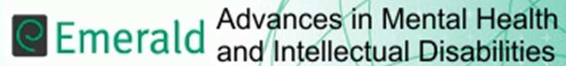


# The Case for Guided Self Help for People with intellectual disabilites


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|---|---|
| Journal: | *Advances in Mental Health and Intellectual Disabilities* |
| Manuscript ID | AMHID-10-2016-0030.R1 |
| Manuscript Type: | Personal View |
| Keywords: | Intellectual Disability, Guided self-help, Mental Health, Psychological treatments, Depression, anxiety |
| | |


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# The Case for Guided Self Help for People with Intellectual Disabilities


## Abstract

### Purpose

This article examines Guided Self-Help (GSH), and some of the barriers as to why it is not routinely available for people with intellectual disabilities (ID).

### Design

This article offers an overview of GSH and the potential benefits of it as an intervention for people with ID with mild depression and/or anxiety.

### Findings

The current literature reports the successful use and effectiveness of GSH in the general population. However despite this there is little evidence that it is being used in practice for people with ID.

### Originality

This paper offers an overview of GSH and advocates for its increasing use for people with ID to help bring about equality in mental health care.


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## Introduction

It is accepted that people with intellectual disability (ID) have higher rates of mental illness. Indeed it is estimated that between 20.1% -22.41% of adults will experience mental illness (excluding challenging behavior (CB) (Cooper, Smiley, Morrison, et al, 2007). This compares to an estimate of 16% in the general population (Department of Health, 2003). This article looks at Guided Self-Help (GSH) and examines why it is not being made routinely available for people with ID, in spite of evidence of its efficacy in the general population. GSH is fast becoming an important intervention for the management of common mental health problems such as depression and anxiety (National Collaborating Centre for Mental Health, 2010). However there little evidence to suggest this treatment is available to or being developed for people with ID is  Mild depression and anxiety are the targets of GSH, however often these conditions can be overlooked, both people with ID and in the general population, where it is estimated that a third of people with depression and half of those with anxiety are undiagnosed and therefore not treated. This has a financial and human cost with milder forms of depression and anxiety being associated with increased risk of mortality (Russ, Stamatakis, Hamer, et al, 2012).

National Policy such as the Green Light Tool Kit (National Development Team for Inclusion, 2013) has attempted to improve mental healthcare for people with ID and drive the mainstream agenda of equitable access to mental healthcare. For many there is still difficulty accessing mental health services and those that do are less likely to receive psychological treatments (Michaels, 2008). Paradoxically the availability of psychological interventions for people with ID with a range of less intrusive person centered treatment options being available. Indeed only a decade ago ID was an exclusion criterion in studies evaluating psychological treatments. Mason, (2007) puts forward five factors that are believed to influence psychological therapy outcomes:

- the perceived effectiveness of clinicians
- individual clinician competence
- how well the service is resourced in terms of the  number of clinicians
- the level of the client's disability
- the presence of diagnostic overshadowing bias.

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However in spite of a growth in the availability of psychological therapies for people with ID, a reliance on proxy based reporting has meant that self-report options have traditionally been ignored (Fujiura, 2012).

**Barriers to psychological treatments and GSH**

There is little in terms of self-help materials available to people with ID outside the context of individual psychological therapy. Internet GSH, may not be an option for some as they cannot be easily accessed; other GSH programmes may require high levels of health literacy about a condition e.g., depression, which could exclude people with ID. People with ID may lack opportunities to engage in or to enjoy activities that enhance or protect their mental wellbeing. Given a lack of accessible GSH materials there are a number of things to be aware of when providing treatment such as difficulty in comprehension, being able to understand their feelings and emotions or conceptualise. e.g. guilt, low self-esteem or self-worth. The inability to articulate or the clinician's style of questioning or basic awareness of ID can mean these complex emotions are missed and therfore not considered.

For those who do access treatment a lack of knowledge of the needs of and how to support people with ID can lead to treatment failure and fuel the idea that these types of treatments do not work and are of little use. Reasonable adjustments are required to enable equitable access to healthcare and health outcomes. These factors should not be a barrier to treatment, but something that needs to be considered when planning treatments. For example a clinician might ask a patient with ID to complete an online measure of depression as part of their commitment to offering equal access to services. However if they cannot read or can't understand the questions they will be unable to participate. Adding a reasonable adjustment such as a voiceover or access to someone who can support the activity is likely to contribute to a better health outcome and ensure equity.

**What is GSH**

The NICE Guidelines (GG90) (National Collaborating Centre for Mental Health, 2010, p182) define GSH as,

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"… a self-administered intervention designed to treat depression, which makes use of a range of books or other self-help manuals derived from an evidence-based intervention and designed specifically for the purpose. A healthcare professional (or paraprofessional, for example, graduate and low-intensity workers in mental health) facilitates the use of this material by introducing, monitoring and reviewing the outcome of such treatment.

The use of low-intensity interventions such as GSH to treat mild depression and promote positive mental health, mean that many people do not need or go on to receive more intrusive treatments, that may produce unwanted side effects and that are less well tolerated. GSH allows the involvement of others who are important to the person to support them either formally or informally in line with Recovery principles (Lovell & Richards, 2008), allowing self-management of symptoms where possible to reduce dependence on services (Lovell, Bower, Richards*, et al*, 2008). There have been attempts to standardise the implementation of GSH within the United Kingdom, although there is as yet no consensus. NICE (2010) and the Scottish Executive (2006) both identified four essential components of GSH:

| **NICE (2010)** | **Scottish Executive (2006)** |
|---|---|
| • frequent support | • information on common mental health problems |
| • minimum support, | • advice and coping |
| • group psychoeducation | • self-directed structured plan |
| • support by mail | • supported self-help |

According to NICE guidelines, individual GSH programmes based on Cognitive Behavioural Therapy should:

- Include the provision of written materials of an appropriate reading age (or alternative media to support access)
- Be supported by a trained practitioner, who typically facilitates the self-help programme and reviews progress and outcome

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- Consist of up to six to eight sessions (face-to-face and via telephone) normally taking place over 9 to 12 weeks, including follow-up.

(National Collaborating Centre for Mental Health, 2010, pp., 13-214).

**Evidence for GSH as an effective Mental Health Intervention**

Research into GSH in ID is poor. There are case studies that have focused on self- and the use of techniques and strategies involving diaries, self-monitoring and relaxation exercises, which are completed as homework, following individual or group sessions. These studies have demonstrated that people with ID are able to use and benefit from self-help techniques central to GSH. Taylor (2002) reported twelve studies (1986–2002) the majority of which focused upon skills training within a cognitive behavioural framework, using self-instruction and interpersonal problem solving aimed at addressing cognitive deficits, rather than to modify cognitive content and distortions. These studies measured a number of variables, including anger, aggression, self-esteem and depression. Although not all participants showed a decrease in these behaviours, there was evidence of measurable improvements for participants.

In the general population, studies of GSH using CBT techniques have reported positive outcomes and have been endorsed by the Government as an effective means of combating depression (Department of Health, 2001a). The evidence base for GSH has been subject to a number of reviews. The NICE guidelines (National Collaborating Centre for Mental Health, 2010, pp. 184-187) reviewed 18 book based GSH using Randomised Controlled Trials (RCT) methodology. Two of the studies reported a beneficial effect for those with mild depression and sub threshold depression, trending towards statistical significance. The five studies characterised by frequent support with minimum duration reported a large effect when reporting reduction of depressive symptoms with waiting list controls. The other studies considered had insufficient data and wide confidence intervals, to be able to reach any meaningful conclusions. Of the eighteen RCTs reported in the NICE guidelines that met inclusion criteria, two examined individual GSH with guided support, ten individual with minimal support, three groups GSH (psycho education) and three GSH by mail.

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Gellatly, Bower, Hennessy*, et al* (2007), examined the role of moderators on effectiveness of GSH e.g., patient populations, study design, intervention content and compared RCTs versus controls in the treatment of depressive symptoms. Thirty-four studies were identified which included 39 comparisons. Greater effectiveness was associated with a number of factors including: recruitment outside of clinical settings, those with a diagnosis of depression rather than people at risk of depression and use of CBT techniques. In terms of delivery, Lovell, Bower, Richards*, et al* (2008a) found no evidence that the number of sessions or how GSH was delivered e.g., mail, computer face to face was related to outcomes. However outcomes improved when GSH was based on CBT and those with mild to moderate depression were found to do better than those with a more severe clinical presentation.

Since the NICE guidelines on depression were originally published both GSH and self-help have received greater recognition and acceptance as a legitimate treatment modality for depression (IAPTs, 2010). There has been further guidance published to help those facilitating the treatment and to distinguish it from other interventions. IAPTs (2010) has given guidance on developing self-help materials, which includes that they are technically accurate, engage with the person and maintain that engagement, the sessions reflect the persons own life and provide a structure so that they can see change bought about by the treatment. For this to happen it is necessary that appropriate materials are available to support the person during the intervention.

**Psychological input and GSH for people with ID**

There is evidence that people with ID not only can benefit from, but can be instrumental in developing new approaches with clinicians e.g. The SAINT (Chaplin et al, 2014, 2017). The SAINT is a GSH resource for people with ID, presented in an easy read format, designed to encourage people with an ID to recognise and identify their feelings, particularly those that may cause or lead to distress and impact on the person’s daily lives and mental health. The person is encourages with or without support to identify their feelings and following this is asked to select an appropriate coping strategy or intervention from a checklist to use. The person also

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has a diary which can be used to record not only their feelings and what strategies they used to cope, but also the things they may have done well or enjoyed during the day. This provides an insight into a person's mental health over time, and can assist families, carers and professionals to not only monitor threats to mental wellbeing, but also to see the effects of any coping strategies used. Currently the SAINT is being tried in clinical practice and we are to await the report (Russ, 2016). In addition the author has received reports of its use in local services not only to provide GSH but to act as a structure for nurses to base 1:1 or group sessions they have with clients with ID and to assist treatment goals such as problem solving and teaching good mental health strategies. In terms of feedback from those receiving the SAINT, below is a selection of comments

"I like the coping strategies"

"I just used the book any time I get depressed"

"I use it during the day if I got staff I can talk to. Some staff can be sort of thing, not very understanding"

"I have found it very good and found it very helpful a lot of people have written down feeling diaries sad and helpless sought of thing and has helped me with my moods as well"

**Conclusion**

There is a considerable burden of mental health for people with ID and it is only in recent history that psychological treatment options such as GSH have been explored. Self-help and GSH have been found to be effective in the wider population and the absence of specific evidence of its effectiveness relating to people with ID should not preclude its use, providing reasonable adjustments are made.

People with ID are more at risk to mental health problems. These conditions can be difficult to detect and therefore can go unnoticed. There are a number of reports of the successful use of various self-monitoring and stress management techniques including symptom diaries and the use of strategies aimed at reducing distress that are consistent with GSH approaches. There are few GSH materials available for people with ID. However early evidence of the SAINT demonstrate that people with ID can engage and use this intervention to improve their health and mental

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wellbeing. The use of low level treatments such as GSH should be made more widely available for people with ID particularly given the evidence for its effectiveness in the general population.

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