for patients and their families.

When the College first published the 'Depression' Help is at Hand leaflet more than 10 years ago, there was a paucity of mental health promotion materials (<http://www.rcpsych.ac.uk/info/help/dep/>). The existing materials at the time were antimicrobial and antipsychiatry in tone. Now, there is a proliferation of self-help organisations for almost every physical, neurological and mental disorder. Virtually all the organisations in the mental health field have produced training and self-help materials for service users, carers and professionals, all of variable quality and promoting sometimes contradictory messages. So for the ordinary person in the street, finding reliable information can be very difficult.

With the development of electronic media it has become increasingly confusing for patients and their carers to know which sites are relevant or provide accurate and helpful information – is some form of regulation on the cards?

We hope that you will find this series of articles on self-help resources helpful.

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Self-help resources for adults with a learning disability

People with a learning disability are increasingly having their skills recognised as well as their disabilities. A wide variety of resources are now available that harness these abilities and enable people with a learning disability to help themselves. In this review, we cover resources that deal with mental health problems, coping with psychosocial changes, getting proper access to health services and self-advocacy. In a future Reading about review Regan and Hassiotis (2001) will describe resources available to children and families and give detailed self-help resources for people who have particular syndromes such as Down's syndrome or fragile X syndrome.

Mental health problems

There are few self-help resources available that specifically address mental health problems in people with a learning disability, and we review all that we have found. The Royal College of Psychiatrists has published one leaflet about mental health problems in people with a learning disability, which is available on their website (<http://www.rcpsych.ac.uk/info/learning.htm#leaf>). The leaflet is appropriate and useful for carers because depression can be difficult to recognise in people with a learning disability. It is not suitable for people with a learning disability to use because of the complexity of the language.

A book that describes the experience of depression from the perspective of an adult with a learning disability is *Feeling Blue* (Hollins & Curran, 1995). This is one of a series of self-help books for people with learning disabilities called Books Beyond Words. These all rely on pictures to tell a story about someone with a learning disability experiencing a particular problem or life change. They use a system of 'key colours' to illustrate emotions, in addition to other non-verbal signs such as facial expression and body posture. They are designed to be used flexibly, with support from carers as appropriate. *Feeling Blue* can also be used as a communication aid in psychiatric consultations, as it contains scenes illustrating various symptoms, and illustrates different treatment options.

An alternative resource that does not focus on specific mental illnesses but can be useful in evaluating someone's mental state is *Exploring your Emotions* (Holland *et al*, 1998). This is a set of 30 photographs (plus manual) that can encourage people with learning disabilities to describe their own emotions.

We have designed a series of eight leaflets about psychotropic medications for people with mild and moderate learning disabilities (Strydom *et al*, 2001). This was with the aim of improving these people's ability to consent to treatment. The leaflets were designed using a rigorous user consultation process, and were systematically evaluated using a single-blind randomised controlled trial methodology (Strydom & Hall, 2001). They are published by the Elfrida Society (<http://www.elfrida.com>).

Psychosocial problems

There are many more self-help resources that address the varied psychosocial problems that people with a learning disability may experience. These can play a very significant role in the aetiology of mental illness, and can be usefully explored as part of treatment. The Books Beyond Words series covers a variety of such issues. These include, for example, bereavement (Hollins & Sireling, 1989), sexual abuse (Hollins *et al*, 1998) and relationship problems (Hollins & Roth, 1995). Again these books can be used in different ways, both in a formal therapeutic context and as a more informal aid to communication.

Many people with mild learning disabilities become parents. The experience is often positive, but it can be traumatic if the parent has not had the opportunity to develop appropriate skills. The *I Want to be a Good Parent* series (McGaw, 1995) may help address this. It includes five booklets with supporting audiotapes and illustrated cards, and covers issues such as feeding, safety, child health and emotional development. Another such resource, *Being a Parent* (Booth & Booth, 1998), is produced by the Norah Fry Research Centre.

Moving house or changing accommodation is a frequent occurrence in the lives of people with a learning disability. The closure of institutions precipitated many such moves, but they continue to happen even now when most mental handicap hospitals are closed. This is often a major life event, and resources are available to prepare people for it. The Plain Facts (<http://www.bris.ac.uk/Depts/NorahFry/PlainFacts/Index.html>) and the British Institute of Learning Disabilities (BILD; <http://www.bild.org.uk>) websites



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list resources dealing with housing and support issues.

Drug and alcohol misuse may also become a problem when people with a learning disability have access to these substances in the community. The Elfrida Society has developed a *Drug Pack* (Forster, 2000) for people with learning disability. The pack contains 12 leaflets describing a range of misused drugs, using simple text, illustrations and photos, as well as a supporting handbook that explores drug-related issues in more detail. *Coming for a Drink?*, in the *Healthy Living* series (Band, 1998), promotes sensible alcohol use. People with learning difficulties have piloted these booklets, but the publishers recommend that staff and users use them together.

Access to health

Some resources that promote access to health for people with a learning disability focus on specific conditions. The BILD publishes a series of three booklets about HIV and AIDS, one of which is designed to give practical advice to service users with learning disabilities (Cambridge, 1996). Epilepsy is common in people with learning disabilities and resources are available in both the *Healthy Living* series of booklets (Band, 1998) and the Books Beyond Words series.

Other resources aim to help guide people with a learning disability through the often complicated process of accessing health care. Two of the Books Beyond Words address this issue. Other resources include *Your Good Health* (BILD, 1998), a set of 10 illustrated booklets to inform people with a learning disability about health issues. The booklets explain how to get help for a variety of health problems. The Elfrida Society, in conjunction with specialist clinicians, has created medical procedure leaflets for having a computed tomography scan, magnetic resonance imaging, blood tests and electroencephalogram (Forster *et al*, 1999).

Self-advocacy

People with a learning disability are increasingly making important decisions about their own lives. The medication information leaflets for people with a learning disability that we developed were designed to enhance our patients' ability to consent to medical treatment. Other resources address wider self-advocacy

skills. Most are aimed at staff and professionals or carers, but some can be used by people with a learning disability themselves. BILD and Plain Facts list such resources on their websites.

Sexuality and personal relationships are another area where self-advocacy is important, and a variety of resources are available to help people with a learning disability make informed choices. One example is *Your Rights about Sex* by McCarthy and Cambridge (1996). This was developed following substantial research projects investigating sexuality in people with a learning disability. It addresses rights and responsibilities that many of the research participants did not know about.

People with a learning disability are often victims of crime, and Plain Facts have produced an information package to increase awareness, called *Crime and Abuse* (Williams, 1998). This is available on their website, and includes a spoken version that can be played with suitable software.

Discussion

There is a considerable range of self-help resources available for use by people with a learning disability, but the following caveats should be borne in mind before recommending their use.

First, people with a learning disability will very often need support in using these resources, so it is misleading to describe them as 'self-help' resources. This support can range from being on hand to answer queries, to a psychotherapeutic relationship.

Second, any of these resources have considerable face validity and have been piloted by user groups, but few have been formally evaluated. When we conducted a randomised controlled trial of drug information leaflets specifically designed for people with learning disabilities, we found that our leaflets may confuse some people (Strydom & Hall, 2001). This led to us modifying the leaflets and also the advice we gave about their use. If other resources were similarly evaluated, their usefulness might be shown to be less than initially thought.

In our search for resources, we found none that address specific mental illnesses, with the exception of depression. It would be useful to develop resources that explain common illnesses such as schizophrenia, bipolar disorder

and anxiety as well as psychological and medical treatments. We also had difficulty in finding out about some of the resources reviewed here, and most websites and resource libraries would be inaccessible to people with learning disabilities. We would like to see improved access to information resources, particularly on the internet, for those with learning disabilities.

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