

Abstract

Background

Psychological therapies with a proven efficacy in the general population are being adapted for use with people who have intellectual disabilities in community settings.

Methods

A systematic review of peer-reviewed literature published between 1980-2010 was carried out, to identify the evidence base for effective psychological interventions in challenging behaviour. Relevant databases were searched using applied key terms. Evidence was graded, according to the quality of the research. A best-evidence Matrix was produced to improve guidance for service providers and practitioners in the range, volume and quality of psychological interventions.

Results

There is a limited amount of efficacy research that meets the most stringent standards of empirical evidence.

Conclusions

It is important to broaden the evidence base and consider the context of psychological interventions, alongside the values underpinning care and treatment.

Introduction

Whilst the move from larger scale to community based models of care for people with intellectual disabilities in Scotland has led to an improved quality of life, there is a concern that existing services have difficulty supporting adults with the most serious challenging behaviours (Emerson et al, 2000; Kiernan, 1993; Allen 1999; Stalker and Hunter, 1999; RCP/BPS/RCSLT, 2007; Emerson & Enfield, 2011).

Using an evidence base in relation to effective interventions in health and social care is not new. There are a large number of “what works” reports, identifying the best research evidence and benefits of particular interventions used in the management of specific mental health conditions in the UK (e.g. Royal College of Psychiatrists, 2008; National Institute for Health and Clinical Excellence (NICE), 2011; DHSSPS, 2010; Scottish Government, 2008). It is only relatively recently however, that attempts have been made to interrogate such an evidence base and apply it to mental health conditions in people with intellectual disabilities. (e.g. APA Presidential Task Force on Evidence-Based Practice, 2006; Royal College of Psychiatrists/ Royal College of General Practitioners, 2008).

The evidence related to pharmacotherapy and psychological treatment is, in general, either lacking or poor. This does not suggest that these treatments are necessarily ineffective but that there is not enough good quality evidence to support their usefulness. (Antonacci, Manuel & Davis, 2008)

In the absence of a credible evidence base for psychological *or* psychopharmacological interventions, medication continues to be prescribed widely for challenging behaviour (Cullen, 2000; Ahmed et al, 2000; Verhoeven & Tuinier, 1999; Brylewski & Duggan, 1999; Emerson, Robertson, Gregory et al 2000; Royal College of Psychiatrists, 2006; Emerson & Enfield, 2011).

In December 2008 the Scottish Government published “*The Matrix - A Guide to delivering evidence-based Psychological Therapies in Scotland*”. The Matrix was produced to help National Health Service authorities in Scotland to efficiently deliver the range, volume and quality of psychological therapy required for the effective treatment of common mental health problems. This was part of a

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larger, national health improvement initiative to establish and measure waiting time targets from referral to treatment for psychological therapies (Scottish Government, 2011a, 2011b). In 2010 the Scottish Government commissioned a review of effective psychological therapies in relation to adults with intellectual disabilities, as an extension of the original evidence Matrix. The diagnostic model used to structure the document presented some conceptual difficulties for those more familiar with psycho-social or constructionist thinking rather than medical or biological models, but the editor permitted use of the problem category of “challenging behaviour” as representing a significant area of business for those providing services to people with an intellectual disability. This paper reports on the evidence for effective psychological interventions in relation to adults who have intellectual disabilities and challenging behaviour, and how plausible it is for clinicians to use these interventions in everyday practice.

For the purposes of this review a working definition of challenging behaviour was used:

“behaviour of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion.” (Royal College of Psychiatrists/British Psychological Society/Royal College of Speech and Language Therapists, 2007)

This definition does not address the needs of children, older people or adults who commit offences (forensic) (RCP/BPS/RCSLT, 2007)

Challenging behaviours are more prevalent in individuals with intellectual disabilities, and the likelihood of challenging behaviours increases with the severity of the disability (Borthwick-Duffy 1994; Janssen, Schuengel & Stolk 2002; Chadwick, Kusel & Cuddy, 2008) and with prevalence of mental health symptoms (Moss, 2000). For example, in a prevalence study of 1023 people with intellectual disabilities, Cooper et al (2007) found 22.5% of the sample had a clinical diagnosis of “problem behaviour”. Typical examples of challenging behaviour in people with intellectual disabilities include physical aggression, disruptive or antisocial behaviour, stereotyped and repetitive behaviour and self-injurious behaviour (SIB). These behaviours reduce a person’s quality of life, present barriers to community and social integration and have resource implications for specialist accommodation and support services (Totsika & Hastings, 2009; Broadhurst & Mansell 2006; Moss,

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Bouras & Holt, 2000; Macleod et al. 2002; Mansell, McGill & Emerson 2001; Thompson & Reid 2002; Totsika et al, 2008).

There is a growing, but still limited body of evidence on the effectiveness of psychological therapies for people with an intellectual disability and challenging behaviour (Emerson, 2006; Irvine, McCusker, Coulter et al., 2011). In 50 years this evidence base has moved interventions from basic “*reliance on psychopharmacological restraint and operant conditioning*” (Rhodes, Whatson, Mora et al, 2011), to more enlightened and needs led approaches.

An evidence based approach aims to transfer research findings into practice, on the basis of their effectiveness, safety and ethical acceptability. The most recent best-practice guidelines in the UK (RCP/BPS/RCSLT, 2007), references reviews and meta-analyses of the evidence for the effectiveness of psychodynamic, cognitive-behavioural and cognitive therapies. Generally the evidence supports the effectiveness of these therapies for adults with mild intellectual disabilities and, in much smaller numbers, for people with more severe intellectual disabilities. These psychological interventions have been defined previously as:

“attempts to make changes in people, their behaviour, the systems around them or their interpersonal relationships, using methods derived from a psychological knowledge and understanding of individuals and their world.” (p. 69, BPS 2004)

In common with other groups of service users requiring multi-disciplinary support, there is a great deal of co-morbidity: challenging behaviour and mental health problems often occur together (Cooper et al, 2007; Cooper & van der Speck 2009). Individuals described as having intellectual disabilities are a heterogeneous group, and those with more significant impairments may be unable to report their symptoms, making it difficult to use existing diagnostic categories. The referral route for people with an intellectual disability is also different and they rarely refer themselves for professional help, relying on others to identify their problems and seek professional input on their behalf (Willner, 2005; Taylor, Lindsay & Willner, 2008).

Psychological therapies with a proven efficacy in the general population are being adapted for use with people who have intellectual disabilities, with varying degrees of success. The amount of adaptation needed has to be commensurate with the severity of the disability and some interventions are more suitable for adaptation than others (Royal College of Psychiatrists, 2004; Taylor, Lindsay &

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Willner, 2008; Brown & Marshall, 2006). It is also evident that the *pace* of therapeutic change for people with intellectual disabilities is likely to be slower than for the general population or other care groups. Consequently, interventions are likely to take longer and require delivery at a higher level of intensity (number of treatment sessions or period of time over which treatment occurs) than equivalent interventions in the general adult population.

This paper takes as its starting point the review of the literature carried out for the Scottish Government to produce the Matrix concerning the delivery of psychological interventions for people with intellectual disabilities presenting challenging behaviour. However, stringent criteria were set for levels of acceptable evidence for the Matrix, with randomised controlled trials being the “gold standard”, followed by well conducted clinical trials without randomisation. However, as the highest levels of evidence trump lower level studies, only a sub-section of papers are presented in the Matrix to provide evidence of the efficacy of different interventions. Moreover less rigorous research, such as single case studies, were excluded from the Matrix. The aim of this review was to offer a more comprehensive account of the studies identified in the literature search.

There are several reasons for taking this different approach. In the first instance, there are significant ethical and logistical obstacles to carrying out randomised control trials with people who have intellectual disabilities and challenging behaviour. These issues have been discussed by Oliver et al (2002), and include the difficulty of recruiting sufficient numbers of participants for purposes of statistical power, and the heterogeneity of the population. Hence, there is a very limited number of randomised control trials in this area, and a focus on higher-level evidence might also mean that a number of promising clinical innovations are missed.

Another reason for including the full range of studies identified in the search is that this paper is concerned not only with evidence of efficacy, but also with the *translation* of the evidence base to everyday clinical practice. Victora, Habicht and Bryce (2004) make the distinction between ‘probability’ and ‘plausibility’ when discussing how public health interventions should be evaluated. They argue that whilst trials provide evidence about the probability of an intervention being effective,

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if these interventions are going to be translated into everyday practice then more information is required about the mechanisms of change, including contextual factors that influence outcome. Observational studies or single case studies might play a role in identifying motivational or interpersonal factors crucial to the success of an intervention for challenging behaviour. For example, how the therapist engages with the family or staff team to ensure they are motivated to carry through an intervention could be crucial to the completion of such an emotionally taxing task. Hence, the aim of this review is to analyse further the evidence about the effectiveness of interventions in the Matrix produced for the Scottish Government. The main research question is whether the inclusion of apparently weaker evidence would inform the practice of staff working on a daily basis with people with serious challenging behaviours.

Methods

A systematic review was conducted on peer-reviewed literature published between 1980-2010, to identify the evidence base for psychological interventions used with people who have intellectual disabilities and challenging behaviour.

For the purposes of this review a working definition of challenging behaviour was used:

“behaviour of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion.” (Royal College of Psychiatrists/British Psychological Society/Royal College of Speech and Language Therapists, 2007)

In addition, the inclusion criteria for papers specified that the level of challenging behaviour presented by participants should be considered complex and enduring, requiring a Secondary level of Care such as that provided by in-patient services and specialist community health services in the UK's NHS (Simpson, 1995). Only papers written in English were included.

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The search was conducted using the databases ERIC, PsycINFO, PsycARTICLES, Web of Science MEDLINE, Cochrane Library and follow-up hand searches. Applied search terms were combinations of:

"psychological ther*" OR "psychological interv*" OR "psychotherap*" OR "behav* therap*" OR "treatment*"

AND

"learning disab*" OR "disab*" OR "retard*" OR "handicap*" OR "mental handicap*" OR "intellectual* disab*"

AND

"challenging behav*" OR "evaluat*" OR "review*" OR "effacac**" OR "effective*" OR "outcome*" OR "meta*"

The search was augmented by additional citations obtained from books and journal articles. The literature identified in this search was then further interrogated for research articles specific to adults and involving intervention characteristics and intervention effects. The available evidence was then categorized using standards set in The Matrix of Psychological Therapies for people with common mental health problems (Scottish Government, 2008). Articles were independently rated by the main and contributing authors, and the grading of evidence was done using A, B or C levels as follows:

A - At least one meta-analysis, systematic review, or randomised control trial of high quality and consistency aimed at people with intellectual disabilities and challenging behaviour.

B – Well conducted clinical studies but no randomised clinical trials directly applicable to the target population, and demonstrating overall consistency of results.

C - Widely held expert opinion but no available or directly applicable studies of good quality.

Academic and research practitioners on a Scottish Government Psychological Therapies intellectual disabilities sub-group were consulted as to relevance and accuracy of this evidence base. Only a very small number of examples of the highest level of evidence for each intervention were included in the

Matrix of evidence

final published Matrix of psychological therapies (NHS Education for Scotland (2011) to guide practitioners in delivering the recommended approach with appropriate integrity. All level C evidence was omitted from the final Matrix publication in an effort to be consistent with other published national guidelines, and where there was a publication of a higher level of evidence, publications at a lower level of evidence on a similar intervention were omitted. The current review reports on the final set of papers identified and also reports in more detail on a number of relevant variables for each of the papers; design, number of participants/studies, age range, behaviours, setting, type of intervention and outcomes. See Tables 1 & 2.

The ‘intensity’ of the interventions was also considered– in terms of the number of sessions / time needed and skills of the therapists. The challenging behaviour interventions considered for this review required specialist, individually tailored input from a range of psychological models, aimed at service users with highly complex and/or enduring disorders, and would normally last for 16 therapeutic sessions or more (NHS Education for Scotland, 2011).

Results

Full results, analysis and critical comment are presented below, in Tables 1 and 2, and in the discussion. This review reports on evidence from level A, B and C papers.

Using combinations of the search terms to interrogate each of the databases, an initial list of 782 papers was produced. Examining these papers, to determine whether they were consistent with the working definition of challenging behaviour and met other inclusion criteria reduced the number of papers to 59. Of these, 39 were excluded as they did not meet the A, B or C level of evidence required (see Methods and Tables 1 & 2). Specific reasons for rejected papers were as follows:

- Incorrect population – not a study involving people with intellectual disabilities (e.g. Durand & Carr, 1991; Schilling & Poppen, 1983; Lowe et, al. 1996)
- Incorrect population – not a study where the target problem was challenging behaviour (e.g. Lindsay et, al.,1989, 1996)
- Incorrect population - all the sample were children (e.g. Fisher et, al., 1998; Durrand, 1999; Carr & Durand, 1985; Hudson et al., 2003; Lopata, 2003; Durand & Carr, 1991)

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- Duplicate studies where there was an included paper at a higher level of evidence
- Papers to be reviewed in the full Matrix under a separate heading, but not in the Matrix of challenging behaviour, e.g. Cognitive Behavioural Therapy (CBT) was included in a separate part of the published Matrix under the diagnostic/ problem category of “Anger Management”, rather than challenging behaviour (Willner, Jones, Tamsy & Green, 2002; Hagiliassis, Gulbenkoglou, Di Marco, Young & Hudson, 2005; Taylor, Novaco, Gillmer & Thorne et al 2002, 2005).
- Interventions specific to short-term management, rather than longer-term treatment of challenging behaviour (Campbell 2010)
- Audits, rather than reviews/meta-analyses (e.g. (Feldman, 2004; Desai et al., 2009)
- Full text of paper not available and/or full-text not able to be retrieved
- Pharmacological interventions
- Studies did not compare time periods within the same population (pre- and post-intervention).

For psychoanalytically based psychotherapies there is evidence that psychodynamic approaches can be effective in the reduction of psychological distress and interpersonal problems associated with challenging behaviour, particularly in people with milder intellectual disabilities (RCP/BPS/RCSLT 2007). There are good quality studies showing promise of efficacy (outcome studies by Beail & Warden, 1996 and Beail, 1998), but, expert opinion remains that further research is needed on the outcomes of psychoanalytically based psychotherapies for challenging behaviour (Xeniditis, Russell & Murphy, 2001; Willner, 2005; RCP/BPS/RCSLT 2007). Although no such studies were included in the Matrix at Levels A or B, in this review the work of Beail (1998) and Prout & Nowak-Drabik, (2003) are both included at Level C.

There were 20 papers which met the inclusion criteria as follows: 8 at level of evidence “A”; 4 at level “B”; and 8 at evidence level “C”. The papers are divided into individual/ clinical studies (Table 1) and reviews and meta-analyses (Table 2).

The papers with the highest level of evidence, i.e. those included in the Matrix (A & B) were:

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- 5 meta-analyses of previous research on psychological treatment effectiveness
- 1 review of operant extinction in clinical settings and factors that may affect the success of extinction.
- 1 randomised control trial of specialist behaviour therapy team
- 1 matched control group design
- 1 comparison of a pharmacological vs behavioural treatment for self-injury
- 1 comparison of Interactive training alone vs Interactive training plus Active Support training for staff and impact on engagement with adults with challenging behaviour
- 1 controlled trial of effectively designed and supported leisure activities as an intervention for reducing challenging behaviour
- 1 intervention outcome study on social problem-solving skills training (SPSST)

The papers with the level of evidence C were:

- 1 preliminary outcome study on psychoanalytic psychotherapy
- 1 literature review and small meta-analysis on psychotherapy
- 1 service evaluation of the impact of a Special Projects Team
- 1 multi-element design study comparing fixed-time and extinction schedules
- 1 single case study distinguishing between extinction and punishment effects
- 1 multiple case study on social problem-solving skills training
- 1 multi-element design study investigating different effects of an establishing operation on challenging behaviour
- 1 historical review of Positive Behaviour Support

Table 1 Individual Clinical Studies

Study/ Level of eviden ce	Level of eviden ce	Interve nion type	Desig n	Partici pants	Behaviou s		
Sigsfoo s & Kerr	B	Active suppor	Multip le baseli	3 Age	PA SIB ST SI	IRH	Provision of leisure activity was associated with increased adaptive behavior and reductions in problem behaviours.

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(1994)		t	ne design with observation of service users	19-30 "Severe learning disabilities"	D		
Beail (1998)	C	Other	Case series. No controls No baseline.	20 Aged 16-42 Degree of intellectual disability unknown	PA SI	IRH	In most cases the problem behavior was eliminated and this was maintained at 6 month follow up.
Allen et. al. (2006)	C	Functional analysis and behavioural interventions	Service evaluation	N/A	N/A	N/A	N/A
Vollmer, et. al. (1998)	C	Functional analysis and behavioural interventions Extinction	Multi-element design Session order was either quasi-random or counter balanced	3 Aged 6, 16, 22 "severe mental retardation" + 2 x "moderate mental retardation"	ST PA D SIB	IRH	Fixed time schedules were generally more effective than extinction schedules in reducing aberrant behavior
Smith et. al. (1999)	C	Extinction	Simple case study ABA CAB	1 Age 41 Degree of intellectual disability unknown	SIB	Unknown	For this patient, blocking functioned as an extinction procedure
Anderson & Kazantzis (2008)	C	Social problem solving	Multiple case study	3 Aged 19-52 "Mild intellectual disabilities"	Unknown "all presented with challenging behavior"	SV	Preliminary evidence that SPS training could be an effective intervention tool for the treatment of psychological distress in mild LD

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					and comorbid mental illness”		
O’Riley et. al. (2006)	C	Functional analysis and behavioural interventions Extinction	A multi-element design was used in each phase of the experiment	1 Age 20 “functioned at the 4-year level on the Vincel and ABS)”	SI D	SV	Results of final phase indicate that no access to the reinforcer prior to extinction had an evocative effect (produced high levels of responding) during extinction sessions.
Fisher et. al. (1998)	Not included (Children)	Functional analysis and behavioural interventions Functional equivalence / Functional communication training Extinction	Multi-element design	2 Aged 13, 14 “Mild-moderate” “Severe”	D PA VA	IRH	Treatment effective at reducing D behaviour
Durrand, (1999)	Not included (Children)	Functional analysis and behavioural interventions Functional equivalence / Functional communication training	2 stages Functional analysis Within subjects design	5 Aged 3.5-15 “Moderate – severe”	SI SIB D PA	HC + SV	It successfully reduced problem behaviour.
Schilling & Poppen (1983)	Not included (Not Intel. Dis.)	Competing response	Randomised control trial	13 Aged 20 – 29 Degree of intellectual	None	IRH	Positive result In BRT, BIO and PMR group but not the MUS group

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				disability unknown			
Lindsay et. al. (1996)	Not included (Target problem not CB)	Competing response	Within subjects controlled case series	5 Aged 25-47 "Profound LD"	PA SIB SI D ST	IRH	2 x improvements w procedures 1 x improvement w relaxation 2 x no response w treatment
Lindsay et. al. (1989)	Not included (Target problem not CB)	Competing response	Randomised control trial with control group	50 Aged 25-69 "Severe mental retardation (IQ 30-55)"	VA Poor attention span Low concentration Periods of agitation Restlessness	IRH	BRT is more affected than APR in both group and individual forms.
Grey & McLean (2007)	Not included (Staff)	Staff training in PBS	Matched control group design	30 target group + 30 matched control group Aged 3-70 "Mild-Profound"	SIB SI PA VA ST	HC	Significant reductions in frequency, management difficulties, and severity of CB for target group
Carr & Durand (1985)	Not included (Children)	Functional equivalence / Functional communication training	Controlled trials	4 Aged 7-14 "1 x Autism, 2 x 'Brain damage' and 1 x Developmentally delayed"	PA SIB D	SV	Produced replicable suppression of behavior problems
Hudson et. al. (2003)	Not included (Children)	Functional equivalence / Functional communication	Randomised control trial	115 (mother-child dyads) Aged 4.6-19 "Mild"	unknown	Group condition - SV Phone condition -	Signpost materials led to parents feeling: less stressed, more efficacious about managing behavior and less hassled about meeting their own needs and that their children's behavior had improved

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		unication on trainin g		(47%) Moder ate (49%) Severe (4%)”		HC Indiv idual cond ition - HC	
Lopata (2003)	Not include d (Childr en)	Function al analysi s and behavi oural interve ntions	Stratif ied rando m cluster sampli ng group design	24 Aged 6-9 Degre e of intelle ctual disabil ity unkno wn	Unknown	SV	Supported PMR as a proactive short-term aggression reduction intervention
Lowe et, al. (1996)	Not include d (Not Intell. Disab.)	Function al analysi s and behavi oural interve ntions	Contr ol trial - 2 exper imental groups and 1 compa rison group	30 18- Servic e A 12- Servic e B 21 contro l Ages unkno wn Degre e of intelle ctual disabil ity unkno wn	Unknown	IRH + HC	Positive client change was evident with respect to one service, with little change noted with respect to the other.
Feldma n (2004)	Not include d (Audit)	Audit of many differe nt interve ntions	Rando m sampl e, large scale audit	625 (careg ivers of people with LD) Aged 2.6- 85.4 “Bord erline (8%), mild (20%) , moder ate (26%) , severe (15%) and profou nd	Target behavior classified as ‘dangerou s’: SIB, PA, D, inappropri ate sexual behavior, overeating , elopement and alcohol/su bstance abuse	N/A	55% of 2506 different ints. were informal. Sig. more informal than formal behav. int and counselling. No sig difference in informal vs formal intrusive int. Beh control med was paired more often with formal (67%) ints.

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				(8%), not available (23%) "			
Durand & Carr (1991)	Not included (Children)	Functional equivalence / Functional communication training Functional analysis and behavioural interventions	Three experimental conditions in a ABA CAC ABA design	3 Aged 9, 12, 12 "Moderate- Severe "	ST SIB D PA	SV	Int substantially reduced CB but also these rates transferred across new tasks, environments and teachers. Generally maintained 18-24 months following
Desai et, al. (2009)	Not included (Audit)	N/A	Survey of health care professionals working with adults with LD and CB	16 - case notes reviewed 16 - Survey 1 34 - Survey 2 Ages unknown Degree of intellectual disability unknown	N/A	Unk now n	75% of CB referrals were from GPs Survey 1: 70% were unaware of RCP report on CB. 80% had received training in the field. 60% specified a course attended. Survey 2: 75% unaware of RCP guidelines.

Key

TYPE OF BEHAVIOUR	
Self-Injurious	SIB
Physically aggressive	PA
Verbally aggressive	VA
Destructive / Disruptive	D
Stereotypical	ST
Socially Inappropriate	SI

TYPE OF INTERVENTION	
Functional analysis and behavioural interventions	
Positive behavioural support	
Active support	
Functional equivalence / Functional communication training	
Extinction	
Competing response	
Social problem solving	
INTERVENTION INTENSITY	
<i>Definitions as defined in MATRIX</i>	
Low Intensity interventions	L

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SETTING	
Home / Community	HC
School / Vocational	SV
Institution / Research Unit / Hospital	IRH

High Intensity interventions	H
Specialist interventions	S
Highly Specialist interventions	HS

Table1 shows a summary of the individual/clinical studies which met the inclusion criteria A, B or C.

Details are shown of the interventions, study design, participant characteristics, behaviours, setting and findings. Functional analysis features in six out of the twelve interventions carried out, including both of the studies categorised as having level A evidence. Active Support was the form of intervention implemented in two out of the four studies with level evidence B. The two studies categorised as having level A evidence are both randomised trials, with a range of study designs across the other studies, including multi-element approaches, group comparisons and case studies.

There are considerable variations in the number of participants, ranging from 1-63. In six out of the twelve studies self-injurious behaviour (SIB) is one of the targeted challenging behaviours, in studies where behaviours were specified. In the studies where settings are reported, only two studies were carried out in a community setting. Four of the twelve studies were carried out in an institutional or research unit setting, and three in school or vocational settings.

INSERT TABLE 2 HERE

These literature reviews and meta-analytic studies covered a broad range of effective interventions.

Table 2 shows a summary of the review/meta-analyses studies which met the inclusion criteria A, B or C, based on the quality and consistency of the design, and thoroughness of the review. Details are shown of the interventions, study design, participant characteristics, behaviours, setting and findings.

Matrix of evidence

Four of the papers categorised at Level A are meta-analyses and two are systematic reviews. The Level C papers consist of one combined review and subsequent meta-analysis and one detailed description of the history of an intervention.

The total number of individual papers included in reviews and meta-analyses, where reported, ranges from 635 (Harvey et al., 2009) to 13 (Shogren et al., 2004). The intervention types reviewed and analysed in the eight papers cover the full gamut of approaches to challenging behaviour, but behaviourally based interventions feature in all papers in Table 2.

In the papers where details of settings are reported, the most common setting for studies is in institutions or controlled clinical settings, followed by schools then community or home settings. Only one review reports on a majority of studies carried out in community settings (Harvey et al., 2009). Regarding findings, five of the eight papers identify functional analysis as a key component in successful interventions.

For the full Matrix of psychological therapies published by the Scottish Government (NHS Education for Scotland, 2011) only studies at Levels A & B were included; whereas studies for Levels A, B *and* C are included in Tables 1 & 2 for this paper.

The findings and recommendations from papers identified in Tables 1 & 2 offer consistent evidence that psychological interventions can effectively reduce challenging behaviour. Interventions are most effective when linked to functional behaviour analysis. Constructional approaches -teaching replacement skills, social problem skills, choice making- are also effective, most often when used with well-planned antecedent and consequence manipulation. The use of specialist behaviour therapy teams are more clinically effective than standard multi-disciplinary teams working alone. Active support training for staff, combining evidence about the most effective ways of supporting activity with a strong values base has proven to work well with people who present the most difficult challenging behaviours. An analysis of the findings of treatment effectiveness research such as this must include possible effects of study design, and this is considered in the discussion.

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The findings of Tables 1 and 2 can be summarised in the findings of the systematic review by Harvey et al (2009): there is no one intervention or combination of interventions associated with highly effective results for *all* categories of behaviour.

Discussion

The main questions asked in this review were, “*What interventions work, for whom and in what context?*” When reviewed using the most rigorous standards, the recent evidence base for successful psychological interventions for use with people with intellectual disabilities and challenging behaviour is thin. The current review of research papers identified 8 papers at level of evidence A, 4 at level B and 8 at evidence level C. See Tables 1 & 2, which also illustrate the range of papers meeting the inclusion criteria.

There have been a number of systematic reviews of interventions for specific challenging behaviours and for behaviours more generally (e.g. Cullen, 2000; Health Evidence Bulletins Wales, 2001; NHS QIS 2004; Harvey, Boer, Meyer, et al, 2009; Brosnan & Healy, 2011). Recognising the paucity of well-designed randomised controlled trials in this area, Ball & Bush (1998) made recommendations for “good” and “essential” clinical practice guidelines for psychological interventions for people with severely challenging behaviour, with the majority of the recommended guidelines being classified as “good” practice. The guidelines were recommendations for a framework to assess and plan interventions for challenging behaviour, rather than specifically intervention focussed. For each guideline, the level of evidence to support it was given as 1, 2 or 3. A total of 51 practice guidelines were identified, of which only 7 were supported by level 1 evidence and 8 by level 2 evidence. This finding was consistent with the current literature review, confirming the paucity of what is considered to be the most robust evidence in the field.

It has been suggested that interventions with proven efficacy in the general population should be adapted for use with people with intellectual disabilities (Prout & Nowak-Drabik, 2003). There are limits to this however. Some interventions are not accessible for those with more significant impairments (Michael, 2008; Taylor, Lindsay & Willner, 2008; Didden, Korzilius, van Oorsouw & Sturmey, 2006).

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One drawback for the development of the current intervention Matrix was that much of the challenging behaviour research has been small ‘*n*’ experimental work in specialist or laboratory settings, and there is a need to build a better evidence base about sustainable interventions that can be generalised in ordinary community settings. (For example, in Table 1 only two studies were carried out in a community setting and in Table 2 only one review reports on a majority of studies carried out in community settings.)

Using randomised control trials to investigate therapeutic interventions for seriously challenging behaviour poses ethical problems for researchers (Oliver, Piachaud, Done et al, 2002) and the number of “*methodologically adequate*” RCTs for cognitive behavioural treatments for aggression during a 20-year interval was just four, according to recent systematic reviews (Hassiotis & Hall, 2008; Hassiotis & Sturmey, 2010). Similarly, the small numbers of individuals with discrete diagnoses can make it difficult to carry out properly powered trials.

These are key issues in translating trial and experimental evidence into everyday practice. Identifying effective interventions from research literature is not enough; this needs to be linked to guidelines for practice, not just for specialist professionals but for those supporting people with intellectual disabilities and challenging behaviour in community settings. There is a limited amount of pertinent research available, and it is vital to broaden the evidence base and build on current good practice in the field. Collecting data about the effectiveness of new, innovative practice is necessary to properly represent the *range* of psychological therapies carried out across the range of service settings. The papers included as Level C illustrate both the benefits and some of the limitations of having a strictly drawn inclusion criterion; whilst the best level of experimental evidence is highlighted, some potentially valid and effective approaches are excluded; some interventions currently in use by practitioners are difficult to research to the highest standards. There is a government policy in the UK to move to more individualised funding and a personalisation agenda in services to people with intellectual disabilities (Scottish Executive, 2001; Scottish Executive, 2006a; NHS Education for Scotland, 2011). This drive towards a personalisation of services – in the form of person-centred planning, person-centred funding and person-centred action has also been seen in the USA, Canada and New Zealand and has gained government support (Pykett, 2009). With this change has come a shift in the balance of evidence-based and values-based practice, particularly in community services.

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Professional knowledge and intuition and a more holistic vision of the needs of people with intellectual disabilities has a more prominent role (McCarthy & Rose, 2011). In this context, evidence-based practice means that practitioners should be aware of the evidence for interventions, but should *also* be aware of how strong or weak that evidence is. This position can be extended to include explicit reference to values based practice in clinical supervision (Scottish Executive, 2006b).

The national guidance in the “Matrix” (NHS Education for Scotland, 2011) proposes that all psychological therapies will be delivered within a matched/stepped-care model of service delivery. The stepped care model is intended to ensure that the delivery of interventions matches the level of need, in terms of the intensity of the therapeutic intervention required by the client and the skills required by the therapist to deliver the intervention (Bower & Gilbody, 2005; Scottish Government, 2008). In other words, the more complex the difficulties, the greater the input that is required and the more skilled the therapist should be. In terms of challenging behaviour, therapists will be expected to have received accredited and regulated training in one or more major psychological therapy to deliver interventions. “Capable environments” provided by “competent providers” (RCP/BPS/RCSLT, 2007) will be required, i.e. high level specialist services, able to deliver integrative and individually tailored psychological interventions.

Although each kind of intervention is listed separately in the Matrix, in the literature we have reviewed there is a widely recognised correlation between “success” as measured by reduced challenging behaviour, and use of functional analysis (Scotti et al, 1991; Didden et al, 1997; RCP/BPS/RCSLT, 2007; Harvey, Boer, Meyer & Evans, 2009; Hassiotis et al, 2011), regardless of the strength of the evidence base for any single intervention used alone. This parallels the emphasis on formulation-driven approaches in other forms of psychological therapies. Similarly, best practice suggests that a recognised “assessment cycle” should be followed for all interventions, i.e., Pre-assessment, Assessment, Formulation, Intervention, Feedback, Evaluation of effectiveness.

In reality, rather than in research, psychological interventions for people who have intellectual disabilities are rarely clinic based, and are usually carried out on an outreach, multi-disciplinary basis to ensure that the intervention is ecologically valid and translates into observable quality of life outcomes. What is statistically significant may not always be *clinically* significant, however, and some studies do not assess whether gains from focussed training generalise to practice (Loumidis &

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Hill, 1997). This difference between efficacy research and effectiveness research is poorly acknowledged in the reviewed literature.

Crucially, there is very little evidence in the literature about the most effective ways of *delivering* interventions, in the context of necessary staff skills and effective service characteristics (Dept. of Health, 2007). Some studies have tried to evaluate the effects of a specific kind of training on intervention delivery (Totsika, 2010), more comprehensive staff training in environmental factors, skills development and reinforcement schedules (Grey and McLean, 2007) or a specific model of service delivery (Hassiotis et al., 2009 ; Lowe et al. 1996). Further research in these areas will be valuable in determining suitable service models for the future.

The need for appropriately trained professionals is an essential component of any effective intervention, and their role in providing focussed training and guidance for families and paid carers is particularly important when implementing behavioural interventions over a longer period, to what may be lifelong patterns of behaviour. Positive behavioural interventions have evolved to provide effective help for individuals living in community settings (Carr et al 1999; Harvey, Boer & Evans, 2009), with a growing emphasis on *working alongside* those providing service users with formal and informal support. It should be acknowledged also that the type of training for paid staff may not be the same as that required for families.

The existing evidence base for psychological interventions has been described as one of “*sub-optimal research designs*” (Willner, 2005; RCP/BPS/RCSLT, 2007), i.e. evidence used in evaluating effectiveness includes expert opinion, uncontrolled and controlled single-subject and group designs, with few randomized controlled trials. It is relevant to note that in a wider health context, the National Health Service Executive in the UK stated that, ‘*in the absence of well designed randomized trials, clinicians may legitimately draw upon analysis of expert opinion and past experience*’ (NHS Executive, 1996).

A related issue here is the influence of study design on recommendations for treatment outcomes. In a major study of 319 meta-analyses of psychological, behavioural, and educational treatment research, Wilson and Lipsey (2001) found that, “*study methods accounted for nearly as much variability in study outcomes as characteristics of the interventions*”. This highlights the more obvious difficulty in extrapolating from smaller scale studies of challenging behaviour interventions, but also cautions

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against too readily accepting the recommendations from larger studies, with careful interpretation on the influence of methods; for example, type of comparison group, sample size and design type.

Finally, enquiries into the abuse of people with intellectual disabilities nationally have identified challenging behaviour as a characteristic of many people at risk of harm (Healthcare Commission, 2007a; Healthcare Commission, 2007b). On the basis of this evidence it would be naïve and dangerous to recommend that interventions in challenging behaviour should be administered by anyone using a “cookbook” approach, without specialist training and competencies, or without supervision or regular updates in skills. In intellectual disability services generally, minimum standards of staff training remain largely aspirational, and comprehensive training for staff has proven an elusive goal (Campbell, 2007).

Translating the evidence base for effective interventions to everyday settings has long been a challenge for both researchers and practitioners (Burton & Chapman, 2004) with the added complication of differentiating *efficacy* research - about relieving symptomology- from effectiveness research, about the more general usefulness of interventions in clinical practice.

The idea of basing practice on evidence is clearly not wrong, but completing the sequence from production of evidence through dissemination to use of that knowledge in services to people with challenging behaviour is achieved only rarely. The adoption of Positive Behavioural Support frameworks and the use of Active Support interventions are welcome developments in services to people with an intellectual disability and challenging behaviour. These approaches comes closer to addressing the key research question of, “What should the person be doing *instead* of challenging behaviour?”; a question that is very different from “How can we clinically intervene to stop challenging behaviour?”.

There are barriers to getting information about interventions to where it is needed most; in settings where staff with and without appropriate training are working on a daily basis with adults with serious challenging behaviours. We need to ask what needs to be done to improve the use of evidence. Given the paucity of evidence available for interventions in challenging behaviour it is important to adapt the criteria by which this evidence is judged, to include accepted good practice in the field and ensuring that the context of psychological interventions is integral in any guidelines, i.e. not just “what

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works”, but where it works best and with whom. For example, in the references identified in this review there are questions about “where it works best”- Lerman & Iwata (1996) reviewed findings predominantly from laboratory settings; and “with whom” – in the Harvey et al (2009) the meta-analysis of intervention research the majority of studies involve people with mild and moderate intellectual disabilities.

A recent review of psychological treatments for people with intellectual disabilities (Bhaumik, Gangadharan, Hiremath et al, 2011) proposed that the way forward is to divide interventions into three distinct categories: interventions with no evidence; interventions with limited but promising evidence; and interventions with “adequate “evidence. Each category of evidence then receives a differential research approach, rather than a single hierarchy with random control trials at the apex, as a strategy for building the evidence base overall. This is a promising framework. Given the long standing and continuing gap between research and practice in this area it would be useful to ensure that all interventions are rated not just on the quality of evidence for efficacy but also on optimal ecological conditions for *delivery* of the intervention. Too many of the existing evidence based interventions remain good practice ideals rather than guidance for good practice to staff working on a daily basis with people with serious challenging behaviours.

The best-evidence Matrix (NHS Education for Scotland, 2011) was produced to improve the range, volume and quality of psychological interventions available in Scotland. This is a clinically motivated decision, but there is also a policy aspect to this with wider, international relevance. Government bodies who fund services are increasingly using effectiveness as criteria for decisions on how money is to be spent. There is a need to avoid oversimplification of the concept of effectiveness into “what works/doesn’t work” categories, without a full consideration of who the interventions work for, when, where and how.

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