

Centre for Intellectual and Developmental Disabilities

# Supporting people with Intellectual Disabilities who challenge or who are ageing:

A rapid review of evidence

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# **A rapid review of literature relating to support for people with intellectual disabilities and their family carers when the person has: behaviours that challenge and/or mental health problems; or they are advancing in age**

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## **Ministerial Foreword**

I am pleased to commend to you this Research Review that is one of a series focussing on priorities identified through the Action Plan that supports the Executive's response to the Bamford Review Recommendations. The Bamford Action Plan (2009-2011) is driving much-needed change in how we care for people affected by mental health or intellectual disabilities. One in six of our population has a mental health need at any one time, and it is estimated that between 1-2% of our population, that is around 24,000 people, have an intellectual disability. In addition, there are many others who have or will develop dementia in the future.

Our highly committed staff who deliver health and social care services have expertise and skills that must be supported by the best up-to-date knowledge. Through research, new knowledge is created. But it is now recognised that, for a variety of reasons, essential knowledge does not always reach the people who most need to use it. The knowledge can vary from better understanding of the causes of poor mental health or intellectual disabilities through to evidence on which services bring about the greatest improvements to the lives of people or their carers. To bring together this knowledge we have commissioned five Research Reviews.

Each Review was written by a team of experts in academia, clinical services and care who have collected the most up-to-date evidence from research done locally or globally. All of the review teams were based in Northern Ireland so we know that the Reviews are relevant to our local situation. The quality of each Review has also been assured through input from experts who are based in other parts of the UK or internationally.

The priority areas addressed by the Reviews are:

- Children & Young People including early interventions, the needs of looked-after children and the development of resilience;
- Patient Outcomes including the measurement of recovery and the capture of patient feedback;
- Intellectual Disability including the management of challenging behaviours;
- Psychological Therapies including how to embed these in services for children and adults across the lifespan and including those with intellectual disability and severe mental health problems;

- Primary Care including aspects important to the prevention, recognition and management of mental health in the community.

As well as providing accessible knowledge and information, each Review has highlighted gaps in our knowledge. We will commission new research projects aiming to fill those gaps.

My final acknowledgement is of contributions made by local people, patients and their carers who assisted in the selection of the priority areas covered by the Reviews and provided extremely helpful feedback to the review teams. Some of those people also serve through their membership of our Bamford Monitoring Group.

I dedicate these Reviews to the people who are affected by mental health or intellectual disabilities. I urge our health and social care staff, education professionals, members of voluntary organisations and others to use these Reviews so that all members of our community may receive the best possible support to live their lives with dignity.

**Edwin Poots MLA**

**Minister for Health, Social Services and Public Safety**

## **EXECUTIVE SUMMARY**

A significant care need for service commissioners and providers of services for people with intellectual disabilities (ID) is presented by people with behaviours that challenge and/or have mental health problems, and ageing people with an ID. In addition family caregivers of both these populations can face many obstacles in their caring roles if adequate supports are not in place to help them.

### **Review method**

This rapid review was undertaken using a framework adapted from the NHS Centre for Reviews and Dissemination (CRD, 2009) and the Rapid Review Methodology (NHS, Wales 2006).

### **Review aims**

The aims of the review are as follows.

#### Aims and review questions – behaviours that challenge

In relation to people who challenge the aim was to search for, evaluate and prioritise studies or other robust literature that have focussed on the following main review question.

What services and support do people with ID who display behaviours that challenge and their caregivers require to meet their needs?

The focused questions addressed that are integral to this overarching question are:

- 1) *What living option models are most supportive for people who challenge?*
- 2) *What day opportunities meet the needs of people who challenge and how effective are these?*
- 3) *What support requirements do family carers of people who challenge require and are services adequate to meet their needs?*
- 4) *What therapeutic support services/interventions are effective in meeting the needs of people who challenge?*

#### Aims and review questions – older people with intellectual disabilities

The main overarching question related to older people with an ID is as follows.

What services and support do older people with ID and their caregivers require to meet their needs?

The focused questions addressed that are integral to this overarching question are:

- 1) *What are the most effective means of managing health-related conditions in older people with ID?*
- 2) *How might 'ageing in place' for older persons with ID alongside their parent carers be facilitated?*

3) *What supports are required to facilitate succession planning for older people with ID and their ageing family carers?*

4) *What supports do older people with ID and their ageing family carers require to help them negotiate through formal services?*

5) *Can mainstream services contribute to the support of older persons with ID and their family carers?*

### **Key recommendations based on findings**

Policy dictates a fundamental shift in how people with ID are supported away from a 'treatment model' directed at grouping of patients to one of 'supporting people' to maintain or regain a good quality of life within their natural environments and with equality of opportunity to generic and specialist services. However, there is a large gap between policy intention and its implementation.

### **People who challenge**

- Based on a conservative estimate across all setting in Northern Ireland (NI), 2228 people with an ID, 958 children and 1270 adults, are likely to have behaviours that challenge others.
- These people require a significant input from services to maintain them in their own home.

### **Practice and services**

- Specialist community challenging behaviour teams have been found to be successful and these should be developed across NI.
- Service users and families should be considered partners in care planning and delivery and this should apply across agencies and not only disciplines.
- There should always be a functional analysis of behaviour undertaken to determine the cause/s of the behaviour that challenges and what function it has for the client.
- The development and use of proactive person-centred positive behavioural support (PBS) programmes, as a first line intervention to reduce behaviours that challenge but that can be delivered in a partnership way (parents and professionals) should be implemented.
- Early intervention is a guiding principle of interventions to prevent behaviours becoming long-standing and difficult to treat.
- A more flexible range of community-based services for both children and adults should be developed as alternatives to institutional care.
- Short term respite breaks should be more available for people who challenge and involve a variety of approaches that meet the needs clients and family.
- Specialised treatment and assessment units have a role to play but ought to be used only for this purpose and not for long-term care, but there needs to be

adequate community services to prevent delayed discharges. There should be consideration given to the development of small scale local based assessment and treatment facilities that are part of a supporting community service rather than hospital-based facilities that tend to retain many of the older care principles associated with institutional care.

- Services should be evidence-based and underpinned by the substantive evidence found in this review but should also be open to ongoing evaluation in line with best practice taking into account cost and outcomes.
- Day opportunities for people who challenge needs to be widened to a range of services beyond traditional day centres to include education, vocational training, work experience, paid employment, voluntary work, social and leisure activities.
- Future planning involving parents and clients in a true person-centred way is necessary to prepare for transitions between childrens and adult services and future need.
- The same range of psychotherapeutic interventions for mental health that is available to the general population should be available to people with ID (although more research on the efficacy of these for ID people is recommended).
- CAMHS (child & adolescent mental health services) ought to be as open to referrals from children and adolescents with ID as they are to other members of society. However, for those young ID people who do receive input from CAMHS it is also necessary to focus on service availability to meet their mental health needs when they reach transition to adulthood and therefore adult services.
- Medications should only be used when indicated for the treatment of physical causes of behavioural problems or treatment of psychiatric illness and be used to supplement other interventions rather than as a stand-alone treatment.

### Education

- Education and training of parent caregivers in evidence-based approaches to support their son or daughter to include ABA (applied behavioural analysis), PBS (positive behavioural support), Active Support as well as knowledge about what services are available and the back-ups they can call on is required.
- Increased training for front-line support workers on how to deal with behaviours that challenge on similar aspect to parents (consider joint parent front-line staff training) is needed.
- The review found evidence that although a number of interventions (such as behavioural approaches) do have a strong evidence-base they are still not applied widely in practice. ID staff would benefit from education on evidence-informed practice and using evidence to guide practice.
- Education provision on the mental health needs of ID people needs to take place. Consideration of the model this would follow suggests a number of potential approaches as follows. 1) Staff in current ID services being trained-up in the

mental health needs of ID people. 2) Specialist mental health teams for people with ID being developed, and staff in these trained accordingly. 3) Mainstream mental health services addressing the mental health needs of people with ID and mainstream staff being provided with education and training for this. 4) A fourth approach might involve drawing on each of these three but would still require varying degrees of education and training of staff within the applicable services.

#### Translation of research into practice - people who challenge

Several key recommendations for future research are identified in the discussion and synthesis sections of the report. However, it is also recognised that in the fiscal environment that services have to work within not all areas can be researched. In view of this the review prioritised four key areas for research developments to take place. Three of these could be undertaken within a reasonable time period of approximately two years and the fourth area (early intervention) would need a much longer time period of around 3-5 years with follow-up work involved. The four priority research areas are:

- 1.** In general specialist Community Support Teams for People who Challenge have been found to be effective in this review but the way they are structured and operate vary. Research could involve a two year study that would compare the effectiveness and efficiency of differently structured teams across the five Trusts in NI. Relevant outcome measures for individuals and for their carers would be selected alongside the perceived effectiveness of each team as viewed by professionals and service users. A second part of this study would attempt to cost such teams in comparison with generic teams and hospital-based services.
- 2.** The review found limited day opportunities for people who challenge with an over-reliance on traditional day-care centres (almost 50% more here than in England and Scotland). A scoping study could be undertaken that would explore alternative innovative day opportunities for people who challenge within NI but also undertaking comparative work with similar services in the Republic of Ireland and GB. A parallel study using action research methods would describe and evaluate a new service in one Trust area in Northern Ireland possibly based around individualised funding packages.
- 3.** The use of mainstream mental health services by people with ID remains a contentious issue in NI. A two year study could be undertaken across ID and mainstream mental health services in one or more Trust to identify mental health services that are being used by ID people and compare the experience of these clients with another selected group of comparable age, gender and diagnosis. Comparisons could be made in terms of assessments, treatments and access to support services as well as the outcomes achieved for clients and carers. The views of professionals involved in referring as well as service delivery would be sought.
- 4.** Early intervention is crucial to alleviate behaviours that challenge and mental health problems but it is dependent on identifying the precursors of such behaviours and then

putting in place suitable interventions to help prevent or ameliorate their occurrence. Longitudinal studies are needed but they are resource intensive. Pre-adolescence into adolescence should be the focus with children showing early signs (or considered at particular risk) having low-level interventions by families and schools. The children would be monitored regularly over a 3-5 year period and comparisons drawn with a contrast group who receive standard services over an equivalent period.

### **Older people with ID**

- Among the 16,720 people known to services in NI most (almost 90%) live in their family or a community home, with the others living in some form of congregated setting.
- Over the next 30-50 years more people with ID in NI will be living longer into their fifth, sixth, seventh and even eighth decades.
- This places an onus on statutory services to forward plan for accommodating the growing numbers of older persons with ID so they may remain in their home but also taking into account their complex needs for out-of-home placements if this is required.

### Practice and services

- Greater co-ordination between ID services and mainstream older people's services, as well as voluntary and private sectors should take place.
- A key person should be identified to co-ordinate between the family home and statutory services including: transport, making appointments, domiciliary care, financial support.
- Succession planning should start early; have clear communication and information strategies, identified databases of ageing family carers and older people with ID, identifying those people with ID not known to ID services early.
- Statutory services should develop both proactive and reactive strategies (e.g. future planning, or emergency plans).
- There needs to be regular annual health checks that include cognitive and behavioural assessments from as early as 35 years of age for ID people.
- Healthier lifestyles, better nutrition and more exercise, and a greater surveillance of health risks should be promoted to improve the health of this population.
- Development of high quality older person day-care, respite and recreational services for older people with ID within both ID services and mainstream older people's services should be put in place and used.
- Development of specialist ID nursing facilities to manage older people with ID particularly within the mid and end stages of dementia are required.

### Education

- A range of training for ID frontline staff and informal carers in working with people with ID and dementia should be provided.
- For those individuals with Down syndrome they are more likely to develop dementia at an earlier age, therefore training should be mandatory for all ID staff with respect to this.

- Training and education should be given to all older people teams, dementia staff and also palliative care staff to include older people with ID into their programmes.
- Mainstream older people day care facilities ought to be educated/trained to accommodate older people with ID.

*Translation of research into practice – older people*

The review also found evidence of the need for a number of key recommendations for future research in relation to older people with ID and their family carers. A process of prioritising as took place for people who challenge was undertaken in relation to older people with ID. The outcome to this process was that the review prioritised four key areas for research developments to take place with respect to older people with an ID and their family carers. The four priority research areas are:

**1.** In this first research priority there are four inter-related research questions that could be answered within a two-year study, the first three-parts will help to answer the fourth research question:

a) To describe how and when older people with ID retire in NI from day centres and employment.

b) To examine what older people with ID would like to do when they retire

c) To explore age appropriate ID day facilities within traditional day care centres with a particular focus on older people and those with dementia and the specific adaptations and supports that are required to accommodate older people with ID to utilise such opportunities.

d) In collaboration with one or more H&SCT in NI to develop, pilot and evaluate a new innovative day care approach for older people with ID based on research evidence of effectiveness.

**2.** The second research priority is to develop and evaluate a new hybrid support model, employing a family-centred approach that addresses both the needs of the older person with ID and their ageing family carers. This model could be delivered between Learning Disability and mainstream older people and/or dementia services. A two-year study could be undertaken in one or more collaborating H&SCT to develop collaborative working focusing on staff training, joint screening, obtaining an accurate diagnosis, treatment options, management of behaviours, supporting ageing family carers and joint working protocols.

**3.** The third research priority is to identify, test and pilot a number of health screening instruments for older people with ID. The instruments should include physical, cognitive, mental health and behavioural assessments to identify the early signs of physical and mental illness, as well as dementia. As well as developing appropriate screening instruments, staff will need to be trained in use of these and proactive supports and

interventions instigated to maintain levels of functioning. Such health screening and management could be evaluated by research within a two-year time-frame.

4. The fourth research priority is to develop a parental education/support programme that focuses on futures planning. The education programme would offer appropriate information and emotional and instrumental support to older family carers to build upon their existing strengths. This programme can be either delivered as a group education curriculum or by an identified professional who can deliver the programme on a 1-1 basis within the ageing carer's home and outcomes to it could be researched within a two-year period.

## **Conclusions**

The review concludes that:

- The best available information that could be accessed from over the past decade on the evidence that informs (or should inform) practice for older people with ID and people with ID who have behaviours that challenge has been accessed.
- This has allowed recommendations to be made in relation to practice, education and future research focused on clients themselves, family caregivers and formal service providers.
- The review has identified the supports that are required for both these client populations to enable them to live in their own homes in as far as is possible and to live dignified meaningful lives maintaining a quality of life (QoL) that is a right of all citizens.
- Overall conclusions suggest that in some areas there is limited evidence to inform practice but in many areas there is ample evidence of what helps. However, even where such evidence exists it is not always the case that practice is informed by and follows this evidence. A major question stemming from the review is why this is so. Simplistic answers to this question such as there not being enough resources can only offer answers to this question that are far from satisfactory. This is because for many services, for example specialist challenging behaviour teams, the cost is no more than traditional services when various factors that create the need for high cost interventions or out-of-home admissions are accounted for if these teams are not present. Cost of care is of course a major concern but it should not be the only one. If services are available for one group in society, for example the general older population; but not for another i.e. older people with an ID then this is a form of discrimination towards this vulnerable group and their caregivers that should not be tolerated.

## 1. INTRODUCTION

People with intellectual disabilities (ID) are exposed to a range of health problems and social inequalities across their life span. These may impact on the individual and their family at any time from childhood, through the transitions to adolescence, in adulthood and also in aging people who have an ID. Reports from across the UK countries indicate that people with ID are disadvantaged in many areas of their health and well being (DoH, 2000a; DoH, 2001a, 2009; Welsh Assembly Government, 2001). A major review of mental health and ID services here in Northern Ireland (NI) the Bamford Review incorporating the 'Equal Lives' report (DHSS, 2005) identified similar health inequalities and well being issues for ID people here. Behaviours that challenge in people with ID remains an issue to be addressed by services with respect to the individual, their family and service commissioners and providers (Bamford, DHSS, 2005).

The WHO (2000) indicated that older people with ID and their ageing family carers were two joint vulnerable groups that were at particular risk as housing was often inadequate, health provision neglected, there was a lack of co-ordinated supports and such individuals were not productive members of their societies. McConkey (2006a) stressed that the demands for statutory support services for older people with ID and their ageing family carers will rise, particularly as these 'double generation families' are living longer. There is an onus to plan mechanisms and structures that facilitate the emerging needs of ageing family carers to continue caring for their son/daughter with ID who are also growing older. Continuing to do nothing about this and not plan for the future is no longer an option.

This review has been undertaken to inform service commissioners and providers of current evidence in relation to supporting people with ID who have behaviours that challenge and their family or other caregivers. The second stand of the review addresses the needs of older people with ID and what their future care needs may be.

Within this introduction to the review core key definitions are presented and this is followed by details on the prevalence of both the aging population of ID people and prevalence of people who present behaviours that challenge others.

The next main section discusses the policy context against which the review is set with particular reference to the core groups of concern to the review – older people with ID and people with ID who challenge, including their family carers.

Following from this detail of the methods of the review are presented. It is emphasised that the review questions (that are presented in the two main 'synthesis of evidence' sections below) related to people with ID who challenge and older people with ID are far reaching and diverse. In fact it may have been viable to undertake a rapid review of evidence related to any of the single review questions. Adding to this the nature of the literature located was not amenable to a structured review of RCTs or meta-analysis as little of the evidence found met these standards. The review therefore is adapted to meet the principles of a rapid review structure as is detailed in the review methods section.

The two most substantive parts of the review are then presented, firstly the section that reviews the evidence on supporting people with behaviours that challenge or mental health problems, and secondly the section on support needs of older people with an ID. Including support needs of family caregivers in both groups. Aims and review questions for each of these sections are presented at the beginning of the relevant section. Finally, a discussion section is included in which aspects related to the overall findings of the review and limiting factors of it are presented.

## **1.1 Definitions**

### 1.1.2 Intellectual disability

The World Health Organisation (WHO) defines intellectual disability (ID)<sup>1</sup> as ‘significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development.’ (WHO, 2011). They also indicate in their report on children with ID that children with autism and an ID are included in this definition but not those who have higher-level functioning autistic spectrum disorders, not involving an ID (WHO, 2010).

### 1.1.3 Behaviours that challenge

Among the issues for people with ID and their caregivers identified and verified in previous literature are significant levels of mental health problems and behaviours that challenge (Alexander, et al. 2001; Allen, 2000, 2008; Cooper et al, 2007; Mansell Report, DoH, 2007). In this review the term behaviours that challenge others is used rather than challenging behaviour with the intent of lessening the potential stigmatising label that the term challenging behaviour may portray. The definition of behaviours that challenge in the review is taken from Emerson (1995, 44) as follows

*‘severely challenging behaviour refers to culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour that is likely to seriously limit use of, or result in the person being denied access to ordinary community facilities’.*

This definition of ‘challenging behaviour’ has been widely used and has gained acceptance so it is adapted here even though the term ‘behaviours that challenge’ is used in the report. For operational purposes within this review the term behaviours that challenge is used and this is inclusive of mental health problems in ID people. However, although behaviours that challenge is inclusive of mental health problems there are some disagreements in terminology and therefore the next section presents detail on what is meant by ‘mental health problems’.

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<sup>1</sup> When the term people or person with an intellectual disability (ID) is used throughout this review it relates to adults and children unless otherwise stated. Internationally ‘intellectual disability’ is the preferred term to refer to this population of people.

#### 1.1.4 Mental health problems

There is a recognised co-morbidity between ID and mental health problems, and behaviours that challenge may be an expression of mental health problems in this population (Deb et al, 2001a; Ross and Oliver, 2002; Bouras, 2004; Myrbakk & von Tetzchner, 2008). Although people with ID have been reported to experience the same range of mental illnesses including affective disorders, psychotic conditions, personality disorders, eating disorders and so on as others there is not always agreement on definitions and terminology used to refer to such conditions with this population. This lack of an agreed term for 'psychiatric disorders' in people with a learning disability has created problems regarding acceptable terminology. Various terms have been used inter-changeably e.g. 'mental illness', 'mental disorder', 'psychiatric disorder', 'mental impairment', 'emotional distress' and 'emotional disorders'. Bouras (1999) suggests using the term 'mental health problems' as it is more in keeping with a 'bio-psycho-social' approach to understanding the co-morbidity between the two conditions (Aman 2000; IASSID 2001).

Dual diagnosis is a term that has also been used to explain the co-existence of ID and mental health problems (McConkey et al, 2004a). However, this term can cause confusion as it has been employed within mainstream psychiatry to refer to people with a dual diagnosis of mental illness and an addictive disorder, most commonly an addiction to alcohol. Within this review the term 'mental health problems' as forwarded by Bouras (1999) is used and where this co-exists with an ID and behaviour that challenges the term co-morbidity is applied.

#### 1.1.5 Old age

As the general population are ageing, with advances in medicine, nursing and technologies people with ID are also living longer, with many people living into their 70' and 80's now (WHO, 2000). In terms of definition of old age in the general population, it is generally determined by chronological age (i.e. 60-65 years), retirement from work, and also the person's physical or mental health status that impacts upon their capacity to function. However, such milestones have recently become blurred as the pension age in the UK and other westernised countries has recently increased (it is now 66 years and expected to increase). Many people are retiring early or later from their jobs, and also the person's adjustment to growing older can be viewed as subjective.

Such universal agreed milestones for the general population have limited application to most people with ID as they grow older. Firstly, it has been strongly argued within the empirical literature that the ageing process commences younger in people with ID at approximately 40-50 years. Adults with Down syndrome are more likely to develop dementia from their late 30's and early 40's, and consequently are more likely to die younger. Likewise, adults with severe and profound ID are also more likely to die from respiratory, epilepsy and cardiovascular related health issues, and also cancer, at a younger age. Nevertheless, many more people with ID are living longer than their parents today. Secondly, the majority of people with ID will not be in employment, they will have limited day care options, fewer respite breaks, and educational, social and recreational activities, as well as fewer social networks. Furthermore, many adults with ID will not be married, therefore, will have no spouse or dependents to care for them later in life; parents (and even siblings) will have to continue caring for their

son/daughter as they also grow older. And thirdly, little is known about the mental health of older people with ID in terms of how they cope and adapt to the process of ageing. McConkey et al. (2004) stated that 'it may be more informative and meaningful to identify how this group are affected by ageing than to dwell unnecessarily on how old age is defined.'

#### 1.1.6 Support

As this review is concerned with the support people require to help them lead more fulfilling lives and diminish distressing symptoms they may be exposed to (in the case of clients) and help them to continue to live where they choose to. Or, in the case of family caregivers (or other informal carers) to provide them with the support and resilience they need to fulfil their caregiving role without suffering from adverse health and social impacts it is important to define what is meant by support. In this review for ease of presentation support is considered to mean two broad categories. Firstly, formal support refers to services, agencies, or education usually provided by health and social care or educational professionals for people with ID and their families. However, it may involve other mainstream services that according to human rights should be accessible to ID people. In short formal support will relate to professionals or others who are paid for the services they provide. Secondly, informal support in this review relates to those such as family caregivers, relatives or friends of the person with an ID who are the primary caregiver of the individual. In most instances this is found to be a parent but it could be another family member. Informal carers in general are not paid for the caregiving support they provide (although they may be in receipt of some benefits). For the purposes of this review support is viewed as being provided by either formal or informal carers.

There are some grey areas in considering support from these two perspectives – formal and informal. Firstly, there are also voluntary sector providers that may be difficult to place in terms of providing formal or informal support but in general although such services are voluntary they are more often considered to fall within the remit of formal support. This is because in some instances there may be voluntary organisations that receive financial support from the state or other donations and are thus paid for the service they provide. Secondly, in no way should the term informal support by caregivers be considered in any way to be inferior to formal support. The expertise of family caregivers is widely recognised and approaches to support that are underpinned by person-centred planning recognise this. Family care should be viewed as a philosophy underpinned by a 'shared approach' with formal and informal carers working and planning in partnership placing the family and service user at the centre. So far from informal caregiving support being in any way inferior to formal it is considered essential and without this form of support many people with an ID could not remain in community living.

## **1.2 Prevalence**

### 1.2.1 Behaviours that challenge (inclusive of mental health problems)

The prevalence of behaviours that challenge in people with ID has been fairly well reported elsewhere but ranges in prevalence differ greatly depending on location and

the severity of behaviours that are included as well as the person's age. For example, the following ranges of behaviours that challenge in people with ID have been reported:

- between 7% in community services and up to 30% in institutional settings (Hassiotis & Hall 2004);
- between 2-20% of people with an ID have been reported to display aggressive behaviour (Allen, 2000);
- for the most severe types of behaviour problems 7-15% is the estimate (Emerson, 2001; Emerson, et al, 2001);
- 19% display some degree of behavioural challenge (Joyce, et al. 2001).

Other studies found much higher rates of behaviours that challenge, for example in children with ID it has been reported that as many as 30-50% have behaviour problems or co-morbid mental health problems (Emerson, 2003; Kaptein, et al 2008). In NI based studies rates of behaviours that challenge in people with ID who accessed the hospitals that still exist here found as many as 70% of those admitted over an 18-month period had behavioural problems or mental health issues (McConkey et al, 2004). Assessment and treatment units have been established here in NI for people with ID and an evaluation of one of these units found that of a total of 48 admissions over a 15-month period the main reason for the admissions were behavioural problems for 20 (41%) and mental health problems for 18 (38%) individuals (Slevin, et al, 2008). In addition this study found that behaviours that challenge were significantly associated with a longer stay in the unit. Table 1 over page presents a range of reported studies on the prevalence or challenging behaviour in people with ID including studies related to adults and children in settings such as the family home, community residence, congregated settings and hospitals.

In a study of the prevalence of ID here in NI McConkey et al, (2003) estimated that there are 16,720 people with an ID known to services, this represents people in family homes, living in hospitals at that time and in supported residential community facilities. As this is an estimate of people with ID taken from mixed settings a conservative estimate of people who challenge can be taken from the prevalence figures as found in the literature from across mixed settings (see Table 1) and applied to this figure,. When these estimated prevalence figures are extrapolated to the McConkey et al (2003) study of prevalence of ID in NI a conservative estimate of numbers of people with behaviours that challenge is as follows:

- Among 8,150 children/adolescents identified to be living with their family in the community 958 (11.75%) may have behaviours that challenge;
- Among 6,650 adults, either living with their family (n=6160) or in a community dwelling (n=490), 579 (8.7%) may have behaviours that challenge;
- Among 1920 people, living in either congregated settings (n=1480) or hospital (n=440), 691 (36%) may have behaviours that challenge;

- Based on this conservative estimate across all setting in NI, 2228 people with an ID, 958 children and 1270 adults, are likely to have behaviours that challenge others.

Table 1: Conservative estimate of behaviours that challenge from across studies  
(BC = behaviours that challenge others)

|   |                        | <b>Family/<br/>Community</b>    | <b>Congregated<br/>settings/<br/>Hospital</b> |
|---|------------------------|---------------------------------|---|
| <b>Authors</b>  | <b>Adults/Children</b> | <i>Estimated %<br/>Range BC</i> | <i>Estimated % Range<br/>BC</i>               |
| Hassiotis & Hall, 2004                                      | Adults                 | 7%                              | 30%   |
| Allen, 2000   | Adults                 | 2%                              | 17%   |
| Emerson, 2000, Emerson et al, 2001                          | Adults                 | 7%                              | 17%   |
| Joyce, et al. 2001  | Adults                 | 19%                             |   |
| Mansell et al 2002  | Adults (90%)           |                                 | 48-76%  |
| Based on Range of studies in N. Ireland McConkey et al 2004 | Adults                 |                                 | 38-70%  |
| <b>Conservative Estimate of Adults with BC =</b>            |                        | <b>8.7%</b>                     | <b>36%</b>                                    |
| McConkey 2010   | Children/Adolescents   | 10-15%                          |   |
| Qureshi and Alborz cited in McConkey et al 2004             | Children               | 8-14%                           |   |
| <b>Conservative Estimate of Children with BC =</b>          |                        | <b>11.75%</b>                   |   |

### 1.2.2 Older age ID people demographics

There have been a number of national and international studies that have examined the ageing profile of people with ID and the universal consensus is that this population are living longer and such life expectancy will continue (Bittles et al., 2002, Thompson, 2002, 2004). The DoH (2001) within the UK stated that life expectancy for people with ID is predicted to increase by 11% between 2001 and 2021. Mulvany & Barron (2002) undertook a study to examine the prevalence rates of older people with ID using the NADD data base in Rol (Republic of Ireland). From 1974 through to 2002, the number of people with ID on the Irish database aged 35-54yrs increased by 368% and those over 55yrs by 249%. Providing services for this ageing population and supporting their facilities are areas that statutory services have struggled to plan for and yet staff are receiving little training for this. Bigby (2010) further stated that in the last 30 years the life expectancy of people with ID has increased more dramatically than that of the general population.

The most up to date prevalence study of people within NI with an ID found there to be 16,720 people known to services here (McConkey, 2006, McConkey et al., 2003). Taken from this study by McConkey et al (2006) Table 2 shows the breakdown by age of the 16,720 people known to services and also rate of adults with an ID (per 1,000 of the population) living in various settings. Based on these figures in Table 2 it can be calculated that 50% of people with ID are aged between 0–19 years; 21.7% are aged between 20–34 years; 13.6% are aged 50 years plus; with close to 15% aged 35–49 years. Among the 16,720 people the living arrangements are the family home for 14,310 (86%) people, a community home for 490 (3%), a congregated setting for 1480 (9%) and some 440 (2%) people are in a hospital. The vast majority of people therefore live in the community. However, note these figures are based upon people with ID known to services, there is approximately another 15,000 people with borderline/mild ID not using ID services or other statutory services and many of these people will only become known to services when a crisis arises (DoH, 2001, McConkey et al., 2004).

Although life longevity is increasing for people with an ID and many should expect to live a similar number of years as others there remains an increased mortality for some members of the ID population (Lin et al, 2011, Torr et al, 2010, Lavin et al, 2006, Durvasula et al, 2002, Decoufle, 2002). Of particular significance are people with the most severe levels of ID many of whom have coexisting complex health needs. In a study conducted using the National Intellectual Disability Database in Ireland Lavin et al (2002) found the average age at death (N=1120 people) who died between 1996 and 2001 was 45.68 years, significantly less than for the general population in Ireland which is 75.75 years. This study found that having a profound level of intellectual disability predicted the shortest lifespan with the mean age at death of this group being 29.37 years. These findings are similar to that in N.I. where a prevalence study conducted by McConkey et al (2003) found there were almost a quarter fewer persons with profound/severe ID identified (N=1432) compared to people with moderate ID (N=5365) in the lower age groups 0-19 years and there were close to 50% fewer people with an ID in the 50+ age group (N=623) compared to those with a moderate ID (N=1228). These prevalence figures for NI can be interpreted as indicating two aspects i.e. more people with profound/severe ID may die during early life and fewer live to beyond 50 years of age. It should be noted that there is conflicting evidence on life expectancy of people with ID with some studies suggesting the longevity in most developed countries has increased for this population dramatically and is now in the range of 60-70 years on average (Bittles and Glasson, 2004; Bittles et al, 2007). However, from a range of studies there is evidence that those with the most severe level of intellectual disability have the shortest life span (Torr et al, 2010, Lavin et al, 2006, Bittles et al., 2002, 2007; Patja et al., 2000). Formal and informal caregivers need to be aware of this and training is needed to help them recognise the differences in disability-related and early age-related health problems (Lin et al, 2011).

However, there is enough evidence to assert that over the next 30-50 years more people with ID in NI will be living longer into their fifth, sixth, seventh and even eighth decades. Most of these people live in their family home and statutory services therefore need to ensure that this growing older population with ID can continue to be cared for by their ageing parent(s) within their own family homes within a proactive model rather than the crisis approach that exists today. Likewise, where older people with ID and their

ageing carers cannot be supported within their family homes, then alternative appropriate living models or options have to be developed to meet the complex needs of this population. This places an onus on statutory services to be forward thinking in planning for and accommodating the growing numbers of older persons with ID taking into account their complex needs for out-of-home placements.

Table 2: Estimated number of people with ID living in NI

| Age          | Family                         | Community Housing           | Congregated settings         | Hospital                    | <b>Total</b>                 |
|--------------|--------------------------------|-----------------------------|------------------------------|-----------------------------|------------------------------|
| 0-19         | 8150                           |                             |                              |                             |                              |
| 20-34        | 2649<br>[7.53]                 | 89<br>[0.25]                | 280<br>[0.80]                | 100<br>[0.28]               | <b>469</b><br><b>[1.33]</b>  |
| 35-49        | 1722<br>[4.93]                 | 177<br>[0.51]               | 523<br>[1.50]                | 178<br>[0.51]               | <b>878</b><br><b>[2.51]</b>  |
| 50-64        | 681<br>[2.61]                  | 177<br>[0.68]               | 456<br>[1.75]                | 128<br>[0.49]               | <b>761</b><br><b>[2.91]</b>  |
| 65+          | 108<br>[0.48]                  | 47<br>[0.21]                | 221<br>[0.98]                | 34<br>[0.15]                | <b>302</b><br><b>[1.35]</b>  |
| <b>Total</b> | <b>14,310</b><br><b>[4.36]</b> | <b>490</b><br><b>[0.41]</b> | <b>1480</b><br><b>[1.25]</b> | <b>440</b><br><b>[0.37]</b> | <b>2410</b><br><b>[2.03]</b> |

Number of people with ID [rate per 1,000 of NI Population for Adults]

## 2. LEGAL AND POLICY CONTEXT FOR THE REVIEW

This section summarises the legal and policy context of modern services for people with intellectual disabilities from an international and national perspective. Particular attention is paid to the two sub-groupings within the wider population of persons with ID that are the focus of this Rapid Review, namely those with severe behaviours that challenge and/or mental health problems and older persons with additional needs arising from the ageing process.

This summary serves two purposes: firstly it highlights the values and aspirations that underpin the translation of research findings into practice and secondly, it provides a framework against which research priorities can be assessed and the extent to which an evidence-base exists to aid service planning and implementation.

### 2.1 United Nations Conventions on the Rights of Persons with Disabilities (2009)

The United Kingdom endorsed this Convention on Rights in 2010 which covers all persons with disabilities “*who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others*”.

Article 19, which relates to living independently and community inclusion, is particularly relevant to the two sub-groupings of persons covered by this Review as:

*States party to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:*

*(a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;*

*(b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;*

*(c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.*

Other pertinent Articles in the Convention relate to Mobility (#20), Respect for Home and Family (#23.2), Education (#24), Health (#25), Habilitation (#26), Work and employment (#27), Adequate standard of living and social protection (#28) and Participation in cultural life, recreation, sports and leisure (#30).

Within the Convention, there is scant mention of ageing as a specific issue facing persons with disabilities. Two articles however stress the need to prevent age-related disabilities (#25) and to promote the social inclusion of older persons (#28).

Many of the principles contained in the Convention find expression in international and national policies in relation to ageing and for persons with behaviours that challenge and mental health problems. These are summarised in turn.

## **2.2 Policies in relation to ageing**

The most comprehensive review of policy in relation to ageing was undertaken by the World Health Organisation (2001) in association with an 'expert' group of researchers drawn from the International Association for the Scientific Study of intellectual Disability (IASSID). Their report identified a number of policy guidelines which can be summarised as follows:

- Age related change appears to occur when people with ID are in their fifties although premature ageing can be present in persons with profound and multiple disabilities and frequently in those with Down Syndrome. Moreover life expectancy is shortened by poor health status and poverty. Hence planning and provision for people with ID cannot be based solely on chronological age cut-offs.
- Throughout the life span, public policies should be supportive of healthy ageing with opportunities for older persons to remain socially active and contributing to their well-being. This should reduce the burden on health and social care services resulting for higher levels of dependency over a prolonged period of old age.
- Ongoing research and evaluation is required to identify effective intervention programmes to promote healthy ageing within three broad domains: 1) maintaining functional abilities and extending competence in later life, 2) enhancing older

people's quality of life (notably in residential care) and 3) identifying the factors that promote increased inclusiveness with society.

- The needs of people with ID should not be cut-off from the wider field of ageing. This avoids duplication of services, encourages the sharing of expertise and in rural areas in particular, assists with maintaining people within their local communities. This policy objective requires the development of common infrastructures for accessing services, shared training for professionals and the wider public.
- However it was acknowledged that specialist resources should be available to which clinicians, families and carers can seek information, referral and training.

With regard to the particular issue of dementia and people with ID, an international round-table drew up what has become known as the 'Edinburgh Principles' (Wilkinson & Janicki, 2001). These define internationally applicable working practices for community supports for adults with a learning disability who have Alzheimer disease based on the above policy guidelines.

### 2.2.1 Implementation of policy on ageing

There is widespread agreement internationally as to the two core features underpinning a policy on ageing and ID in relation to accommodation options: 1) people should 'age in place' rather than leaving their home to live elsewhere, and 2) shared responsibility for this client group across aged-care services and disability provision. On reviewing the implementation of these twin policies across five countries – Australia, Canada, Ireland, UK and USA – Bigby (2010) concluded that service practices fell short of aspirations.

*"Data from all countries suggest that broad policy intentions have not reached as far as program development or funding policies. Supporting residents to remain in their own homes, which are often group homes, appears to be feasible but is hampered by the absence of firm policy commitment and defined programmatic strategies such as provision of flexible funding"* Bigby, 2010, p. 10).

The reasons given for policy failures were:

- A much clearer conceptualisation is required of 'ageing in place'.
- A lack of clarity about policy goals and unresolved tensions around them.
- A failure to identify and agree on the needs that exist.
- Obtaining funding commitments from the two sectors – older persons and disability – alongside a lack of dedicated additional resources required to enable partnerships to be built and sustain joint working across both sectors.
- Lack of strong allies in arguing for funding in competition with other needy groups.

Bigby (2010) concluded that:

*"the disability service system will have to reorient to incorporate knowledge and expertise around age-related support needs ... and take responsibility for the development of specialist age-related services. It may also give the disability sector a much clearer mandate to lead and adequately resource partnerships with existing services or organizations (Bigby, 2010, p.11).*

### **2.3 Northern Ireland Policy on Ageing**

The Equal Lives Report (2005) from the Bamford Review identified ageing as an area that required specific planning within ID services.

*“The Department of Health, Social Services and Public Safety and Health and Social Services Boards should produce a strategic plan to address current deficiencies in services and future service provision for older people with a learning disability and their families” Recommendation 52..*

Under Disability Discrimination Legislation, presumably the six policy goals outlined by the DHSSPS (2005) in their paper on *Ageing in an Inclusive Society* would have to inform such a plan.

- 1. To ensure that older people have access to financial and economic resources to lift them out of exclusion and isolation;*
- 2. To deliver integrated services that improve the health and quality of life of older people;*
- 3. To ensure that older people have a decent and secure life in their home and community;*
- 4. To ensure that older people have access to services and facilities that meet their needs and priorities;*
- 5. To promote equality of opportunity for older people and their full participation in civic life, and challenge ageism wherever it is found;*
- 6. To ensure that Government works in a coordinated way interdepartmentally and with social partners to deliver effective services for older people.*

#### **2.4 Quality Standards for older person services**

As yet the development of quality standards for service provision for older persons with ID has been limited. In these islands, NHS Scotland (2004) is the only country to have issued Quality indicators for Learning Disability Services. The ones directed to older persons are as follows.

- There is appropriate health and social care intervention for older people with an ID.
- There is joint working between ID and older people’s services.
- The needs of adults with ID approaching 65 years of age are identified in care plans with consideration, as appropriate, to accessing older people’s services.
- There is evidence that the needs of adults with ID are taken into account within other strategies or plans such as mental health, older people, and physical disability.

#### **2.5 Behaviours that Challenge and Mental Health**

Internationally it is acknowledged that the needs of people with ID whose behaviours challenge or who have additional mental health needs should be met within the broad values and policies that guide all services for this population. And as argued above in relation to the topic of ageing, the policies informing mental health services for the wider population are also applicable to these individuals (e.g. Bamford Review and the proposed DHSSPS Service Framework for Mental Health and Wellbeing).

However these new policy goals are not easily achieved as often these persons with additional needs have experienced the most social exclusion and lack of opportunities. In the United Kingdom, the influential Mansell Report (DoH, 2007) identified a number of key policy imperatives which echo those contained in the Equal Lives Report (2005) for Northern Ireland (NI):

- The provision of more local services and a reduction of people having to move away from their local area.

- Improved service models for housing and day care, and for family short breaks (so as to reduce residential school placements);
- The commissioning of more local smaller, individualised services;
- More specialists, multi-disciplinary support teams with 24 hours a day, seven days a week access along with appropriate mental health services with access that meets the needs of ID people.
- Direct payments should always be considered in planning for individuals and be made more widely available

Latterly McGill et al (2010) surveyed eight English local authorities and concluded that: “There was no evidence of significant, ongoing local work to implement the recommendations of the revised Mansell Report” (p.2).

Two proposals were made to assist commissioners in developing new initiatives for this client group. Firstly a nationally co-ordinated programme of work is undertaken that examines the development of personalised supports and of services that have the capacity to intervene earlier with persons at risk of behavioural and mental health problems. Secondly, to instigate a new website that would collate evidence and examples of good practice in a manner that is accessible to commissioners and service planners and which encourages the sharing of lessons through specialist networks. This Rapid Review is hopefully a step towards these objectives for commissioners in NI.

## **2.6 Policy and family carers**

Given the high proportion of persons with ID that live with family carers in NI especially, it is important that cognizance is taken of Governmental policies in relation to carers. The policy objective is to retain people within families through the provision of support to their carers; a more cost-beneficial option than people moving to State-funded care. The DHSSPS (NI) issued a *Valuing Carers strategy* in 2002 which identified five key principles:

- *Carers are real and equal partners in the provision of care.* Carers must have equal status with other providers of care, e.g. access to training opportunities.
- *Carers need flexible and responsive support.* This includes formal support – e.g. having a named contact person in social services – as well as informal support such as that provided by carer support groups.
- *Carers have a right to a life outside caring.* Carers need rest, relaxation and a social life – hence the need for ‘respite’ breaks - and if they wish to work outside the home, they should have the opportunity to do so.
- *Caring should be freely chosen.* Carers should be allowed to decide what level of caring support, if any, they can offer at any particular time. ‘Shared care’ arrangements may be necessary.
- *Government should invest in carers.* This means addressing the personal needs of carers as well as those of the person for whom they care.

The foregoing points are especially applicable for carers of people with behaviours that challenge and mental health problems as there is a plethora of research evidence that documents the stresses and strains these carers experience and the consequential ill-health that often results.

## **2.7 Carers of older persons**

Given the increased life expectancy of persons with ID, many older persons are now living with family carers and indeed may outlive their parents. Mencap (2002) among other organizations, has highlighted the extra future demand that will fall on services. Moreover the Commission for Social Care Inspection (CSCI, 2007) found many local authorities were failing to plan for this ageing group.

The Department of Health in England (2010) through their Valuing People Strategy have placed particular emphasis on policy initiatives in relation to older carers of persons with learning disabilities. They note that an estimated one in four older families with a family carer aged 70 or over was unknown to services, until there was a crisis, such as the family carer becoming ill or dying. In these circumstances service responses can be limited and often inadequate as nothing has been established in advance. Moreover the family members at times of crisis are often worried and distressed.

The result is often a service response that nobody would ideally have chosen, for example admission to a residential centre or nursing home (Kelly & McConkey, 2011). This also raises the issue of 're-institutionalisation' of people with ID in later life as health and support needs changes and service commissioners seek cheaper options for service provision

A report by an international panel of experts (IASSID, 2010) identified improvements in support services for ageing carers.

- Services should combine expertise from different sectors, such as older people's services, advice services and/or voluntary organisations supporting older people or people with a ID;
- Greater advocacy for older family members – both for the person with an ID and for the older family carer;
- Information (in different formats) that explains the older families' options for support at the moment, in emergencies and in the longer term;
- Training and improved awareness for people working in different sectors in older family issues, and fuller explanation of the options for supporting them (this is often most effectively delivered by older families themselves, either in person or through a DVD presentation).

## **2.8 Conclusions**

As this summary indicates, there is international agreement on the policies that should underpin services for persons with ID, including those with additional needs arising from ageing or behavioural and mental health problems. Fundamentally the shift is away from a 'treatment model' directed at grouping of patients to one of supporting people to maintain or regain a good quality of life within their natural environments and with equality of opportunity to generic and specialist services. However, there is a large gap between policy intention and its implementation. Lawson et al, (2008, p.3) state that "Governments mediate, through their architecture of machinery and policy, access to rights and, by extension, to services." There is a need for people with ID and their carers to break through this architecture to obtain the services they need. One possible bridging mechanism is the evidence and insights provided by research and evaluation

studies undertaken locally, nationally and internationally. Hence a focus of this rapid review is to assess the evidence that can guide policy implementation and to identify the translational research strategies that will lead to more effective service provision for these subgroups within the wider population of people with intellectual disabilities.

### 3. METHODS OF THE REVIEW

This review was undertaken by using a framework adapted from the NHS Centre for Reviews and Dissemination (CRD, 2009) and the Rapid Review Methodology (NHS, Wales 2006). Because of the nature of the review questions and the broadness of the topics strict adherence to systematic or rapid review methodologies could not be adhered to so the review followed an adapted approach as follows.

#### 3.1 Review aims and questions

The review aims and questions were developed from the review call and as such they stemmed from aspects within the Bamford 'Equal Lives' report (DHSS, 2005) and were largely informed by this as well as the introductory background policy literature for this review as included above. Typically reviews of this nature focus on one clinical, social or health aspect but this review needed to focus on people who challenge and older people with an ID. Review questions had therefore to be adapted to priority main areas and these are reflected in the questions under aims that are detailed in the later sections on synthesis.

#### 3.2 Selection of studies and data extraction

Pre-determined inclusion criteria to guide the search were established for the review and these were as follows.

- Published within last 10-years (seminal or highly significant older publications were included).
- In English language only.
- Research papers but not restricted to RCT or quantitative studies only.
- Reports or other literature if undertaken by an expert/group and based on sound evidence.
- Grey literature that is robust and informative even if not published but needed to inform the evidence of the review.
- Had to address the review questions (as stated under synthesis sections below).

The inclusion criteria allowed the search and extraction of literature to be undertaken by the following methods.

- Data bases were searched on-line using identified key words related to each of the review questions (key words can be obtained from the authors). The main data bases searched were: CINAHL, Medline, ASSIA, PsycInfo, and the Cochrane Library. Relevant conference papers identified from ISI Proceedings (<http://wok.mimas.ac.uk>). Unpublished research dissertations via abstract dissertations ([www.theses.com](http://www.theses.com)) were searched.
- Manual library searches and scanning of reference lists in published papers was also undertaken.
- E-mail requests were sent to several noted authors requesting if they had any literature that they could share with the review team.

Any useful web sites found in the course of the review were looked at and a glossary of www sites that hold information relevant to the review was developed. This glossary is included in Appendix 1 (pp.137-141) as a resource to facilitate access to various useful web sites.

Selection of studies to include in the final review involved initial sifting through articles/publications or reports based on their title and then reading abstracts. This initial sifting allowed literature to be excluded and identification of those to be included in the review. The final studies, reports or other literature were included in the study and evaluated according to the review appraisal methods as detailed below.

### 3.2.1 Consultation process

In addition to the literature accessed to inform the evidence for this review a process of local consultation was also undertaken. This involved the following two approaches.

- A scoping e-mail was sent out via members of the Review Advisory Group to managers, assistant directors, psychiatrists and clinical psychologists in NI.
- A consultation with key stake-holders was undertaken at a meeting. This involved asking participants key questions and advice that would inform the review. Membership of the consultation group included three senior staff from special schools, three parent carers of older children and an older lady with LD, two nurses, a consultant psychiatrist, consultant clinical psychologist and two senior managers from Trusts. Key findings of the consultation are presented in Appendix 2 (pp.142-147) and are referred to in appropriate places in the report.

### 3.3 Appraisal of quality of publications selected

As stated previous due to the diverse nature of the review questions literature of various kinds was accessed to inform the evidence for this review. As studies or literature included were publications of different types various approaches to appraising their quality were adapted and these included

#### 3.3.1 PICOS (population, interventions, comparators, outcomes, study design)

If the type of paper reviewed met the criteria for PICOS (CRD, 2009) they were appraised according to these criteria. Weaknesses or strengths in each of these areas were used to prioritise papers to include and the strength of evidence that outcomes to the study could be allocated. Whenever a study met these criteria this was used with some of the other approaches below to appraise impact within the review.

#### 3.3.2 Appraisal of impact of cause and effect studies (quantitative)

To appraise studies that researched impact or cause and effect we used the Maryland Scale (Sherman et al, 1998). The weaker the study in determining a casual relationship the lower the score on the 5-point scale and those studies rated highest were considered most valid. Table 3 below presents the rating.

In rating a study four main threats to internal validity were considered:

- 1) *Causal direction*, whether a program or intervention causes the impact, or vice versa.
- 2) *History*, if the passage of time might have resulted in the impact or effect rather than the programme/intervention or model of care.
- 3) *Chance factors*, any events taking place parallel that could have been the true cause of any measured outcome.
- 4) *Selection bias*, if the study sampling process might have led to an impact on outcomes.

Table 3: Maryland Scale (Sherman et al, 1998)

| <b>Rating</b> | <b>Detail/Description on which article/report is rated</b>  |
|---------------|---|
| 1             | Correlation studies i.e. that there is a relationship between variables but the direction of this may not be clear & relates to a given time with limited evidence on if it is sustained. |
| 2             | A comparison group study but might lack comparability to the target group. Or, where no comparison group is present, before and after measures have been obtained.                        |
| 3             | A comparison between two or more groups, one receiving an intervention and the other not. But, outside or extraneous variables may not be controlled for.                                 |
| 4             | Similar to 3 above, but controlling for other variables that might influence the results. Or using comparison evidence with only minor differences.                                       |
| 5             | Full RCT design with random assignment, matching, adequate control and appropriate measures to test the intervention effects.   |

(Note: Single papers that are robust systematic reviews of a number of studies are rated at 4 or 5)

Where a study is rated on the Maryland scale from weakest to strongest depends not only on the type of study design but the four above internal validity criteria. Where each of these four threats to validity is present and not well controlled the study is rated lowest 1-2. Where the four threats are well controlled the study is rated higher, with a study rated at 5 controlling all four validity criteria and therefore indicating the most robust confidence in cause and effect.

### 3.3.3 Appraisal of qualitative studies

Appraisal of qualitative studies was undertaken by using the Critical Appraisal Skills Programme (CASP) guide for qualitative studies. The CASP guide presents three broad areas to appraise qualitative research, these being rigour, credibility and relevance. Following this 10 questions that deal with some of the principles of qualitative research are considered. The first two of the 10 questions are yes or no answers and these are:

- Was there a clear statement of the aims of the research?
- Is a qualitative methodology appropriate?

If these questions are answered in the affirmative then the other eight questions are used to evaluate the study but if one or both are answered no then a decision was made about whether or not to exclude the study without considering all the other questions. The full CASP guide is presented in Appendix 3 (pp.148-150).

### 3.3.4 Appraisal of other studies (EPPI Centre)

Although assessing studies did vary depending upon the type of research design concerned some studies do not necessarily fit neatly into a particular method and increasingly researchers use mixed methods approaches. In order to determine individual studies contribution to the conclusions this review also used the Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI-Centre) Weight of Evidence (WoE) framework (Gough, 2007). The framework has four elements. WoE 'A' is the quality of the conduct of the study. WoE 'B' is the suitability of the study design for the review question. WoE 'C' is the relevance of the individual study to the review question. WoE 'D' is an overall quality score based on an average score for the three components. Therefore, the first three criteria are used to summarise the WoE of each

study. For some reviews just one or two of the criteria may apply, for example if there is little variability in the study designs, or in the focus of the studies. Under ‘D’ the study is rated as low, medium or high in overall WoE, based on A-C. Table 4 below outlines the framework and this has application to various research designs.

Table 4: Framework – A to C provide overall WoE rating of Low, Medium, High rated at D

|              |   |
|--------------|---|
| <b>WoE A</b> | Quality of study, and robustness of findings judged against the accepted standards for undertaking a study of that specific research design (methodological quality)  |
| <b>WoE B</b> | The appropriateness of the research design and analysis used for answering the review questions (methodological relevance)  |
| <b>WoE C</b> | The appropriateness of focus of the research for answering the review questions (topic relevance). Based on study focus, sample, measures, scenario, or other indicator of the focus of the study to the review question. Relevance and generalization to the rapid review of evidence. |
| <b>WoE D</b> | An overall weight taking into account A, B, C and rated as Low, Medium or High.   |

### 3.4 Review team rating and conciliation checking

Whichever of the above appraisal frameworks were considered appropriate were used and for some studies a number of these were used. Based on this we applied a rating of 1-3 where studies rated as 1 were lowest in terms of evidence they provided and those rated at 3 were considered highest. To do this literature rated as 1 on the Maryland Scale, or low in the WoE framework above were rated as 1; those rated 2-3 on the Maryland Scale, or medium in the WoE framework above were rated as 2; those rated 3-5 on the Maryland Scale, or high in the WoE framework above were rated as 3. For qualitative studies we allocated the rating of 1-3 based on the three underpinning criteria in the CASP guide that is rigour, credibility and relevance taking into account the checklist in Appendix 3 (pp.148-150). We also cross rated these studies with the WoE framework as high, medium, or low. This allowed qualitative studies to also be rated from 1-3.

Other types of literature accessed included government reports, or reports by established teams of experts or types of grey literature that was difficult to determine the evidence-base for. The review team in appraisal of some of these used our knowledge and professional/academic theoretical sensitivity gained over many years experience working with people with ID, researching in this area and providing education and training to staff working with this client group and their families to rate these. In some cases we were able to apply the 1-3 rating but in others this was difficult. However, in order to guard against bias we worked in teams on the review three reviewers on each of the main focused areas – older people and people who challenge. We then reviewed the literature in the teams based on a process of conciliation checking paying particular

attention to any grey literature. In addition a number of meetings took place to achieve agreement on literature to be included and this process avoided bias in any particular direction in the review.

### 3.5 Synthesis and discussion

These two sections are presented below in the final two review sections and are the main results and outcomes to the review. As there are two substantive areas to the review with various questions to each the two areas – older people and behaviours that challenge are presented as separate sections, that is a synthesis section for each. The method used to undertake and present findings of the synthesis and discuss outcomes as for the full review are adapted from CRD (2009) and the Rapid Review Methodology (NHS, Wales 2006). In respect to synthesis of the evidence this involved

- Drawing together the main findings of the review
- Exploring agreements and disagreements between studies
- Practical and clinical inferences based on the review findings
- Detailing interventions, approaches, models or theories that are of value stating for whom and the strength of evidence supporting
- Strengths and limitations of the review
- How the findings fit to the context current and future policy and practice
- Suggestions for further research
- Overall conclusions that can be drawn from the evidence reviewed

Presentation of the synthesis of the review findings utilises tables that include details on author, sample, methods and outcomes of included studies supplemented by narrative commentary. Besides these studies that are included in tables in appendices a vast amount of other supporting rigorous literature was accessed in relation to the review questions.

The final section of the review is a discussion that includes the following.

- How the review has achieved the main review aims.
- Commentary of the review process and how this went.
- What the main findings of the review are including what can be recommended and what remains unanswered and therefore represents gaps in knowledge.
- Translation of findings to practice.
- Suggested areas for future research, education or practice development.
- Overall conclusions that can be drawn and any limitations to the review.

## **4. SYNTHESIS: BEHAVIOURS THAT CHALLENGE**

A substantive amount of evidence indicates that behaviours that challenge in people with ID create difficulties for clients, and challenges for their family and services. In addition the cost and resource implications for this population are considerable (Knapp, et al 2005; Allen, et al 2007; Hassiotis, et al 2008).

As it was a rapid review not all aspects could be reviewed and it was necessary to focus on what is known (or where gaps exist) in relation to the areas identified in the aims and review questions below.

### **4.1 Aims and review questions – behaviours that challenge**

The aim of this part one of the review was to search for, evaluate and prioritise studies or other robust literature related to behaviours that challenge in people with ID that have focussed on the main research question. The main overarching question being:

What services and support do people with ID who display behaviours that challenge and their caregivers require to meet their needs? The focused questions addressed that are integral to this overarching question are:

- 1) *What living option models are most supportive for people who challenge?*
- 2) *What day opportunities meet the needs of people who challenge and how effective are these?*
- 3) *What support requirements do family carers of people who challenge require and are services adequate to meet their needs?*
- 4) *What therapeutic support services/interventions are effective in meeting the needs of people who challenge?*

Evidence from the review related to the four questions regarding people with ID who have behaviours that challenge others are synthesised below under headings that reflect the review questions. In addition to the literature located for the review (as in appendices) additional literature that has found similar or opposing views is referenced.

### **4.2 Living support options**

The importance of appropriate living arrangements for people with ID was highlighted in the 'Equal lives report' (DHSS, 2005) which proposed that policy should be directed towards the key objectives of ensuring "that all men and women with a learning disability have their home, in the community, the choice of whom they live with, and that where they live with their family their carers receive the support they need" and that an extended range of housing options should be developed for men and women with ID. In this review 10 key papers that inform the question on living options for people who challenge and have mental health problems were accessed, these can be seen in Appendix 4 (pp.151-155).

#### **4.2.1 The choice to remain at home**

Epidemiological research evidence suggests an increasing need and demand for housing supports amongst people with ID (Hatton, 2001). But, in the UK and Ireland, as in many countries in the world, life-long care for the majority of adult persons with an ID is provided by their natural families. In Northern Ireland proportionately more people live with their families than in Great Britain and the Republic of Ireland and the underlying

assumption in much current service provision is that most people with an ID will continue to live with family carers, partly because this is their wish (McConkey et al, 2006) but also because of the cost restraints on funding alternative care (McConkey, 2005). However, as carers age they may become unable or unavailable to continue their caring role and with changes in family life-styles across wider society, service planners need to be aware of the growing numbers of individuals who are likely to require some form of alternative care provision in the future. This is discussed further in the later section on older people and was also an issue identified by the consultation group, see Appendix 2.

Like anyone else people with behaviours that challenge are likely to want to remain in their family home, but for some the challenge becomes too much for the family to cope with. The issue of living support option stretches across the life-span, behaviours that challenge in people with ID are associated with a range of difficulties and present a major challenge to families, educational settings, and all aspects of community participation (Glasberg, et al, 2006). For some this may lead to children being placed in residential schools (McGill et al., 2006a) and out-of-home placements (McIntyre et al. 2002).

#### 4.2.2 Out of home placements for children

Due to the challenges that some ID children present for their family or carers they may not be able remain at home and therefore require a placement away from the family. In such situations the option may be residential schools, but there is little evidence on any benefits of these schools and if they outweigh the disadvantages. Government policy concerning both education and social support services for children with an ID who challenge is characterised by a philosophy of social inclusion, yet there has been little consideration of whether residential special schools have a future. The White Paper, Valuing People, for example, while recognising that placement in a residential school may result in 'isolation from normal childhood support', simultaneously acknowledge that many placements are 'highly valued by children and families' (DoH, 2001a, p.37). The Government itself has stated that not enough is known about disabled children in residential schools (DoH, 2001a, p.37).

McGill et al (2006) surveyed 73 parents whose children were in residential schools. Parents were critical of services and supports received prior to their child's entry into the school and reported high rates of exclusion from local services. The residential schools were generally perceived as providing a good quality of service, though considerable concern was expressed about their geographical distance from the family home and this had a significant impact on the frequency of visits by parents and siblings. This has implications for the detection of any negative experiences of the young person. The authors highlighted three benefits from the child's attendance at residential schools:

1. First they provide an intensity of educational support not typically available in local SLD (severe learning difficulties) schools the absence of which may have led to the children's exclusion or the schools acceptance that their needs are better met elsewhere;

2. They provide year-round respite for the families of children and young people who, in a context of inadequate or non-existent local support, may have found their situation unsustainable;
3. By providing a 24-hour service or “curriculum” they ensure a consistency of provision which facilitates the development and management of their pupils.

As highlighted by McConkey (2010) in a report on ‘Supporting families with Disabled Young People who’s Behaviour is Severely Challenging’, these functions are provided at considerable financial and social cost. Studies with adult persons living in ‘out of area’ placements have found worse outcomes in relation to choice, community involvement and standard of accommodation thus it is questionable whether this option is best for children and young people.

A study by Taggart et al (2007) found that of the 37 young people (aged 10-15) with mild to moderate ID living in residential care and foster care in NI over 90% were in out-of-home placements deemed to be “long-term”. Yet as more than three quarters (77.1%) of these young people scored within the abnormal range of the Total Difficulties Score of the SDQ, indicating behaviours that challenge and the potential presence of a psychiatric disorder, it is reasonable to assume that this may impact on their capacity to be fully integrated into their communities as adults and presents a challenge for the successful management of transition from children’s to adult services.

#### 4.2.3 Community-based support

The development of community-based services as alternatives to institutional care for people with ID first originated in the 1950s and this has been probably the most important change in policy and the pattern of service provision in ID in the last 50 years. Supported staffed homes are now the most common form of living support in Britain, North America and Australia (Braddock et al. 2001). The evaluation of community-based models of care for people with ID in comparison to institutionalised care generally shows a relatively clear picture highlighting the superiority of community-based services (Mansell, 2006). Nevertheless there is considerable debate about deinstitutionalization for people with behaviours challenge. The consultation group also identified a number of gaps in community care (Appendix 2).

Mansell et al (2001) evaluated the development of residential care in specialised staffed houses offering ‘active support’ for 35 individuals aged 13-39 with extreme behaviours that challenge, originally destined for institutional care in South East England. Placement outcomes were noted and residents’ quality of life (QoL) was measured by direct observation with time-sampling and data collected using a hand-held computer. It was found that all participants showed an increase in the overall level of participation in meaningful activity after transfer to staffed houses. Nevertheless, average social interaction remained low and although average level of major and minor behaviour problems were lower after transfer, this was not statistically significant and showed great variability among individuals. Support from local managers and professionals’ was however recognised as crucial to placement success although this was not always forthcoming. No major negative effects were recorded in co-tenants without behaviours that challenge and this was highlighted as a priority for future research. Finally, and

perhaps surprisingly, it was noted that the specialised residential care services had similar costs to specialised institutional care.

In a more recent study Perry et al, (2011) also found that resettlement of adults with severe behaviours that challenge from a traditional ID hospital to new purpose-built specialist settings resulted in quality of care and QoL outcomes superior to previous hospital levels. Two areas where improvements over time were demonstrated included greater family contact and reduction in staff-reported behavioural problems. However, the authors suggest a need for a longer-term follow-up study to identify whether improvements in the early stages of the move are maintained or enhanced.

However, caution should be exercised with regard to grouping people with behaviours that challenge in specialised settings. Robertson et al (2005) undertook a longitudinal study comparison of 25 people with ID living in noncongregate community settings where the minority of residents had behaviours that challenge, and 25 people with ID living in congregate community settings where the majority of residents had behaviours that challenge. They found that co-locating people with behaviour disorders in congregate community-based supported accommodation was associated with more physical restraint and reliance on medication to manage behaviour. The data regarding change over time suggest that these approaches do not appear to be effective in reducing behavioural challenges and the authors conclude that the specialist nature of congregate settings appears to be limited to more staff being trained in control and restraint with an increased reliance on this a means to control behaviour. In both types of settings, behaviour disorders were stable over a 10-month period and there were few ABA technologies in place to reduce behaviour (<15% of service users). However, having an Individual Programme Plan (IPP) with a goal of reducing behaviour problems was associated with some reduction in these behaviours.

Mansell et al (2003) also found negative impacts when people with behaviours that challenge are grouped together. As well as this Robertson and colleagues (2004) also found that grouping people with behaviour disorders together in community-based supported accommodation was associated with greater cost.

In a review of U.S. research studies between 1980 and 1998 Kim et al. (2001) reported that 3 of the 12 contrast group studies found improvement in behaviours that challenge for individuals living in the community when compared with those who remained institutionalised, including one study that found a statistically significant improvement. Two studies reported deteriorations that were not statistically significant, while the remaining studies “showed no significant change”. Of the 25 longitudinal studies reviewed, 10 reported improvements (6 were statistically significant); while 6 actually found increased levels of behaviours that challenge after the move (2 were statistically significant). The authors also note that “a common argument against deinstitutionalization is that behaviours that challenge will deteriorate when the person moves”. However, in a review which expanded and updated the work of Kim et al (2001), Lemay (2009) found that this was not supported by the literature but noted continuing mixed results from research into the impact of deinstitutionalization on behaviours that challenge. Nevertheless he concludes that people “do no worse” outside of institutions, though he does argue that community services may be

underperforming due to lack of training on how to deal with challenging and self-injurious behaviour.

Research on deinstitutionalisation and community living shows that, although results are more mixed in respect of behaviours that challenge than some other domains, many studies do show that at least some people's behaviour improves after transfer (Young et al, 1998; Kozma et al, 2009).

In a literature and policy review of services in North America, Europe and Australasia, Mansell (2006) further supports the view that community-based services are superior to institutions and argues that effective responses to behaviours that challenge require organisation and management of services as a system of interdependent components, in which there are many different options. Paradoxically this very variability in service delivery means evaluation of services is difficult and this undermines the consensus supporting deinstitutionalisation and community living.

Slevin et al (2008) studied 48 people with ID in an assessment and treatment unit in Northern Ireland using a specially designed pro-forma alongside the Mini psychiatric assessment schedule for adults with a developmental disability (PAS-ADD) and the aberrant behaviour checklist (ABC). An analysis found significant reductions in behaviours that challenge and mental health problems following admission to the unit and pointed to the success of coordinated onsite multidisciplinary working with close involvement of service users (90%) in their own care plans. It was concluded that short-term assessment and treatment units for people with ID can have a valuable contribution to make to practice. Assessment and treatment units are discussed later in the section on service interventions.

#### 4.2.4 Policy guidance

Policy documents which aim to provide standardised guidelines have been developed. The Royal College of Psychiatrists, the British Psychological Society and the Royal College of Speech and Language Therapists (2007) produced an inter-disciplinary report which aims to have relevance to all professionals who work with people with ID to inform and guide policy, service provision and commissioning. It places an emphasis on the design of effective environments and professional support for placements. It is recommended that assessment and treatment units should be used only for this purpose, mechanisms should be in place to ensure that out-of-area placements reflect individual choices and that an independent mental capacity advocate should be appointed if there is to be a change in the provision of accommodation to a service user. Consideration is also given to human rights issues and it is noted that services that are unnecessarily restrictive of an individual's freedom could be in breach of the European Convention on Human Rights (this could include practices such as locking doors and restrictive care practice). It is emphasised that the use of seclusion, defined as 'supervised confinement in a room, which may be locked' should not be used outside the mental health act.

A guide by the National Development team for Inclusion (NDTi) has been designed to help commissioners to implement Government policy on how to commission cost and outcome effective services. Based on evidence collected by studying locations that have made good progress in supporting people who challenge in ways similar to those

envisaged in the Mansell Report, the NDTi (2010) the guide outlines seven broad factors which they found to be associated with success. These were: decisions based on a clear vision and set of values, strong, knowledgeable and empowered leadership, strong relationships and a 'no-blame' culture, an evidence-based Service Model, skilled providers and support staff, evidence-based commissioning and specific commissioning actions such as upfront investment & flexible contracting systems.

#### 4.2.5 Recommendations

Based on the evidence of this review it is recommended that:

- A flexible range of community-based services for both children and adults be developed as alternatives to institutional care
- Living arrangements should take into account the individual's need for choice and their human rights
- The needs of co-tenants without behaviours that challenge should be taken into account
- The development and use of proactive person-centred behaviour programmes as a first line intervention to reduce behaviours that challenge and help people remain in their home should take place
- Increased training for front-line support workers on how to deal with behaviours that challenge in the client's home or residence should occur
- Specialised treatment and assessment units have a valuable role to play but should be used only for this purpose and not for long-term care
- Interdisciplinary and multi-agency working with engagement from local managers and professionals is required
- Services should be evidence-based and evaluated in line with best practice taking into account cost and outcomes.

### **4.3 Day opportunities**

Related to this review question 11 key studies were identified that provide evidence on day opportunities for people who challenge (see Appendix 5, pp.156-162). Day opportunities for people who challenge include three areas day centres, employment and education. However, there is a striking lack of evidence on the impact of day services for this population (DoH, 2001; Mansell Report, DoH, 2007). Those who are more severely disabled and who are more challenging tend to experience less social inclusion, meaningful activity and less choice.

The paucity in current available evidence makes it difficult to assess both the extent and scope of day opportunities for people with ID and behaviours that challenge. There are indications of an overall shortfall, but lack of standardised information about the use of alternatives to day centres makes the extent of the shortfall hard to estimate. Many forms of day service for this marginalised population remain largely unevaluated. This is supported by Verdonschot et al. (2009) in a recent systematic review on community participation of persons with an intellectual disability. Although findings suggest that

little is known about the community participation for people with ID, and most studies focus on people with mild ID, no studies reported on community participation of people with an ID that had behaviours that challenge others.

The DoH report (2001) 'Valuing People' set out the Government's proposal for improving the lives of people with ID and their families and carers in England, based on recognition of their rights as citizens, social inclusion in local communities, choice in their daily lives and real opportunities to be independent. Despite this the report also recognises the problems and challenges in achieving this given the complex needs of this group.

Although there is growing consensus of the need to widen the range of options available beyond day centre attendance to include further education, vocational training, work experience, paid employment, voluntary work, social and leisure activities, these alternatives are not without their difficulties. McConkey et al. (2004) in an Audit of ID services noted a number of barriers to social inclusion including the availability of choices in any one locality; lack of finance to initiate and sustain new services. The authors suggested that the solution probably lies in refocusing the 'problem' of day services from one that is addressed as a subset of ID services to an issue of social inclusion for a marginalised group of people within our society.

Behaviours that challenge in people with ID is associated with a range of difficulties and presents a major challenge to families, educational settings, and all aspects of community participation (Glasberg, Martins, & Harris, 2006). For some this may often lead to children being placed in residential schools (McGill et al., 2006a) and out-of-home placements (McIntyre et al. 2002) as have been discussed in the previous section on living options.

#### 4.3.1 Day centres

Information from the NI Audit of ID services (McConkey et al., 2004b), indicates that more people are attending day centres in NI (23.5 per 10,000 of total population) compared to Scotland (15.1 per 10,000 of total population) and England (12.0 per 10,000). It also reports that in the RoI around 6, 700 people living with family carers or in community accommodation attend some form of day provision. In 2004a McConkey identified during the NI review of day services a total of 77 day centres. More recently Emerson (2005) noted that 39% of all adults with an ID in England were attending a day centre, two-fifths of whom were attending five days a week. Findings from the postal survey to day centre managers indicated that each centre had a median of 8 people with behaviours that challenge.

Further research conducted here by Foyle HSS Trust (2000) contrasting centre attendees in 1994 and 1999, found an increased number of people with medium and high dependency allied with behaviours that challenge. One Derry centre in particular had transformed into a 'high dependence care facility' as more able clients had moved on to vocational training, supported employment and outreach centres.

#### 4.3.2 Education

The majority of students with significant behaviours that challenge can be accommodated within safe early childhood centres/services and schools, provided that support and specialised training services are available to teachers and caregivers within an inclusive education model. Typical centres and schools must have in place a transparent, comprehensive behavioural environment that provides positive behavioural support for all children and youth in the programme, augmented by additional individualised special education services for those children with significant needs (Carr et al., 2002; Scott, 2001).

One of the most complex social systems in which children who challenge must function is that of the school. This context has been investigated within the Positive Behaviour Support Model (Turnbull, et al., 2002). Inclusive schools represent one of the major practical sources whereby stigma associated with ID can be addressed. Thus teacher attitude and the climate of the classroom and the school become very important variables. Educational policies interact with social perception. For example, it is now standard practice to add extra educational supports for children with disabilities via the transdisciplinary team, instead of the older 'pull out' procedures.

In a Position Paper by the South Eastern Education and Library Board (SEELB) entitled "Emotional and Behavioural Difficulties" (2003) it was reported that recent statistics collated by the Principals of Severe Learning Difficulty (SLD) Schools indicated that a total of 114 pupils (24%) presented with behaviours that challenge. In all 44 (9%) are described by the principals as presenting with behaviours that severely challenge.

There has been an ongoing debate within the field of education on the inclusion of children with special needs in mainstream schools. Research has highlighted barriers that can prevent the successful implementation of inclusion in many mainstream classrooms. One major barrier is pupils who have special educational needs and emotional and behavioural difficulties, specifically those children that display behaviours that challenge (Croll, 2001; Visser and Stokes, 2003).

The high needs of people who challenge are often a barrier to successful inclusion, and new approaches that enable both class and specialist teachers to minimise its occurrence need to be developed. Although barriers still exist to the inclusion of students with severe disabilities, there is evidence that inclusion can work successfully (Coulter, 2008).

Many people with ID make use of further education provision, Local Education Authority adult and community education and adult work-based training opportunities to develop and extend their skills (DoH, 2001), but this is not true of those who challenge. It has been acknowledged that they need to have the same access as other people to opportunities for education and lifelong learning (DoH, 2001; DoH, 2007).

Watson (2009) examined the barriers to inclusive education in Ireland for pupils with a diagnosis of intellectual and/or pervasive developmental disabilities. For phase one of

the study questionnaires were sent to principals of primary schools in counties Dublin and Kildare. The questionnaire asked principals about their schools' experiences of catering for pupils with intellectual and/or pervasive developmental disabilities and the level of training in special education and learning support attained by the teaching staff. Principals were also asked if they ever had occasion to deny enrolment and if so to explain why and to provide further information that they believed was relevant to the provision of universal enrolment. A total of 245 (42%) questionnaires were returned: 65% from mainstream schools, 25% from mainstream schools with a variety of special classes/units 9% from special schools and under 1% from ABA centres. Phase two, a follow-on Parents' Survey asked parents of children with intellectual or pervasive developmental disabilities (N=119) about their experience in accessing enrolment for the children. The main findings were that parents and teachers felt they needed more training, mainstream teachers had limited access to support from psychologists or AHPs and they had concerns about their ability to teach ID pupils. However, the mainstream teachers did suggest that if more teachers were trained in this area then more ID pupils could attend mainstream schools. Other studies have found that teachers hold positive views on having ID pupils in their school but they also expressed concerns about their knowledge, skills and understanding of ID pupils needs and that they would need additional training to meet this need (Garner, 2000; Rae, et al 2011).

#### 4.3.3 Out of area placements

For children out of area placements may involve residential schools, these are not discussed here as they have been in the previous section above on Living Support options. It is not only children who on occasion need periods of residential support due to behaviours that challenge. Adults, many who have protracted behavioural issues do from time to times require out of home placements for stabilisation or assessment and treatment. Since the closure of long-stay hospitals many people with an ID who challenge have had to be supported in 'out-of area' placements away from their home area. A survey of all local authority commissioners conducted in 2002 mapped the scale of the problems and explored the factors that either led to people being placed out of area and/or to such placements being maintained. These factors included issues around quality of service; joint working; capacity; workforce issues; local issues and transition (Pritchard & Roy, 2006). This issue has been a central concern in a number of recent reports that have recommended there is a need to focus on out of area placements (DoH, 2007; McGill et al, 2010). The main area of concern is that such placements can lead to extreme difficulties for families to maintain contact with the person who is placed there and day opportunities that client's have established near their home over many years can be lost.

Future planning is required early for adults or children with behaviours that challenge so as to alleviate the difficulties that out-of-area residential placements can create. Among the difficulties are break-down in communication with families and extreme difficulty returning the person to their home. Overall a range of recent literature shows that care management processes are frequently weak and ineffective for people placed out-of-area (Ritchie et al, 2005; Beadle-Brown et al, 2006; Mansell et al, 2006a; Mansell et al, 2006b; Allen et al, 2007; Beadle-Brown et al, 2009).

#### 4.3.4 Employment

People with an ID are amongst those in society with the lowest employment rate. The most recent statement of general policy towards people with ID estimates that less than 10 percent of this population in the UK are in employment (DoH, 2001a). This is supported by the work of McConkey and Mezza (2001) who estimate the rate to be 9 percent. Valuing People (DoH, 2001a) noted that 8800 people with ID were employed in supported employment schemes run by the Department for Education and Skills in the UK. Beyer (2001) estimated that a further 7000 are assisted by independent agencies.

It has been well documented that people with ID often experience employment difficulties and a great deal of research has been conducted on this issue (Stephens, et al., 2005; Capella, Roessler & Hemmeria, 2002; McConkey & Mezza, 2001). However, employment figures are not available for those people with an ID that challenge and they have limited employment opportunities. The limited opportunities for employment for this population may be attributed to the lack of understanding of the reasons for behaviours that challenge as well as a lack of expertise regarding behaviour management and autism (McGill et al. 2006b). Rose et al. (2005a) in a study aimed to identify factors that may affect the likelihood that people with intellectual disabilities will find employment through a supported employment agency found staff motivation to be the only significant predictor of employment outcome.

Cole et al. (2007) brought together key themes and issues emerging from a review of UK literature and a survey of best practice of community-based day activities for people with ID. It identified that sufficient time and resources are needed to explore gaps around the provision of community-based day opportunities for people from ethnic communities, people with profound and multiple learning difficulties, people who present behaviours that challenge, and people in older and younger age categories.

#### 4.3.5 Staff training and service procedures

Issues around poor staff training and professional support are implicated in day services which had higher rates of placement breakdown due to behaviours that challenge. Most of the research to date has concentrated on the training needs of staff working with this population. A study undertaken by McClean et al., (2005) suggests that person-focused training (PFT) is a model of service delivery which provides staff with skills in functional assessment and intervention development.

Grey et al. (2007) in a special issue of JARID on staff training and challenging behaviour states that given that there is considerable evidence for the efficacy of behavioural interventions in the development of life skills and in the remediation of behaviours that challenge for individuals with ID it can be argued that staff competence in the application of behavioural support is critical for improving the quality of life of this population and also in reducing the frequency of those behaviours that challenge (McLean et al., 2005).

Grey et al, (2007) summarises barriers to staff implementing effective behavioural interventions found in previous studies:

- Absence of an organisational ethos supporting behavioural supports, combined with disparity in belief systems on the causes of behaviours that challenge (Ager & O'May, 2001)
- The absence of adequate performance management systems for the implementation of behavioural interventions (Reid et al., 2005)
- Poor competency-based training (Murray et al., 2000)
- Negative staff perceptions of behavioural interventions and poor understanding of such interventions (Ager & O'May, 2001).

Grey et al., (2007) suggested that perhaps it's time for a reappraisal of the research agenda for staff training and behaviours that challenge. Research into cognitive and emotional processes in staff working with behaviours that challenge has been justified largely on the basis that an understanding of these processes provides a fuller picture in understanding the determinants of carer behaviour towards clients with behaviours that challenge. However, research following this track has failed to show evidence of associations between cognitive and emotional variables and staff behaviour. Similarly, there is no evidence that changing staff cognitions or emotions will benefit service user's behaviour that challenge directly.

These authors follow on to suggest that one answer is to clearly develop more research that includes observable outcome measures for staff and service user behaviour. We need a functional analysis of staff behaviour so that training interventions for staff are following evidence-based practice based not only on analysis of client behaviours but analysis of behavioural interaction between client and staff (or caregiving parent). Services' being more aware of service users needs was an aspect that generated considerable debate at the consultation meeting for this review (Appendix 2).

#### 4.3.6 Recommendations

Based on the evidence found in relation to day opportunities for people who challenge the following recommendations are forwarded.

- Less reliance on traditional day centre attendance and replace this with more further education, vocational training, work experience, paid employment, voluntary work, social and leisure activities.
- Education for children with ID should follow an inclusive model to prevent social exclusion from others that can perpetuate discriminatory attitudes.
- Behaviours that challenge can create difficulties for children being included in education but approaches such as positive behavioural support (PBS) can overcome many of these difficulties (see later section on interventions).
- A working group could be established to consider innovative further education and work opportunities for people with ID who have behaviours that challenge.
- Development of efficient staff training approaches, to enhance staff knowledge, skills and attitudes to reduce behaviours that challenge and thus impact on day opportunities, therefore bringing about improvements in clients' QoL.
- For those clients who have difficult long-lasting behaviours that challenge it may be necessary to develop specialist day opportunities that accommodate them within a safe but therapeutic environment.

- Research on the functional analysis of staff behaviour in interactions with clients who challenge so that training interventions for staff can be planned not only on analysis of client behaviours but analysis of behavioural interaction between client and staff (or caregiving parent).

#### **4.4 Family Support**

Some 10 studies were identified in relation to family support for caregivers where a family member has ID and behaviours that challenge (see Appendix 6, pp.163-167). There seems little doubt that family caregivers of a person (adult or child) with behaviours that challenge need support if they are to adequately fulfil this role and avoid care in the home breaking down. McConkey et al (2004b) in an Audit of ID services accessed for this review suggest the need for family support that for some needs to be intensive, should be person-centred and that there is a requirement to recognise that support needs to fit in with family dynamics and context. It is also recognised that if out of home placements are required when these are in out of area locations difficulties with family contacts can occur and thus it is recommended that if support is required out of home this should be available at local level (DoH, Mansell Report, 2007; McGill, et al 2010).

##### 4.4.1 Family views

By and large the evidence suggests that many families are dissatisfied with the availability of services, access to support and in addition when support is accessed they expressed frustration with the services in terms of the help provided for them (Wodehouse & McGill, 2009; McGill et al, 2006b; NDTi). In a NI study located for this review the perceived effectiveness of 145 community learning disability team (CLDT) members, 27 family caregivers and 21 people with ID reported high levels of perceived effectiveness with the services provided by the CLDTs, but caregivers gave the lowest satisfaction ratings (Slevin et al, 2007). In this study some of the main concerns raised by carers included:

- Limited respite services
- Long waiting lists to access some services, especially psychology, speech and language therapy and other AHPs
- Having to 'fight' to get services
- That emergency cover at out-of-hour times was limited and patchy across various Trusts (a view echoed by the consultation group Appendix 2).

Kenny & McGilloway (2007) also found significant dissatisfaction from formal care services in the RoI (Dublin area) and that parents found most satisfaction from informal support such as spouse, other parents or other children. Similar dissatisfaction by service users has been reported in other countries where it has been suggested direct care staff are not well equipped to provide behavioural support (Philips et al, 2010). This can have negative consequences as it has been found that caregivers with unmet needs are more liable to experience mental health problems (Caldwell, 2008; Herring, et al 2006).

#### 4.4.2 Transitions and future planning

Caregiving parents need support for future planning for their son/daughter to prepare them for transitions in life and for what will happen when they are too old to remain the primary caregiver (Minnes & Woodford, 2004; Kenny & McGilloway, 2007). This worry about future transitions is not confined to parents. One of the review studies also found that siblings of children with complex behaviours have concerns about when their brother or sister moves from school to adult services, and what this will mean for them (Rawson, 2009). In the same study the siblings indicated that to support them in arranging or providing care for their sibling in the future they felt a need for: training in legal/fiscal issues, written information to guide them, having a named sibling support person within the organisation and a website for networking with other siblings (Rawson, 2009). In the study cited above that evaluated CLDTs in NI future planning was also a major expressed concern of carers of people with ID (Slevin et al, 2007) and this was further verified here by the views on this expressed by the consultation group (Appendix 2).

Transitions in life are important for everyone but even more so for ID people who have special needs or who challenge as they often face more transitions in life than others (Barron & Hassiotis, 2008 Myers, 2006). In addition although a person may be at the chronological age to receive adult services their disability and functioning may still require inputs that children's services provide and this is frequently overlooked (Beresford, 2004). These transitions may involve among other changes: from home to school, school to work or day care, home to residential facility, institutional to community setting, the loss of a family member, children to adult services and between and across various agencies. Transitions can create stress for both the client and their family e.g. when they leave school young people with ID have less opportunities for employment, to make friends, develop skills, have social networks and the loneliness they face can exacerbate their behavioural or mental health problems (Raghavan & Pawson, 2008, Heslop et al, 2002, Hanson et al, 2000). It has also been reported that client's themselves and family carers are poorly understood, feel they are not kept fully involved in decisions about transition planning and successful transition from childhood to adult is rare with poorer post-school outcomes for ID people (Grigal et al, 2011, Unwin et al, 2008, Beresford, 2004, Ward et al, 2003, Heslop et al, 2002).

Some studies have identified what is needed for successful transition planning. There is a need for good communication between sending and receiving services staff and the family should be kept at the centre in all communications. A multi-agency approach and good support will help achieve optimum outcomes for young people and their families (O'Brien, 2006; Beresford, 2004). Forbes et al (2002) reported that continuity in the transition from child to adult services is essential and a dedicated transition co-ordinator helps the process. Planning for transitions needs to take place well in advance and be underpinning by accurate assessment of the person and family needs, validated assessment instruments will help with this (Silberman et al, 2009). The following have also been reported to help with transitions: education in psychosocial development; understanding changed relationships with parents/carers; provision of choice and information (a person's ID should not negate their right to make decisions) and focusing on the person's strengths and not only behavioural problems (Murphy et

al, 2011, DoH, 2006, 2009, Dee & Byers 2003, Forbes et al, 2002). The issue of choice by the client him/her self is not straight forward in all situations as at times there will be conflicts with parents and as Pilnick et al (2011) found in such conflicts parents wishes usually prevail. But, even in these situations negotiation with the client can help reduce ill feelings. For those who move out of institutional care they will “need access to a comprehensive array of individualized services and supports to enable them to maximize their independence, productivity, inclusion, and self-determination in the community” (Silberman et al, 2009, p.521). Finally, there needs to be trained staff skilled in all aspects of transitioning who will work with clients and families using a person-centred approach to facilitate a successful process that leads to optimum outcomes.

#### 4.4.3 Support programmes

The Signposts Programme is a support approach for families of children with behaviours that challenge that is in operation in Victoria Australia. It was initially reported by Hudson et al. (2003) and involves providing parents with a package that includes books, video and workbooks. The package is underpinned by applied behavioural analysis principles. Parents are provided with one of three types of support: group support, telephone support and self-directed. Hudson et al (2003) reported that use of the system led to a decrease in stress by parents, confidence in dealing with their children and improvement in their children’s behaviours. In a much larger pre-test post-test evaluation Hudson et al (2008) reported on a sample of 1790 families and found similar positive outcomes including, higher self valuing by parents, greater satisfaction, reducing daily dissatisfaction and reduction on depression measurements on the scale used. The programme evaluation also found positive impacts and improvements in the behaviours of the children.

As part of the Signposts programme dissemination of knowledge and skills involved training and education of 554 staff in schools, local agencies, community services & private practitioners. Following the training 203 practitioners (39%) were active in the ongoing delivery of the Signposts program at 6 months post study. Overall this study shows impressive results to this programme that suggest it could be implemented on a trial here if funding were available. Training of parent caregivers is an essential requirement of family support. McConkey (2010, p.21) in a review of literature on behaviours that challenge in children concluded that, ‘the implementation of systematic programmes for managing behaviours has been of assistance and parents might benefit from training in these approaches. There is a need for greater investment on locally available specialist provision to prevent children leaving the family home.’

#### 4.4.4 Short breaks

Short breaks to provide respite are an essential element of family support if a person in the family has behaviours that challenge. However, the views of family caregivers are very important and if their son/daughter is placed for a short break it can result in undue stress for parents if they have not confidence in the setting and staff. Preece (2009) identified the features that families whose children had ASD valued in making the short break provision effective for them. These were:

- Adaptations to the physical environment

- Consistency across environments
- The use of ASD-appropriate approaches
- Staff attributes, including their understanding of ASD
- Individualisation
- Successfully accessing the community
- Grouping of children staying in the house at the same time.

McConkey (2010) has identified the main types of short breaks that should be available and he provides details of the benefits and limitations of these. See Appendix 14 (p.195) for detail of these as cited from McConkey (2010). Many of these concerns are echoed by the consultation group for this review (Appendix 2).

#### 4.4.5 Recommendations

Based on the evidence of this review it is recommended that:

- Family caregivers who seem dissatisfied with services they receive should be listened to and their views incorporated into service delivery
- Future planning involving parents and clients in a true person-centred way needs to take place to prepare for transitions and the future
- Attention needs to focus on siblings and their views on being potential future main caregivers (this is an area that would benefit from future research).
- Services should be provided in the home to support families as far as possible and family caregivers should be provided with education, training and support for their caring role.
- Short term respite breaks should be more available and meet the complex needs of people who challenge
- If out of home placements are required these should be available at local level and be for short duration.

This sub-section has provided an overview of the support that families need if they are to maintain their son/daughter living in their home and continue with their caregiving. However, it is recognised that within a person-centred approach family caregivers are partners in provision. Professionals need to support caregivers in this role by working in partnership with them and by providing training in various interventions. The next section presents the evidence on interventions and services that can be used to support people with ID who have behaviours that challenge or/and mental health problems. Much of what is presented in the next sub-section is highly relevant to support and education of parent caregivers as well as professionals who will work in partnerships with them.

### **4.5 Interventions and services**

There is a proliferation of literature around the area of people with ID and behaviours that challenge or/and mental health problems. Perhaps this is an indication of how crucial these aspects are as they present one of the greatest challenges to community care. From the array of literature that is available 17 key papers were selected and these are presented in Appendix 7, pp.168-176.

Over the past decade there has been consistent agreement in the literature that applied behavioural analysis (ABA) is one of the most effective intervention approaches (if not the most) to support people with ID who present behaviours that challenge. Rush and Frances (2000) published guidelines on the treatment of people with ID who have a mental illness or behaviours that challenge. These were developed by an expert panel and recommended use of: ABA, service user education; creating positive environments; Cognitive-Behaviour Therapy (CBT); counselling and psychotherapy. The expert panel agreed that the most highly recommended interventions in most situations were ABA, managing the environment, and individual and/or family education (Rush and Frances, 2000) although medications remain highly used as a treatment for people who challenge. Behavioural interventions remain at the forefront of interventions for this client population and evidence supporting the approach continues to be extensively reported and includes thorough assessments, incorporating functional analysis with preventative and reactive strategies, within a positive behavioural approach (Carr et al., 2002; LaVigna & Willis, 2005; Lowe et al., 2005; McClean et al., 2005).

Overall the reported evidence indicates that the most effective approaches to help people with ID with behaviours that challenge fall within the positive behavioural paradigm. This is supported by the RCP (2007) who state that the paradigm emerged from three main sources i.e.:

- “applied behaviour analysis
- the normalisation/inclusion movement
- person-centred values.

Positive behavioural support integrates the following components into a cohesive approach

- comprehensive lifestyle change
- a lifespan perspective
- ecological validity
- stakeholder participation
- social validity
- systems change
- multi-component intervention
- emphasis on prevention
- flexibility in scientific practices
- multiple theoretical perspectives” (Royal College of Psychiatrists, 2007, p.26).

There are a range of approaches and service models that are underpinned by positive behavioural support (PBS) or that draw on one or a number of the components identified above. The evidence from this review firstly presents approaches that have been found beneficial and this is followed by presentation of wider service model or systems that have reported value.

#### 4.5.1 Assessment

A logical starting point in management or treatment of behaviours that challenge is to attempt to be proactive and prevent the behaviour taking place, or failing this to reduce problem behaviours before they escalate or become intractable. It has been reported that the cause of most behaviours that challenge can be identified as a reaction to physical health problems; environmental factors, mental health problems, learned behaviour or as a reaction to not being able to communicate effectively other than by expressing behaviours that challenge (Slevin, 2007). However, the aetiology of the behaviour may be due to a number of these factors in combination. A core principle of behavioural interventions is that a 'functional analysis' assessment of behaviours is undertaken to identify the cause of the behaviour and its function for the client. For example, problem behaviour may be assumed to be the outcome of a learned behaviour and therefore be managed by a behavioural intervention programme aimed at unlearning that behaviour. However, if the said behaviour was a manifestation of a psychotic mental illness then a behavioural programme may be inappropriate.

Functional assessments are integral to applied behaviour analysis (ABA). In discussion on similarities and differences between ABA and positive behavioural support (PBS) Dunlap et al (2008) suggest that although PBS evolved from ABA it has extended this to take on a wider perspective in assessments to include medical, behavioural, educational, psychosocial and wider organisation, contextual aspects as well as individual factors (Carr et al, 2002; Carr & Owen-DeSchryver, 2007; Dunlap et al 2008). It cannot be assumed that a displayed behaviour should be treated or managed by a particular intervention until the nature, cause and function of that behaviour is known at an individual level but also considering the wider systems context. Assessments will involve a multidisciplinary approach but central to PBS is a person-centred approach and therefore it should involve other key stakeholders such as parents, siblings, perhaps grandparents other family members, employers and teachers. Assessment of behaviours should be undertaken before commencing an intervention to determine what the function of the behaviour for that individual is within their social context.

As stated above assessment needs to be individual focused as well as considering wider contextual variables. At the individual level assessment may involve communication, medical aspects, antecedents and consequences of behaviour and mental health. Checklists can be useful for individual assessments and in addition they can provide baseline measures against which subsequent intervention outcomes can be evaluated. Unwin and Deb (2008) reviewed published papers that used various check lists and from this they identified those listed in Table 5 as the most commonly used. Unwin and Deb (2008) identify these as the most cited scales used in the review they undertook and they refer the reader to Deb et al, (2001b) and O'Brien et al, (2001) where a more extensive list of scales is provided. Assessment should therefore involve

Table 5: Assessment Scales used for BC or Mental Health (cited from Unwin & Deb, 2008, 38)

| Scales for challenging behaviour or mental health assessment  | No. of publications identified |
|---|--------------------------------|
| Aberrant Behaviour Checklist  | 13                             |
| AAMD Adaptive Behaviour Scale   | 19                             |
| Behaviours Problems Inventory (BPI)   | 4                              |
| Matson Evaluation of Social Skills in Person with Severe Mental Retardations (MESSIER)                                | 6                              |
| Motivational Assessment Scale   | 4                              |
| Psychiatric Assessment Schedule for Adults with Developmental Disabilities (PAS-ADD, PAS-ADD checklist, Mini PAS-ADD) | 6                              |
| Reiss Screen for Maladaptive Behaviour  | 6                              |
| Diagnostic Assessment for the Severely Handicapped (DASH1 & 11)   | 9                              |
| Psychopathology Instrument for Mentally Retarded Adults (PIMRA)   | 8                              |

an individual focus using scales such as those above or similar, a functional analysis within an ABA framework and a multi-element assessment of wider contextual aspects in keeping with PBS.

#### 4.5.2 Behavioural interventions

It is evident that previously published literature reviews and empirical research on the long term significance of the presence of behaviours that challenge highlight the importance of successful intervention in order to have overall benefits for people with ID, their families, and society. There is quite a lot of research on interventions for people with ID who have behaviours that challenge and several key papers have been accessed for this review. However, even though there is published evidence, for example on behavioural interventions less is known about why such evidence-based interventions are not used more in practice. It seems that for many interventions knowledge exists but translation of this evidence into practice is not taking place as it should.

Didden et al., (2006) conducted a meta-analysis of single-subject research on the behavioural treatment of people with behaviours that challenge who had a mild ID. This meta-analysis showed that behaviours that challenge in persons with mild ID were effectively managed using predominantly behavioural intervention methods and, to a lesser extent, with cognitive behavioural packages, such as anger management. Some have questioned the evidence for behavioural interventions (Beail, et al, 2005; Taylor, 2005) but there is a body of evidence indicating that behavioural interventions for behaviours that challenge are effective with people who have ID. However, it should be noted that the majority of studies in the meta-analysis by Didden et al (2006) involved children and adolescents. Their conclusions regarding the overall effectiveness of behavioural interventions may apply best with respect to this population because the majority of studies in the analysis were conducted with these groups. The author's

conclusions may, nevertheless, also hold true for adults, although more research is needed in this area.

Meyer & Evans (2006) undertook a literature review on interventions for behaviours that challenge and they report that virtually all children in the early childhood to middle years who exhibit severe behavioural challenges can be accommodated in typical school and community environments with the availability of PBS and supplemental caregiver training. For very young children who have disabilities and behaviours that challenge, there is evidence that placement in proximity to appropriate non-disabled peer role models is essential as a supplement to structured educational interventions. The authors review supports the effectiveness of inclusive school placements in classrooms with same-age non-disabled peers for most children and youth with severe disabilities and behaviours that challenge, provided that schools have in place systemic child supports and capacity for individualised interventions including the availability of trained personnel and family supports. A range of approaches have been used for children of different ages. An exhaustive account of these is not presented here but a Table is included in Appendix 15 (pp.197-198) that lists main approaches that have been found useful and their underpinning principles.

Some of the interventions in the Table in Appendix 15 are also appropriate for adolescents and adults. For adults those most likely to be effective include skills replacement training, attention to antecedents and reinforcing consequences in combination with a wider systems change approach — which in turn can signify altering environmental contingencies so that the natural environment is refocused on providing incentives and motivation for using new skills rather than being rewarding of problem behaviours. ABA that is underpinning by technologies involving operant learning involving reinforcement, contingency change, shaping and fading, and stimulus variations have been found effective. These have been found effective when combined with PBS involving approaches that are person-centred, are supported, practical and sustainable, and focus on prevention with positive interventions taking place when the behaviours that challenge are not present. In addition interventions should have social validity to the real world of the client and their family and draw on multi-element approaches (Carr et al, 2002; Carr 2007; Dunlap et al, 2008).

#### 4.5.3 Medication

Medication remains one of main treatments in the management of mental health problems, and behaviours that challenge in those with an ID. Medication prescription to treat physical health problems that may have an aetiological relationship to behaviours that challenge in ID people by and large has little controversy. However, this is not so for the use of psychopharmacology as many of these drugs are indicated for treatment of mental illness yet they have been commonly used for behavioural management when a co-morbid mental illness has not been present. Psychopharmacology has been reported to be prevalent (Aman 2000; Emerson et al, 2000) and Taggart (2003) also reported high levels of prescribing for 154 people admitted into a specialist hospital in NI. Antipsychotic medications continue to be prescribed to treat people with ID for a wide range of behaviours that challenge, despite there not being a strong evidence-base for their use (Singh, et al, 2005; Matson & Neal, 2009).

In an audit of 382 sets of notes examined (89% of the case-loads) for a community ID service Marshall (2004) found that 102 clients received regular medication for behaviours that challenge (26.7%), PRN medication was not included. Antipsychotics were found to be the main drug prescribed with 98 (96%) clients receiving one or more of these. When the average duration of treatment with the drugs was analysed this was found to be 5.3 years.

Brylewski and Duggan (2004) in a Cochrane Review investigated the effectiveness of antipsychotic medication for people with ID and behaviours that challenge who had not additional mental illness. They accessed nine RCTs and based on the analysis they found no evidence of whether antipsychotic medications were beneficial or harmful for adults with ID. In an update to this review in 2009 there were no changes to the findings.

In another systematic review of the use of the antipsychotic clozapine Singh et al (2010) reviewed 13 studies and although none met the inclusion criteria for RCTs that they set, included studies did report improvements for clients on global scales. However, as these authors state the global scales use subjective data and it is difficult to rely on use of these to test outcomes. In four of the studies rating scales were used, which are recommended to allow more objective measurement of outcomes and these studies showed less positive effects. Overall they found the outcomes to using clozapine to treat behaviours that challenge in people with ID inconclusive. In the studies Singh et al (2010) reviewed a number of side effects to use of clozapine are identified including weight gain, extra pyramidal symptoms and tachycardia. Many of the studies reported that side effects were mild and tolerable. But, 'the decision that side effects were mild and tolerable seems to have been made from the viewpoint of the treatment team and not the individual, thus the determination was subjective and did not assess the impact of these side effects on the individual's quality of life' (Singh et al, 2010, 1137).

As a number of studies have found use of antipsychotics for people with ID who challenge lacking in evidence as to whether or not they are beneficial, especially for people without co-morbid mental health problems the question needs to be asked why is there such a high rate of usage of these drugs? Bhaumik & Michael (2004) state, the potential reasons for this might be to fill resource service gaps and respond to requests for rapid actions to deal with behaviours that challenge.

In conclusion this review found the use of antipsychotic medications to treat behaviours that challenge in people with ID where no coexisting mental illness is present is questionable. There are occasions according the RCP (2007) when medications are justified for the treatment of underlying mental health problems in people with ID but these should be seen as an adjunct to other interventions and not as the sole treatment. The RCP (2007) have produced guidelines for the use of medications with this population that offer sound advice.

#### 4.5.4 Early intervention

One of the most discussed issues in the child treatment literature is the success of early intervention programmes with children who have an ASD (Matson & Minishawi, 2006; Moore & Goodson, 2003). The consensus is that early intervention is valuable and, within limits, the more intense the intervention, the greater the gains despite variability in

outcomes within groups of children treated (Symes et al., 2006). It has been found that the earlier interventions begin, for example with interventions such as ABA the more positive outcomes are likely to be. To date early and behaviourally-based interventions have been found to be by far the most effective means of intervention for children with ASD (Lipkin & Schertz, 2008; Schreibman, 2000).

A number of other studies have recently indicated that behavioural interventions are effective in children (Eldevik et al. 2010) and adults (Probst et al. 2010) with ASD.

Recent developments in NI have proved to be successful in the delivery of early intervention programmes to families of children with ASD and include:

- *The Keyhole Early Intervention Project*: This home based programme was developed by Autism NI (formerly PAPA) in conjunction with speech and language therapists and early childhood educators. It consists of a series of visits by an early intervention therapist to the child's home during which careful assessments are made of the child and an individual programme of activities is drawn up in association with parents to further the child's communication, play and social interactions.
- *The Belfast Board's Pre-school Home Intervention Service* provides support to families of children with significant developmental delays. Educational psychologists make referrals to the service. The children are usually supported until they are old enough to attend mainstream or specialist nursery provision. In recent years an increasing proportion of these children have a diagnosis of ASD.
- *Oakwood Support Team* was established in January 2001, and is located at Oakwood Special School. It presently consists of one full-time and one part-time ASD support teacher but a second full-time teacher is being appointed. This service provides support to families of children with ASD, and will in due course take over support for children with ASD from the Pre-school Home Intervention Service. The service also provides support in nursery settings and in primary schools.

However, despite recent developments, the Belfast Board's services are being outstripped by the increasing demands made on them and they are not always able to provide the breadth and depth of input that may be requested by the parents or indicated by the individual needs of the child (Report of the Task Group on Autism, 2002).

#### 4.5.5 Health

People with ID have been reported to have higher morbidity levels than the general population in most of the common illnesses and diseases (Robertson, et al. 2000; Sutherland, et al. 2002). With respect to unmet health needs among people with ID there is evidence that adequate health service access and attention can be a problem (Hunt, et al., 2001; Cassidy, et al., 2002). In addition although longevity for people with ID has increased as a population their life expectancies remain lower than the general population (Felce, et al., 2008). Some of these health problems relate to co-morbid

complex health problems in this population e.g. high levels of epilepsy, sensory or muscular impairments, respiratory or cardiac problems and neurological or physical disabilities (Sutherland, et al. 2002; Ouellette-Kuntz, 2005).

Some of these health problems are due to genetic predisposition to various syndromes that cause ID but others are due to poor attention to the health of this population and their life styles, for example many have poor dietary habits, lead sedentary lives with little exercise and are therefore more obese than the general population (Marshall, et al, 2003; Emerson, 2005; Rimmer, et al. 2007). In a study conducted here in N. Ireland it was found that ID school children were significantly more likely to be overweight or obese than children without an ID (Slevin et al, 2008).

The relationship between health and behaviours that challenge can operate at a number of levels. Firstly, behaviours that challenge may be a reaction to pain or malaise that results from ill health. Secondly, psychological impacts of adverse health conditions may impact on people's mental health. Thirdly, there is an association between behaviours that challenge and some of the complex health problems people with ID may have, for example epilepsy. It is therefore important that health is monitored principally for the health and well-being of the individual but also as an integral aspect of assessing behaviour in individuals.

Health checks are an important aspect of assessment of people with ID. In a study conducted by Baxter et al (2006) among 181 individuals who had health checks it was found that 93 (51%) had newly diagnosed health problems, 16 of these presenting potentially serious health risks. Following on from this a study was conducted by Felce et al (2008) on repeated health checks. The study aimed to identify the optimum time for repeated health checks. The sample drawn from GPs was 267 and for various reasons the final sample was n=108. Using an experimental design participants were divided into groups with one group having health checks at a lesser frequency than the other. Based on the findings they suggested that health checking is an effective intervention for identifying health problems among people with ID, and annual health checks for this population were recommended. Interestingly among this sample of 108 clients, 35% of them were identified as having behaviours that challenge (based on 5 behaviours rated '3' or a total score of 31 or more on the Aberrant Behaviour Checklist) and 86% met threshold levels on the Psychopathology Instrument for Mentally Retarded Adults. Although this study did not identify the specific impact of health checks on behaviours that challenge as a proactive strategy to assess the causative relationship between health and behaviours that challenge health checks may form a useful preventative strategy and health monitoring has been recommended by various UK policy initiatives (Welsh Assembly Government, 2001; DoH, 2001a, 2009; Bamford Review 'Equal Lives' DHSS, 2005).

#### 4.5.5 Mental health

As stated previously in this report behaviours that challenge are often associated with an underlying mental health problem. In these circumstances as stated above psychopharmacology medication may be an appropriate treatment in combination with other therapies. It is now becoming more widely accepted that many of the therapies

that can help the general population who develop mental illness should according to an inclusion rights based approach be available to people with ID.

- Cognitive Behaviour Therapy

There is growing empirical evidence of the effectiveness of using Cognitive-Behaviour Therapy (CBT) in successfully treating mental health problems in people with a learning disability. In a special issue in JARID (2006) on CBT Willner & Hatton highlight that little attention has been paid to CBT interventions with people with ID and mental health problems. There has been a lack of advanced training for professionals wishing to conduct CBT with people with ID and a lack of large-scale studies concerning the approach.

Since that time Willner (2007) undertook a literature review of studies that used CBT as a therapy for anger management in people with ID. Although it was found that many studies used uncontrolled trials making the evidence-base of their effectiveness less robust Willner did identify several studies since the year 2000 that have demonstrated benefits to using CBT in anger management. The studies identified are cited from Willner (2007, 15) in Table 6 below.

Table: 6 Effectiveness of CBT for anger v waiting-list control (cited from Willner, 2007, p. 15)

| <b>Study</b>            | <b>date</b> | <b>N</b> | <b>Setting</b>  | <b>Format</b> | <b>Sessions</b> | <b>Duration</b> |
|-------------------------|-------------|----------|---|---------------|-----------------|-----------------|
| <b>Anger Management</b> |             |          |   |               |                 |                 |
| Rose et al              | 2000        | 25       | Community   | Group         | 16 x 2h         | 32h             |
| Willner et al           | 2002        | 16       | Community   | Group         | 9 x 2h          | 18h             |
| Lindsay et al           | 2004        | 47       | Community   | Group         | 40 x 1h         | 40h             |
| Willner et al           | 2005        | 17       | Community   | Group         | 12 x 2h         | 24h             |
| Rose et al              | 2005        | 86       | Community   | Group         | 16 x 2h         | 32h             |
| Hagiliassis et al       | 2000        | 25       | Community   | Group         | 16 x 2h         | 32h             |
| <b>Anger Treatment</b>  |             |          |   |               |                 |                 |
| Taylor et al            | 2000        | 20       | Forensic  | Individual    | 16 x 2h         | 32h             |
| Taylor et al            | 2004        | 17       |   |               |                 |                 |
| Taylor et al            | 2000        | 40       | <i>(This includes participants from 2 previous studies)</i> |               |                 |                 |

As Willner (2007) reports each of these studies found there to be significant improvements in anger management by clients in comparison to clients on waiting lists who had not yet received interventions. The studies also reported that for the clients on the waiting lists the anger did not reduce without intervention and for the CBT intervention groups improvements were maintained at 3-12 months follow-up to the interventions.

Murphy et al (2007) undertook a study involving CBT with men who had an ID and who were known to have undertaken sexually abusive behaviours. This intervention that

lasted for 12-months with 15 men led to significant improvements in their knowledge, attitudes and empathy with victims. At 6-month follow-up none of the men had any further convictions for sexual offences and only 3 of the 15 had indulged in sexually abusive behaviour. For one this involved non-touch behaviours of others i.e. indecent exposure and for two it involved sexual touching of others through clothing without their agreement. The authors acknowledge further research is needed in this area but findings do indicate this is a promising approach for some ID men who indulge in inappropriate or sexually abusive behaviours.

In another study conducted by Bruce et al (2010) they found that with appropriate adaptations and support people with ID could benefit from CBT. In the past the value of CBT for people with ID has been questioned but there is a growing body of evidence that this therapy can be significantly beneficial for people with ID who have anger and other mental health related problems. It seems that depending on the nature of the presenting behaviour that challenges CBT can be an effective group or individual based intervention to help people with ID.

- *Psychotherapy and therapeutic counselling*

Various talk therapies are available to the general population who have mental health problems but it is not always clear how accessible such therapies are for people with ID who have behaviours that challenge. Although, as stated above there is a growing awareness that CBT may be an effective therapy, the case for other psychodynamic therapies for people with ID who challenge or have mental health problems is less well established. In addition, according to Sturmey (2005, 2006) much of the research that purports to investigate psychotherapeutic interventions does in fact research behavioural approaches rather than psychodynamic underpinned studies. For example, in systematic review of psychotherapy in people with ID undertaken by Prout & Nowak-Drabik (2003) close to 50% of the studies reviewed related to behavioural or CBT interventions, and over a third had no identified theoretical origins and the few psychodynamic studies identified were in the main case reports.

Mason (2007) surveyed 133 psychologists and 90 psychiatrists in ID from across the UK about their perceptions of the use and effectiveness of psychotherapy. The study reported that the most important factors in clinicians perceptions on the use of psychological therapies are competence in using psychodynamic therapy, the level of the clients disability with effectiveness decreasing for those with the lowest degree of ID and perceptions that psychological symptoms may be 'part of having an ID' and not necessarily related to co-morbid mental health problems.

In a study reported by Beail et al (2005) 20 adult clients with ID and various behavioural or mental health problems were offered the opportunity to take part in a study using psychodynamic psychotherapy as part of routine clinical support. Although this was evaluated as part of the normal service and therefore not adequately controlled the clients did show improvements following weekly 50-minute therapy sessions. Outcomes were significant improvements in psychological distress, interpersonal functioning improved and there were increases in the self esteem of the clients who

underwent the therapy. Beail et al (2005) has shown that psychotherapy can be successfully employed to treat people with ID, although they acknowledge outcome research is in the early stages of development for these therapies.

Other authors have reported that people with ID can effectively engage in therapeutic counselling regarding bereavement (Dowling, et al. 2003; Persaud and Persaud 2003). However, psychotherapy and therapeutic counselling is rarely offered to people with a learning disability across the UK (Hassiotis 1999; Hollins and Dowling, 2002). These findings have been echoed in Taggart's (2003) study that examined the community services offered to people acutely admitted into, and following discharge, from a specialist hospital in Northern Ireland.

In a more recent discussion paper Beail (2010) alludes to the difficulties that are faced in undertaking robust RCTs with these therapies with people who have ID. There can be ethical problems with consent to treatment, there are limited valid and reliable instruments to measure outcomes and there is no agreement on length of time that therapy is required to continue for ID people to achieve optimum outcomes. In this present review there is limited evidence on the use of psychodynamic therapy with people who have ID and behaviours that challenge or mental health problems to either support or refute the value of the therapy. In addition the value that has been demonstrated in the few studies that exist relate to the therapy being used as a treatment intervention for existing mental health or behavioural problems and no studies were found to indicate it could be used in a proactive fashion as many behavioural approaches can.

- *Active support*

Active support is an approach that focuses on supporting people with ID to participate in meaningful activities in their everyday lives, either within or outside their homes. The model is based on the premise that active participation can improve the quality of people's lives. Early work in active support focused mainly on engagement in activities as an outcome but more recent studies have looked at the impact of active support in terms of impact on behaviours that challenge and mental health problems (Mansell et al, 2002; Mansell et al, 2008; Stancliffe et al, 2010).

Active support involves direct support to people with severe ID to facilitate them to engage in meaningful activity and interactions with others. Staff are educated to discover opportunities for engagement and facilitate active participation of clients through a range of approaches that are mainly underpinned by behavioural principles. Services that follow an active support model are encouraged to support and educate staff in these principles (Mansell et al. 2005). Mansell et al (2002) reported modest improvements in behaviours that challenge when people with ID are engaged in meaningful activities in residential care settings. In a later study Mansell et al (2008) investigated staff and organisation culture in 72 residential homes for 359 adults with an ID. The study focused on engagement in activities by people with ID as it is suggested that there is concern around the 'extensive inactivity and isolation still seen in community services' (Mansell et al, 2008, 398). PCAS (person-centred active support) interventions groups were found, in comparison to groups who had no PCAS, to engage in more meaningful activity and this increased activity was significantly associated with reduced stereotyped behaviour by residents.

In a recent study on active support Stancliffe et al (2010) found that the approach led to significant improvements in behaviours that challenge and depression in a sample of 41 people with an ID in group homes in an Australian city. Overall in this study there were significant increases in engagement in meaningful domestic activities, improvements in adaptive behaviours, reduction in behaviours that challenge and although depression scores were low pre-intervention they also showed significant reduction post-intervention for 71% of the residents, with only two showing no change. The authors note that among the residents four people who had the most severe depression at pre-test (according to depression scale scores) showed the most significant improvement at post-test.

The improvement in behaviours that challenge that can result from active support has been previously reported (Mansell, et al, 2002; Koritsas, et al, 2008). With respect to depression behavioural activation has a strong evidence-base supporting its use in non-ID populations (Sturmey, 2009; Lejuez, et al, 2011) although in these circumstances it tends to be a very much self-directed approach drawing on similar principles to CBT. However, active support is a promising intervention for use with ID people who challenge or who have depression. It seems unlikely that supporting people to undertake mere activities such as domestic tasks is the principle impacting factor of active support on behaviour and mood, although there is a known association between activity and depression. Improvement outcomes of the activity in these areas are suggestive of an underlying therapeutic influence that may have more to do with relationships and positive affirmation of the client. This is an area in need of further research in order to determine if the positive impact on behaviour and depression that Stancliffe et al (2010) found can be further substantiated.

#### 4.5.6 Environmental management

The Challenging Behaviour Foundation (2010) in their Charter stress that: *Challenging behaviour is often perceived as a 'problem' or 'illness' to be 'treated', 'cured' or 'stopped'. The problem is seen as being part of the person rather than the focussing on what needs to change around the person, such as their environment or how people support them.* (cited in McConkey, 2010). This statement acknowledges that the environment has a key role to play in behaviours that challenge in people with ID. The previous section on support and housing indicates that the living environment of the individual can impact on behaviour with in general larger congregated living models being more associated with display of behaviours that challenge. International evidence indicates behaviours that challenge will improve or at least stay the same for most people who are deinstitutionalised (Kim et al, 2001) and other advantages such as improved QoL in terms of choice and inclusion have been reported (Young et al, 2000).

An expert panel who developed guidelines on interventions for people who challenge uniformly agreed that the most highly recommended interventions in almost every situation were ABA, managing the environment, and individual and/or family education (Rush and Frances, 2000). As noted this group included managing the environment as one of the core interventions for people who challenge.

Clarke and Dunlap (2008) also noted that from 1999 to 2005, research articles published in the Journal of Positive Behavioural Interventions 63%–69% of the venues

described involved interventions in naturalistic, activity, and social contexts. Therefore the context and environment in which behaviours that challenge occur is an important variable. Preventative interventions that are 'proactive' and aim to promote alternatives or prevent behavioural challenges taking place will therefore frequently involve environmental and antecedent manipulation, skill building and reinforcement based approaches (Adams & Allen, 2001, p.335).

Making changes to the environment is a powerful strategy in helping people who challenge. A number of different approaches can be used in this strategy. One is what Fox (2003) referred to as 'accommodation' that is, to change the person's environment with the aim of reducing their behaviour problems, following having identified that antecedent environmental aspects are causing the behaviour. Some of the other interventions identified in previous sections of this review are underpinning by environmental management e.g. TEACCH involves structuring the environment as an aid to education but it is also useful in reducing behaviours that challenge (Van Bourgondien et al, 2003; Panerai et al, 2002). Active support approaches as detailed above and PBS may also involve environmental changes to support people who challenge.

Environment is not only concerned with buildings but also with people who support those with behaviours that challenge. The mind-set, attitudes and education of staff who work with ID people are vital components of the support needed by these clients. In staffed accommodations, or other community based services, staff education and training, good professional supervision, strong networking and communication systems, stress management and team building arrangements, effective monitoring systems, procedures in place to facilitate 'whistle blowing' if required and an environment in which staff feel empowered are essential components.

#### 4.5.7 Family interventions and education

The evidence for this review found that programmes involving PBS and early intervention approaches (as identified above) can be successful in supporting people with ID who challenge and their families. However, in modern community services it is recognised that interventions need to take place in naturalistic settings and involve family caregivers in partnership with professionals working in a person-centred way with clients to achieve optimum and lasting success. Interventions need to be applicable across all settings and times, taking into account service user contexts (Clarke & Dunlap, 2008; Dunlap et al 2008; Bambara, 2005). As Dunlap et al (2008, 693) state 'Interventions that are not aligned with the preferences of the individual (or family) consumer are not likely to be effective, and it is recognized that consumers have different preferences and define individual dignity and respect in idiosyncratic ways.' The earlier in life that interventions take place the higher the probability of success. Children who experience high quality early education environments with supporting caregiver interactions are more likely to have fewer behavioural problems (Dunlap et al, 2006). However Bailey et al (2005) in a national follow-up of over 2,500 families who had participated in early intervention programmes for children with disabilities found that parents were very positive about helping their child to learn and looking after their personal care needs but over a third of families 'often have a difficult time figuring out what to do about my child's behaviour'.

Beresford (2009) undertook a review of evidence on the effectiveness of 'parent-involved' behavioural interventions in managing problem behaviours among disabled children. In all, only 13 studies met the inclusion criteria set for acceptable research methodologies and used 11 different types of interventions, based around manuals or training curricula with groups of parents and with individuals. These are described in detail in the report. The main conclusion was that improving parent's skills in the management of behaviours that challenge using behavioural principles is a successful intervention approach. It was further noted that the interventions that were most effective in improving child behaviour and attaining positive outcomes for parents were those that had been developed specifically for children with ID and which incorporated both behaviour management and teaching skills. However a number of studies highlighted the difficulty of maintaining change in child behaviour and/or parenting strategies which suggests that some form of ongoing support may be necessary (Mc Conkey, 2010).

The issue of maintaining a consistent unified approach with family caregivers is one that has led to programmes breaking down and therefore failing to succeed. Approaches that involve working with the family and providing them with the support they need are most successful (see previous section on family support). A useful and effective approach is 'Team Around the Child' (Limbrick 2005). This involves a small team of key professionals working in a coordinated person-centred way with regular therapeutic contact to meet the needs and aspirations of the child and family. Partnership working between professionals and families is at the core of the approach to ensure a consistent alliance that respects the family and child values and wishes.

Other approaches to support and educate families in caregiving have been identified elsewhere in this review. See 'Signposts' (Hudson et al, 2003, 2008) in the section on family support; the early interventions section, including the Table in Appendix 15 and interventions discussed previously.

#### 4.5.8 Other interventions

There are a number of other interventions that have been found to have some success supporting people with ID who challenge, although the evidence-base for these may be at an early stage or less developed.

- Social stories

A Social Story is described by Gray (2011) as a story told to a child (or perhaps more than one) about "a situation, skill, or concept in terms of relevant social cues, perspectives, and common responses in a specifically defined style and format... to share accurate social information in a patient and reassuring manner that is easily understood ... Half of all Social Stories developed should affirm something that an individual does well. [The goal is not] to change the individual's behavior, [but] individual's improved understanding of events and expectations may lead to more effective responses." Gray also indicates that although initially developed for young children the approach is also being used with older children and adolescents. Social stories should contain four elements within the story and these are to: describe situations, be directive, present perspectives and affirmation of the child's value. In addition according to Gray two other types of sentences can be included 'control' and

'cooperative' sentences. Control and cooperative aspects are about contractual agreements by the person with ASD about strategies they can use and who they might work in partnership with (Reynhout and Carter, 2006).

Reported use of social stories as an intervention have detailed the approach being used with children who have an ASD as it is believed that the social limitations, communication difficulties and behavioural problems of some of these children can benefit by the learning of appropriate social skills and behaviours through social stories (Kuoich and Mirenda 2003; Barry & Burlew 2004; Reynhout and Carter, 2006).

Reynhout and Carter (2006) undertook a review of the empirical evidence supporting social stories as an intervention. In total 16 studies were identified (5 were dissertations) and most involved stories with individual subjects, 60 were boys and 17 were girls, aged 3–15 years, all but one had an ASD. Six studies targeted behaviours that challenge, 9 social skills, 4 communication and 4 on-task behaviours. Findings of the review were that in relation to effectiveness there were inconclusive outcomes, with disparity in responses to interventions across participants or behaviours. 12 of the studies involved single-subject designs which have limited power to support evidence. In addition a number of the studies used supporting approaches such as prompting and reinforcement along with the stories. Another issue of concern in the reviewed studies were that not all adhered to the set criteria for social stories as suggested by Gray (2011) and therefore control of other impact variables may have been a factor.

Based on the review by Reynhout and Carter (2006) it can be suggested that Social Stories may have benefits for children with ID who have behaviours that challenge. But, the evidence-base at the time of this review was inconclusive. All but one of the studies they reviewed involved participants with an ASD. Therefore, the effectiveness of Social Stories in promoting behaviour change in children with disabilities other than autism or Asperger's is an area that may provide fruitful future research.

In a more recent study Ozdemir (2008) undertook a study involving use of Social Stories as a stand-alone intervention with three children aged 7, 8 & 9 who had autism. The aim of the study was to evaluate the efficiency of Social Stories in reducing targeted behaviours that challenge displayed by the children. Using a multi-baseline design this study found that Social Stories as a stand-alone intervention was effective in reducing the behaviours that challenge in these children. In addition the children appeared to enjoy the stories and it led to them interacting more with their class peers in sharing the experience and the approach was fully accepted by the teachers.

There is also evidence that Social Stories can be used with groups as well as individual children. Kalyva and Agalotis (2009) undertook an experimental study with 31 children with ID having Social Stories as an intervention twice a week for one month, while 32 children with ID in the control group did not receive any intervention. Before the study both groups chose mainly avoidance and hostile strategies in interactions, but following the intervention children in the experimental group chose more positive strategies and displayed significantly less inappropriate social behaviours.

- Gentle teaching

Gentle teaching is a relatively different style of approach to dealing with behavioural difficulties developed in the 1980s by McGee and colleagues (McGee et al, 1987). The approach was received with enthusiasm by clinicians. It is based on mutual 'bonding' between carer and client, relationship building, encouraging feelings of connectedness, affirming self worth in clients, rejection of the use of punishment interventions and integrating these values into interactions between people (Slevin, 2007; van de Siepkamp, 2010). The approach has not been extensively researched but in a study conducted by Gates et al., (2001) that compared three groups gentle teaching, a well-established alternative (behaviour modification group) and a control group it was found that there were few differences between the three groups, variations in outcomes that did exist generally favoured the behaviour modification interventions.

- Multisensory therapy

Multisensory therapy provides sensory stimulation for people who due to their ID would not spontaneously seek such stimulation. This is achieved in a constructed environment, usually a purpose designed room equipped with various lights, projection equipment and sound effects and furnishing to relax on, such as floor cushions and water or air beds (Slevin and McClelland, 1999). Chan et al (2010) undertook a systematic review of literature to determine the effectiveness of multisensory therapy in reduction of behaviours that challenge and promoting positive behaviours in adults with ID. The review found that although there were positive outcomes to the use of multisensory therapy these related to the relaxation, enjoyment and social aspects of being in the multisensory environment. There is limited evidence that benefits generalise to beyond the environment with respect to supporting people with ID who challenge. The therapy was developed as a leisure activity for adults or children with an ID and it accomplishes this function well according to available evidence but further research on it as a treatment intervention for behaviours that challenge needs to take place.

#### 4.5.9 Conclusion to interventions and recommendations

A range of interventions are identified from the literature accessed for this review and in some respects this has not changed radically over the last decade. Behavioural interventions underpinning by ABA and increasingly a wider behavioural perspective following a PBS model are most effective in supporting people with ID who have behaviours that challenge. Medication use is still recommended but not as a stand-alone intervention and it should be prescribed to individuals who have been assessed to benefit from this. There is also a general consensus that early interventions are more likely to achieve success. Family caregivers remain those who bare most responsibility in supporting their ID son/daughter with behaviours that challenge. Interventions are most likely to be effective when delivered via a family support and education approach that facilitates consistent interventions across various settings and most importantly in the home. But, families need support in this and should not be left isolated. Treatment of mental health problems in people with ID were found to be at a fairly early stage of development. Some approaches such as CBT are now well established support interventions for people with mental health problems but there is less evidence on the

availability and efficacy of psychotherapeutic or psychodynamic interventions for people with ID who have behaviours that challenge. Active support as an intervention for people who challenge or who have mental health problems such as depression might be a promising approach and is worthy of further research as a treatment modality for mental health problems. There are some other approaches that this review identified that may have utility as interventions to support people who challenge (social stories, gentle teaching, and multisensory therapy) but current evidence is inconclusive in supporting these for people with ID who exhibit behaviours that challenge, although social story telling seems the most promising of these based on the evidence found.

#### 4.5.10 Recommendations

- There should always be a functional analysis of behaviour undertaken to determine the cause/s of the behaviour that challenges and what function it has for the client.
- Interventions should include ABA, PBS and a range of associated approaches. Research is needed on why these approaches, despite having a strong evidence-base are not widely used.
- Medications should only be used when indicated for the treatment of physical causes of behavioural problems and where indicated to treat psychiatric illness and be used to supplement other interventions rather than a stand-alone treatment.
- Health checks should form part of the regular reviews for people with ID and health should be assessed as a potential precursor of behaviours that challenge.
- Research on the impact of health checks on behaviours that challenge and mental health should be undertaken.
- The same range of psychotherapeutic interventions for mental health that is available to the general population should be available to people with ID. Research on the use of these therapies is required.
- Early intervention should be a guiding principle of interventions to prevent behaviours becoming long-standing and difficult to treat.
- Interventions should be person-centred with client and family being true partners in care.
- Family caregivers should receive education and back-up support to allow them to fulfil their supporting role for the client
- Some other interventions found for the review have limited evidence to support their use but among three identified Social Story telling may be the most promising and would be worthy of research.

Finally, the interventions identified are those that are most likely to be able to sustain people with ID who have behaviours that challenge in their home and with their family. Interventions are presented as discreet variables, and are often researched as such.

However, it is likely that a range of these interventions in combination, multi-element approaches, will meet with most success as they need to be person-centred and delivered in accordance to individual and family need as identified by robust assessments. Interventions of course do not exist in a vacuum but require to be framed within delivery models, services and approaches and these are now presented.

#### **4.6 Service models or approaches**

Both adult and child mental health services have traditionally been poor in meeting the specific needs of adolescents. This has led to the development of an increasing number of specialist services across the UK designed to address the mental health needs of adolescents. Young people with ID, particularly if their disabilities are anything but mild, are frequently excluded from these services. In turn, within specialist ID services treatments which are deemed particularly suitable for adolescents, such as family therapy and group therapy, are frequently not available. It has been stated that the potential for behaviours that challenge arising and increasing in severity is greater in services that are not well organised (Mansell Report, DoH, 2007). In the previous section on interventions it was identified that the starting point needs to be assessment of individuals. However, recent work on behaviours that challenge has not only focused on the assessment of behaviour as an individual phenomenon but on the assessment of the residential placement in terms of factors predicting breakdown (Broadhurst and Mansell, 2007). The implication of this is that the important function of teams may not be to intervene with individuals but to intervene to improve the functioning of services (Mansell Report, DoH, 2007; RCP, A Unified Approach, 2007). It is important therefore that services are active in assessing and evaluating what they provide to support people who challenge the emphasis being that it is others (in this case the service that is challenged). Appendix 8, pp.177-179 includes 7 papers related to services accessed.

##### 4.6.1 Specialist teams for people with behavioural challenges

In order to meet the complex needs of those individuals who exhibit an array of behaviours that challenge, and/or mental health problems, 'community specialist teams' have been established. There is strong empirical evidence of the effectiveness of these teams and in particular how they can diminish the need for hospital or specialist unit admissions (Emerson, 2001). The core advantages of such teams relates to them being community-based, accessible and consisting of a multi-professional, multi-agency approach (Allen and Felce, 1999). In relation to the advantages of community support teams for people with ID who have behaviours that challenge it has been reported that they can be effective in providing PBS, reducing admission to hospital or out of home placements and they can improve QoL (Emerson, 2001).

However all teams are not uniformly successful and the availability, variation and effectiveness of specialist community teams has been found to be considerable (Allen & Felce, 1999). In addition among people with ID who have behaviours that challenge relatively few are likely to obtain access to such teams (Joyce et al., 2001). In a study conducted in NI that evaluated the perceived effectiveness of community learning disability teams (CLDT) service gaps were identified in relation to 24-hour services,

out-reach teams, forensic community teams and children and adolescent services that meet the mental health needs of ID clients (Slevin, et al 2005).

One of the Trusts in NI established an Adult Challenging Behaviour Service (ACBS) in 2004 and when evaluated after the first year they had intervened in the lives of 42 individuals and their carers (NHSCT, 2005). The team reported positive outcomes in terms of reductions in frequency and severity of behaviours that challenge, improved life-experiences for clients and preventing residential and/or day-care placement breakdowns for most clients. In addition the levels of their carers' psychological wellbeing had improved and overall, users of the Service reported being (very) satisfied with the services they have received. The team did express disappointment that two clients needed to be admitted to the local ID hospital (Muckamore). Two clients are relatively few representing only 4.7% of the 42 people served. Overall, it can be concluded that the service has been effective for 95.3% of the clients and their families. The fact that the team were disappointed with two people being required to be admitted can be seen as confirmation of team commitment to strive to provide optimum support for all clients in community settings.

This ACBS has now been in place for over 5-years and on-going evaluations of the service have taken place (NHSCT, 2009). It continues to show success and after its first 5-years it has received some 204 referrals in respect of 172 clients. The service has extended and increased its staffing levels accordingly. A new working relationship has been developed with Muckamore Abbey Hospital and the ACBS has recently been involved in the transition of 9 clients from hospital to community placements. The team has also been involved in the delivery of PROACT-SCIPr-UK training courses on behaviours that challenge and have increased this. Other work of the team includes involvement in the development of specialist respite projects. Team effectiveness has found that it has achieved.

- A significant impact on maintaining placements that were identified as being 'at risk'.
- A significant number of admissions to hospital have been prevented, although some clients have still had to be admitted due to difficulties in managing their behaviour within community settings.

The service has expanded and they are developing an information leaflet on the service for parents and carers and potential referrers. Currently, the service is not provided on a 24-hour basis, although the introduction of clients into challenging behaviour respite beds has resulted in more 'out of hours' working by members of the team. But, the team have conducted service user satisfaction surveys that have been very positive and have not indicated a need for extended hours of provision.

An issue the preliminary findings of the research did raise was continued beneficial outcomes following clients' discharge from the service. If an intervention is not being implemented fully or consistently following the service's withdrawal then benefits gained can be lost. Ways of addressing this have been considered and include:

- Keeping involved for longer periods of time, but this would mean operating with much larger caseloads.

- Protocols for monitoring the long-term effectiveness of interventions by family or residential staff.
- Repeated reviews around 12 months after discharge, when a one-off review of previously introduced interventions could be undertaken and feedback provided.
- Consider training provision, both to carers and facility-managers, specifically on ways to maintain behavioural changes and avoid the onset of programmatic decay.

Overall, the ACBS continues to provide a much-valued service in the care of adults with an ID and behaviours that challenge. However, as this team acknowledge many of these proposed service developments do require additional resources (NHSCT, 2009).

The same Trust in NI have now developed a children's challenging behaviour service (CCBS) which was evaluated following the first year in operation (NHSCT/NEELB, 2009). This team is unique here as it is the first that has involved a joint venture between the education and health and social care boards. In the first year the team intervened in the lives of 73 children and young people with an ID and severe behavioural challenges, significantly more than the Adult CBS saw. The team has not had a full staff complement for the first year but despite these difficulties, the CCBS has had positive outcomes that include.

- Levels of behaviours that challenge have fallen as a result of the CCBS interventions, leading to improved children's QoL.
- Psychological and attitudinal wellbeing of their carers have increased.
- Maintained, and in some cases extended, the residential, respite and educational placements of a number of children.
- Only one young person known to the Service was admitted to hospital during the year, and that for a period of only a week.

There has been some concern as the CCBS was not so highly rated by its users in two areas. Firstly, referral and acceptance criteria were mooted by Paediatric staff, and secondly, disquiet over the length and slowness of the assessment process in particular by the school Principals. With respect to the first of these the CCBS could not possibly provide a service to all children with any degree of behavioural problem as it must prioritise those with most severe difficulties. But, when clients are inappropriately referred to the CCBS, every effort is made to suggest a more appropriate alternative service to which they should be referred.

More valid is the second concern that has been expressed about the speed with which those children who are accepted into the Service are processed along the stages of assessment and intervention. It is certainly acknowledged that the high rate of referrals to the Service, coupled with a less-than-optimal staff complement throughout the year, has led to longer response times than the team wished. The Service has recently set itself challenging targets to address this and continue developing the service.

Overall the model of a specialist community team for people with ID who challenge seems to be an effective service that evidence suggests should be an essential component of service delivery here. It is commendable that over the 5-years this team (for adults) and first year (for children) has researched the efficacy of service delivery. It should be noted that managers who attended the consultation also indicated how effective these teams can be (Appendix 2).

In a RCT reported by Hassiotis et al (2009) involving 63 ID people with behaviours that challenge, 32 clients received support from a specialist challenging behaviour team and the control group continued to receive standard care from a generic community team. The study found significant improvements in the intervention group behaviours and mental health status from pre to post intervention as measured on valid assessment scales and these improvements were maintained at 6-months follow-up. An interesting additional finding to this study was that a cost analysis found the specialist behavioural team was no more expensive than the standard team suggesting this is not only an effective service but also an efficient fiscal approach.

#### 4.6.2 Specialist assessment and treatment units

A number of studies identified in the previous section on Living Support Options in this review provide clear evidence that supported community residences are superior in most aspects of QoL for people with ID, including those who challenge, see for example (Mansell et al, 2001; Kim et al, 2001; Robertson et al, 2005; Mansell, 2006; Perry et al, 2011). They also found that in general smaller congregated residences are more effective than those with larger congregated numbers of people living together. The ideal is of course that people are facilitated to live in their own homes or with their families. To achieve this or for the person to maintain their supported community living arrangement from time to time people with ID who have behaviours that challenge will require periods of assessment and treatment of their presenting conditions.

To meet this requirement, and as the long-stay hospitals and institutions have been closing, new styles of residential assessment and treatment units for people with ID who have behaviours that challenge developed as a recognised service need (Xenitidis, et al, 1999). It seems these may have value in providing people who have behaviours that challenge with intensive therapy from professionals, but staff in the units should be highly skilled otherwise they are liable to fail in their goals.

Mackenzie-Davies and Mansell (2007) undertook a survey of assessment and treatment units across England. The definition of assessment and treatment units was adapted from the Specialised Services National Definitions Set (Department of Health 2002) and included:

“An inpatient facility that provides intensive treatment and assessment for people with severe complex needs that cannot be managed in a community setting, including:

- People with ID and severe challenging needs presenting major risks to themselves and/or others

- People with ID who have severe mental health problems which cannot be addressed by general psychiatric services
- People with ID and ASD with severe behaviours that challenge and/or mental health needs.” (DoH, 2002, cited in Mackenzie-Davies and Mansell, 2007, p.803).

They found that among 138 agencies contacted 44 reported they had an assessment and treatment unit and 38 (86%) completed questionnaires. The main findings to the survey were that 333 people were in units at the time of the survey (average age was 36 years and they were predominantly men 69%). The number of the units has doubled in the 2000s in comparison to the numbers in the 1990s and there has been a shift in client profile from almost 85% of residents having a severe/profound ID in 1991, to 20% of the clients in this 2007 study having a severe/profound ID. Length of stay in the units had improved with 65% remaining in them beyond 2-years in the early 1990s in comparison to the 2007 study where 25% had been in the units for over 2-years. However, managers remain unhappy with being unable to find suitable community accommodations for these clients to be discharged.

Advantages to the units were described as knowledge and skills of the staff teams and the multidisciplinary support provided, although many reported under-staffing as a problem. Disadvantages were reported to be delayed discharges, in-patient mix not always being appropriate i.e. clients with different dependency levels some borderline ID and some without an ID. Having to cater to such varied needs can impede unit function (Mackenzie-Davies and Mansell, 2007).

In N.I. there are two dedicated assessment and treatment units for people with ID. Slevin et al (2008a) undertook a study of 48 people with ID admitted to one of these assessment and treatment units and found the admission led to significant reductions in behaviours that challenge and mental health problems in the clients. It was concluded that short-term assessment and treatment units for people with ID can have a valuable contribution to make to practice (a fuller report of this is provided in the Living Support Options previous).

Since early research on assessment and treatment units in a response to the gap that existed for people with behaviours that challenge outside institutional care (Murphy et al, 1991) to the most recent evaluations of these units (Mackenzie-Davies and Mansell, 2007) it appears that they can provide high quality assessment and treatment. But, as findings of these studies have also reported there are problems relating to the services from which people come and to which they should return, for example the person not being facilitated to return to their pre-admission residence. In addition the studies report that some independent sector services appear to use more restrictive practices and have more problems of various kinds.

#### 4.6.3 Combined specialist support services

Community teams and specialist units as unitary service models may have weaknesses. One way to improve on weaknesses of each is to combine both within a service. Such a model is a specialist Intensive Support Service (ISS) in Wales that was

evaluated by Allen and Felce (1999). The ISS consists of a small team of clinicians, a community support team and a 6-bed admission unit (Allen & Felce 1999). While Allen and Felce acknowledge the ISS has problems as do other models it has reported success in:

- Creating positive change in clients behaviours and mental health (Lowe et al.1996)
- Enhancing skills and improving quality of life
- To be associated with significant reductions in institutional admissions (Allen 1998).

A service such as this may be well placed to provide seamless care delivery for people with behaviours that challenge as it can facilitate community support and in-unit assessment and treatment if this is required (McConkey, et al 2004).

Specialist support services need to be exposed to robust evaluations and they need to evolve and change to meet the complex needs of people with ID who challenge. These new styles of service have potential but they will only be successful if well resourced with staff skilled in the various strategies that have been identified in this review.

#### **4.7 Mental health services**

There are a number of mental health services that may or may not provide services for people with ID, although it can be argued that they should. This section provides a range of these services, not as the review found strong evidence that these were all used by ID people but more as an illustration of services that exist and should within a human rights-based approach be available to any citizens who need such services.

Some argue that ID people should receive support for their mental health from within ID services. The viewpoint here is that mainstream mental health services do not have the expertise to provide a service for people with ID because this is a specialist area and therefore staff within ID services that are not experienced in mental health care should be educated and trained-up to meet this need as mainstream mental health services are not well equipped to meet the needs of ID people (Jess et al, 2008; Donner et al, 2010).

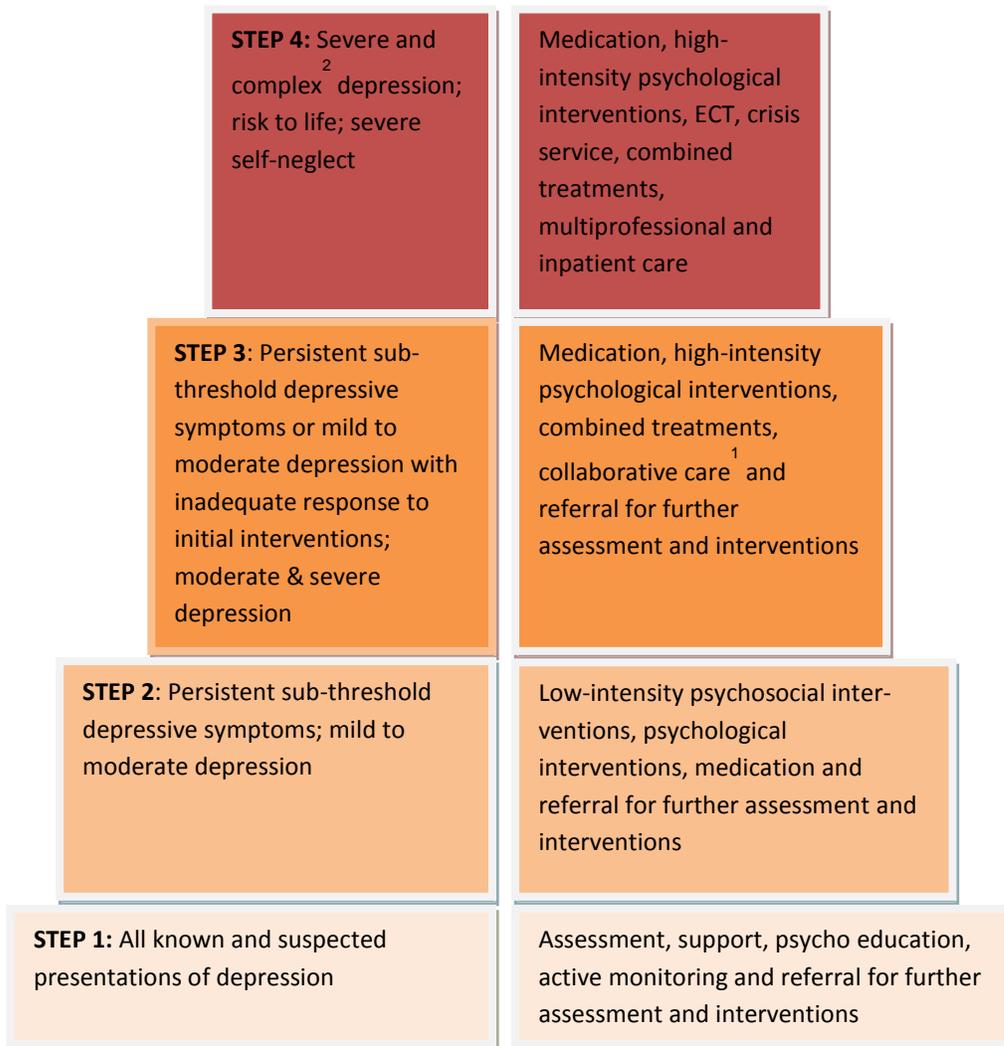
The opposing argument is that in line with inclusion and current policy on human rights when a person with a ID requires support for a mental health issue just like anyone else they should receive this by being referred to mainstream mental health services. Linked to this a person would access various primary health care systems and so on before being referring to a specialist mental health service. Cumella suggests that moving to the use of more mainstream mental health service usage for people with ID is in favour in the UK (McConkey et al, 2004; Cumella, 2009).

This system of accessing services leading from primary care to specialist mental health services is often provided within a tiered model approach. Tiered model systems originated in the USA and have been adopted by many services in the UK. Such systems may also be called 'stepped care'. The National Institute of Health and Clinical Excellence (NICE, 2009) identify such a stepped model in their guidance on management of depression. In this they identify the responses required at each step to support people with depression. See Figure 1 over page which is taken from the NICE guideline. NICE state in this guideline that "A 'stepped care' model ... draws attention

to the different needs that depressed individuals have depending on the characteristics of their depression and their personal and social circumstances and the responses that are required from services.”

Stepped care provides a framework in which to organise the provision of services supporting both patients and carers, and healthcare professionals in identifying and accessing the most effective interventions.” (NICE, 2009, p. 29). However, how accessible this type of service is for people with ID who have mental health needs is debatable.

**Figure 1. The stepped care model (NICE, CG 90, page 28)**



<sup>1</sup> Only for depression where the person also has a chronic physical health problem and associated functional impairment (see ‘Depression in adults with a chronic physical health problem: treatment and management’ [NICE clinical guideline 91]).

<sup>2</sup> Complex depression includes depression that shows an inadequate response to multiple treatments, is complicated by psychotic symptoms, and/or is associated with significant psychiatric comorbidity or psychosocial factors.

#### 4.7.1 Assessment and treatment units for people with ID

Assessment and treatment units have been discussed above but it should be pointed out that the main reasons for admission to these units that have been found in research undertaken in NI is not only behaviours that challenge but as many as 30-50% of those admitted are also found to have mental health problems (Slevin et al, 2008; Taggart, 2003).

Typically such units aim to admit people assess them, establish a treatment plan and then discharge the person back to the community within a short period of time. The units are designed for small numbers of clients (usually somewhere between 10-20 beds) and are staffed by a team of multi-professionals. Such units are however not without problems. Among issues that can arise for people with ID with mental health problems are the following:

People remaining in the unit for a prolonged period of time, as stated previously in this review as many as 25% remain as delayed discharges in some units in excess of 2-years (Mackenzie-Davies & Mansell, 2007) . For this reason such units should have a policy of putting in place a discharge plan (with date) from as soon as the client is admitted.

Repeated admissions referred to as 'revolving door admissions' where the same client although he/she may not stay in for a prolonged period has multiply admissions.

Not all units provide an out-reach service. In the ideal world specialist units like this would provide an out-reach service involving staff with specialist skills and knowledge going out to the community to provide their service to clients and family carers but this is not always evident and the units are not always resourced well enough to do a lot of this. This is an area that could benefit from future research as it can interrupt transition of care that should be seamless in both directions that is between unit and community staff and vice versa.

#### 4.7.2 Admission units in mainstream mental health

As has been stated previously in line with the philosophy of inclusion people with learning disabilities should be able to access the same range of mental health services as others (DoH, 2005 Bamford Review; Barr, 2007). However, it is not clear if and how often admission units in mental health (psychiatric) hospitals are accessed by ID people who develop severe or sudden on-set mental health problems. In addition it has been reported that people with ID are often excluded from a range of mental health services (Scior and Grierson, 2004).

Admission units for people with mental health problems are considered specialist services that are located at the top of the tiered service identified previously. People admitted to these units would typically have a severe mental illness that requires assessment and treatment. Either presenting with a mental health problem for the first time, or they may be someone who is known to the service who perhaps has a reoccurring or chronic mental illness; although here in NI it is not known how many people with ID would fit within the spectrum of known mental health service user. Like others individuals with an ID should be seen and assessed by a number of mental

health professionals for assessment, diagnosis of any mental illness and to have treatment/therapy commenced or resumed.

#### 4.7.3 Specialist In-patient Mental Health Services

There is little evidence on how facilitative some other mainstream mental health in-patient units that are specialist in nature are for clients with ID who have specific mental health needs or conditions (Cumella, 2009). Some of these units or services in keeping with the principles of inclusion should admit people with ID when they present with that specialist need. Such services might include:

*Substance Abuse:* These mainly admit people who misuse drugs or alcohol to such an extent that they need a period of admission to begin therapy to allow them to stop the substance. In addition some people may need physical support in the form of medication to help them deal with physical withdrawal symptoms. While the treatment of an individual in these services will require treatment for the underlying mental health problem the aim of treatment for the substance abuser is to empower the person to make life changes. To come to terms with his/her problem and make the necessary life changes to deal with it. Staff work in partnership with the client and motivational interviewing (MI) is often used to empower the client and place him/her in the centre of their own treatment. Models of engagement and change guide the service.

*Eating disorders:* Eating disorders present as disturbances in eating involving emotional distress that ultimately may be exhibited as mental illness. The most common eating disorders are anorexia nervosa or bulimia nervosa. Like most mental health problems it is best to treat such conditions in the community but these distressing disorders can sometimes be so severe that the individual requires admission to a specialist unit where staff who specialise in this area can offer therapy. The aims is to provide therapeutic relationships to encourage the client to: develop self awareness, to become self-valuing, to learn behaviours to deal with the disorder, to be self affirmed and to become motivated to change to a healthy life style. This requires specialist skills and knowledge that are unlikely to be found in ID service staff, unless they have had additional training in this.

*Dementia Services:* Dementia services are another service that may fall within the remit of mental health services but these are discussed in length in the older persons section of this review.

#### 4.7.4 Forensic Services

Forensic mental health care is a highly specialised area that has a focus on people who have disorders or personalities that lead them to habitually indulge in behaviours that are anti-social or offending (in relation to the law). Wheeler et al (2009) in a study identified the most common forensic behaviours in a group of ID people as: physical and verbal aggression; damage to property; and inappropriate sexual behaviour. Often the behaviours are exacerbated by a dual diagnosed substance abuse. When offending behaviour is most severe it can lead to an individual being admitted to a high secure hospital, medium secure unit, or for less severe behaviours to a low secure unit.

*High Secure Hospitals:* High Secure Hospital Provision (UK and Northern Ireland) are provided at: State Hospital Carstairs, Scotland (Serves Scotland and Northern Ireland) and there are high secure units at Ashworth, Broadmore, and Rampton Hospitals in

England. While the Central Mental Hospital, Dundrum serves Southern Ireland. High Secure Hospitals provide inpatient treatment for those who present a high risk of immediate and serious harm to others and they would cause grave concern if managed elsewhere. Most patients are admitted from prison, either as a result of court proceedings or are transferred during their sentence.

*Medium Secure Units:* There is only one purpose built Regional Medium Secure unit in Northern Ireland – Shannon Clinic (34 beds) based at Knockbracken Health Care Park, Belfast. Referrals generally come from the criminal justice system (CJS), generic adult psychiatry and high secure hospitals.

Threshold for admission is usually

- Patients who require higher levels of security and observation
- Have a definable mental disorder/illness (generally psychosis, a high percentage have co-morbidity)
- The conviction of a serious index offence or the propensity to commit an offence (generally have a forensic history)

Most patients in these units are detained under mental health legislation.

*Low Secure Units:* Individuals with a mental health disorder requiring low secure provision receive this at Clare ward at Knockbracken, Belfast. People with an ID requiring low secure accommodation receive this service at the Six Mile Clinic a purpose-built Regional Low Secure unit at Muckamore Abbey Hospital, Antrim.

Staff who work in secure units are similar professionals to those in mainstream but will have undertaken additional specialist training. E.g. A forensic psychiatrist will have undertaken an additional 3-years training related to the interface of mental health (or mental illness) and the law and will be able to provide forensic reports for courts. Nurses will have undertaken an additional 1-2 years specialist forensic course to their initial training and others such as social workers and psychologists will also be specialists in this area.

The aim of these units are to provide the same range of therapeutic interventions as mainstream mental health services but there will be more emphasis on risk assessment, cognitive and behaviour interventions, psychotherapy, liaison and multiagency programmes as well as putting in place panels to identify risk and advise courts. Research by Alexander et al (2006) suggests there are limited numbers of forensic services for people with learning disabilities but in their study they found good outcomes in people discharged from medium secure units in terms of lower levels of reconviction compared to generic forensic services.

In a later study Alexander et al (2011) evaluated the outcomes of a medium secure unit for 138 people who had been admitted to a medium secure unit. The study evaluated 77 clients who were discharged and 61 who were still inpatients, 36 of whom were identified as difficult to discharge clients. Of those clients discharged 90% moved to a lower secure units, it seems it is difficult to get people rehabilitated back to the community from these units. In addition a significant core of clients who mainly have difficult criminal histories, have been abused and have personality disorders are very difficult to discharge. Overall the medium length of stay in the unit was 2.8 years. The range of interventions that are provided can be seen in Alexander et al (2011) paper.

Some people with ID due to forensic behaviours can enter the prison system. It is interesting that in part of the consultation for this review discussion with a mental health professional working within the prison system indicated that there was an issue with ID people coming into prison but that it is difficult to assess as the numbers are not actually known. People with mild or borderline ID are difficult to identify within prison unless they are previously known to services and mental health care programmes yet to meet the needs of such individuals would be an essential requirement. This area would benefit from research as an unmet need could be going unrecognised.

#### 4.7.5 Community Teams

The above services are a range of those that are at the upper most specialist end of a tiered or stepped service model. While there is likely to be a continued need for a number of the admission services detailed above community care teams have proliferated, although perhaps with more specialist options in mainstream mental health than in ID services. The following are some of the main community teams that are liable to provide a service for this population.

- Community Learning Disability Teams (CLDT)

It is most likely that care that a person with a ID who has a mental health problem receives will be from a CLDT. CLDTs are structured in a number of variations most often they are made up of multidisciplinary professions but some also operate as unidisciplinary teams. Although these teams are considered 'general ID community teams' as opposed to specialist challenging behaviour or forensic teams most studies have found high numbers of people with behaviours that challenge and mental health problems make up the case-loads of such teams (Slevin et al, 2008a; McConkey, et al 2004). How well teams can provide support for people with ID who have mental health problems depends on the skills and training of team members, and there is considerable variation in this in relation to mental health support. To date this review has established that one specialist community team for people with ID who have mental health problems has been established in NI but there has been no evaluation of this as it is in its infancy.

- Community Mental Health Teams (CMHT)

CMHTs are similar in construction to the CLDTs that have been identified above but they mainly provide a service for people who have not got a co-existing ID. However, as has been detailed previously according to the policy of inclusion some people with ID should have access to these teams if required. The vast bulk of the work of these teams will be supporting main-stream populations who have mental health issues.

There is still debate about whether or not people with ID who have mental health problems should be supported by mainstream CMHTs or if they should remain within the case-loads of CLDTs. Much research is needed in this area as there are various ways that services can be delivered. The debate is 1) that CLDTs should provide mental health care support to clients with ID; 2) that when a person with an ID has a mental health problem they should pass to a CMHT; 3) that there should be more joined-up working between these teams and services.

- Community Forensic Mental Health Teams (CFMHT)

There are four dedicated CFMHT in NI, one in each of the four Health and Social Care Trusts. The CFMHTs work alongside Shannon Clinic, and the Six Mile Clinic, Generic Mental Health Teams, and Criminal Justice Agencies including the Probation and Prison Service.

The work includes providing comprehensive risk assessment and risk management plans including discharge plans and an Assertive Outreach Model of Care within a community setting. The term a parallel approach is often applied to CFMHT services as this indicates such services provide the same services as mainstream community mental health teams but specialise more, advise courts, and tend to have smaller case-loads that they maintain for many years. Parallel CFMHT tend to apply an Assertive Community Outreach approach (see below) in which they work at outreach from admission centres. Or alternatively they may apply an integrated approach meaning they are integrated as part of the overall CMHT.

- Assertive Outreach Teams (AOT)

AOT serve populations that have persistent and enduring mental health problems such as psychotic and major affective disorders. Clients served are also likely to have co-existing problems such as substance misuse and offending behaviours and may be those who are frequently admitted to in-patient services (revolving door admissions) or other clients who are difficult to engage. Team membership has a similar multidisciplinary membership to CMHTs but they may have additional specialist staff e.g. in substance abuse, and the AOT functions in a different way in that they:

- Maintain smaller case-loads, perhaps 10-12
- Have a high degree of contact with clients (weekly and sometimes daily)
- Provide interventions long-term based on continuity of care
- Maintain therapeutic contacts with service users and families
- Have an emphasis on team coordination
- Provide assertive follow-up in the clients home and community
- Interventions include medication management, education on symptom recognition, dealing with crisis, engagement and relationship forming, preventing or reducing relapse, improving QoL, enhancing independence, and helping the person integrate with their community.

Although AOT have shown evidence of success in the general population evidence of effectiveness for this approach with ID people who have mental health problems is less conclusive. Martin et al (2005) found assertive treatment to be no more effective than the standard CLDT approach in supporting people with ID with mental health problems in a study they conducted. But, again this is an area that is in need of further research.

- Crisis resolution home treatment teams (CRHTT)

An individual or their family may experience a crisis due to a mental health problem at any time. The crisis could be anything from an individual being in danger of self-harm or harming others to an acute exacerbation of a mental health problem. CRHTT originally operated with specific clients such as those who have PTSD (post traumatic stress disorders) but increasingly the service is provided for a wide range of mental health problems and there also seems to be a trend to focus on the same difficult to

engage people with severe and enduring mental illnesses that AOTs do as detailed above. CRHTT also function in a similar way to AOT but operate with the following additional principles:

- They offer a rapid response
- Operate 24-hours 7-days per week
- Provide intensive support from beginning of crisis
- Provide a triage approach by phone or attendance where they can identify and prioritise a crisis
- Interventions are short-term in that they deal with the immediate crisis
- Provide a service for people who would otherwise require hospital admission
- There is a strong emphasis on analysis of crisis and learning from this
- Service users and family are at the centre of care.

Membership of CRHTT again reflects that of most community teams but there will be staff trained specifically to deal with a crisis. For example a 24-hour phone service may be provided by nurses who have the skills and experience to provide triage decisions. Provision of CRHTT is said to be patchy (Brown, 2004) and it takes a lot of resources to run these teams, however they can pay off in the long-run as they potentially prevent an even more costly service (hospital admission) from being required. They also provide support to clients and their family at times when they are most in need. Such crises do of course occur for people with ID and their families and like other mental health services use of these services by ID people is under researched.

- Early Intervention Teams (EIT)

EITs as the name suggests are teams that aim to intervene early in a proactive way to help reduce the impact of a mental health problems and promote recovery. The EIT in mental health services has a different theoretical underpinning to early intervention in ID services, where this concept means early intervention with children. With mental health the focus is mostly on people aged from 14-35 years old and there is also a tendency to aim the care towards those with psychotic conditions.

In mainstream mental health services Onyett (2009) summarises the functions of an early intervention service as follows.

- Identify need for early intervention in psychosis and reduce stigma
- Hasten diagnosis and treatment/intervention commencement
- Provide a symptoms management approach and not only diagnosis
- Promote recovery at an early on-set stage
- Stabilise service users lives
- Help with transition from child to adolescent, to adult services across multi-agencies and that transfers are sensitively handled
- Provide social family-centred support

However, with respect to EITs these services are not widely available across the UK (Pinfold, et al, 2007). Some individuals develop psychotic episodes at a young age and these may be a precursor to development of a psychotic illness such as schizophrenia. These prodromal psychosis episodes can indicate EIT to intervene at this stage in the hope of preventing or reducing the impact of a full psychosis illness. But, in a Cochrane

systematic review of EIT services by Marshall and Rathbone (2006) they concluded that there is currently insufficient evidence to make firm recommendations for this model of service in practice and more research into EITs is required. This of course relates to early intervention for psychosis in mainstream populations and as an EIT service for people with ID who have psychotic episodes even less evidence exists.

#### 4.7.6 Child and Adolescent Mental Health Services (CAMHS)

CAMHS teams provide a service for children and adolescents who have mental health problems and they also have a focus on early intervention. CAMHS are provided within a similar 4 tier framework as presented previous (Box 1 below). As can be seen in Box 1 the framework suggests a service that is extensive and ranges in provision from primary care at Tier 1 to, more specialist services in Tiers 2-3 with Tier 4 representing services for those with severe mental health problems and complex needs.

| <b>Box 1: The four-tiered CAMHS framework</b>  |
|--|
| <b>Tier 1: Services provided by practitioners working in universal services (such as GPs, health visitors, teachers and youth workers), who are not necessarily mental health specialists. They offer general advice and treatment for less severe problems, promote mental health, aid early identification of problems and refer to more specialist services.</b>                                  |
| <b>Tier 2: Services provided by specialists working in community and primary care settings in a uni-disciplinary way (such as primary mental health workers, psychologists and paediatric clinics). They offer consultation to families and other practitioners, outreach to identify severe/complex needs, and assessments and training to practitioners at Tier 1 to support service delivery.</b> |
| <b>Tier 3: Services usually provided by a multi-disciplinary team or service working in a community mental health clinic, child psychiatry outpatient service or community settings. They offer a specialised service for those with more severe, complex and persistent disorders.</b>  |
| <b>Tier 4: Services for children and young people with the most serious problems. These include day units, highly specialised outpatient teams and inpatient units, which usually serve more than one area.</b>  |

Cited from “Children and young people in mind: the final report of the National CAMHS Review (2008) London: DoH <http://www.dh.gov.uk> p. 17”

CAMHS also works across various professionals and is multidisciplinary, especially at the higher tiers. As well as this they work across agencies with integrated working being a key feature. Therefore staff (depending on the tier) that children or adolescent clients might come into contact with could be: school staff; health visitors; community workers; police; GP and other health professionals in primary care (Tier 1). An example of staff in Tier 2 would include staff in paediatric clinics such as paediatricians, AHPs, psychologists. At Tier 3 and 4 would be the full range of multidisciplinary specialist workers that work within mental health services, but they will have specialised in child and adolescent mental health. In addition some professionals such as social workers will take on a much more key role because of their role in child protection etc.

The above presentation of CAMHS is however not universal, in fact McCulloch and Ford (2009) suggest that on the ground this framework remains a conceptualization that is not yet fully established across all areas. In relation to ID difficulties have been reported with CAMH services. For example, Kaehne (2011) undertook a study related to transition of ID young people from CAMH services to adult mental health services (AMHS). They found a number of difficulties around transition from CAMH to AMHS including a lack of clear criteria for transfer, poor transition planning and that both services seem to operate with different philosophies that often lead to people with ID falling between 'service gaps'. A number of others have identified difficulties with transitions for this population (MHF, 2002; McCarthy and Boyd, 2002; Unwin et al, 2008). However, it is hoped that the National CAMHS Review shall lead to the permeation of this framework across all services for children and adolescents. But, such services should be available to children and adolescents with ID who have mental health problems that some may carry with them into adulthood.

#### **4.8 The Troubles**

An aspect for consideration in this review was the "troubles" and if this had any impact on the mental health or other aspects related to ID people. The review found no published evidence on this. It was discussed at the consultation meeting and the general consensus was that the impact of the troubles on ID people was similar as it was for others. Members of the consultation group gave accounts of some people not wanting to go into the other community to receive services and there were some reported cases of families been directly impacted upon. For example, a family with a child who had ASD having to move home due to noise related to the troubles. Or where parents have got caught up in unrest and for example have been imprisoned this has had negative impact on children's behaviour. But, by and large there is little evidence that the troubles have had widespread impact on ID people and if any affect it seems to have been similar to the impact on others in society (Appendix 2).

#### **4.9 Conclusion**

In conclusion services for people with ID who have behaviours that challenge should be built around the client and family to facilitate the client remaining in their own home, or in their community residence for those who live there. There are a range of specialist ID services that can help by providing this support. They include CLDTs and specialist community teams for people who challenge. When necessary specialist assessment

and treatment units can provide a service and with a short period as an in-patient the client should be able to return to their community home with on-going support. However, the evidence suggests that a number of clients who are admitted to assessment and treatment units remain there on a long-stay basis, for 25% of people this goes beyond 2-years classifying them as delayed discharge patients. One of the most promising ways of dealing with this issue might be by use of a model that provides combined specialist support services. This involves small assessment and treatment facilities that are integrated with specialist community teams. Such a service can create a true seamless service that prevents delayed discharges.

A full range of mental health services are identified, even though evidence for use of these services for people with ID who have behaviours that challenge and mental health problems are not well established. The reason for presenting these is that although the services exist use of them by ID people remains an issue to be addressed. There is a need for sound research on how valuable, or not a number of these mental health services are in supporting people with ID and their family caregivers.

#### 4.9.1 Recommendations

- People with ID who present with behaviours that challenge and their family caregivers (or formal carers if living in a community residence) should have access to a specialist behavioural team to provide them with support as required.
- Assessment and treatment units should be available to provide specialist care for those who need this, but there needs to be adequate community services to prevent delayed discharges.
- A service that provides joint in-patient specialist assessment and treatment if required incorporating an out-reach team should be implemented and evaluated by research to determine if this is the most effective service for this population.
- Programmes that involve skilling parents for their caregiving role with their family member who challenges should be put in place and not only provide education sessions but ongoing back-up support.
- Service users and families should be considered partners in care planning and delivery and this should apply across agencies and not only disciplines.
- For clients with mental health problems they should have access to the same range of mental health services as other citizens. However, there is a need to research; 1) the effectiveness of mainstream services in meeting the needs of ID people, 2) the effectiveness of ID services that are trained-up to meet clients mental health needs.
- The Tiered Model system that frames provision in various mental health services should be introduced, piloted and researched in ID services for those who need this, but some cautions are suggested and these are detailed in the discussion section later.
- CAMHS should be as open to referrals from children and adolescents with ID as they are to other members of society but special consideration needs to be given to ID young people in transitions to adult services.

## **5. SYNTHESIS: AGING IN PEOPLE WITH ID**

As with the previous section not all aspects could be reviewed in relation to older people with ID. It was necessary to focus on what is known (or where gaps exist) in relation to key aspects as identified in the aims and review questions below.

### **5.1 Aims and review questions – older people with ID**

The aim of this part one of the review was to search for, evaluate and prioritise studies or other robust literature related to older people with ID that have focussed on the main research question. The main overarching question being:

What services and support do older people with ID and their caregivers require to meet their needs? The focused questions addressed that are integral to this overarching question are:

- 1) *What are the most effective means of managing health-related conditions in older people with ID?*
- 2) *How might ‘ageing in place’ for older persons with ID alongside their parent carers be facilitated?*
- 3) *What supports are required to facilitate succession planning for older people with ID and their ageing family carers?*
- 4) *What supports do older people with ID and their ageing family carers require to help them negotiate through formal services?*
- 5) *Can mainstream services contribute to the support of older persons with ID and their family carers?*

### **5.2 Managing health-related conditions in older people with ID**

#### **5.2.1 Physical health of older people with ID**

In relation to health and dementia in older people with ID 17 papers were retrieved, these are presented in Appendix 9 (pp.180-187). Haveman et al. (2010) undertook a critical review of the international literature from 1999–2009, which focused on age-related health risks, age related oral health and lifestyle health risks in older people with ID. The authors report on evidence which shows that cardio-vascular disease is as prevalent and as common a cause of death amongst people with ID as in the general population. There are, however variations in prevalence and these are reported to be culturally dependent. This review reported on high health risk factors associated with digestive problems, including high rates of helicobacter pylori, gastroesophageal reflux disease and constipation.

Lifestyle health risks included poor nutrition, a lack of exercise and poor mobility leading to higher obesity levels. As in the general population, healthier lifestyles, improved nutrition and increased exercise as well as regular health checks to improve surveillance of health risks are reported by Haveman et al, (2010) as key to improving the health status of older adults with ID. Healthy ageing in people with intellectual disabilities is a matter that is receiving growing attention in the literature (WHO 2000, Evenhuis et al, 2000, Walsh et al 2000, Thorpe et al 2000, Hogg et al 2000). The WHO paper provides an overview of the broad issues and challenges of healthy aging within the ID population, whilst, Evenhuis et al (2000) provides a particular focus on Physical health issues, Walsh et al (2000) is particularly attentive to Women’s health, Thorpe et

al (2000) concentrates on the links between physical health and biobehavioural issues, whilst Hogg et al (2000) review international social policy in relation to healthy ageing. An over-riding principle reported is that:

*Over the life-span, adults with intellectual disabilities should maintain the same array of preventative health services as those offered to the general population. (WHO 2000, 19)*

### 5.2.2 Dementia in people with ID

As the longevity of people with ID increases it is likely that there will be a consequent increase in the numbers of these people suffering from age related diseases such as dementia (Prasher 2005). Dementia is defined as:

*A syndrome due to disease of the brain, usually of a chronic progressive nature, in which there is disturbance of higher quarter functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgment. (WHO, 1992).*

Prasher (2005) notes that for people with ID, the degree of ID, combined with social, environmental and health factors will contribute to the presentation of the disease. The increased presentation of dementia amongst people with ID presents significant challenges to formal and informal carers, their extended families, their local communities, ID services, also primary healthcare, and not least those experiencing the disease themselves.

- Prevalence of dementia

Whilst rates of dementia are likely to grow as the life expectancy of people with ID lengthens, there is evidence of a strong association between Down syndrome and Alzheimer's type dementia (ATD). Thompson (2002) details the rates of dementia in people with Down syndrome in the UK: in the older age bands this is reported as 9.4% for those aged 40-49, 36.1% in 50-59 age group and 54.5% in the 60-69 age group (Llewellyn et al 2008).

Strydom et al. (2009) reported prevalence of potential development of dementia in people with ID to be 2-3 times more likely than in the general population. They report that age is a strong risk factor but there was no association between degree of ID or gender. Whilst the literature reports that dementia is common in older adults with ID, prevalence is found to differ according to the diagnostic criteria used. (Strydom & Hassiostis 2007).

- Screening and diagnosis

The literature highlights difficulties in the diagnosis of dementia in people with ID. McCarron (2005) states that there is a lack of diagnostic tools that are appropriate for this population and adds that baseline screening is limited while family and professional carers are found to confuse symptoms of early dementia with typical aging as well as with co-morbidities that may display similar symptoms to dementia such as depression. Watchman (2003) too raises the issue of staff/carer alertness to early symptoms of dementia as well as high staff turnover in support settings, which interrupts continuity of care.

A number of diagnostic tools have been reviewed (Burt et al 2005, Mohr & Gray 2005, Prasher et al 2004, Shultz et al 2004, Strydom & Hassiotis 2003, Kay et al 2003, Dalton

et al 2002, Hoekman & Maaskant 2002, Thompson, 2001). Llewellyn (2011) in a review of the literature on dementia and people with ID identifies 27 different tools that may help diagnose dementia in this population and these instruments can be seen in Llewellyn's paper. However, there is a broad consensus that use of a single instrument to diagnose dementia in this population is not advisable (Llewellyn 2011, Strydom & Hassiostis 2003, McQuillan 2003, Hoekman & Maarskant 2002), but that instruments should be used in combination either with other diagnostic tools (Burt et al 2005) with appropriate clinical assessment (Prasher 2005) or with carer report (Kay et al 2003).

Recommendations for improvements in screening and diagnosis include a) the routine gathering of baseline data so as to monitor suspected cognitive deterioration, b) regular, possibly lifelong health screening should include screening for dementia (Lane 2005), because for example, Coppus et al. (2006) report that a history of depression was strongly associated with dementia; c) longitudinal measurement would enable assessment of changes in cognitive function over time (McCarron 2005, Lane 2005, Shultz et al 2004, Strydom & Hassiostis 2003, Burt & Aylward 2000). Coppus et al. (2010) report on a recent study of women with Down syndrome and found a significant link between age of dementia diagnosis and menopause. Early age at menopause is associated with a 1.8 fold increased risk of dementia.

Literature reports that ageing family members and formal carers who are well known to the individual are likely to be the most sensitive to small changes in function. Training to assist formal and informal family carers to recognize symptoms, such as personality behaviour change and functional decline (Ball et al 2006) combined with a regular physical and psychiatric professional assessment (Lane 2005), may enable early diagnosis (McCarron 2005) and the possibility of therapeutic intervention and improved prognosis (Ball et al 2006, Mohr and Gray, 2005, Prasher 2004, Watchman 2003, Levitas & Selka 2001, Holland 2000).

- Support and intervention

The literature recognizes that as the occurrence of dementia is expected to rise proportionately with the increase of longevity among adults with ID, care systems will have to become dementia ready by improving their diagnostic and technical resources, as well as their care management supports (Janicki 2000). However, this presents significant challenges to existing service provision.

In response to a recognised inconsistency in service provision and responses to people with ID and dementia, a panel of experts convened to develop a set of guiding principles and practices. These became known as the *Edinburgh Principles* (Janiki, 2002) and they offer good practice in dementia care by the following of a set of principles in relation to continued community supports and services for people with ID affected by dementia. The document proposed that governments, organizations and providers adopt the principles for use in supporting those adults with ID affected by Alzheimer disease and other similar conditions resulting in dementia.

The literature describes some service responses to the provision of support for adults with ID who develop dementia. Maybin (2002) reported on a survey of 44 ageing family carers in NI who were caring for an older ID person with dementia. They state that the most support they received was from a social worker and their GP; of which they

received a visit once to twice a year from the social worker into their family home. The majority of the carers reported they wanted accessible information on ID and dementia, but were reluctant to attend formal training sessions preferring personal contacts or leaflets.

McCarron et al. (2005) highlight how the needs of individuals with dementia will change over time and that staff responses will need to adjust to these changing needs. For people to remain in their place of residence carers will need to be able to provide support appropriate to individual need and disease progression. Reilly (2005) notes that to continue to respond to changing need care planning meetings should be held every six months.

McCarron & Lawlor (2003) and McCausland et al. (2006) developed specialist memory clinics in Ireland for people with Down syndrome and dementia by the Sisters of Charity and at St Michael's House respectively. Rosewarne (2001) describes a therapeutic support group that provides a range of person-centred approaches, which include reminiscence, memory and orientation work using visual reinforcement and personnel support. Outcomes reported were the maintenance of levels of verbal communication as well as evidence of participants taking on new information. In addition the programme was found to have a motivating effect on support workers. Orange & Zanon (2006) call for research on the language and communication of people with Down syndrome and Alzheimer's to establish an evidence base, they highlight the need for empirical verification of descriptive accounts of how to maintain the language of this population.

Whilst there is evidence of therapeutic interventions, which aim to ameliorate the effects of the disease, this review did not find evidence of the use of medication that is available to lessen the impact and slow the progress of dementia. Nice Guidelines (NICE 2011) now recommend the use of three drug treatments for people in the early to mid stages of Alzheimer's dementia. This overturns previous guidance where the drug treatments were restricted to people in mid-stages of the disease (The Telegraph Jan 2011). It appears that drug treatments are becoming more widely recommended; research into their use in the ID population would assist in the development of the range of responses to this disease in this population. Davies et al. (2002) advocate for equal access to treatment drugs for the ID population. But, Coppus et al (2006) reported that people with Down syndrome and dementia are more frequently treated with antiepileptic, antipsychotic and antidepressant drugs.

There is a significant focus in the literature on the training needs of carers; family carers as well as frontline and other professional staff in working with people with ID who develop dementia. Training needs identified are in relation to recognition of the early symptoms of dementia (McCarron 2005) as well as preparing carers who support people with dementia (Wilkinson et al. 2005, McBrien 2005). Raising attention to the issue of professional staff being aware of the needs of people with ID who have dementia, Forbat (2006) proposes that GP's have specific training in working with this population; presumably the same argument could apply to other health and therapeutic staff who may provide care.

### 5.2.3 Recommendations

- Regular baseline assessments of cognitive, behavioural and adaptive functioning from an early age to allow for identification of later cognitive decline (where present) and thus assist with diagnosis.
- Research into the use of therapeutic medication with this population would develop the evidence base to further treatment options.
- A range of training for ID frontline staff and informal carers in working with people with ID and dementia is advocated in the literature. Training helps staff morale.
- Healthier lifestyles, better nutrition and more exercise, and a greater surveillance of health risks were seen as the ways to improve the health of this population.

### **5.3 'Ageing in place' for older persons with ID alongside their parent carers**

Six studies that informed the evidence of ageing in place were found for the review and these are presented in Appendix 10, p.188.

#### 5.3.1 Family home

Within the UK the majority of people with ID live within their family home (Foundation for People with ID, 2006). Likewise, as people with ID grow older (40–50 years plus) they continue to live with their ageing parents. It is estimated that across the UK over 30,000 older parents (60 years plus) are caring for their son/daughter with an ID; the majority (90%) of whom are mothers (Lambe & Hogg, 2003).

McConkey (2006) in a comparative report between NI and ROI respectively, found that 47.4% (versus 56.6%) of people with ID lived with both parents, 32% (versus 28%) lived with one parent, 19.8% (versus 13.8%) lived with a relative and 0.8% (versus 1.6%) with a foster relative. Most family carers (64.8%) were aged between 40–64 years and 32.7% of family carers were 65 years plus. Just over 15% of people with ID were 50 years plus. More people with ID in NI were reported to have a severe/profound ID, to be more dependent and they had higher support needs compared to older people with ID living with their ageing parents in ROI. Lone carers were mainly women of older people with ID in NI and were found to be twice the national average. McConkey concluded that these numbers will increase faster and provide families with added pressure to continue their caring role compared to ROI and Great Britain.

Barron et al. (2006) undertook another detailed analysis of NI and ROI's databases respectively. Using both databases, data were obtained on over 12,500 people with ID living with family carers; half lived with two parents, 30% with a lone parent, and just under 20% with another relative. More people in NI were identified as living with family carers, which was attributed mainly to less available residential alternatives. Almost twice as many people with ID lived with family carers in NI (4.35 per 1000) compared with ROI (2.67 per 1000). For people with ID aged 50 years plus: 3.5% (1.6% in ROI) lived with two parents, 11.4% (7.4% in ROI) with one parent, and 46.9% (46% in ROI) with a relative / other carer. The demand for out of home placement was much greater in NI, especially for lone carers: this was not broken down by age. The authors concluded that family care arrangements have received relatively little attention within government policy making, and hence service provision has been largely reactive. Future research should focus on the changing needs of ageing family carers over time

and how they can be better supported in their role to continue caring for their older son/daughter with ID.

Black & McKendrick (2010) in their recent study of 36 older carers (50 years plus) in NI, found that 81% of carers were female and 19% were male (mean age 70 years, range 52–87 years): 58% of carers were lone parents with three-quarters of these carers being female.

Taggart et al. (current funded study) in their study of 18 ageing family carers (60 years plus) of older people with ID (40 years plus) in NI report that the majority of carers were widowed (61.1%); four carers were married (22.2%), two carers divorced (11.1%) and one was not married (5.6%). Three quarters of ageing family carers were lone carers, mainly mothers. Of those five male ageing family carers, they had become the main carer as a result of their wife dying. The duration of time caring varied ranging from 5-56 years with a mean of 34 years. The ages of the ageing family carers ranged from 65-89 years and the age of the people with ID person ranged from 40–63 years. The majority of the carers were caring for a daughter (61.1%), a son (n=5; 27.8%) or a sister (n=2; 11.1%). Several of the widowed male carers identified issues of concern about caring for a daughter with ID pertaining to personal care.

This review found that there was a sizable number of older people with ID living with ageing family carers that were unknown to statutory ID services, therefore the true size of this population is underestimated (DoH, 2001b, Haley & Perkins, 2004, McConkey et al., 2004b, Barron et al., 2006). Thompson (2002) estimated that 25% of older people with ID do not become known to statutory services until their family carer dies or becomes unable to look after them, thereby developing into an emergency crisis.

Often services for older people with ID are viewed in terms of economic cost benefits. For example, Llewellyn (2011) identified in her review that specialist units may be beneficial in terms of economics but such units can isolate and exclude clients. Family carers are greatly concerned that the person they care for will continue to live a quality of life that they have been accustomed to. In a study conducted by Forbat (2006) carers planned and expressed hopes for the future that assured access to respite for their family, housing policies that combat exclusion and most importantly the provision of extra support to allow people with an ID to remain in their own homes enjoying the quality of life they always have.

Aging in place is important as it has been reported that changes in accommodation tend to be associated with negative impacts on quality of life for some people such as those with Downs syndrome and relocations, although seen to be cost effective can have negative impacts on mortality and health status (Meehan et al. 2004). The older the person is the more likely they are to experience life changing events that can negatively impact upon them (Hamilton et al. 2005; Patti & Tsiouris 2006; Patti, 2010). Patti (2010) states “service providers need to weigh the risks versus benefits of relocation with the types of potential services that the person would receive in a new setting.” (p.544). Therefore, although relocation of some aging people with ID may seem to have a cost benefit this may well be at the price of human-cost for the individual’s quality of life and health status.

### 5.3.2 Residential facilities

McConkey et al. (2003) examined the existing databases within NI and the RoI and found that 1358 adults with ID living in some form of residential accommodation in NI. They reported that 646 adults (47.6%) were aged 25-49 years and 712 adults (52.4%) were aged 50 years plus. McConkey et al. (2003) concluded that fewer adults with ID resided in residential accommodation in NI compared to RoI and the Great Britain. These figures indicate that over the next two to three decades, and even longer, there will be fewer residential beds available for those older people with ID who are living with their ageing family carers. This situation thereby places greater stresses on family carers to continue caring despite the effects of the ageing process and ill-health, and also places greater demands on statutory services to identify alternative forms of residential care.

McConkey (2006b) undertook a census of all persons in all forms of residential placement using a range of existing databases to identify the population in NI. Around 440 persons lived in hospitals and 1,970 resided in large congregated settings such as residential care homes and nursing homes. Most congregated places were provided by the private sector although voluntary organisations and housing associations managed around one-third of places. Compared to Britain and the RoI there is an under-provision of residential placements in NI. To date, funding from outside of health and social services has been the main driver for this of type of accommodation provision.

Service providers may be cost-driven in their plans to meet residential need and therefore opt for larger and more specialist facilities that Llewellyn (2011) has identified might be economically cost efficient. However, such facilities although economically cost-effective can have a negative social-cost in how they impact on people's quality of life. Chaput (2002) compared group homes with specialist dementia units in terms of their impact on quality of life for people with Down syndrome and dementia. It was found that smaller group homes promote maintenance of past life, endorse a therapeutic philosophy of care, encourage inclusion and reduce dependence as well as empowering people.

### 5.3.3 Mainstream residential and nursing homes

Thompson (2000) surveyed the placement of older people with ID living in both mainstream residential and nursing homes in England. A sample of 230 people with ID was found to be residing in these facilities. A third of people with ID were admitted from their family homes shortly after their main family carer had died, these were deemed emergency admissions. A quarter of people with ID came from a residential facility or re-organisation or closure of a facility. Thompson found this cohort of people with ID to be younger compared to non-ID people admitted into these residential and nursing homes. Issues of the QoL of the person with ID, poor access to day-care/recreational activities and regular family contact were raised. The residential and nursing home staff expressed anxieties about the adequacy and confidence of their training to work with people with ID, staffing levels, the activities available and how people with ID 'fitted in' to these facilities. Thompson's also raised questions about the appropriateness of mixing people with ID with different needs into mainstream residential and nursing homes with

people without ID. Thompson also reported on an exemplar practice where a 54 year old man with ID and his elderly mother both moved into a nursing home together. This was seen as desirable because it kept them together. However, overall Thompson's study raises questions about the QoL of older people with an ID living in mainstream nursing homes. Others such as Higgins and Mansell (2009) suggest that ageing in place (i.e. in a group home for people with intellectual disabilities rather than in an old person's home) would lead to higher quality of life.

Bigby et al. (2008) in a postal survey of 826 mainstream residential aged care facilities in Australia, found adults with ID who were admitted into these facilities were younger, had entered at an earlier age and remained longer than other non-ID residents. Their reported dependency profile was similar to the general aged care population, although the incidence of dementia was lower. Primary areas of concern identified by providers were: inability to fit into the resident community, lack of participation in activities and lack of meaningful relationships. There were no figures found for the number of adults with ID admitted into mainstream residential and nursing homes in NI for this review.

#### 5.3.4 Summary

- Within NI more older people with ID continue to live with their ageing family carers compared with Great Britain and the RoI: this number is predicted to continue to rise over the next three decades
- Figures are based upon those people with ID known to ID services; there is a sizeable population of older people with ID not using statutory services
- There are more single female carers compared to male carers; although male carers raised issues caring for their daughters with ID, and some siblings were taking on the main caring responsibilities in absence of the ageing parent
- There are fewer ID residential options for older people with ID in NI compared to Great Britain and the RoI
- Older people with ID have been placed into mainstream residential/nursing facilities as a result of a shortage of specialised ID accommodation and inadequate resources to support 'ageing in place' but figures for how many people are in this situation in NI were not available for this review.
- There are no specialised ID ageing residential/nursing facilities within NI to meet the needs of older people with ID

### **5.4 Facilitating and supporting older people with ID and their ageing family carers through succession planning**

In relation to succession planning 12 papers that informed the evidence for the review were located and these are presented in Appendix 11 (pp.189-190).

#### 5.4.1 Family support

As reported above, the main caregivers of older people with ID are their ageing family carers, mainly mothers. From the evidence provided, many older people with ID are living longer with their ageing family carers in NI compared to RoI, Great Britain and other countries. It is clear from the growing literature that ageing family carers want to continue caring for their son/daughter with ID (Foundation for People with ID, 2003, McConkey et al., 2005). Likewise, older people with ID would also like to continuing

living with their parent(s) within their family homes (McConkey, 2004). Black & McKendrick (2010) undertook a scoping study of 36 older carers (50 years plus) in NI and found that the majority of parents wanted their relative to remain with them in their family home. Krauss & Seltzer (1993) explained why family carers wanted to continue to care for their son/daughter: 1) parents self-select to continue to care rather than having their relative placed in care, 2) after many years of caring parents adjusted and accommodated to the caring role, and 3) parents build a long-term relationship with their son/daughter and do in fact gain and feel they have a purpose in life full-filling the caring role. But, the impact of the various health needs of older people with an ID can have far reaching affects on their ageing family carers.

Yamaki et al. (2009) examined the health profile of 206 ageing family caregivers supporting older adults with ID living within their family home in the USA. Arthritis, high BP, obesity, poor mobility, increased diabetes and cholesterol were commonly reported. Llewellyn et al. (2008) in a study of 64 ageing family carers of older people with ID in Australia found that better health was correlated with having a partner, close support of family, friends and neighbours and a lower burden of care. Younger family carers (55-64 years) reported to have more mental health issues compared to the more ageing family carers. Family carers were satisfied with the demands placed upon them by the multiple tasks of caring but reported they became stressed more when they felt helpless or not in control, and also received poor professional support.

Dillenburger & McKerr (2009) in a study of 29 ageing family carers in NI using a structured interview format reported the complex relationships of networks that the carers utilised including siblings, extended family members, neighbours and church contacts. However, 36% of carers did not report use of informal support. The authors also reported the ageing family carers were twice as likely to experience psychological ill-health. McConkey (2005) and Black & McKendrick (2010) both in NI further reported that ageing family carers were also more likely to be socially and economically disadvantaged. Taggart et al. (2011) ongoing study of 18 ageing family carers (60 years plus) older people with ID (aged 40 years plus) in NI reported that they suffered from chronic physical illnesses and also emotional ill-health (i.e. stress and anxiety, depression) from their caring roles.

Bigby (2003) reported that as people with ID age, support from family tends to decline as parents age and there is greater pressure required from formal services to provide a range of support options.

Heller & Arnold (2010) undertook an international literature review to examine the health of siblings of adults with ID. Of 23 studies reviewed, the authors presented a mix of results but overall there was a positive picture of psycho-social outcomes being reported. Siblings reported maintaining long-lasting close relationships with their ID sibling and also anticipated taking on greater supportive roles as they grow older. Bittles et al. (2002) reported that as non-ID women are giving birth to fewer babies today than in the 1950's, therefore the number of siblings to look after a brother/sister with a ID will be diminished, therefore this informal support network that has traditionally supported ageing family carers in the past may decrease.

Increased longevity of people with an ID has led to changed contexts in care as increasingly some ID people are reversing the caring role and they themselves are caring for older frail relatives and this is likely to increase in the future. Little has been reported on this contextual change but research is beginning to take cognisance of this. Williams and Robinson (2001) researched the impact of the UK Carers Act 1995 on families with an ID member. They examined the views of people with ID about their experience of assessments and their relationships with the family. It was reported that many people with ID expressed empathy for their carer's point of view and that several people, including those with high support needs, were performing tasks for their elderly parents. However, no one appeared to recognise the situation as one of mutual care, and carers generally carried on defining themselves as carers since they took responsibility and exercised control. Williams and Robinson (2001) concluded that mutual caring is far more common than is recognised and includes people with severe intellectual disabilities.

Mutual care is negotiated between caregiver and the care recipient. From this perspective caregiving relationships are seen as dynamic and interdependent with caregiver and care receiver equality. Lloyd (2003) suggests that inequality and lack of mutual respect between carer and care recipient can work against the interests of both. Recognition of the person with a disability taking an active role in what then becomes 'family caring' underpins this perspective. Knox and Digby (2007) in a qualitative study exploring caregiving in families found that participants, including the person with an ID perceive caring as "family business" in which members of the family help each other as needed. Family members take on roles, including the ID person. "The allocation of roles moved the person with a disability away from the disabled role and enabled him or her to take on different roles that served a critical function within the family... The context in which tasks and routines occurred, roles were allocated, and family independence was achieved was one of love, trust, and security." (p.295).

The evidence reviewed highlighted that the main concern for the majority of the ageing family carers was what would happen to their son/daughter with ID in the future when they died (Bowey & McGlaughlin, 2004, Black & McKendrick, 2010, Taggart et al., current funded study). Weeks et al. (2009) in Canada examined the current and future concerns of ageing family carers of older people with ID, they undertook ten 1-1 interviews followed by 33 in-depth structured interviews. The authors found that the main concern expressed by the ageing family carers was worry about the future, followed by concerns about funding of services in the future, appropriate housing and care options. They were also concerned about care providers not fully understanding the needs of the older person with ID, and supporting the person with ID to become a productive and active member of society.

#### 5.4.2 Facilitating succession planning

'Succession planning' is based upon ageing family carers proactively planning in the event that they become unable for whatever reason, normally deterioration in their own health or their death, to continue to care for their son/daughter with an ID within their own home. The health of the person with ID, including their physical and mental health as well as chronic and enduring behaviours that challenge, may also lead to ageing family carers exploring alternative care arrangements as they can no longer provide

long-term care. Furthermore, ageing family caregivers need also to develop 'emergency plans' in the event that due to illness they are unable to care for their son/daughter with ID for a short-period of time. Magrill (2005) reported that ageing family carers wanted to continue caring for as long as possible, and also wanted to engage in emergency plans and future planning, if the issues around such decisions were dealt with sensitively and carefully. Without adequate plans and supports in place, individuals with ID may be placed in inappropriate settings as highlighted above.

Ageing family carers of older adults with ID experience unique challenges, however a number of these carers and people with ID are unknown to ID and older people support services and a case is made to proactively engage them to assist in future planning for their adult children.

Black & McKendrick (2010) in their study of 36 older carers (50 years plus) in NI found a third of the family carers reported having an emergency plan in place, mainly involving contacting family members for support until the crisis is over. However, two-thirds of family carers did not have an emergency plan in place.

Thompson (2002) in an editorial comment highlighted that there were detrimental changes to, and withdrawal of, service provision as people with ID get older. These were underpinned by resource deficits, but there are also clear manifestations of ageism in services for people with ID. Thompson explained that older people with ID and their ageing family carers faced very insecure futures, in avoiding premature and inappropriate placements in mainstream older people's residential services. Issues of appropriate planning, ensuring the person with ID and their ageing family carers were supported to maintain contacts were fundamental to succession planning. There were also issues regarding whether staff received the appropriate training to fully support both the ageing family carer and older person with ID to make the succession plan.

Black & McKendrick (2010) in their study of 36 older carers (50 years plus) in the RoI, found no clear and detailed plans for succession planning. The majority of family carers (61%) expressed that they would like their relative to remain supported within their own family home with support as their first option, then to live within supported accommodation with other people with ID as their second choice, and their third option was to live with another family member. Very few family carers wanted their son/daughter with ID to reside within mainstream residential and nursing home accommodation, although the family carers did recognise this was dependent upon the person's level of disability and medical needs. The location of future accommodation was also important to the ageing family carers with family, friends, day time activities and social opportunities were to be close at hand. Taggart et al. (2011) ongoing study of 18 ageing family carers (60 years plus) of older people with ID (40 years plus) in NI reported that just less than half of carers had made future plans; although for most these plans were informal plans (i.e. legal and financial issues had not been addressed and agreed upon). The majority of the elderly family carers indicated that they would prefer for their son/daughter with ID to reside within their own family home with support, the next choice was that a sibling would provide their long-term care and their final choice was that they would reside within a residential facility with other people with ID.

McConkey (2006) reported that 35% of health staff in NI indicated the older people with ID will require a move within the next ten-years from their family home. Predictors for those requiring a move included:

- The person with ID had high dependency needs,
- The ageing family carer was aged 75 years plus,
- Both the ageing family carer and older person with ID were living in unsuitable accommodation,
- The ageing family carer was experiencing greater than average care burden and stress
- The ageing family carers were on income from social security benefits.

In this review the evidence found that succession planning should start before the problems associated with age and ageing become apparent in the both the person with ID and the family carer (Walker & Walker, 1998, Black & McKendrick, 2010).

#### 5.4.3 Psychosocial interventions

There are a range of psychosocial interventions offered to ageing family carers focusing on providing information, and offering emotional and instrumental support to families in order to build upon their existing strengths. These psychosocial interventions empower families within their own social context as a form of prevention, maintenance and also crisis management. According to Seltzer & Gidden (2011) there are six key concepts of psychosocial interventions:

- 1) Enhancing a sense of community
- 2) Mobilising resources and supports
- 3) Sharing responsibility and collaboration
- 4) Protecting family integrity
- 5) Strengthening family functioning
- 6) Adopting proactive programme practices.

There are a number of innovative psychosocial interventions targeted at ageing family carers and siblings of adults with ID such as future planning, support groups, support co-ordination and direct services, and sibling support interventions. These groups provide a range of services including: education and training, counselling, information on future planning, advice on statutory ID services and mainstream community provision, mailing lists of other ageing family carers, how to obtain home modifications, guardianship, and legal and financial planning (Janicki et al., 2003). Within the USA, Canada, Australia and the UK, specialist centres have also been funded and developed through government funds, and private and charitable grants targeted at serving older family caregivers of adults with ID. These centres are designed as co-ordinated, 'one-stop' informational centres for older family cares of adults with ID. However, ageing family carers are less likely to utilise the statutory services (see below) or psychosocial interventions compared with younger family carers as a result of fewer services being available a number of years ago, mistrusting services, previous negative encounters, lower expectations of such services and fear that their son/daughter would be removed from their family home (Seltzer & Gidden, 2011).

A brief summary of the different types of psychosocial interventions is as follows:

- Future Planning

- 1) Family Planning Futures Project, Rhode Island, USA. Based upon ten education sessions for ageing family carers of older people with ID. A facilitator supports the family carer to develop a succession plan.
- 2) Planned Lifetime Advocacy Network, Canada: Using a six step guide to planning the family carer's future, these steps include: clarifying the vision, building relationships, controlling the home environment, preparing for decision making, developing the will and estate plan, and securing a plan. Face to face workshops, on-line and tele-learning workshops are used (PLAN, 2008).
- 3) Family-to-Family Project, USA: Development of eight family-to-family centres in one state. Presentations, resource manuals and parent support groups help parents to develop a future plan using circles of support and self advocacy.
- 4) The psycho-educational group intervention for ageing parents, USA: Professional education support group for older family carers. Three sessions on family carers expressing concerns about the future/care and three sessions on getting information from experts (i.e. legal, financial). Botsford & Rule (2004) evaluated 27 ageing family carers who received the programme, the carers reported better knowledge of awareness of resources for planning, a stronger sense of confidence and competence in their ability to make future plans, and progress in making residential and legal plans.
- 5) Future is Now Programme, USA: Training both the ageing family carers and the person with ID. Based upon Person-Centred-Planning and a peer support model, that includes the carers and people with ID as co-leaders. Heller & Caldwell (2006) followed-up 49 ageing family carers. They found those family carers who received the programme were more likely to complete letters of intent, take action on residential planning and develop special needs trust. The family carers also reported decreased carer burden and increased opportunities for daily choice making for the person with ID.

- Support Groups

Professional led support groups are common for parents of children and adults with ID and have been reported to be very positive. Many parent support groups employ online format, message boards and lists in order to help parents connect. But, few support groups have been developed for ageing family carers of older people with ID. However, Parents Helping Parents (2008) based in the USA is one specific support group targeted at older family carers of children with ID that has been found useful. Likewise, another support group developed in the USA for ageing family carers of older people with ID and/or mental health problems was developed. Both support groups focused on future planning, developing carer coping strategies, residential options, community services, social networking and emotional support. Two small evaluation studies of these support groups were undertaken; both show positive appraisal and positive networking (Smith et al., 1996, Mengel et al., 1996).

- Support co-ordination and direct service programmes

Several projects in the UK and Australia provide models for support co-ordination and direct family support services for older family carers of older people with ID.

- 1) *Options for Older families, Australia*: This support co-ordination model is based upon a proactive intervention and crisis prevention framework. The programme provides trained support workers that can go into the family home and also offer education sessions for the older family carers. It was reported that that 66% of older family carers increased access to out-of-home activities and 59% of families were better able to make plans and decisions about the future (Bigby et al., 2002, Bigby & Ozanee, 2005).
- 2) *Carers FIRST, UK*: Is an organisation dedicated to comprehensive help and support to older family carers via information, resources, discussion, advocacy, 1-1 support and it accommodates family carers to meet.
- 3) *Sharing Caring Project, UK*: Is an organisation that supports ageing family carers of older people with ID by providing information packs for family carers, life books for the person with ID and in partnership with Sheffield NHS to provide direct preventative support and also cultural supports, for example for Asian families.

Sibling Support interventions include conferences, support groups (in-person and on-line) and information provision. There have been two such types of interventions. Firstly, a conference was held in London in 2008 entitled 'Working for adult siblings of disabled people' (SIBS, 2008), and secondly, the National Sibling Leadership Conference, USA (Heller & Kramer, 2007, Heller et al., 2008). These conferences provided opportunities for siblings to increase their involvement in disability advocacy, policy making and services. Such events have also occurred in Canada, Japan and Australia.

Planning for the future was also a major concern expressed by the consultation group for this review, see Appendix 2 (pp.145-146).

#### 5.4.4 Summary

- Ageing family carers want to continue caring for their son/daughter with ID, likewise the older person with ID wants to continue to live with their parent(s), in their own family home
- Ageing family carers physical health is declining as they age yet having the support of a partner, support of family/friends and community lowers the burden of care
- Ageing family carers can suffer from stress and the emotional impact/mental health problems of long-term caring when not supported by statutory services
- Ageing brings a loss of family and friends for many family carers decreasing their social network, accompanied with economic challenges, this places greater pressure on statutory services to provide a range of support options: however such support options are lacking within NI.
- The main concern for the ageing family carers is what would happen to their son/daughter with ID when they can no longer care for them (or they die) with respect to financial support and appropriate housing options
- There are exemplars of a range of proactive psychosocial family interventions offering information, emotional and instrumental support to ageing family carers and older people with ID; however no evidence was found that these interventions were being used within NI

- Future planning projects, support groups, support co-ordination and direct service programmes, and sibling support were interventions that specifically targeted older people with ID and their ageing family carers
- Succession planning is rarely developed within NI although ageing family carers would like to engage in this, but this needs to be handled sensitively
- Succession planning should start early, have clear communication and information strategies, identified databases of ageing family carers and older people with ID identifying those people with ID not known to services early
- Statutory services should develop both proactive and reactive strategies, for example emergency plans
- Appropriate information resources/packages, in large font, with full details of housing options should be made available
- Routine health screening of both the older person with ID and the ageing family carer should take place
- A key person should be identified to co-ordinate between the family home and statutory services including: transport, making appointments, domiciliary care, financial support

### **5.5 Supporting older people with ID and their ageing family carers through formal services**

The search for evidence to inform support of older people with an ID through formal services resulted in 7 articles and these are presented in Appendix 12 (pp.191-192). Like many family carers of children and adults with ID across N. Ireland, RoI, Great Britain and other westernised countries there are a range of statutory supports provided. These include day centres, alternative day options, supported employment, education, respite care, domiciliary support and financial support. Furthermore, there are also a range of leisure activities for people with ID again provided by statutory services but also by voluntary organisations such as Mencap and mainstream organisations. Research shows that older people with an ID received less day-care, less respite care, were less likely to have a social worker, received less domiciliary support and received less input from most health services.

There is some debate that traditional day-care centres prevent older people with ID from retiring as there appears to be no upper age limit. Bigby (2004) found that when she interviewed older people with ID in Australia that they valued continued active engagement with their local communities, expressed a desire to continue learning, still wanted to participate in more leisure activities and placed a high value on structured activities. However, many older people with ID are reliant upon ageing family carers and/or formal carers to present opportunities and provide support to exercise and support them in participating in activities. Bigby (2005) in a review of the comparative programme options for older people with ID highlighted three models:

- Traditional day centres for people with ID of all ages
- Age specific ID programmes
- Use of mainstream older people day services (LePore & Janicki, 1997, Bigby et al., 2004).

McConkey (2006) found that 48% of older people with ID (aged 50 years plus) were attending a traditional ID day centre within NI and the remainder of older people were not utilising any other form of structured day-care. This review did not identify age specific ID day programmes and also older people with ID attending mainstream day-centres.

Ageing family carers were also using a range of other statutory supports such as respite care, domiciliary support services and befriending services although this varied depending upon the Trust the carers lived in (McConkey, 2006, Black & McKendrick, 2010, Taggart et al., current study). McConkey and Adams (2000) reported that there was an increase need for respite and domiciliary care in NI for all people with ID including older people with ID.

Many older people in general enjoy an active social life and some take on new careers. However, for the older person with an ID few have opportunities to take part in leisure pursuits (McConkey et al., 2004). This is due to the health problems they face, perceptions of them as a lower social status group, exclusion rather than inclusive within their community and lack of support to access leisure activities. Not surprisingly, when access to leisure is so difficult for this population the chances of obtaining employment are even more difficult, in fact many have never had meaningful employment when they were younger.

A number of studies have identified that older people with ID under-use health services; this includes health screening, health promotion and health education opportunities (McConkey et al., 2004).

The Direct Payment Scheme was introduced to allow family carers to define, choose and direct their own supports giving them increased control over the services most suitable for their son/daughter with ID and also the family's requirement. The money allocated can be utilised to pay for personal/support assistants, domiciliary care, day-care, transport, supported employment, home modification, respite care and therapies. There is growing evidence to illustrate the success of the direct payment scheme for older family carers in the UK and USA (Stainton, 2002, Stainton & Boyce, 2004, Heller & Caldwell, 2005, Caldwell & Heller, 2007, Caldwell, 2008). Ageing family carers reported the scheme to be very positive; giving them increased choice and empowerment, increased flexibility in scheduling services and a greater sense of trust of the personal assistants. In addition, these ageing family carers also indicated greater feelings of confidence and optimism, and decreased their anxieties about going out for social activities and out to work. The older people with ID also experienced greater community integration and leisure satisfaction. But, there is no indication that direct payments are widely used in NI.

In a survey for the Foundation for People with Learning Disabilities (2003), they reported that the monitoring of needs of ageing family carers is ad hoc and poor across the UK. It seems that while policy directives aim for improvements in care, such suggested improvements are slow to filter through to practice for this client group. Reilly and Conliffe (2002) undertook an analysis of the NADD existing data sets in NI and the RoI, and also conducted interviews with 31 ageing family carers caring for their older son/daughter with ID. The authors concluded that as a sizable number of family carers

will be ageing in the future, therefore some formalised assistance for future planning is needed. A focus should not only be on planning future accommodation but also the person's quality of life. A planning instrument was developed 'What the future holds' for all focusing on health, financial, vocational, social, civil and residential well-being.

The evidence reviewed highlighted that staff training and education was essential in order to prepare front-line staff to meet the evolving physical, mental and social needs of older people with ID (McConkey et al., 2004). McCarthy et al. (2009) in the ROI developed an education programme for front-line staff pertaining to dementia and end-of-life care in older people with ID. The results of the programme indicated that the training supported 'ageing in place', and the preparation for a good death including support for staff, peers, and family in their grief and bereavement. McLaughlin (current PhD study) in NI is developing a training manual for ID staff and palliative care staff in this area.

### 5.5.1 Summary

- Many older people with ID are not involved in structured activities, recreational activities, education, employment and social activities
- There is a lack of alternative day opportunities for older people with ID
- There is a lack of quality respite care for older people with ID, particularly for people with dementia
- Ageing family carers use health care services less including health screening, health promotion and health education opportunities
- No studies have examined the impact of Direct Payments in ageing family carers in NI with respect to any benefits of this system for the older person with ID
- ID staff require training in order to meet the needs of older people with ID, and also supporting this population through the different stages of dementia and end-of-life care
- Likewise, dementia staff and palliative care staff also require training and support to care for older people with ID, dementia and end-of-life care
- Mainstream older people day care facilities can be supported to accommodate older people with ID

## **5.6 The contribution of mainstream services for older persons with ID**

Few studies have examined people with IDs use of mainstream older people day-care facilities, 10 papers were located and these can be seen in Appendix 13 (pp.193-194). Bigby & Balandin (2005) examined the extent to which programmes available to the non-ID aged community are accessible to older people with ID in Australia and 40 day and leisure centres were identified. More than half of these services were accessed by a small number of people with ID and overall there was a willingness to include this group in generic services. The findings indicate that the issues for older people with ID differ little from those of other minority groups. The authors proposed that ID services have a role in brokering services for their older ID clients, and continued planning and collaboration between ID and older people services can benefit all older people.

### 5.6.1 Models of service provision for older people with ID

In a critical analysis of the international literature, Parish & Lutwick (2005) reported that there was limited consensus about whether services for older people with ID should be integrated within mainstream older people services or specialist ID services to meet the need of this population. When people with ID reach old age they are expected to integrate with mainstream older people's services, but issues arise as such mainstream older people's services do not have the training and expertise to work with people with ID. Service provision for older people with ID is fragmented and piecemeal and it is not clear which agencies are responsible for service development. The authors stated that there were very limited opportunities for older people with ID to express their views. Barriers include negative staff attitudes, the dominance of carer's views, lack of time, and the one size model fits all approach (Wilkinson et al., 2005, Jenkins, 2009). Factors that facilitate choice are knowledge of the service user's wishes, time to explore ways of communicating and full assessment of changing needs and the need to use a family centred approach in older people with ID.

### 5.6.2 Dementia models

Kerr et al. (2006) in a report of a study commissioned by the Joseph Rowntree Foundation described three models of support for older people with ID and dementia:

- 1) Ageing in place: the older person with ID and dementia remains within their own family home with appropriate support and adaptations if necessary. The following are required to support the individual early screening, clear diagnostic pathways, improvements to the environment, outreach services, palliative care services, SLT, respite care, carer education and training.
- 2) In place progression: environment developed to become increasingly specialised to provide care within an ID setting. This requires staff education and training, waking night staff, environmental adaptations, outreach services, palliative care services, SLT (King, 2004)
- 3) Referral out: move to long-term (usually nursing) facilities outside ID services but staff in these facilities need training to work with older people with ID and dementia.

Llewellyn et al. (2008) undertook a review of 170 articles examining dementia in people with ID focusing on diagnosis, needs and models of support and service provision. The authors concluded that papers that focus either or in part on models of service models for older people with ID and dementia vary between the generic and the specific models as identified above.

Research shows that a number of countries have advocated for a generic model of dementia care that adapts to suit the needs of older people with ID and dementia (Earnshaw & Donnelly, 2001, Janicki et al., 2002, Thompson, 2000, 2004). Janicki et al. (2002) described a general model of agency planning and service design aimed at providing a responsive dementia capable support programme (ECSPS). This generic model can be adapted to the needs of older people with ID and dementia and focuses on:

- Early screening and diagnostics
- Clinical supports

- Environmental modifications
- Programme adaptations
- Specialised care

However, there are a relatively small number of specialised ID dementia services that have been developed (Northway & Jenkins, 2007, Jenkins, 2009). McCarron et al. (2002) developed the Caregiver Activity Survey (CAS-ID) to aid ID staff in identifying, planning and measuring care and resources for older people with ID and dementia throughout different stages of the dementia process. Adams (2001) highlighted the importance of ID staff training focusing on a bio-psycho-social model together with ethical and spiritual approaches, empowerment, reality orientation, development of shared ownership and the progression of skills development. McBrien et al. (2005) emphasised the requirement to establish a register of those adults with ID at risk of dementia and also that annual baseline assessments of cognitive and adaptive functioning should take place from around 30 years of age for those with Down syndrome. They additionally recommended the development of training for ID staff on dementia and also high quality co-ordination between mainstream dementia and ID services.

McCarron (2005) further highlights that different stages of the dementia process demand different responses from care providers, therefore, ID services will require the specialised input from dementia services. Persaud & Jaycock (2001) also indicate that dementia care mapping can aid ID front-line staff to measure quality of care from the perspective of the older person with ID which in many studies has not been recognised. Llewellyn et al. (2008) concluded that the general consensus within their comprehensive literature was that ID services should be the main provider of care. Although older people with ID and dementia should have the same access to dementia services as those without ID and there needs to be greater co-ordination between ID and mainstream dementia services (Holland, 2000, Dodd, 2003, Watchman, 2003, Hatzidimitriadou & Milne, 2005, Kalsy et al., 2005, McCallion et al., 2005, Forbat, 2006). Davies et al. (2002) undertook a study of 37 adults with ID and dementia (aged 31–65 plus) in NI and recommended multi-agency and multidisciplinary modes of support. The requirement for joint working between specialised ID and mainstream dementia services appears frequently in policy agendas across Great Britain (DoH, 2001, 2009, National Service Framework for Older People, 2001, Scottish Executive, 2001, DHPSSNI, 2005) and the ROI (DoH, 2006) but despite this no clear model has been developed and tested.

### 5.6.3 Recommendations

- The requirement to establish a register of those adults with ID and also those at risk of dementia
- The older person with ID requires a annual baseline medical, behavioural, adaptive and cognitive assessment from 35 years onwards
- Waking night staff are important in ID residential facilities for older people with ID who have dementia, and housing should be adapted and modified early to meet people's needs

- Specific training and support for ageing family carers and also ID staff supporting older people with ID in dementia and end-of-life carer
- Also specific training and support for mainstream dementia staff working with older people with ID, this also includes primary healthcare services
- Development of quality dementia day-care and respite care facilities
- Multi-agency and multidisciplinary modes of support required

## 6. DISCUSSION

This review was undertaken to inform key stakeholders about the evidence that exists to inform practice for two groups of people with ID. Firstly, the review considered the evidence in relation to people with an ID who challenge and may have comorbid mental health problems. For this group of people and their family or other care providers the review questions related to supporting living, day opportunities, family support and interventions or services that have an evidence-base applicable across settings. This group of people has been an ongoing concern of commissioners, care providers and most importantly family caregivers for several decades and they continue to present challenges for community care provision and education.

Secondly, the review looked at the evidence in relation to what might be considered a new and evolving area, that of people with ID who are reaching (or have reached) old age and in many cases are being cared for by older caregiving family members. It might be questioned as to why this should be considered a new area as there is little more predictable in life than that a significant number of people will live into old age. However, as the review has detailed this assumption did not always hold true for people with ID. Now though it seems that with improvements in health care and technologies many more people with ID are living into old age. There are also predictions that longevity for this population will endure and with it will come previously unidentified needs. For people with ID and their carers the review focused on health, aging in place, succession planning, formal service provision and use of mainstream services.

### 6.1 Review aims

An extensive range of literature was accessed to underpin the policy perspectives and inform the evidence on which the review outcomes are based. The questions posed in the review were too many and wide scoping to allow adherence to the strict guidelines of a systematic rapid review. Systematic rapid reviews usually address single interventions focusing on outcomes and as such can allow analysis of a smaller number of studies such as RCTs to assess impact, for example use of a medication. The synthesis in such reviews is amenable to procedures involving meta-analysis of a number of studies or other similar methods. This rapid review differs in that the literature informing the answers to the review questions, because of the conceptual nature of the questions, had to draw on the evidence that was available from various sources. It was reported by McClean (2008) in relation to publications in a major ID journal that only 5% reported outcomes. It can be argued that if for example, this review had of restricted the search to only RCTs a number of the questions would not have been answered at all. This is because as Hassiotis and Sturmey (2010, 39) indicate RCTs are used less frequently in research involving people with ID who challenge than in wider health care research. They go on to state *“most interventions for people with intellectual disabilities are based on information from non-experimental descriptive studies, case-control studies (grade 3) and expert committee reports, opinion and/or clinical experience from respected authorities (grade 4), in contrast to the general population where meta-analyses (grade 1a) and RCTs or quasi-RCTs (grade 2a) are the norm.”* In fact as Hassiotis acknowledges in a Cochrane systematic review on use of CBT for people with an ID and aggressive behaviour only five studies that met the rigours of a RCT were found in a search extending well over 20 years (Hassiotis and

Hall, 2008). It is even less likely that rigorous RCTs would be used in research involving older people with ID.

Thus studies in this review are heterogeneous because of the diverse nature of the review questions and the nature of the evidence that exists. The view taken was that these questions are much too important to the lives of people with ID and their caregivers not to attempt to answer them with whatever form of evidence was available. Views of people about services are best evidenced by the voices of those people in their day-to-day experiences (in this case family caregivers and people with ID themselves, or those who work with them) so qualitative studies and consultations were included. When interventions were amenable to objective measurements with methods like RCTs or systematic reviews of a number of RCTs, for example behavioural interventions where base-line measures along with repeated measures and good control could be used to evaluate evidence then such studies were used. Or, for wider philosophical evidence that can be quite difficult to evaluate, for example human rights and inclusion issues related to older people with ID policy documents and expert panel guides were accessed.

Therefore, by using an extensive and multiple range of literature there is confidence that the best evidence available, even in aspects where evidence is notoriously difficult to establish have been used and in doing so the review questions have been answered according to the extant knowledge at this time. The review team are confident that the best evidence-base that could be established within the time frame of the review has been located and this has provided answers to the review questions to enable the overall aims to be realised.

## **6.2 Review process and methods**

As discussed above it was not viable to adhere to the rigours of a rapid systematic review. This being so the review has nonetheless been framed within the methodological rigours of a systematic review, following the principle of a rapid systematic review as outlined in the methods section of the report in as far as this was feasible (CRD, 2009; Rapid Review Methodology, NHS, Wales 2006). It was viable to follow most aspects of these frameworks but there were some difficulties. The first difficulty encountered was in establishing inclusion and exclusion criteria for the review. This relates directly to the discussion under aims above and the type of literature that is most commonly published in relation to ID, that is most is expert committee reports, based on opinion or experiential. Research studies tend to be descriptive surveys, qualitative accounts and where outcome studies are used they are often of poor design. To address this early in the review stage it was decided not to have exclusion criteria other than English language and limiting to the year 2000 and later in order that the evidence that was published, of whatever type would be retrieved. This led to a second difficulty and that was how various reports, qualitative and quantitative studies and other types of published evidence would be selected and rated for the review, as the papers were so heterogeneous. In order to get around this difficulty a number of different rating scales and approaches to appraise the studies were used, these are identified in the method section of the report (Maryland Scale, Sherman et al, 1998; WoE Framework, CRD, 2009; CASP, Gough, 2007). An approach was developed in which a 1-3 rating could be applied to the literature based on whatever scale was used and this was found

to be a successful method to appraise the papers/reports taking into account their disparate nature. The review was successful in overcoming this problem and found the appraisal was effective. Therefore, besides the outcomes to the review being successful in identifying the evidence-base to inform practice in most of these areas, the approach followed offers a practical guide to reviewing and appraising literature from diverse sources. It is asserted here that this is a methodological outcome to the review that can be a useful guide to others who need to evaluate evidence from diverse sources. This is particularly relevant to ID due to the nature of evidence that informs this area of practice.

### **6.3 Main findings of the review – people who challenge**

The initial section on policy highlights the values that should inform practice and that a person-centred human rights based approach ought to be the essence of the support that is available. The policy suggests that principles such as equality, choice, security, respect and dignity, inclusion and freedom from discriminatory practice should guide the care and support of people who challenge. To some this might seem aspirational but if these principles do not underpin the provision and support for people with ID who challenge and their family caregivers then they are liable to remain isolated and disenfranchised from their community and wider society. In relation to people with ID who challenge although four questions were addressed in the review with respect to supporting living, day opportunities, family support and interventions or services these should not be considered in isolation. To support a person with ID the evidence needs to be amalgamated from each of the areas in a person-centred way to meet the needs of the individual and their family.

Support in where the person lives if guided by a human-rights based approach should have as a starting point the use of many of the resources evidenced in this review to maintain the person in their own home, if this is their wish. Many of the interventions and services that have been identified in the review such as PBS, use of community challenging behaviour teams, short breaks, CBT and teaching and supporting caregivers have been found successful in supported people who challenge to remain at home. It has also been found that appropriate day opportunities form an essential part of the package that is needed to maintain the individual in their home but the review found that day opportunities for people who challenge have not been adequately researched.

Family support is an essential component of the matrix of care that this review found is needed to support an individual with ID who challenges in the community as well as allowing them and their family to lead lives that are meaningful and fulfilling. If the family caregiver is not supported then they will become overburdened and as well as being exposed to stress themselves it can lead to a breakdown in care arrangements.

With respect to interventions the review found some expected outcomes that have remained unchanged for a number of decades. Medications are a highly used treatment for people who challenge but there are now clearer guidelines on use for behavioural management. Behavioural interventions, based on a PBS model have been found most effective in supporting people with ID who have behaviours that challenge.

Family caregivers remain those who provide most support, mainly mothers. Interventions are most likely to be effective when delivered via a family support and education approach that facilitates consistent interventions across various settings and via a partnership approach with formal carers. Treatment of mental health problems in people with ID is developing in some areas, such as CBT but in others involving more psychodynamic than behavioural based interventions there is less supporting evidence. Active support as an intervention for people who challenge or who have mental health problems such as depression seems a promising approach. Social story telling might be a relatively useful approach that is not as labour intensive as other interventions and it is worthy of consideration to help children or adolescents with ID who challenge.

The review identified a range of specialist ID services that have evidence of success in helping people who challenge. Specialist community teams for people who challenge are a highly effective service. When necessary specialist assessment and treatment units can provide a useful service and with a short period as an in-patient the client should be able to return to their community home with on-going support. However, the evidence suggests that a number of clients who are admitted to assessment and treatment units remain there on a long-stay basis, for 25% of people this goes beyond 2-years classifying them as delayed discharge patients. One of the most promising ways of dealing with this issue is by a model that provides combined specialist support services. This involves small assessment and treatment facilities that are integrated with specialist community teams. Such a service can create a true seamless service that prevents delayed discharges.

A full range of mental health services are identified in the section on synthesis of findings but the review found limited evidence that this full range of services for people with ID who have behaviours that challenge and mental health problems use these in great numbers. This remains an issue for debate in terms of how accessible and valuable mental health services are in supporting people with ID and their family caregivers. In addition there is still an unanswered question with regards to the mental health needs of people with ID and if this should fall within the remit of main-stream mental health services, as inclusion would suggest it should; or whether it should remain within ID services.

### 6.3.1 Recommendations: people who challenge

This review found sufficient evidence to make a number of recommendations, some of which it is not clear why they have not permeated into practice previously and others that the evidence indicates would need additional education and training of key stakeholders to facilitate translation into practice. The review also identified a number of gaps in knowledge suggestive of further research.

#### Practice and services

- Specialist community challenging behaviour teams have been found to be successful and these should be developed across NI.
- Service users and families should be considered partners in care planning and delivery and this should apply across agencies and not only disciplines.
- There should always be a functional analysis of behaviour undertaken to determine the cause/s of the behaviour that challenges and what function it has for the client.

- The development and use of proactive person-centred PBS programmes, as a first line intervention to reduce behaviours that challenge but that can be delivered in a partnership way (parents and professionals) should be implemented.
- Early intervention is a guiding principle of interventions to prevent behaviours becoming long-standing and difficult to treat.
- A more flexible range of community-based services for both children and adults should be developed as alternatives to institutional care.
- Short term respite breaks should be more available for people who challenge and involve a variety of approaches that meet the needs clients and family.
- Specialist treatment and assessment units have a role to play but ought to be used only for this purpose and not for long-term care, but there needs to be adequate community services to prevent delayed discharges. There should be consideration given to the development of small scale local based assessment and treatment facilities that are part of a supporting community service rather than hospital-based facilities that tend to retain many of the older care principles associated with institutional care.
- Services should be evidence-based in line with the evidence found in this review and be open to ongoing evaluation to ensure best practice taking into account the economic and social costs and outcomes.
- Day opportunities for people who challenge need to be widened to a range of services beyond traditional day centres to include education, vocational training, work experience, paid employment, voluntary work, social and leisure activities.
- Future planning involving parents and clients in a true person-centred way is necessary to prepare for transitions and future need.
- The same range of psychotherapeutic interventions for mental health that is available to the general population should be available to people with ID (although more research on the efficacy of these for ID people is recommended).
- CAMHS should be as open to referrals from children and adolescents with ID as they are to other members of society. However, for those young ID people who do receive input from CAMHS forward planning on what services are available to meet their mental health needs when they reach transition to adulthood and therefore adult services is required.
- Medications should only be used when indicated for the treatment of physical causes of behavioural problems and to treat psychiatric illness. In accordance with best practice medication when used should be a supplement to other interventions rather than a stand-alone treatment.

### Education

- Education and training of parent caregivers in evidence-based approaches to support their son or daughter to include ABA, PBS, Active Support as well as knowledge about what services are available and the back-ups they can call on is required.
- Increased training for front-line support workers on how to deal with behaviours that challenge on similar aspect to parents (consider joint parent front-line staff training) is needed.

- The review found evidence that although a number of interventions (such as behavioural approaches) do have a strong evidence-base they are still not being widely applied in practice. ID staff would benefit from education on evidence-informed practice and using evidence to guide practice.
- Education provision on the mental health needs of ID people needs to take place. Consideration of the model this would follow suggests a number of potential approaches as follows. 1) Staff in current ID services being trained-up in the mental health needs of ID people. 2) Specialist mental health teams for people with ID being developed, and staff in these trained accordingly. 3) Mainstream mental health services addressing the mental health needs of people with ID and mainstream staff being provided with education and training for this. 4) A fourth approach might involve drawing on each of these three but would still require varying degrees of education and training of staff within the applicable service.

### *Knowledge gaps and translation of research into practice - people who challenge*

This review found a number of gaps in knowledge and aspects where research is not translating into practice as it should do. A number of key recommendations to address this can be made based on the findings of this review in the following six areas.

#### *1) Sustaining the person in their own home*

To facilitate the individual with behaviours that challenge to remain in their home the following should take place.

- Specialist community challenging behaviour teams have been found to be successful but they have not proliferated here. Further research on these teams is required and might involve a study to compare this with places external to NI where these teams have been found successful e.g. these teams have been found successful in inner London areas such as Camden.
- Exploratory research with family caregivers to identify the services they need including siblings and their views on being potential future main caregivers.
- There has been limited research on the views of people who challenge themselves and research that would allow their views to be expressed regarding what they feel would help them to remain in their home would be useful.
- Although house adaptations are common place for people with physical disabilities there has been limited research on house adaptations that are needed to sustain a person who challenges in their home. A study of this nature could allow the identification of adaptations that may help people who challenge and their family.
- There have been few studies on use of direct payments and how family caregivers may create an individual package of care to meet their needs when a family member has behavioural problems. Research on how this individualised approach compares with more traditional commissioned service provision is required.

#### *2) Improving parent caregiver ability to cope with their caring role*

- As identified under education above it is recommended that both family and formal carers are provided with education to support people with ID who challenge. An innovative approach to this would be to design training that can be undertaken jointly by informal caregivers (family) and formal (professional)

carers. Research has found that family caregivers have many misgivings about services they receive and joint education programmes would not only be more efficient but may lead to closer working relationships between formal and informal carers. A programme such as this could be implemented as a pilot and evaluated by research.

- Action research has the potential to lead to improvements in practice. An action research study on improving caregiver's ability to manage could be undertaken using a shared participatory approach involving carers working with professionals to harness and implement interventions that they find work for them.
- Short breaks are an essential component of family support but the nature of these for people with behaviours that challenge can be limited. Research is needed on type of short break needed and how this might best be provided to support families.

### 3) *Prevention and planning for the future*

- Research is needed on the potential to prevent behaviours that challenge taking place. Such a study might involve exploring joint school and family interventions aimed at identification of potential precursors of behaviours that challenge and putting in place interventions to prevent the behaviours taking place or escalating. A range of alternative approaches that might be used for this could be the focus of research in this area.
- Linking to above is potential research on early intervention approaches that involve putting in place robust evidence-based interventions as soon as possible that would prevent behaviours deteriorating and becoming entrenched.
- Future planning can be difficult when a family member has behaviours that challenge but research could investigate how this might be facilitated, when it should take place and who should be involved in this.

### 4) *Research involving staff to help them support people who challenge*

- Education and training of staff in areas such as mental health needs of people who challenge are identified under education above. This and/or other education e.g. on PBS could be combined with pre and post programme research to evaluate staff skills and knowledge.
- There has been little research on interactions between staff and people who challenge. Rather than looking at both as discrete groups there is a need for research on the interactions between frontline staff and people who challenge. This might involve observational research combined with a follow-up action research practice improvement study.
- Organisation of staff has not received attention with respect to support for people who challenge. Research on services managerial approaches are needed in this area. For example, a number of staff have undertaken behavioural support education but have not been given leadership roles in this within their service. A study that would evaluate a service that appointed a leader and coordinator in respect of service delivery for people who challenge could be explored.

### 5) *New models of service delivery to support people who challenge*

- Research is required on day opportunities for people, who challenge, to attempt to identify innovative new approaches that are not day-centre dependent.

- At one above it is recommended to research the effectiveness of challenging behaviour teams. A new model might extend such a team to it becoming an integral service with a small local assessment and treatment unit. Evaluation of a model such as this would identify its effectiveness.
- Although a range of mainstream mental health services might be recommended for people with ID as a right, there is also a need to research what model of practice is most suitable here. 1) Expand the access to mainstream services (training staff in the psychiatric need of ID people). 2) Train ID services to specialise in this area. 3) A model of joint working between services.
- The Tiered Model system that frames provision in many mental health services could be introduced, piloted and researched in ID services for those who need this. However, some cautions about this tiered model need to be kept in mind. Notably that it usually ties level of support to location, with access to the most support requiring inpatient admission. While that may be relevant for some medical conditions, it can be seen to run counter to the principles of the 'support model' (provide whatever support the person needs in the community so as to sustain their family life and community membership). Application of the tiered model in ID services might best be actualised by higher tiers working in support of the foregoing tiers and not the other way; that current resources tend to be tied into the higher tiers with rationed provision in earlier tiers and that staff working in tiers 3 & 4 are available in community settings and not tied into specific locations such as hospitals.

#### 6) *Other potential areas for research*

One to five in the above list are not mutually exclusive and a number of these interventions overlap in their potential value to helping maintain people who challenge in their home or residence. There are also a number of other interventions that this review found could have potential benefits for this client population and research on these might involve.

- Active support as an intervention for people who challenge or who have mental health problems such as depression seems a promising approach and is worthy of further research.
- Research on the impact of health checks on behaviours that challenge and mental health should be undertaken.
- Social Story telling may be a promising approach as an intervention for children with behaviours that challenge and would be worthy of research within one or more school settings.
- Positive behavioural support (PBS) has been found to have high potential in supporting people who challenge yet it seems it is not used as it should be. It also might be that medication is used as an alternative to PBS interventions. A study that would involve putting in place behavioural aspects involving PBS with people on behaviour modifying medications could be implemented with the intended outcome being reduction or stopping of the medication.
- There is a paucity of knowledge about people with ID within the prison system here. Research is required to identify the numbers of people receiving forensic care support, number of people with ID within prisons and how/if the needs of these people are being met.

- Finally, it is widely believed that caring for people who challenge is an expensive service. This may be so but this review found some evidence that specialist services, for example challenging behaviour teams, may be no more expensive than standard care when all the additional need that standard care has to use on people who challenge is taken into consideration. Research is needed involving a cost-analysis of various interventions, such as specialist challenging behaviour services in comparison to standard existing services to determine if specialist services are more expensive as has been claimed.

#### **6.4 Main findings older people with ID**

Most people with ID wish to continue to live in their family home when they reach old age, and the review found that ageing family carers want to continue caring for their son/daughter as they age. However, family caregivers have expressed fears about what will happen to their son/daughter in the future as they feel there is a lack of future planning for this, this apprehension about the future was a major theme in the consultation undertaken for the review (Appendix 2).

The review found that as people with an ID age they are susceptible to the same range of health problems as others in society but they may face these earlier in life than others. As well as this there are higher rates of many age related conditions, for example dementia, among ID people than in the general population. Aging is a normal phenomenon and with it comes health decline at some stage for all in society. But policy and human rights dictate that not to facilitate access to treatment for older people when appropriate is ageism and a contravention of human rights. This is so for everyone in society but it seems ID people may be 'set aside' in this respect. For example, medications that can help with dementia and are prescribed to many non-ID people with this condition are seldom offered to ID people. Appropriate health screening is needed for older people with ID and their family carers but there is scarce evidence that this happens, or if health problems are detected that they are investigated and treated with the same fervour as they would be in other populations.

Staying healthy for as long as possible for ID people, as for anyone requires good nutrition and more exercise, combined with greater surveillance of health risks. Mental health is also impacted upon by such health improving behaviours as well as by continuing to remain active and having a meaningful life that is valued by others and which makes the individual feel valued. Training is required for frontline staff on these and other needs of older people with ID and in the skills to help older ID people, either in supported living arrangements or in partnership with carers in the family home.

It is inevitable that some people among older age populations will become old and frail and require placement in residential or nursing homes. This is also the case for ID people but evidence from this review suggests that facilities that are geared towards the needs of older people with ID, with staff that have expertise in ageing and ID are at best scarce and at worst in many locations they are non-existent. Nursing or residential placement should not be the first call for older ID people who seem to be no longer able to remain in their home. A range of intermediate care facilities (step-down and step-up) should be used to allow people to have periods of short breaks, admission for assessment and treatment or monitoring during a crisis period or as a trial for more

long-term out of home care. Use of such facilities can help the person return to their home and it should not be assumed that because a person is a particular age that they may not be able to return to their normal home or residence. Based on the findings of this review the recommendations below have merit.

#### 6.4.1 Recommendations: older people

The review found sufficient evidence to make the following recommendations, on practice, need for additional education and training of key stakeholders and to facilitate translation into practice. The review also identified a number of gaps in knowledge suggestive of further research.

##### Practice and services

- Greater co-ordination between ID services and mainstream older people's services, as well as voluntary and private sectors should take place.
- A key person should be identified to co-ordinate between the family home and statutory services including: transport, making appointments, domiciliary care, financial support.
- Succession planning should start early; have clear communication and information strategies, identified databases of ageing family carers and older people with ID, identifying those people with ID not known to ID services early.
- Statutory services should develop both proactive and reactive strategies (e.g. future planning, or emergency plans).
- There needs to be regular annual health checks that include cognitive and behavioural assessments from as early as 35 years of age for ID people.
- Healthier lifestyles, better nutrition and more exercise, and a greater surveillance of health risks should be promoted to improve the health of this population.
- Development of high quality older person day-care, respite and recreational services for people with ID within both ID services and mainstream older people's services should be put in place and used.
- Development of specialist ID nursing facilities to manage older people with ID particularly within the mid and end stages of dementia are required.

##### Education

- A range of training for ID frontline staff and informal carers in working with people with ID and dementia should be provided.
- For those individuals with Down syndrome they are more likely to develop dementia at an earlier age, therefore training should be mandatory for all ID staff with respect to this.
- Training and education should be given to all older people teams, dementia staff and also palliative care staff to include older people with ID into their programmes.
- Mainstream older people day care facility staff can be educated/trained to accommodate older people with ID.

##### Knowledge gaps and translation of research into practice – older people

From the evidence presented within this review it is clear that there are still gaps in research knowledge and practice internationally but also the knowledge that has been gained is not commonly applied within Health and Social Services provision in NI. Four

key areas are highlighted with a primary focus on translational research. These are posed as questions with some recommendations regarding the research topics that require investigation.

1) *What supports are required to aid older people with ID to 'age in place' (either within their family home or supported accommodation):*

- The development of a parental education/support programme that focuses on futures planning. Such an education programme would offer appropriate information and emotional and instrumental support to families in order to build upon their existing strengths. This programme can be either delivered as a group education curriculum or by an identified professional who can deliver the programme on a 1-1 basis within the ageing carer's home and outcomes to it could be researched.
- Likewise, to develop an education/training programme that will aid front-line staff to support people with ID to grow older and remain in their supported accommodation. Particular attention within this programme will need to be focused upon the early and mid stages of dementia as well as end-of-life care. The use of 'Active Support' strategies with adaptations to meet the specific needs of adults with ID who age seems a promising approach worthy of evaluation. Both these education/training programmes will be required to be developed and tested with ageing family carers and front-line ID staff.
- There may be potential to develop an education support programme that could be undertaken jointly by both front line staff and family carers. The education and training needs of both these groups are unique but if true partnership working is to take place then joint training initiatives can only help. This would provide a challenge for educators and programme providers but the rewards of such a programme could be immense. An approach such as this would be innovative and it might provide a useful area to pilot within a research study.
- To support older people with ID to continue to be active members of their local communities (i.e. engaging in a full range of typical activities, be involved and share interests with other people, and develop relationships, skills and experiences). The concept of 'circles of support' is worthy of exploration and research in this respect.
- Regular health screening should include cognitive, mental health and behavioural assessment to identify the early signs of dementia, especially in persons with Down syndrome. Appropriate screening instruments will need to be identified and proactive supports and interventions instigated to maintain levels of functioning. Such health screening could be evaluated by research.
- Research is required to examine the use of therapeutic medication with older people with ID particularly those diagnosed with Alzheimer's disease; this would provide a stronger evidence base for further treatment options in this population. It seems that medications that can help dementia that are prescribed to others in society are not frequently used for ID people. For example, donepezil and rivastigmine can help with early dementia and memantine for later dementia but there is little evidence these are widely prescribed to people with an ID and their use needs to be researched.

2) *To develop community supports and succession plans to aid ageing family carers of older people with ID to continue to care:*

- To explore the use by ageing family carers of Direct Payments or individualised payments. These arrangements could empower ageing family caregivers to purchase and use more appropriate services such as personal/support assistants, domiciliary care, day-care, transport, supported employment, home modification, respite care and therapies. The social and economic cost-benefits for the person with ID as well as the family carers should be identified.
- To develop guidelines for health and social care staff, local voluntary agencies and support groups, on working with ageing family carers on 'succession planning'. Succession planning should start early, have clear communication and information strategies, and within local communities should seek to identify those people with ID not known to ID services. Succession plans will also have to develop 'emergency plans', address legal and financial issues, and explore appropriate housing options.
- Research could be undertaken to assess the development of 'support groups' of similar ageing family carers who could act as 'co-tutors' to educate and support other ageing family carers around the topic of 'succession planning'.
- A review is needed of the key skills and attributes required by health and social services staff to engage with older carers around sensitive issues of succession plans, the development of ageing family carer support groups and the co-ordination of support packages.

3) *To support older people with ID through the development of appropriate age related formal services:*

- The development of age appropriate ID day facilities within traditional day care centres with a particular focus on older people and those with dementia. Alternative ID day opportunities need to be explored and what specific adaptations and supports would be required to accommodate older people with ID to utilise such opportunities.
- Likewise, the development of age appropriate older people respite/short break facilities and the value of these for the ageing family carer are required as part of the overall support available to family carers.
- There will increased demand for people to be placed in supported accommodation. In line with the Bamford recommendations that a range of options are required but preferably in small-scale, homely accommodation. Research is needed into the social and economic cost-benefits of existing options for older persons with ID in this respect.

4) *Use of mainstream older people and dementia services:*

- To assess the extent to which older people with ID currently use mainstream supported accommodation, day centres and short break provision and the benefits and drawbacks to this.
- An exploration of what are the understanding, attitudes and willingness of managers in mainstream older people's services to support older people with ID to access their facilities.

- To develop training/education for mainstream older people teams and dementia services, and also palliative care staff, in how to work with older people with ID and evaluate the outcomes of such training.
- To identify the adaptations and supports required to ensure equality of access by older people with ID to the same range of clinical interventions as the non-ID older person and to evaluate by research this accessibility.
- To develop and evaluate a new hybrid support model, employing a family-centred approach, that addresses both the needs of the older person with ID and their ageing family carer(s). This model could be delivered between ID and mainstream older people dementia services.

### **6.5 Priority research areas – people who challenge and older people**

Based on the findings of this review it is evident that there are many areas for promising international research related to people with ID who have behaviours that challenge or/and mental health problems. It is also clear that there are many areas for promising research related to older people with ID and their ageing family carers. However, in the current fiscal environment with limited monies for research, selection is inevitable. Hence as a final part of the Rapid Review, the team held a consultation meeting in Derry attended by a variety of stake-holders (see Appendix 2, pp.142-147) and invited the members of the Review Advisory Group to select their priorities. This along with insights from the external reviewer and team discussions resulted in four key areas related to behaviours that challenge and mental health for translation of research particularly in NI in the immediate future (although there would be international applicability as well).

In the area of behaviours that challenge and mental health three of these could be undertaken within a reasonable time period of approximately 24-30 months but the fourth area (early intervention) would need a much longer time period of around 3-5 years with follow-up work involved. Box 2 below identifies the four priorities.

A similar process was used to identify areas in the context of ageing. In relation to older people with ID and their ageing family carers four key priority areas for research were also identified and these are presented in Box 3.

## Box 2: Four Research Priorities for People who Challenge

- 1.** In general specialist Community Support Teams for People who Challenge have been found to be effective in this review but the way they are structured and operate vary. Research could involve a two year study that would compare the effectiveness and efficiency of differently structured teams across the five Trusts in NI. Relevant outcome measures for individuals and for their carers would be selected alongside the perceived effectiveness of each team as viewed by professionals and service users. A second part of this study would attempt to cost such teams in comparison with generic teams and hospital-based services.
- 2.** The review found limited day opportunities for people who challenge with an over-reliance on traditional day-care centres (almost 50% more here than in England and Scotland). A scoping study could be undertaken that would explore alternative innovative day opportunities for people who challenge within NI but also undertaking comparative work with similar services in the Republic of Ireland and GB. A parallel study using action research methods would describe and evaluate a new service in one Trust area in Northern Ireland possibly based around individualised funding packages.
- 3.** The use of mainstream mental health services by people with ID remains a contentious issue in NI. A two year study could be undertaken across ID and mainstream mental health services in one or more Trust to identify mental health services that are being used by ID people and compare the experience of these clients with another selected group of comparable age, gender and diagnosis. Comparisons could be made in terms of assessments, treatments and access to support services as well as the outcomes achieved for clients and carers. The views of professionals involved in referring as well as service delivery would be sought.
- 4.** Early intervention is crucial to alleviate behaviours that challenge and mental health problems but it is dependent on identifying the precursors of such behaviours and then putting in place suitable interventions to help prevent or ameliorate their occurrence. Longitudinal studies are needed but they are resource intensive. Pre-adolescence into adolescence should be the focus with children showing early signs (or considered at particular risk) having low-level interventions by families and schools. The children would be monitored regularly over a 3-5 year period and comparisons drawn with a contrast group who receive standard services over an equivalent period.

### Box 3: Four Research Priorities for Older People with ID

**1.** In this first research priority there are four inter-related research questions that could be answered within a two-year study, the first three-parts will help to answer the fourth research question:

a) To describe how and when older people with ID retire in NI from day centres and employment.

b) To examine what older people with ID would like to do when they retire

c) To explore age appropriate ID day facilities within traditional day care centres with a particular focus on older people and those with dementia and the specific adaptations and supports that are required to accommodate older people with ID to utilise such opportunities.

d) In collaboration with one or more H&SCT in NI to develop, pilot and evaluate a new innovative day care approach for older people with ID based on research evidence of effectiveness.

**2.** The second research priority is to develop and evaluate a new hybrid support model, employing a family-centred approach that addresses both the needs of the older person with ID and their ageing family carers. This model could be delivered between Learning Disability and mainstream older people and/or dementia services. A two-year study could be undertaken in one or more collaborating H&SCT to develop collaborative working focusing on staff training, joint screening, obtaining an accurate diagnosis, treatment options, management of behaviours, supporting ageing family carers and joint working protocols.

**3.** The third research priority is to identify, test and pilot a number of health screening instruments for older people with ID. The instruments should include physical, cognitive, mental health and behavioural assessments to identify the early signs of physical and mental illness, as well as dementia. As well as developing appropriate screening instruments, staff will need to be trained in use of these and proactive supports and interventions instigated to maintain levels of functioning. Such health screening and management could be evaluated by research within a two-year time-frame.

**4.** The fourth research priority is to develop a parental education/support programme that focuses on futures planning. The education programme would offer appropriate information and emotional and instrumental support to older family carers to build upon their existing strengths. This programme can be either delivered as a group education curriculum or by an identified professional who can deliver the programme on a 1-1 basis within the ageing carer's home and outcomes to it could be researched within a two-year period.

## **6.6 Conclusions**

This review has drawn together the best available information that could be accessed from over the past decade on the evidence that informs (or should inform) practice for older people with ID and people with ID who have behaviours that challenge. In doing this the review has focused on clients themselves, family caregivers and formal service providers.

There are limitations to this review and the main issue in this respect is the form of literature and evidence that was available. However, as discussed above the literature that relates to the review questions was drawn from heterogeneous sources and it is argued that at this time the best available evidence was sourced. Some of the aspects of the review are new and developing areas and as such few RCTs have been undertaken in relation to these, many aspects of care provision for older people with ID fall into this category. In other more developed areas there are increasing numbers of RCT evaluations being undertaken and when this was so such reviews were accessed, examples here include medication trials but increasingly services such as specialist community challenging behaviour teams are being evaluated by RCTs. There remain a number of areas that have to do with care related to social phenomena that is not easy to research by objective cause and effect designs, examples here include the expressed views of service users that can best be gleaned by qualitative approaches and thus such studies were included in the review.

The review has identified the supports that are required for both these client populations to enable them to live in their own homes in as far as is possible and to live dignified meaningful lives maintaining a QoL that is a right of all citizens. Overall conclusions suggest that in some areas there is limited evidence to inform practice but in many areas there is ample evidence of what helps. However, even where ample evidence exists it is not always the case that practice is informed by and follows this evidence. A major question stemming from the review is why this is so. Simplistic answers to this question such as there not being enough resources can only offer answers to this question that are far from satisfactory. This is because for many services, for example specialist challenging behaviour teams, the cost is no more than traditional services when various factors that create the need for high cost interventions or out-of-home admissions are accounted for if these teams are not present. Cost of care is of course a major concern but it should not be the only one. If services are available for one group in society, for example the general older population; but not for another i.e. older people with an ID then this is a form of discrimination towards this vulnerable group and their caregivers that should not be tolerated.

## REFERENCES

- Adams, D. & Allen, D. (2001) Assessing the need for reactive behaviour management strategies in children with severe challenging behaviour. *Journal of Intellectual Disability Research*, 54(4), 335-343.
- Adams, T. (2001) Developing a multi-professional educational training pathway in dementia care. *Mental Health Care*, 4 (11), 370 – 371.
- Ager, A. & O'May, F. (2001), Issues in the definition and implementation of 'best practice' for staff delivery of interventions for challenging behaviour. *Journal of Intellectual & Developmental Disability*, 26 (3), 243-256.
- Alexander, R. T. Hiremath, A. Chester, V. Green, F. N. Hoare, S.G. J.I (2011) Evaluation of treatment outcomes from medium secure service for people with intellectual disability. *Advances in Mental Health and Learning Disabilities*, 5 (1) 22-32.
- Alexander, R. T. Crouch, K. Halstead, S. & Piachaud, J. (2006) Long-term outcome from medium secure service for people with intellectual disability. *Journal of Intellectual Disability Research* 50 (4) 305-315.
- Alexander, R. T. Piachaud, J. & Singh, I. (2001) Two districts, two models: in-patient care in the psychiatry of learning disability. *The British Journal of Learning Disabilities*, 47(2), 105-110.
- Allen, D. & Felce, D. (1999) Service responses to challenging behaviour. In N. Bouras (Ed.), *Psychiatric and Behavioural disorders in development disabilities and mental retardation* (pp. 279-294) Cambridge: Cambridge University Press.
- Allen, D. (1998) Changes in admissions to a hospital for people with learning disabilities following the development of alternative community services. *Journal of Applied Research in Intellectual Disabilities*, 11, 156-165.
- Allen, D. (2000) Recent research on physical aggression in persons with intellectual disability: An overview. *Journal of Intellectual and Developmental Disability*., 25(1), 41-57.
- Allen, D. (2008) A relationship between challenging behaviour and mental ill-health in people with intellectual disabilities: A review of current theories and evidence. *Journal of Intellectual Disabilities*, 12(4), 267-294.
- Allen, D. Moore, K. Brophy, S. (2007) Predictors, costs and characteristics of out of area placements for people with intellectual disability and challenging behaviour *Journal of Intellectual Disability Research* 51 (6), 409-416.
- Allen, D., Lowe, K., Brophy, S. and Moore, K. (2007) Predictors, costs and characteristics of out of area placements for people with intellectual disability and challenging behaviour. *Journal of Intellectual Disability Research*, 51(6), 409-416.

- Aman, M. G. et al. (2000) Special issue, Expert consensus guideline series Treatment of psychiatric and behavioural problems in mental retardation. *American Journal on Mental Retardation*, Vol 105. 159-228.
- Bailey, D.B., Hebbler, K., Spiker, S. et al (2005) Thirty-six-month outcomes for families of children who have disabilities and participated in early intervention. *Pediatrics*, 116,1346-1352
- Ball, S.L. et al. (2006) Personality and behaviour changes mark the early stages of Alzheimer's disease in adults with Down's syndrome: findings from a prospective population-based study. *International Journal of Geriatric Psychiatry*, 21(7) 661-673.
- Bambara, L. (2005) Evolution of positive behavior support: Individualized supports for students with problem behaviors. In L. Bambara & L. Kern (Eds.), *Designing positive behaviour plans* (pp. 1-24) New York: Guilford Press.
- Bamford, D. (Chairman) (2005) *Equal Lives: review of policy and services for people with a learning disability in Northern Ireland*. Belfast Department of Health, Social Services and Public Safety, Review of Mental Health and Learning Disability.
- Barr, O. (2007) Mental health and people with learning disabilities in Northern Ireland: an overview of current policy. *Advances in Mental Health and Learning Disabilities*, 1(1) 13-17.
- Barron D. A. Hassiotis A. (2008) Good practice in transition services for young people with learning disabilities: a review. *Advances in Mental Health and Learning Disabilities*, 2 (3)18-22.
- Barron, S. McConkey, R. and Mulvany, S. (2006) Family carers of adult persons with intellectual disabilities on the island of Ireland. *Journal of Policy and Practice in Intellectual Disability*. 3 (2) 87-94
- Barry, L. & Burlew, S. (2004 ) Using social stories to teach choice and play skills to children with autism. *Focus on Autism and Other Developmental Disabilities* 19 (1 ), 45-51.
- Baxter, H. et al. (2006) Previously unidentified morbidity in patients with intellectual disability. *British Journal of General Practice*, 56 (523), 93-98.
- Beadle-Brown, J. et al. (2006) People with intellectual disabilities in 'out-of-area' residential placements: 2. Reasons for and effects of placement. *Journal of Intellectual Disability Research*, 50 (11) 845-856.
- Beadle-Brown, J., Mansell, J., Whelton, B. and Hutchinson, A. (2006) People with learning disabilities in 'out-of-area' residential placements: 2. Reasons for and effects of placement. *Journal of Intellectual Disability Research*, 50 (2) 845-856.

- Beadle-Brown, J., Mansell, J., Whelton, B. and Hutchinson, A. (2009) People with learning disabilities in 'out-of-area' residential placements: views of families, managers and professionals. *British Journal of Developmental Disabilities*, 55 (108), 15-31.
- Beail, N. (2003) What works for people with mental retardation? Critical commentary on Cognitive-Behavioural and Psychodynamic Psychotherapy Research. *Mental Retardation*, 41 (6) 468-472.
- Beail, N. (2010) The challenge of the randomised control trial to psychotherapy research with people who have learning disabilities *Advances in Mental Health and Learning Disabilities*, 4 (1) 37-41.
- Beail, N. Warde, S. Morsley, K. & Newman, D. (2005) Naturalistic Evaluation of the Effectiveness of Psychodynamic Psychotherapy with Adults with Intellectual Disabilities *Journal of Applied Research in Intellectual Disabilities*, 18 (3 ) 245-251.
- Beresford, B. (2009) Effectiveness of Behavioural Interventions Which Involve Parents in the Management of Behaviour Problems Among Disabled Children: A Rapid Review. University of York, Social Policy Research Unit.
- Beresford B. (2004) On the road to nowhere? Young disabled people and transition. *Child: Care, Health & Development*, 30 (6) 581-587.
- Beyer, S. (2001) Trends in supported employment. *Tizard Intellectual Disability Review*, 6 (3)
- Bhaumik, S. & Michael, D. M. (2004) Pharmacotherapy and pharmacovigilance in learning disability. *Learning Disability Psychiatry*, 6, 9-10.
- Bigby, C. & Balandin, S. (2005) Another minority group: use of aged care day programs and community leisure services by older people with lifelong disability. *Australasian Journal of Ageing*, 24 (1) 18-24.
- Bigby, C. & Ozanee, E. (2005) Comparison of specialist and mainstream programmes for older carers of adults with intellectual disability: considerations for service development. *Journal of Australian Social Work*, 57 (3) 273-287.
- Bigby, C. (2003): Beset by obstacles: A review of Australian policy development to support ageing in place for people with intellectual disability. *Journal of Intellectual and Developmental Disability*, 33 (1) 76-86.
- Bigby, C. (2004) *Aging with a lifelong disability: Policy, program and practice issues for professionals*. London: Jessica Kingsley.
- Bigby, C. (2005) Growing old. Adapting to change and realizing a sense of belonging, continuity and purpose. In G. Grant (Ed) *Learning disability. A life cycle approach to valuing people*. pp. 663-684.

- Bigby, C. (2010) A Five-Country Comparative Review of Accommodation Support Policies for Older People With Intellectual Disability. *Journal of Policy and Practice in Intellectual Disabilities*, 7 (1) 3–15
- Bigby, C. Ozanne, E. & Gordon, and M. (2002) Elements of successful case management practice for older parents of adults with intellectual disability. *Journal of Gerontological Social Work*, 37 (3/4) 25-43.
- Bigby, C. Webber, R. McKenzie-Green, B. & Bowers, B. (2008) A survey of people with intellectual disabilities living in residential aged care facilities in Victoria. *Journal of Intellectual Disability Research*, 52 (5) 404-414.
- Bittles A. H., Bower C., Hussain R. & Glasson E. J. (2007) The four ages of Down syndrome. *European Journal of Public Health*, 17 (2) 221–5.
- Bittles, A. H. , Petterson, B. A. , Sullivan, S . G. , Hussain, R. , Glasson, E . J. & Montgomery, P. D. (2002) The Influence of Intellectual Disability on Life Expectancy *Journal of Gerontology: Medical Sciences*, 57 (7) A: 470–472.
- Bittles, A. H. Glasson, E. J. (2004) Clinical, social and ethical implications of changing life expectancy in Down syndrome. *Developmental Medicine and Child Neurology*, 46 (4)282–6.
- Bittles, A. H., et al. (2002) The influence of intellectual disability on life expectancy. *Journal of Gerontology*, 57 (7) 470-472.
- Black, L. A. & McKendrick, V. (2010) *Careful Plans Report*. Positive Futures Report, Lisburn.
- Botsford, A. L. & Rule, D.A. (2004) An evaluation of a group intervention to assist ageing parents with permanny planning for ageing offspring with intellectual disabilities. *Social Work*, 49 (3) 423-437.
- Bouras, N. (1999) Mental health and learning disabilities planning and service developments. *Tizard Learning Disability Review*, 4 (2) 3-5.
- Bouras, N. (2004) Mental health services for adults with learning disabilities *The British Journal of Psychiatry*, 184 (4) 291-292.
- Bowey, L. & McGlaughlin, A. (2005) Adults with a Learning Disability Living with Elderly Carers Talk about Planning for the Future: Aspirations and Concerns. *British Journal of Social Work*, 35 (8) 1377-1392.
- Braddock D. Emerson E. Felce D. & Stancliffe R. J. (2001) Living circumstances of children and adults with mental retardation or developmental disabilities in the United States, Canada, England and Wales, and Australia. *Mental Retardation and Developmental Disabilities Research Reviews*. 7 (2) 115–121.

- Broadhurst, S. and Mansell, J. (2007) Organizational and individual factors associated with breakdown of residential placements for people with intellectual disabilities. *Journal of Intellectual Disability Research*, 51 (4) 293-301.
- Brown, B. (2004) *Community Mental Health Teams: A guide to current practice*. Oxford: Oxford University Press.
- Bruce, M. et al. (2010) Does training improve understanding of core concepts in cognitive behaviour therapy by people with intellectual disabilities? A randomized experiment *British Journal of Clinical Psychology* 49 (1) 1-13.
- Brylewski, J., & Duggan, L. (2004) *Antipsychotic medication for challenging behaviour in people with learning disability*. *Cochrane Database of Systematic Reviews Issue 3. Art. No.: CD000377. DOI: 10.1002/14651858.CD000377.pub2.* .
- Burt, D.B. & Aylward, E.H. (2000) Test battery for the diagnosis of dementia in individuals with intellectual disability. *Journal of Intellectual Disability Research*, 44 (2) 175-180.
- Burt, D.B., et al. (2005) Tests and medical conditions associated with dementia diagnosis. *Journal of Policy and Practice in Intellectual Disabilities*, 2 (1) 47-56.
- Caldwell, J. & Heller, T. (2007) Longitudinal outcomes of a consumer directed programme supporting adults with developmental disabilities and their families. *Intellectual and Developmental Disabilities*, 45 (3) 161 – 173.
- Caldwell, J. (2008) Health and Access to Health Care of Female Family Caregivers of Adults With Developmental Disabilities *Journal of Disability Policy Studies* 19(2), 68-79.
- Capella, M. Roessler, R. & Hemmeria, K. (2002) Work-related skills awareness in high-school students with disabilities. *Journal of Applied Rehabilitation Counselling*, 33 (2) 17-23.
- Carr, E. G. & Owen-DeSchryver, J. S. (2007) Physical illness, pain, and problem behavior in minimally verbal people with developmental disabilities. *Journal of Autism and Developmental Disorders* 37 (4) 413-424.
- Carr, E. G. (2007) The expanding vision of positive behavior support: Research perspectives on happiness, helpfulness, and hopefulness *Journal of Positive Behavior Interventions* 9(1), 3-14.
- Carr, E.G. et al. (2002) Positive behaviour support: Evolution of an applied science. *Journal of Positive Behaviour Interventions*, 4 (1) 4-16.
- CASP. (Critical Appraisal Skills Programme) (2006) *Collaboration for Qualitative Methodologies*: Public Health Resource Unit, England.
- Cassidy, G. Martin, D. M. Martin, G. H. B. & Roy, A. (2002) Health checks for people with learning disabilities: community learning disability teams working with general practitioners and primary care teams. *Journal of Learning Disabilities*, 6 (2) 123-136.

- Chan, S. W. et.al. (2010) The effects of multisensory therapy on behaviour of adult clients with developmental disabilities-A systematic review *International Journal of Nursing Studies* 47 (1) 108-122.
- Chaput, J. L. (2002). Adults with Down syndrome and Alzheimer's disease: Comparison of services received in group homes and special care units. *Journal of Gerontological Social Work*, 38(1/2) 197–211.
- Church, R.J. (2003) The definition, diagnosis and treatment of children and youth with severe behaviour difficulties: A review of research. *Report to the Ministry of Education. University of Canterbury, Education Department.*
- Clarke, S. & Dunlap, G. (2008) A descriptive analysis of intervention research published in the Journal of Positive Behavior Interventions: 1999-2005. *Journal of Positive Behavior Interventions* 10 (1) 67-71.
- Cole, A. et al. (2007) *Adult Services Review: Having a good day? A study of community-based day activities for people with learning disabilities.* The Foundation for People with Learning Disabilities (FPLD) and the Norah Fry Research Centre (NFRC)
- Commission for Social Care Inspection (2006) *The State of Social Care 2005/06.* London: CSCI.
- Cooper, S. A. et al. (2007) An epidemiological investigation of affective disorders with a population-based cohort of 1023 adults with intellectual disabilities. *Psychological Medicine*, 37 (6) 873-882.
- Coppus, A.M. et al. (2010) Early age at menopause is associated with increased risk of dementia and mortality in women with Down syndrome. *Journal of Alzheimer's Disease*, 19 (2) 545-50.
- Coppus. A. et al. (2006) Dementia and mortality in persons with Down's syndrome. *Journal of Intellectual Disability Research*. 50 (10) 768-77.
- Cosgrave, M. et al. (2000) A five year follow-up study of dementia in person's with Down's syndrome: Early symptoms and patterns of deterioration. *Irish Journal of Psychological Medicine*, 17 (1) 5-11.
- Coulter, V. (2008) *A teacher-centred approach to meeting the needs of children and young people with a learning difficulty and challenging behaviour.* Unpublished PhD thesis. University of Ulster.
- CRD (2009) *NHS Centre for Reviews and Dissemination. Systematic reviews. CRD's guidance for undertaking reviews in health care.* . York: CRD University of York, [http://www.york.ac.uk/inst/crd/pdf/Systematic\\_Reviews](http://www.york.ac.uk/inst/crd/pdf/Systematic_Reviews) Accessed 27 October 2010
- Croll, P. (2001) Children with statements in mainstream Key Stage 2 Classrooms: a survey of 46 primary schools. *Educational Review*, 53 (2) 137-145.

- Cumella, S. (2009) Mental health services for people with a learning disability. *Advances in Mental Health and Learning Disabilities*, 3 (2), 8-14.
- Dagnan, D. (2007) Psychosocial interventions for people with intellectual disabilities and mental ill-health. *Current Opinion in Psychiatry*, 20 (5) 456-460.
- Dalton, A.J. et al. (2002) The Multi- dimensional Observation Scale for Elderly Subjects (MOSES): Studies in adults with intellectual disability. *Journal of Intellectual and Developmental Disability*, 27 (4) 310-324.
- Davies, M. MacGlade, A. & Bickerstaff, D. (2002) A needs assessment of people in Eastern Health and Social Services Board (Northern Ireland) with intellectual disability and dementia. *Journal of Learning Disabilities*, 6 (1), 23-33.
- Deb, S. Matthews, T. Holt, G. & Bouras, N. (Eds.) (2001b) *Practice Guidelines for the Assessment and Diagnosis of Mental Health Problems in Adults with Learning Disabilities*. London: European Association for Mental Health in Mental Retardation (EAMHMR)
- Deb, S. Thomas, M. & Bright, C. (2001a) Mental disorders in adults who have an intellectual disability, 1 prevalence of functional psychiatric illness among a 16–64 year old community-based population. *Journal of Intellectual Disability Research*, 45 (6), 506-514.
- Decoufle', P., & Autry, A. (2002). Increased mortality in children and adolescents with developmental disabilities. *Paediatric and Perinatal Epidemiology*, 16 (4) 375–382.
- Dee, L. & Byers, R. (2003) Facilitating transitions for people with profound and complex learning difficulties. *Journal of Integrated Care*, 11 (4) 34–38.
- Department of Health (2001a) *Valuing People: a new strategy for intellectual disability for the 21<sup>st</sup> Century*, London: Department of Health.
- Department of Health (2002) Specialised Services National Definitions Set. Department of Health, London
- Department of Health (2010) *Valuing older families Now* London, Department of Health.
- Department of Health and Children (2006) A Vision for Change. The report of the expert group on Mental Health Policy. Dublin: The Stationery Office.
- Department of Health. (1993) *Services for people with learning disabilities and challenging behaviour or mental health needs*. London: HMSO.
- Department of Health. (2000a) *The Same as You? A review of services for people with learning disabilities*. Edinburgh: HMSO.
- Department of Health. (2006) *Our health, our care, our say: a new direction for community services*. London: The Stationery Office.

- Department of Health. (2007) *Services for people with learning disabilities and challenging behaviour or mental health needs: Revised edition (Chairman: Prof J.L. Mansell)* London: Department of Health.
- Department of Health. (2009) *Valuing People Now: A new three-year strategy for People with Learning Disabilities*. London: HMSO.
- Department of Health (2001b) *National Service Framework for Older People*. London: HMSO.
- Devine, M. Taggart, L. McLornian, P. (2009) Screening for mental health problems in adults with learning disabilities using the Mini PAS-ADD Interview. *British Journal of Learning Disabilities* 38 (4) 252-258.
- DHSS (2005) *Equal Lives: Review of Policy for People with Learning Disabilities*. Belfast: DHSS.
- DHSSPS (2005) *Ageing in an inclusive society: Promoting the social inclusion of older people*. Belfast: DHSSPS.
- DHSSPSNI (2005) *Equal Lives; Review of policy and services for people with a learning disability in Northern Ireland*. Belfast: DHSSPSNI.
- Didden,R. Korzilius,H. Oorsouw,W.V. & Sturme,y,P. (2006) Behavioural treatment of challenging behaviours in individuals with mild mental retardation: Meta-analysis of single-subject research. *American Journal on Mental Retardation*, 4, 290-98.  
difficulties in England 2003/04, London: Health and Social Care Information Centre.
- Dillenburger, K. & McKerr, L. (2009) “40 years is an awful long time”: parents caring for adult sons and daughters with disabilities. *Behaviour and Social Issues*, 18, 155-174
- Dodd, K. (2003) Supporting people with Down syndrome and dementia. *Tizard Learning Disability Review*, 8 (4) 14 – 18.
- Donner, B. Mutter, R. & Scior, K. (2010) Mainstream In-Patient Mental Health Care for People with Intellectual Disabilities: Service User, Carer and Provider Experiences *Journal of Applied Research in Intellectual Disabilities*, 23 (3) 214-225.
- Dowling, S. Hubert, J. & Hollins, S. (2003) Bereavement interventions for people with learning disabilities. *Bereavement Care*, 22 (2) 19-21.
- Dunlap, G. Carr, E. G. Horner, R. H. Zarcone, J. R. Schwartz, I. (2008 ) Positive Behavior Support and Applied Behavior Analysis A Familial Alliance. *Behavior Modification* 32 (5) 682-698.
- Durand, V.M. (1990). *Functional communication training: An intervention program for severe behavior problems*. New York: Guilford.

- Durvasula, S., Beange, H., & Baker, W. (2002). Mortality of people with intellectual disability in northern Sydney. *Journal of Intellectual & Developmental Disability*, 27 (4) 255–264.
- Earnshaw, K. & Donnelly, V. (2001) Partnerships in practice. *Learning Disability Practice*, 4 (3) 24–29.
- Eldevik S. Hastings RP. Hughes JC. Jahr E. Eikeseth S. Cross S. (2010) *American Journal on Intellectual & Developmental Disabilities*, 115 (5) 381-405.
- Emerson, E. (1995) *Challenging behaviour: analysis and interventions in people with learning difficulties*. Cambridge: Cambridge University Press.
- Emerson, E. (2001) *Challenging behaviour: analysis and interventions in people with learning disabilities*. Cambridge: Cambridge University Press.
- Emerson, E. (2003) Prevalence of psychiatric disorders in children and adolescents with and without intellectual disability *Journal of Intellectual Disability Research*, 47 (1) 51-58.
- Emerson, E. (2005) Underweight, obesity and exercise among adults with intellectual disabilities in supported accommodation in Northern England. *Journal of Intellectual Disability Research*, 49 (2), 134-143.
- Emerson, E. et al. (2000) Treatment and Management of Challenging Behaviours in Residential Settings. *Journal of Applied Research in Intellectual Disabilities*, 13 (4) 197-215.
- Emerson, E. et al. (2001) The prevalence of challenging behaviors: A total population study *Research in Developmental Disabilities* 22 (1) 77-93.
- EPPI. The Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI-Centre) <http://eppi.ioe.ac.uk/cms/Default.aspx?tabid=177> Accessed 20 Jan 2011
- Evenhuis, H. et al. (2000) *Healthy Ageing - Adults with Intellectual Disabilities: Physical Health Issues*. Geneva, Switzerland: World Health Organization.
- Felce, D. et al. (2008) The Impact of Repeated Health Checks for Adults with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities* 21 (6), 585-596.
- Forbat, L. (2006) Valuing People: Hopes and dreams for the future. *British Journal of Learning Disabilities*, 34 (1) 20 – 27.
- Forbes, A., While, A., Ullman, R., Lewis, S., Mathes, L. & Griffiths, P. (2002) *A Multi-Method Review to Identify Components of Practice Which May Promote Continuity in the Transition from Child to Adult Care for Young People with Chronic Illness or Disability*. Report for the National Coordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO). The Florence Nightingale School of Nursing and Midwifery, King's College, London, UK. URL <http://www.sdo.lshtm.ac.uk/continuityofcare.htm>

- Foundation for People with Learning Disabilities (2006) *Planning for Tomorrow*.  
[www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk), Foundation for People with Learning Disabilities.
- Fox, R. A. (2003) Treatment of accommodation for adults with challenging behaviours.  
*American Journal of Mental Retardation*, 41(3), 205-206.
- Foyle HSS Trust (2000) *Review of day care services for adults with learning disabilities*.  
 Londonderry: Foyle HSS Trust.
- Garner, P. (2000) Pretzel only policy? Inclusion and the real world of initial teacher education.  
*British Journal of Special Education*, 27 (3) 111-115.
- Gates, B. Newell, R. & Wray, J. (2001) Behaviour modification and gentle teaching workshops: Management of children with learning disabilities exhibiting challenging behaviour and implications for learning disability nursing. *Journal of Advanced Nursing*, 34 (1) p. 86-95.
- Glasberg, B.A. Martins, & Harris, S.L. (2006) Stress and coping among family members of individuals with autism. In: M.G. Baron, et al. (Eds), *Stress and coping in autism* (276-301) New York: Oxford University Press, Inc.
- Gough, D. (2007) Weight of evidence: a framework for the appraisal of the quality and relevance of evidence. In: J. Furlong & A. Oancea (Eds.) *Applied and Practice-based Research. Special Edition of Research Papers in Education*, 22 (2), 213-228.
- Gray, C. (2011) What are Social Stories. Retrieved March 20, 2011, from  
<http://www.thegraycenter.org/social-stories/what-are-social-stories>. Retrieved 20 March 2011,
- Grey, I.M. Hastings, R.P. & McClean, B. (2007) Staff training and challenging behaviour.  
*Journal of Applied Research in Intellectual Disabilities*, 20 (1) 1-5.
- Grigal, M. Hart, D. Migliore, A. (2011) Comparing the Transition Planning, Postsecondary Education, and Employment Outcomes of Students With Intellectual and Other Disabilities. *Career Development for Exceptional Individuals*, 34 (4) 4-17
- Hagiliassis, N. et al. (2005) The anger management project: A group intervention for anger in people with physical and multiple disabilities. *Journal of Intellectual & Developmental Disability*, 30 (2), 86-96.
- Haley, E. & Perkins. P. (2004) Current Status and Future Directions in Family Care-giving and Aging People with Intellectual Disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 1 (1), 24-30.
- Hamilton D., Sutherland G. & Iacono T. (2005) Further examination of relationships between life events and psychiatric symptoms in adults with intellectual disability. *Journal of Intellectual Disability Research*, 49 (11) 839-44.

- Hanson, M. J., Beckman, P. J., Horn, E., Marquart, J., Sandall, S. R., Greig, D., et al. (2000). Entering preschool: Family and professional experiences in this transition process. *Journal of Early Intervention*, 23 (4) 279-293.
- Hassiotis, A. & Hall, I. (2008) *Behavioural and Cognitive-Behavioural Interventions for Outwardly-Directed Aggressive Behaviour in People with Intellectual Disabilities (Cochrane Review)*: The Cochrane Database of Systematic Reviews.
- Hassiotis, A. & Sturmey, P. (2010) Randomised Controlled Trials in Intellectual Disabilities and Challenging Behaviours – Current Practice and Future Challenges *European Psychiatric Review*, 2, 39-42.
- Hassiotis, A. (1999) Psychodynamic psychotherapy in learning disability theory and practice revisited. *Journal of Learning disabilities for Nursing, Health and School Health Care*, 3 (2) 106–109.
- Hassiotis, A. et al. (2008) Individual Characteristics and Service Expenditure on Challenging Behaviour for Adults with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*, 21 (5), 438-445.
- Hassiotis, A. et al. (2009) Randomized, Single-Blind, Controlled Trial of a Specialist Behavior Therapy Team for Challenging Behavior in Adults With Intellectual Disabilities. *American Journal of Psychiatry*, 166 (11) 1278–1285.
- Hatton, C. (2001) *Strategies for change: implementing Valuing People at the local level. Developing housing and support options: lessons from research*. Lancaster University: [http://www.lancs.ac.uk/fass/ihr/publications/housing\\_support.pdf](http://www.lancs.ac.uk/fass/ihr/publications/housing_support.pdf) [accessed 18th March 2011]
- Hatzidimitriadou, E. & Milne, A. (2005) Planning ahead; meeting the needs of older people with intellectual disabilities in the United Kingdom. *Dementia*, 4 (3), 341-359.
- Haveman, M. et al, (2010) Major Health Risks in Aging Persons with Intellectual Disabilities: An Overview of Recent Studies. *Journal of Policy and Practice in Intellectual Disabilities* 7 (1) 59-69.
- Hedeen, D.L., Ayres, B.J., Meyer, L.H., & Waite, J. (1996) Quality inclusive schooling for students with severe behavioral challenges. In D. Lehr & F. Brown (Eds.), *People with disabilities who challenge the system* (pp. 127-171) Baltimore, MD: Paul H. Brookes.
- Hedeen, D.L., Ayres, B.J., Meyer, L.H., & Waite, J. (1996). Quality inclusive schooling for students with severe behavioral challenges. In D. Lehr & F. Brown (Eds.), *People with disabilities who challenge the system* (pp. 127-171). Baltimore, MD: Paul H. Brookes.
- Heller, T. & Caldwell, J. (2005) Impact of a consumer-directed family support programme on reduced out-of-home institutional placement. *Journal of Policy and Practice in Intellectual Disabilities*, 2 (1), 63-65.

- Heller, T. & Caldwell, J. (2006) Supporting adults with developing disabilities and ageing caregivers in future planning. *Mental Retardation*, 44 (3) 189 – 202.
- Heller, T. & Kramer, J. (2007) Sibling Leadership Network Update (Brochure) Chicago, IL.
- Heller, T., Meyer, D., Fish, T., Kramer, J. & Dufresne, D. (2008): The Sibling leadership network: Recommendations for research advocacy, and supports relating to siblings of people with developmental disabilities. Chicago, IL: Rehabilitation Research and Training Centre on Ageing with Developmental Disabilities and the Vanderbilt Kennedy Centre for Excellence in Developmental Disabilities & Ohio State University Nisonger Centre.
- Heller, T. & Schindler, A. (2011) Family Support Interventions for Families of Adults with Intellectual and Developmental Disabilities. *International Review of Research in Mental Retardation* 37, 299-332
- Heller, T. & Arnold, K.A. (2010) Siblings of Adults With Developmental Disabilities: Psychosocial Outcomes, Relationships, and Future Planning. *Journal of Policy and Practice in Intellectual Disabilities*, 2 (1) 16-25.
- Herring, S. et al. (2006) Behaviour and emotional problems in toddlers with pervasive developmental disorders and developmental delay: Associations with parental health and family functioning. *Journal of Intellectual Disability Research*, 50(12), 874-882.
- Heslop, P., Mallett, R., Simons, K. & Ward, L. (2002) Bridging the Divide at Transition: What Happens for Young People with Learning Difficulties and Their Families? British Institute of Learning Disabilities, Plymbridge, UK.
- Hewitt, A. L. et al. (2010) 'Parental Caregivers' Desires for Lifetime Assistance Planning for Future Supports for Their Children with Intellectual and Developmental Disabilities' *Journal of Family Social Work*, 13 (5) 420-434.
- Higgins, L. and Mansell, J. (2009) Quality of life in group homes and older persons' homes. *British Journal of Learning Disabilities*, 37, 207-212.
- Hoekman, J. & Maaskant, M.A. (2002) Comparison of instruments for the diagnosis of dementia in individuals with intellectual disability. *Journal of Intellectual and Developmental Disability*, 27 (4) 296-309.
- Hogg, J. et al. (2000) *Healthy Ageing - Adults with Intellectual Disabilities: Ageing & Social Policy*. Geneva: Switzerland: World Health Organization.
- Holland, A.J. (2000) Ageing and learning disability. *British Journal of Psychiatry* 176 (1) 26-31.
- Holland, A.J. (2000) Incidence and course of dementia in people with Down's syndrome: Findings from a population based study. *Journal of Intellectual Disability Research*, 44 (2) 138-146.

- Hollins, S. & Dowling, S. (2002) *Helping adults with learning disabilities to survive bereavement and move on*. Paper presented at the IASSID European Conference, Dublin.
- Horner, R.H. et al. (2002) Problem behaviour interventions for young children with autism: A research synthesis. *Journal of Autism and Developmental Disorders*, 32 (5) 423-446.
- Hudson, A. Cameron, C.& Matthews, J. (2008) The wide-scale implementation of a support program for parents of children with an intellectual disability and difficult behaviour *Journal of Intellectual & Developmental Disability* 33 (2) 117-126.
- Hudson, A. et al. (2003) Evaluation of an intervention system for parents of children with intellectual disability and challenging behaviour *Journal of Intellectual Disability Research* 47 (4/5) 238-249.
- Hunt, C. Wakefield, S. & Hunt, G. (2001) Community Nurse Learning Disabilities – a case study of the use of an evidence-based health screening tool to identify and meet health needs of people with learning disabilities. *Journal of Learning Disabilities*, 5 (1) 9-18.
- IASSID Comparative Policy and Practice Special Interest Research Group (2010) *Policies for a good life in the community: sustaining and improving community services for people with intellectual disabilities in difficult times*. [www.iassid.org](http://www.iassid.org)
- IASSID (2001) *Mental health and intellectual disabilities Addressing the mental health needs of people with intellectual disabilities: Report by the Mental Health Special Interest Research Group of IASSID (International Association for the Scientific Study of Intellectual Disabilities) to the World Health Organisation*.
- Janicki, M. et al. (2002) Health characteristics and health services utilization in older adults with intellectual disability living in community residences. *Journal of Intellectual Disability Research*, 46 (4) 287– 298.
- Janicki, M.O. & Wilkinson, H. (2002) The Edinburgh Principles with accompanying guidelines and recommendations. *Journal of Intellectual Disabilities Research*, 46 (3) 279-284.
- Janicki, M.O. McCallion, P. & Dalton, A.J. (2002) Dementia related care decision making in group homes for persons with intellectual disabilities. *Journal of Gerontological Social Work*. 38 (1/2) 179-195.
- Janicki, M.P. & Dalton, A.J. (2000) Prevalence of dementia and impact on intellectual disability services. *Mental Retardation*, 38 (3) 276-88.
- Jenkins R. (2009) Nurses' views about services for older people with learning disabilities. *Nursing Older People*, 21 (3) 23-27.
- Jess, G. et al. (2008) Specialist Versus Generic Models of Psychiatry Training and Service Provision for People with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities* 21 (2) 183-19.

- Joyce, T. Ditchfield, H. & Harris, P. (2001) Challenging behaviour in community services. *Journal of Intellectual Disability Research*, 45 ( 2) 130-138.
- Kaehne, A. (2011) Transition from children and adolescent to adult mental health services for young people with intellectual disabilities: a scoping study of service organisation problems. *Advances in Mental Health and Learning Disabilities*, 5 (1) 9-16.
- Kalsy, S. McQuillan, S. Adams, S. et al. (2005) A proactive psychological strategy for determining the presence of dementia in adults with Down syndrome. *Journal of Policy and Practice in Intellectual Disabilities*, 2 (2) 116 – 125.
- Kalyva, E. & Agaliotis, I. (2009) Can social stories enhance the interpersonal conflict resolution skills of children with LD? *Research in Developmental Disabilities* 30 (1) 192–202.
- Kaptein, S. Jansen, D.E.M C. Vogels, A.G.C. & Reijneveld, S. A. (2008) Mental health problems in children with intellectual disability: use of the strengths and difficulties questionnaire *Journal of Intellectual Disability Research* 52 (2) 125-131.
- Kay, D.W.K. et al. (2003) Preliminary evaluation of a scale to assess cognitive function in adults with Down’s syndrome: The Prudhoe Cognitive Function Test. *Journal of Intellectual Disability Research*, 47 (3) 155-168.
- Kelly, F. & McConkey, R. (2011) *Changes in the provision of residential care for adult persons with an intellectual disability: a national longitudinal study*. Dublin: Health Research Board.
- Kenny, K. & McGilloway, S. (2007) Caring for children with learning disabilities: an exploratory study of parental strain and coping *British Journal of Learning Disabilities* 35 (6) 221-228
- Kerr, D. Cunningham, C. and Wilkinson, H. (2006) Learning disability and dementia: are we prepared? *Journal of Dementia Care*. May/June, 17-19.
- Kim, S. Larson, S. A. & Lakin, K. C. (2001) Behavioural outcomes of deinstitutionalisation for people with intellectual disability: a review of US studies conducted between 1980 and 1999. *Journal of Intellectual & Developmental Disabilities* 26 (1 ) 35-50.
- King, N. (2004) New Provision for Older People with Learning Disabilities, Housing Learning & Improvement *Network Factsheet*, 3, 23/12/2003, updated 2004.
- Knapp, M. et al. (2005) Intellectual disability, challenging behaviour and cost in care accommodation: what are the links? *Health and Social Care in the Community* 13 (4) 297-306.
- Knox, M. & Bigby, C. (2007) Moving towards Midlife Care as Negotiated Family Business: Accounts of people with intellectual disabilities and their families “Just getting along with their lives together” *International Journal of Disability, Development and Education* 54 (3) 287–304

- Koegel, R.L. Openden, D. Fredeen, R. & Koegel, L.K. (2006) The basics of Pivotal Response Treatment. In R.L. Koegel & L.K. Koegel (Eds.), *Pivotal Response Treatments for Autism*. Baltimore: Brookes Publishing Co.
- Koritsas, S. Iacono, T. Hamilton, D. & Leighton, D. (2008) The effect of active support training on engagement, opportunities for choice, challenging behaviour and support needs *Journal of Intellectual & Developmental Disability* 33 (3) 247-256.
- Kozma, A., Mansell, J. and Beadle-Brown, J. (2009) Outcomes in different residential settings for people with intellectual disability: a systematic review. *American Journal on Intellectual and Developmental Disabilities*, 114 (3) 193-222.
- Krauss, M. W. and M. M. Seltzer (1993) Current well-being and future plans for older caregiving mothers. *The Irish Journal of Psychology*, 14 (1) 48-63.
- Kuoch, H. & Mirenda, P. (2003) Social Story interventions for young children with autism spectrum disorders *Focus on Autism and Other Developmental Disabilities* 18 (4) 219-227.
- Lambe, L. and J. Hogg (2003) *Older people with learning disabilities (1999, Updated 2003)* [www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk), Foundation for People with Learning Disabilities.
- Lane, J. (2005) Down syndrome and Alzheimer dementia. *Frontline, Winter*. 22-30
- LaVigna, G. W. & Willis, T. J. (2005) A positive behavioural support model for breaking the barriers to social and community inclusion *Tizard Learning Disability Review* 10 (2) 16-23.
- Lawson, L. Francis, R. Russell, P. & Veitch, J. (2008) Equality and access to human rights for people with both learning disability and mental illness needs. *Advances in Mental Health and Learning Disabilities*, 2 (2) 3-7.
- Lee, S., & Odom, S.L. (1996). The relationship between stereotypic behaviour and peer social interaction for children with severe disabilities. *Journal of the Association for Persons with Severe Handicaps*, 21, 88-95.
- Lejuez, C. W. et al. (2011) Ten Year Revision of the Brief Behavioral Activation Treatment for Depression: Revised Treatment Manual *Behavior Modification* 35 (2), 111-161.
- Lemaire, G.S. & Mallik, K. (2008) Barriers to supported employment for persons with developmental disabilities. *Archives of Psychiatric Nursing*, 22 (3) 147-155.
- Lemay R. A. (2009) Deinstitutionalization of people with developmental disabilities: a review of the literature. *Canadian Journal of Community Mental Health*, 28 (1) 181-194.

- LePore, P., & Janicki, M. (1997) *The wit to win. How to integrate older persons with developmental disabilities into community aging programs*. Albany, NY: New York State Office of Aging.
- Levitas, A.S. & Silka, V.R. (2001) Mental health clinical assessment of persons with mental retardation and developmental disabilities: History. *Mental Health Aspects of Developmental Disabilities*, 4 (1) 31-42.
- Limbrick P. (2005) Principles and practice that define the Team-Around-the-Child (TAC) approach and their relation- ship to accepted good practice. Available at: <http://www.icwhatsnew.com/bulletin/articles/TAC.pdf>
- Lin, Jin-Ding, Wub Chia-Ling, Lin Pei-Ying, Lin Lan-Ping, Chu Cordia M. (2011) Early onset ageing and service preparation in people with intellectual disabilities: Institutional managers' perspective. *Research in Developmental Disabilities*, 32 (1) 188–193.
- Lindsay, W. R. et al. (2004) Anger and aggression in people with intellectual disabilities: Treatment and follow-up of consecutive referrals and a waiting list comparison. *Clinical Psychology and Psychotherapy*, 11 (4), 255-264.
- Llewellyn, P (2011) The needs of people with learning disabilities who develop dementia: A literature review. *Dementia*, 10 (2) 235–247.
- Lloyd, L. (2003). Caring relationships: Looking beyond welfare categories of “carers” and “service users”. In K. Stalker (Ed.), *Reconceptualising work with carers. New directions for policy and practice* (pp. 17–55). London: Jessica Kingsley.
- Lipkin PH, Schertz, M. (2008) Early intervention and its efficacy. In: Accardo PJ, (ed) *Capute and Accardo's Neurodevelopmental Disabilities in Infancy and Childhood: Vol. 1, Neurodevelopmental diagnosis and treatment*, 3rd edn. Baltimore, MD: Paul H Brookes, 519–52.
- Llewellyn, P. Sardi, P. Northway, R. & Jenkins, R. (2008) *Learning Disability and dementia: A review of recent literature*. Faculty of Health, Sport and Science: University of Glamorgan.
- Lord, C. & Hopkins, J.M. (1986) The social behaviour of autistic children with younger and same-age non-handicapped peers. *Journal of Autism and Developmental Disorders*, 16 (3) 249-262.
- Lovaas, O.I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology*, 55, 3-9.
- Lowe, K. Allen, D. Brophy, S. & Moore, K. (2005) The management and treatment of challenging behaviours. *Tizard Learning Disability Review*. 10 (2) 34-37.
- Lowe, K. & Felce, D. et al. (1996) Challenging behaviour: the effectiveness of community support teams. *Journal of Intellectual Disability Research*, 40 (4) 336-347.

- Mac Donald, E. Fitzsimons, E. & Walsh, P. N. (2006) Use of respite care and coping strategies among Irish families of children with intellectual disabilities *British Journal of Learning Disabilities*, 35 (1) 62-68.
- Mackenzie-Davies, N. Mansell, J. (2007) Assessment and treatment units for people with intellectual disabilities and challenging behaviour in England: an exploratory survey *Journal of Intellectual Disability Research* 51 (10) 802-811.
- MacLean, W. (2008) Editorial. *American Journal of Mental Retardation*, 113, 423–6.
- Magrill, D. (2005) *Supporting Older Families: Making a Real Difference*. London: Mental Health Foundation.
- Mansell, J. (2006) Deinstitutionalisation and community living: progress, problems and priorities. *Journal of Intellectual and Developmental Disability*, 31 (2) 65-76.
- Mansell, J. B.-B. J. Ashman, B. & Ockendon, J. (2005) *Person-Centred Active Support: A Multi-Media Training Resource for Staff to Enable Participation, Inclusion and Choice for People With Learning Disabilities* Brighton: Pavilion
- Mansell, J. et al. (2002 ) Engagement in meaningful activity and ‘active support’ of people with intellectual disabilities in residential care. *Research in Developmental Disabilities* 23 (5) 342-352.
- Mansell, J. et al. (2008) Effect of service structure and organisation on staff care practices in small community homes for people with intellectual disabilities *Journal of Applied Research in Intellectual Disabilities*, 21 (5) 398-413.
- Mansell, J. McGill, P. & Emerson, E. (2001) Development and evaluation of innovative residential services for people with severe intellectual disability and serious challenging behaviour. In L.M. Glidden (Ed.) *International Review of Research in Mental Retardation* (245-298) San Diego, CA: Academic Press.
- Mansell, J., Beadle-Brown, J., Macdonald, S. and Ashman, B. (2003) Functional grouping in residential homes for people with intellectual disabilities. *Research in Developmental Disabilities*, 24 (3) 170-182.
- Mansell, J., Beadle-Brown, J., Skidmore, C., Whelton, B. and Hutchinson, A. (2006a) Estimating the number of people with learning disabilities in ‘out-of-area’ residential placements. *Research Policy and Planning*, 24 (1) 53-59.
- Mansell, J., Beadle-Brown, J., Skidmore, C., Whelton, B. and Hutchinson, A. (2006b) People with learning disabilities in ‘out-of-area’ residential placements: 1. Policy context. *Journal of Intellectual Disability Research*, 50 (2) 837-844.

- Marshall M. & Rathbone J. (2006) *Early Intervention for psychosis*. Cochrane Database of Systematic Reviews 2006, Issue 4. Art. No.: CD004718. DOI: 10.1002/14651858.CD004718.pub2.
- Marshall, D. McConkey, R. & Moore, G. (2003) Obesity in people with intellectual disabilities, The impact of nurse-led health screenings and health promotion activities. *Journal of Advanced Nursing*, 41 (2) 147-153.
- Marshall, T. (2004) Audit of the use of psychotropic medication for challenging behaviour in a community learning disability service *Psychiatric Bulletin* 28 (12) 447-450.
- Martin, G. et al. (2005) An exploratory study of assertive community treatment for people with intellectual disability and psychiatric disorders: conceptual, clinical, and service issues. *Journal of Intellectual Disability Research*, 49 (7) 516-524.
- Martorell, A. Gutierrez-Reccacha, P. Pereda, A. & Ayusi-Mateo, J.L. (2008) Identification of personal factors that determine work outcome for adults with intellectual disability. *Journal of Intellectual Disability Research*, 52 (12) 1091-1101.
- Mason, J. (2007) The provision of psychological therapy to people with intellectual disabilities: an investigation into some of the relevant factors. *Journal of Intellectual Disability Research*, 51 (3) 244-249.
- Matson, J. L. & Minshawi, N.F. (2006) *Early intervention for autism spectrum disorders: A critical analysis*. Oxford, England: Elsevier Science Inc.
- Matson, J. L., & Neal, D. (2009) Psychotropic medication use for challenging behaviors in persons with intellectual disabilities: An overview. *Research in Developmental Disabilities*, 30 (3) 572-586.
- Maybin, M. (2002) Report of the Group on older people with learning disabilities. Unpublished paper, Ulster Community and Hospitals Trust.
- McBrien, J. A. et al. (2005) Screening adults with Down syndrome for early signs of Alzheimer's disease. *Learning Disability Review*, 10 (4) 23-32.
- McBrien, J.A. (2005) Down's syndrome and dementia: generating local evidence. *Journal of Integrated Care*, 13 (1) 24-27.
- McCallion, P. et al. (2005) Overview of dementia issues in intellectual disability. *Frontline, Winter*, 14-15
- McCarron, M. & Lawlor, B.A. (2003) Responding to the challenges of ageing and dementia in intellectual disability in Ireland. *Aging and Mental Health*, 7 (6) 413-417.
- McCarron, M. (2005) Assessment of dementia in persons with intellectual disabilities: Challenges and opportunities. *Frontline, Winter* 24-26.

- McCarron, M. et al. (2002) Time spent caregiving for persons with the dual disability of Down's syndrome and Alzheimer's dementia. *Journal of Learning Disabilities*, 6 (3) 263-279.
- McCarthy, E. et al. (2009) Developing an Education Intervention for Staff Supporting Persons With an Intellectual Disability and Advanced Dementia. *Journal of Policy and Practice in Intellectual Disabilities*, 6 (4) 267-275.
- McCarthy, J. & Boyd, J. (2002) Mental health services for young people with intellectual disability: is it time to do better? *Journal of Intellectual Disability Research*, 46 (3) 250-256.
- McCausland, D. et al. (2006) An overview of issues regarding the service needs of older adults with intellectual disabilities. *Irish Psychologist*, 33, 92-94
- McClellan, B. et al. (2005) Person focused training: a model for delivering positive behavioural supports to people with challenging behaviours. *Journal of Intellectual Disability Research*, 49 (5) 340-352.
- McConkey R, McConaghie J, Barr O, & Roberts P. (2006) Views of family carers to the future accommodation and support needs of their relatives with intellectual disabilities. *Irish Journal of Psychological Medicine*, 23 (4) 140-144.
- McConkey, R. & Adams, L. (2001) Matching short break services for children with learning disabilities to family needs and preferences. *Child: Care, Health and Development*, 26 (5) 429-444.
- McConkey, R. & M. Spollen, et al. (2003) *Administrative Prevalence of Learning Disability in Northern Ireland*. Belfast, DHSS&PS.
- McConkey, R. & Mezza, F. (2001) Employment aspirations of people with learning disabilities attending day centres. *Journal of Learning Disabilities*, 4 (4) 309-18.
- McConkey, R. (2004a) *Pressures, Possibilities and Proposals: Northern Ireland Review of Day Services for People with Learning Disabilities*, Belfast: EHSSB.
- McConkey, R. (2005) Fair shares? Supporting families caring for adult persons with intellectual disabilities. *Journal of Intellectual Disability Research*, 49 (8) 600-612.
- McConkey, R. (2006) Variations in residential accommodation for adults with intellectual disabilities: The example of Northern Ireland. *Irish Journal of Psychological Medicine*, 23 (2) 68-73.
- McConkey, R. (2010) *Supporting Families with Disabled Young People whose Behaviour is Severely Challenging: A Review of Literature*. University of Ulster and Action for Children.
- McConkey, R. et al. (2004b) *Audit of learning disability in Northern Ireland*. Commissioned by the Dept. of Health, Social Services and Public Safety (DHSSPS) University of Ulster.

- McConkey, R. Mulvany, F. & Barron, S. (2006) Adult persons with an intellectual disability on the island of Ireland. *Journal of Intellectual Disability Research*, 50 (3) 227-236
- McConkey, R. Spollen, M. & Jamison, J. (2003) *Administrative Prevalence of Learning Disability in Northern Ireland*. Belfast: DHSS&PS.
- McCulloch, A. & Ford, R. (2009) The policy and service context for mental health nursing. In I. Norman & I. Ryrie (Eds.), *The Art and Science of Mental Health Nursing: A textbook of principles and practice* (2nd Edition ed., pp. 115-139) Maidenhead: Open University Press.
- McEachin, J. J., Smith, T., & Lovaas, O. I. (1993) Long-term outcome for children with autism who received early intensive behavioral treatment. *American Journal on Mental Retardation*, 97 (4) 359-372.
- McEachin, J. J., Smith, T., & Lovaas, O. I. (1993). Long-term outcome for children with autism who received early intensive behavioral treatment. *American Journal on Mental Retardation*, 97 (4) 359-372.
- McGee, J. J. Menolascino, F. J. Hobbs, D. C. & Menousek, P. E. (1987) *Gentle teaching a non-aversive approach to helping persons with mental retardation*. New York: Human Sciences Press Inc.
- McGill, P. (2008) Residential schools for children with intellectual disabilities in England: recent research and issues for future provision. *Tizard Intellectual disability Review*, 13 (4) 4-13.
- McGill, P. Papachristoforou, E. & Copper, V. (2006b) Support for family carers of children and young people with developmental disabilities and challenging behaviour. *Child: Care, Health and Development*, 32 (2) 159-165.
- McGill, P. T. A. & Vivien Cooper, V. (2006a) Parents Whose Children with Learning Disabilities and Challenging Behaviour Attend 52-week Residential Schools: Their Perceptions of Services Received and Expectations of the Future. *British Journal of Social Work* 36, 597-616
- McGill, P., Cooper, V. & Honeyman, G. . (2010) *Developing better commissioning for individuals with behaviour that challenges services - a scoping exercise* Canterbury/Chatham: Tizard Centre/Challenging Behaviour Foundation.
- McIntyre, L.L. Blacher, J. & Baker, B.L. (2002) Behaviour/mental health problems in young adults with intellectual disability: the impact on families. *Journal of Intellectual Disability Research*, 46 (3) 239-249.
- McQuillan, S. et al. (2003) Adults with Down's syndrome and Alzheimer's disease. *Tizard Learning Disability Review* 8 (4) 4-13.

- Meehan T., Robertson S., Stedman T. & Byrne G. (2004) Outcomes for elderly patients with mental illness following relocation from a stand-alone psychiatric hospital to community based extended care units. *The Australian and New Zealand Journal of Psychiatry*, 38 (11-12) 948–52.
- Mencap (2002) *The Housing Time Bomb: the housing crisis facing people with a learning disability and their elderly parents*. London: Mencap.
- Mengel, M. H. Marcus, D. & Dunkle, R. E. (1996) What will happen to my child when I am gone? A support and education group for ageing parents as caregivers. *Gerontologist*, 36 (6) 816-820.
- Meyer, L.H. & Evans, I.M. (2006) *Literature review on intervention with challenging behaviour in children and youth with developmental disabilities*. Victoria University of Wellington.
- MHF (Mental Health Foundation 2002) *Count Us In. The Report of the Committee of Inquiry into Meeting the Health Need of Young People with Learning Disabilities*, London: Mental Health Foundation.
- Minnes, P. & Woodford, L. (2004) Well-being in aging parents caring for an adult with a developmental disability. *Journal on Developmental Disabilities*, 11 (1), 48-66.
- Mohr, C. & Gray, K.M. (2005) Assessment in intellectual disability. *Current Opinion in Psychiatry*, 18 (5) 476-483.
- Moore, V. & Goodson, S. (2003) How well does early diagnosis of autism stand the test of time? Follow-up study of children assessed for autism at age 2 and development of an early diagnostic service. *Autism*, 7 (1) 47-63.
- Mulvany F, Barron S. (2002) *National intellectual disability database: annual report*. Dublin: Health Research Board.
- Murphy G. H. & Clare I. C. H. (1991) MIETS: a service option for people with mild mental handicaps and challenging behaviour or psychiatric problems: 2. Assessment treatment and outcome for service users and service effectiveness. *Mental Handicap Research* 4, 180–206.
- Murphy, E., Clegg, J. and Almack, K., (2011), Constructing adulthood in discussions about the futures of young people with moderate-profound intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 24 (1) 61–73.
- Murphy, G. Powell, S. Guzman, A.-M. & Hays, S.J. (2007) Cognitive-behavioural treatment for men with intellectual disabilities and sexually abusive behaviour: a pilot study. *Journal of Intellectual Disability Research* 51 (11) 902-912.

- Murray, C.G. McKenzie, K. Quigley, A. & Sinclair, B. (2000) The relationship between training and the experience of aggression in the workplace and social care staff working in learning disability services. *Journal of Learning Disabilities for Nursing, Health and Social Care*, 3, 214-18.
- Myers, C. T. (2006) Exploring Occupational Therapy and Transitions for Young Children with Special Needs. *Physical & Occupational Therapy in Pediatrics*, 26 (3) 74-88.
- Myrbakk, E. & von Tetzchner, S. (2008) Psychiatric disorders and behavior problems in people with intellectual disability. *Research in Developmental Disabilities*, 29 (4) 316-312.
- National CAMHS Review (2008) *Children and young people in mind: the final report of the National CAMHS Review*. London: Department of Health <http://www.dh.gov.uk> p. 17”
- National Development Team for Inclusion (NDTI) (2010) *Guide for Commissioners of Services for People with Learning Disabilities who Challenge Services*. Bath: National Development Team for Inclusion. [www.ndti.org.uk](http://www.ndti.org.uk).
- NHS Scotland (2004) *Quality Indicators – Learning Disabilities*. Edinburgh: NHS Quality Improvement Scotland.
- NHS Wales. (2006) *Author: Support Unit for Research Evidence [SURE], Cardiff University. Rapid review methodology (based on the Health Evidence Bulletins Wales Project Methodology) Library guide: Rapid Review methodology, Public Health Wales Observatory.*
- NHSCT (2005) *Adult Challenging Behaviour Service, A Service for Adults with a Learning Disability who present with Severely Challenging Behaviour. An Evaluation Report on the First Year of the Service (April 2004 - March 2005)*, Home First Trust: Northern Health & Social Care Trust.
- NHSCT (2009) *Adult Challenging Behaviour Service, A Service for Adults with a Learning Disability who present with Severely Challenging Behaviour. An Evaluation Report of the first Five Years of the Service: April 2004 - February 2009*, Home First Trust: Northern Health & Social Care Trust.
- NHSCT/NEELB (2009) *Children’s Challenging Behaviour Service, A Service for Children with a Learning Disability who present with Severely Challenging Behaviour An Evaluation Report on the First Year of the Service (January 2008 - January 2009)*: Northern Health & Social Care Trust/ Northern Eastern Education & Library Board.
- NICE (2009) Depression: the treatment and management of depression in adults National Clinical Practice Clinical Guideline 90 [www.nice.org.uk](http://www.nice.org.uk)
- NICE (2011) CG42 Dementia. [www.nice.org.uk](http://www.nice.org.uk) accessed 17/03/11

- NICE. (2006) *Dementia: supporting people with dementia and their carers in health and social care, clinical guideline 42*. London: National Institute for Health and Clinical Excellence, [www.nice.org.uk](http://www.nice.org.uk)
- Northway, R. & Jenkins, R. (2007) *Specialist learning disability services*. In Gates B (Ed) *Learning Disabilities Toward Inclusion*. Fifth edition. Churchill Livingstone, Edinburgh.
- O'Brien, G. (2006) Young adults with learning disabilities: a study of psychosocial functioning at transition to adult services. *Developmental Medicine & Child Neurology*, 48 (3) 195–199
- O'Brian, G. Pearson, J. Berney, T. & Barnard, L. (2001) Measuring behaviour in developmental disabilities: a review of existing schedules. *Developmental Medicine & Child Neurology Supplement S87*, 1-72.
- Onyett, S. (2009) Functional teams and whole systems. In I. Norman & I. Ryrie (Eds.), *The Art and Science of Mental Health Nursing: A text book of principles* (2nd Edition ed., 167-193) Maidenhead: Open University Press.
- Orange, J.B., & Zanon, M.V. (2006) Language and communication in adults with Down syndrome and dementia of the Alzheimer type: A review. 1, 53-62.
- Ouellette-Kuntz, H. (2005) Understanding health disparities and inequities faced by individuals with intellectual disabilities *Journal of Applied Research in Intellectual Disabilities* 18 (2) 113-121.
- Ozdemir, S. (2008) The Effectiveness of Social Stories on Decreasing Disruptive Behaviors of Children with Autism: Three Case Studies. *Journal of Autism & Developmental Disorders*, 38 (9) 1689–1696.
- Panerai, S. Ferrante, L. & Zingale, M. (2002) Benefits of the treatment and education of autistic and communication handicapped children (TEACCH) programme as compared with a non-specific approach. *Journal of Intellectual Disability Research*, 46 (4) 318-327.
- Parents Helping Parents (2008) *Parents and caregivers of adult children with developmental disabilities*. (Brochure) San Jose, CA.
- Parish, S.L, Lutwick, Z.E. (2005) A critical analysis of the emerging crisis in long-term care for people with developmental disabilities. *Social Work* 50 (4) 345–354.
- Perry, J. et al. (2011) Resettlement Outcomes for People with Severe Challenging Behaviour Moving from Institutional to Community Living. *Journal of Applied Research in Intellectual Disabilities*, 24 (1) 1-17.

- Patja, K. Vanainen, M. Vesala, H. Oksanen, H. & Ruoppila, I. (2000) Life Expectancy of People with Intellectual Disability: A 35-Year Follow Up Study'. *Journal of Intellectual Disability Research*, 44 (5) 591–9.
- Patti P. J. & Tsiouris J. A. (2006) Psychopathology in adults with Down syndrome: clinical findings from an outpatient clinic. *International Journal on Disability and Human Development*, 5 (4) 357–64.
- Patti, P. Amble, K. & Flory, M. (2010) Placement, relocation and end of life issues in aging adults with and without Down's syndrome: a retrospective study *Journal of Intellectual Disability Research*, 54 (6) 538–546.
- Persaud, M. & Jaycock, S. (2001) Evaluating care delivery: the application of dementia care mapping in learning disability residential services. *Journal of Learning Disabilities*, 5 (4) 345 – 352.
- Persaud, S. & Persaud, M. (2003) Does it hurt to die? Bereavement to help people with learning disabilities. *Bereavement Care*, 22 (2) 9–11.
- Phillips, L. Wilson, L. & Wilson, E. (2010) Assessing behaviour support plans for people with intellectual disability before and after the Victorian Disability Act 2006. *Journal of Intellectual & Developmental Disability* 35 (1) 9-13.
- Pinfold, V. Smith, J. & Shiers, D. (2007) Audit of early intervention in psychosis service development in England in 2005. *Psychiatric Bulletin*. 31, 7-10.
- Pilnick, A. Clegg, J. Murphy, E. Almack, K. (2011) 'Just being selfish for my own sake . . .': balancing the views of young adults with intellectual disabilities and their carers in transition planning. *The Sociological Review*, 59 (2) 303-323.
- Planned Lifetime Advocacy Network (PLAN) (2008) Workshops and seminars. Retrieved 12th Feb 2011: [http://www.plan.ca.resources\\_workshop2.php](http://www.plan.ca.resources_workshop2.php)
- Prasher, V.P. (2005) *Alzheimer's disease and dementia in Down syndrome and intellectual disabilities*. Oxford: Radcliffe Publishing.
- Prasher, V.P. Farooq, A. & Holder, R. (2004) The Adaptive Behaviour Dementia Questionnaire (ABDQ): Screening questionnaire for dementia in Alzheimer's disease in adults with Down syndrome. *Research in Developmental Disabilities* 25 (4) 385-397.
- Preece, D. (2009) Effective Short Breaks Services for Families with Children with Autism Spectrum Disorders: How One Local Authority in the United Kingdom is Working to Meet the Challenge *Practice*, 21 (3) 159-174.
- Pritchard, A. & Roy, A. (2006) Reversing the export of people with learning disabilities and complex health needs. *British Journal of Learning Disabilities*, 34 (2) 88-93.

- Prizant, B.M., Wetherby, A.M., Rubin, E., & Laurent, A.C. (2003). The SCERTS Model: A transactional, family-centered approach to enhancing communication and socioemotional abilities of children with Autism Spectrum Disorder. *Infants and Young Children*, 16 (4) 296-316.
- Probst, P. Jung, F. Micheel, J. & Glen, I. (2010) Tertiary-preventive interventions for Autism Spectrum Disorders (ASD) in children and adults: An evaluative synthesis of two TEACCH based outcome studies. *Life Span and Disability*, XIII (12) 129-167.
- Prout, H. T. & Nowak-Drabik, K. M. (2003) Psychotherapy with persons who have mental retardation: an evaluation of effectiveness *American Journal of Mental Retardation*, 108 (2) 82-93.
- Rae, H. Murray, G. & McKenzie, K. (2011) Teachers attitudes to mainstream schooling. *Learning Disability Practice*, 13 (10) 12-17.
- Raghavan, R. Pawson, N. (2008) Transition and social networks of young people with learning disabilities. *Advances in Mental Health and Intellectual Disabilities*, 2 (3) 25-28.
- Rawson, R. (2009) 'I'm going to be here long after you've gone' - sibling perspectives of the future *British Journal of Learning Disabilities* 38 (3) 225-231.
- Reid, D.H. Parsons, M.B. & Lattimore, L. (2005) Improving staff performance through clinician applications of outcome management. *Research in Developmental Disabilities*, 26 (2) 101-116.
- Reilly, E. (2005) Care planning and care management for people with intellectual disabilities and dementia. *Frontline*, Winter 18-19.
- Reilly, K. & Conliffe, C. (2002): Facilitating Future Planning for Ageing Adults with Intellectual Disabilities Using a Planning Tool that Incorporates Quality of Life Domains. *Journal of Gerontological Social Work*, 37 (3/4) 109 - 120.
- Report of the Task Force on Autism (2001) Educational Provision and Support for Persons with Autistic Spectrum Disorders: the Report of the Task Force on Autism, October 2001 Accessed 15 March 2011 [http://iier.iscii.es/autismo/pdf/aut\\_sped.pdf](http://iier.iscii.es/autismo/pdf/aut_sped.pdf)
- Reynhout, G. & Carter, M. (2006) Social stories for children with disabilities *Journal of Autism and Developmental Disorders* 36 (4) 445-449.
- Rice, J. & Robb, A. (2004) Learning to listen. *Nursing Older People*, 15 (10) 10-13.
- Rimmer, J. H. Rowland, J. L. & Yamaki, K. (2007) Obesity and secondary conditions in adolescents with disabilities: Addressing the needs of an underserved population. *Journal of Adolescent Health*, 41 (3) 224-229.

- Ritchie, F., Goodman, N., Nix, J. and Bowyer, A. (2005) 'Out of area, out of sight?' Review of out of area placement arrangements made by Social Services and Health for people with learning disabilities from the West Midlands. Birmingham: Birmingham and The Black Country Strategic Health Authority and West Midlands South Strategic Health Authority.
- Robertson J, Emerson E, Pinkney L, et al. (2005) Treatment and management of challenging behaviours in congregate and noncongregate community based supported accommodation. *Journal of Intellectual Disability Research* 49 (1) 63–72.
- Robertson J, et al. (2004) Quality and costs of community based residential services for people with mental retardation and challenging behavior. *American Journal Mental Retardation* 109 (4) 332–344.
- Robertson, J. et al. (2000) Lifestyle related risk factors for poor health in residential settings for people with intellectual disabilities. *Research in Developmental Disabilities*, 21 (6) 469-486.
- Rose, J. Loftus, M. Flint, B. & Carey, L. (2005b) Factors associated with the efficacy of a group intervention for anger management in people with intellectual disabilities. *British Journal of Clinical Psychology*, 44 (3) 305-317.
- Rose, J. Saunders, E. Hensel, E. & Kroese, B.S. (2005a) Factors affecting the likelihood that people with intellectual disabilities will gain employment. *Journal of Intellectual disabilities*, 9 (1) 9-23.
- Rose, J., West, C., & Clifford, D. (2000) Group interventions for anger in people with intellectual disabilities. *Research in Developmental Disabilities*, 21 (3) 171-181.
- Rosewarne, M. (2001) Learning disabilities and dementia: A pilot study. *Journal of Dementia Studies*, 9 (4), 18 – 20.
- Ross, E. & Oliver, C. (2002) The relationship between levels of mood interest and pleasure and 'challenging behaviour' in adults with severe and profound intellectual disability. *Journal of Intellectual Disability Research*, 46 (3) 191-197.
- Royal College of Psychiatrists, British Psychological Society, Royal College of Speech and Language Therapists (2007) *Challenging Behaviour A Unified Approach: Clinical and service guidelines for supporting people with learning disabilities who are at risk of receiving abusive or restrictive practices*. London: Royal College of Psychiatrists.
- Royal College of Psychiatrists (2007) *Clinical and service guidelines for supporting people with learning disabilities who are at risk of receiving abusive or restrictive practices*. London: Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists.

- Rush, A. J. & Frances, A. (2000) Treatment of psychiatric and behavioural problems in mental retardation [Special issue expert consensus guideline series]. *American Journal of Mental Retardation*, 105 (3) 159-228.
- Schreibman, L. (2000) Intensive behavioural/psycho-educational treatments for autism: research needs and future directions. *Journal of Autism and Developmental Disorders*, 30 (5) 373-378.
- Schultz, J. et al. (2004) Evaluation of screening tools for dementia in older adults with mental retardation. *American Journal of Mental Retardation*, 109 (2) 98-110.
- Scior, K. & Grierson, K. (2004) Service provision for young people with intellectual disabilities and additional mental health needs: service-providers' perspectives. *Journal of Applied Research in Intellectual Disabilities*, 17, 173-179.
- Scott, T.M. (2001) A school wide example of positive behavioural support. *Journal of Positive Behavior Interventions*, 3 (3) 88-94.
- Scottish Executive Same as you. A review of learning disabilities. Scottish Executive: Edinburgh.
- Seltzer, M. M. (1998) Service utilization patterns and organization of the service delivery system for persons with mental retardation and other developmental disabilities. In S. Allen & V. Mor (Eds.), *Living in the community with disability: A cross-group perspective*. New York: Springer.
- Seltzer, M, & Glidden L. (2011) Family support interventions for families of adults with intellectual and developmental disabilities. *International Review of Research in Mental Retardation*, IN PRESS
- Sherman, L. W. et al. (1998) *Preventing Crime: What Works, What Doesn't, What's Promising* Washington: National Institute of Justice. U.S. Department of Justice Office of Justice Programs. <http://www.ncjrs.gov/pdffiles/171676.PDF>.
- Silberman P. Bodfish J. Brown AT. Wainwright L. Yorkery B. Lichstein J. Alexander-Bratcher K. Davis CS. Lerche J. Holmes M. (2009) Successful transitions for people with intellectual and other developmental disabilities. *North Carolina Medical Journal*, 70 (6) 519-26
- SIBS (2008) *Working with adults siblings of disabled people: Conference for adult's siblings and their supports*. (Brochure) West Yorkshire: Sibs.
- Singh, A. N. Matson, J. L. Cooper, C. L. Dixon, D. Sturmey, P. (2005) The use of risperidone among individuals with mental retardation: Clinically supported or not? *Research in Developmental Disabilities* 26 (3) 203-218.

- Singh, A. N. Matson, J. L. Hill, B. D. Pella, R. D. Cooper, C. L. Adkins, A. D. (2010) The use of clozapine among individuals with intellectual disability: A review *Research in Developmental Disabilities* 31 (6) 1135-1141.
- Slevin, E. & McClelland, A. (1999) Multi-sensory environments: are they therapeutic? A single-subject evaluation of the clinical effectiveness of a multi-sensory environment. *Journal of Clinical Nursing*, 8 (1) 48-56
- Slevin, E. (2007) Challenging behaviour. In B. Gates & H. L. Atherton (Eds.), *Learning disabilities towards inclusion* (5th Edition ed., pp. 361-398) Oxford: Elsevier Limited.
- Slevin, E. McConkey, R. Truesdale-Kennedy, M. Barr, O. & Taggart, L. (2008a) People with learning disabilities admitted to an assessment and treatment unit: impact on challenging behaviours and mental health problems *Journal of Psychiatric and Mental Health Nursing* 15 (7) 537-546.
- Slevin, E. Truesdale-Kennedy, M. McConkey, R. Barr, O. & Taggart, L. (2005) *Community learning disability teams in Northern Ireland: An investigation into their structures, functions and effectiveness in preventing people with learning disabilities being admitted to specialist hospitals* Belfast: Research and Development Office for Northern Ireland and University of Ulster.
- Slevin, E. Truesdale-Kennedy, M. McConkey, R. Fleming, P. Livingstone, B. & Lafferty, A. (2008b) *Prevalence, determinants and strategies for countering overweight and obesity in school aged children and adolescents: a comparison of learning disabled and non-learning disabled pupils*. Belfast: University of Ulster & R&D Office for Northern Ireland.
- Smith, G. C. Majeski, R. A. & McClenney, B. (1996) Psycho-educational support for groups for ageing parents: Developmental and preliminary outcomes. *Mental Retardation*, 34 (3) 172-179.
- South Eastern Education and Library Board (2003) *Emotional and Behavioural difficulties, Board Position Paper 1*. ISBN 1898988145.
- Stainton, T. & Boyce, S. (2004): I have got my life back: user's experiences of direct payments. *Disability and Society*, 19 (5) 443 – 454.
- Stainton, T. (2002): Taking rights structurally: Rights, disability and social worker responses to direct payments. *British Journal of Social Work*, 32 (6) 751-763.
- Stancliffe, R. J. McVilly, K. R. Radler, G. Mountford, L. Tomaszewski, P. (2010) Active Support, Participation and Depression. *Journal of Applied Research in Intellectual Disabilities*, 23 (4) 312–321.
- Stephens, D. L. Collins, M. D. & Dodder, R.A. (2005) A longitudinal study of employment and skill acquisition among individuals with developmental disabilities. *Research in Developmental Disabilities*, 26 (4) 469-486.

- Strydom, A. & Hassiotis, A. (2003) Diagnostic instruments for dementia in older people with intellectual disability in clinical practice. *Ageing and Mental Health*, 7 (6) 431-437.
- Strydom, A. Hassiotis, A. King, M. & Livingston, G. (2009) The relationship of dementia prevalence in older adults with intellectual disability (ID) to age and severity of ID. *Psychological Medicine*, 39 (1) 13-21.
- Strydom, A. Livingston, G. King, M. Hassiotis, A. (2007) Prevalence of dementia in intellectual disability using different diagnostic criteria. *British Journal of Psychiatry*. 191 (2) 150-157.
- Sturme, P. (2005) Against therapy with people who have mental retardation. *Mental Retardation*, 43 (1) 55-57.
- Sturme, P. (2006) On some recent claims for the efficacy of cognitive therapy for people with intellectual disabilities *Journal of Applied Research in Intellectual Disabilities*, 19(1) 109-117.
- Sturme, P. (2009 ) Behavioral Activation Is an Evidence-Based Treatment for Depression *Behavior Modification* 33 (6 ) 818-829.
- Sugai, G. et al. (2000) Applying positive behaviour support and functional behavioral assessment in schools. *Journal of Positive Behavior Interventions*, 2 (3) 131-143.
- Sutherland, G., Couch, M. A., & Iacono, T. (2002) Health issues for adults with developmental disability *Research in Developmental Disabilities* 23 (6) 422-445.
- Symes, M.D. Remington, B & Brown, T. (2006) Early intensive intervention for children with autism: Therapists' perspective on achieving procedural fidelity. *Research in Developmental Disabilities*, 27 (5) 30-42.
- Taggart et al. (2011) Current funded study: *Planning for the future: an exploration of the needs of older family caregivers of older people with learning disabilities living at home*. University of Ulster, Coleraine.
- Taggart, L. (2003) *Service provision for people with learning disabilities and mental health problems*. Unpublished Doctor of Philosophy, University of Ulster, Belfast.
- Taggart, L. Cousins, W. & Milner, S. (2007) Young people with learning disabilities living in state care: their emotional, behavioural and mental health status. *Child Care in Practice*, 13 (4) 401 – 416.
- Taylor, J. L. Novaco, R. W, Gillmer, B. T. Robertson, A. & Thorne, J. (2005) Individual cognitive-behavioural anger treatment for people with mild-borderline intellectual disabilities and histories of aggression: A controlled trial. *British Journal of Clinical Psychology*, 44 (3) 367-382.

- Taylor, J. L. Novaco, R. W. Gillmer, B. & Thorne, J. (2002) Cognitive-behavioural treatment of anger intensity among offenders with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15 (2) 151-165.
- Taylor, J. L. Novaco, R.W. Guinan, C. & Street, N. (2004) Development of an imaginal provocation test to evaluate treatment for anger problems in people with intellectual disabilities. *Psychology and Psychotherapy*, 11 (6), 233-246.
- Taylor, J.L. (2005) In support of psychotherapy for people who have mental retardation. *Mental Retardation*, 43 (6) 450-453.
- The Telegraph (18th June 2011) Early Alzheimer's sufferers to get new drugs after -turn. [www.telegraph.co.uk/health/healthnews/8264049/Early-Alzheimers-sufferers-to-get-new-drugs-after-u-turn.html](http://www.telegraph.co.uk/health/healthnews/8264049/Early-Alzheimers-sufferers-to-get-new-drugs-after-u-turn.html). Accessed 17/03/2011
- Thompson D. (2000) *People with Learning Disabilities Using Residential Services for Older People*. Updates (2) 6, The Mental Health Foundation, London.
- Thompson, D. (2002) 'Editorial – Growing older with learning disabilities.' *Journal of Learning Disabilities* 6 (2) 115-122.
- Thompson, D. Ryrie, I. Wright, S. (2004) People with intellectual disabilities living in generic residential services for older people in the UK. *Journal of Applied Research in Intellectual Disabilities*. 17 (2) 101-108.
- Thompson, S.B.N. (2001) Assessing dementia in Down's syndrome. A comparison of five tests. *Clinical Gerontologist*, 23 (3/4) 3-17.
- Thompson, S.N.B. (2002) Down's syndrome and dementia. *Geriatric Medicine*, 32 (1) 47-50.
- Thorpe, L., Davidson, P., Janicki, M.P., & Working Group. (2000) *Healthy Ageing – Adults with Intellectual Disabilities: Bio-behavioral Issues*. Geneva, Switzerland: World Health Organization.
- Torr, J. Strydom, A. Patti, P. Jokinen, N. (2010). Ageing in Down syndrome: morbidity and mortality. *Journal of Policy and Practice in Intellectual Disabilities*, 7 (1) 70-81.
- Turnbull, A. et al. (2002) A blueprint for school wide positive behaviour support: Implementation of three components. *Exceptional Children*, 68 (3) 377-402.
- Unwin, G. & Deb, S. (2008) Psychiatric and behavioural assessment scales for adults with learning disabilities. *Advances in Mental Health and Learning Disabilities*, 2 (4) 37-45.
- Unwin, G. LeMesurier, N. Bathia, N. Deb, S. (2008) Transition for adolescents and young adults with learning disabilities and mental health problems/challenging behaviours: the parent carers' views. *Advances in Mental Health and Learning Disabilities*, 2 (1) 22-28

- Van Bourgondien, M. E. Reichle, N. C. & Schopler, E. (2003) Effects of a model treatment approach on adults with autism. *Journal of Developmental Disorders*, 33 (2) 131-140.
- van de Siepkamp, P. (2010) An introduction to gentle teaching. *Learning Disability Practice*, 13 (6) 25-27.
- Verdonschot, M.M., de Witte, L.P., Reichrath, E., Buntinx, W.H. & Curfs, L.M. (2009) Community participation of people with an intellectual disability: A review of empirical findings. *Journal of Intellectual Disability Research*, 53(4), 303-18.
- Visser, J. & Stokes, S. (2003) Is education ready for the inclusion of pupils with emotional and behavioural difficulties: a rights perspective? *Educational Review*, 55 (1) 65-75.
- Walker, A. & Walker, C. (1998). Age or disability? Age based disparities in service provision for older people with intellectual disabilities in Great Britain. *Journal of Intellectual and Developmental Disabilities*, 23 (1) 25-39.
- Walsh, P.N. Heller, T., Schupf, N. van Schroyen Lantman-de Valk, H. & Working Group. (2000) *Healthy Ageing - Adults with Intellectual Disabilities: Women's Health Issues*. Geneva, Switzerland: World Health Organization.
- Watchman K. (2003) Why wait for dementia? *Journal of Learning Disabilities* 7 (3) 230.
- Watson, S. F. (2009) Barriers to inclusive education in Ireland: the case for pupils with a diagnosis of intellectual and/or pervasive developmental disabilities. *British Journal of Learning Disabilities*, 37 (4) 277-284.
- Ward, L., Mallett, R., Heslop, P. & Simons, K. (2003) Transition planning: how well does it work for young people with learning disabilities and their families? *British Journal of Special Education*, 30 (3) 132-137.
- Weeks, L. E., Nilsson, T., Bryanton, B. & Kozma, A. (2009) Current and future concerns of older parents of sons and daughters with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 6 (3) 180-188.
- Welsh, Assembly, & Government. (2001) *Fulfilling the promises' Proposals for a framework for services for people with learning disabilities*. Learning Disability Advisory Group. A report to the National Assembly in Wales, Cardiff Welsh Assembly Government.
- Wheeler, J. R., Holland, A. J., Bambrick, M., Lindsay, R. W., Carson, D., Steptoe, L., et al. (2009) Community services and people with intellectual disabilities who engage in anti-social or offending behaviour: referral rates, characteristics, and pathways. *The Journal of Forensic Psychiatry & Psychology*, 20 (5) 717-740.
- Wilkinson, H. & Janicki, M.P. (2002) The Edinburgh principles. *Journal of Intellectual Disability Research*, 46 (4) 279-284.

- Wilkinson, H. and M. P. Janicki (2001) *The Edinburgh Principles with Accompanying Guidelines and Recommendations*. Edinburgh, Universities of Stirling (Scotland); Albany, Illinois & Chicago (USA)
- Wilkinson, H. Kerr, D. & Cunningham, D. (2005) Equipping staff to support people with an intellectual disability and dementia in care home settings. *Dementia*, 4 (3) 387-400
- Williams, V. and Robinson, C. (2001) 'He will finish up caring for me': people with learning disabilities and mutual care. *British Journal of Learning Disabilities*, 29 (2) 56-62.
- Willner, P. & Hatton, C. (2006) CBT for people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 19 (1) 1-3.
- Willner, P. (2007) Cognitive behavioural therapy for people with learning disabilities: focus on anger. *Advances in Mental Health and Learning Disabilities*, 1 (2) 14-21.
- Willner, P. Brace, N. & Philips, J. (2005) Assessment of anger coping skills in individuals with intellectual disabilities. *Journal of Intellectual Developmental Research*, 49, 329-339.
- Willner, P. Jone, J. Tams, R. & Green, G. (2002) A randomised controlled trial of the efficacy of a cognitive-behavioural anger management group for adults with learning disabilities. *Applied Research in Intellectual Disabilities*, 15 (3) 224-235.
- Wodehouse, G. & McGill, P. (2009) Support for family carers of children and young people with developmental disabilities and challenging behaviour: what stops it being helpful? . *Journal of Intellectual Disability Research*, 53 (7) 644-653.
- World Health Organisation (1992) *ICD-10: International Classification of Diseases and Related Health Problems*. (10th rev) Geneva.
- World Health Organisation (2001) Healthy Ageing – Adults with Intellectual Disabilities: Summative Report. *Journal of Applied Research in Intellectual Disabilities*, 14 (3) 256–275
- World Health Organisation (2010) *Better health, better lives: children and young people with intellectual disabilities and their families*. Copenhagen: WHO Regional Office for Europe, Retrieved 28 February, 2011 [www.euro.who.int/intellectual\\_disabilities](http://www.euro.who.int/intellectual_disabilities) .
- World Health Organisation (2011) Mental health Definition: intellectual disability. Retrieved 28 February, 2011, [www.euro.who.int](http://www.euro.who.int)
- World Health Organization (2000) *Ageing and Intellectual Disabilities - Improving Longevity and Promoting Healthy Ageing: Summative Report*. Geneva, Switzerland: World Health Organization.
- Xenitidis, K. I., Henry, J. et al. (1999) An inpatient treatment model for adults with mild intellectual disability and challenging behaviour. *Journal of Intellectual Disability Research*, 43 (2) 128-134.

- Yamaki, K. Hsieh, K. & Heller, T. (2009) Health profile of ageing family caregivers supporting adults with intellectual developmental disabilities. *Intellectual and Developmental Disabilities*, 47 (6) 425 – 435.
- Young, L. Ashman, A. Sigafos, J. & Grevell, P. (2000 ) A preliminary report of the closure of the Challinor Centre. *Journal of Intellectual & Developmental Disability*, 25 (2) 119-126.
- Young, L., Sigafos, J., Suttie, J., Ashman, A. and Grevell, P. (1998) Deinstitutionalisation of persons with intellectual disabilities: A review of Australian studies. *Journal of Intellectual & Developmental Disability*, 23 (2) 155-170.

## Useful Web Sites

**ACCESS TO ACUTE HOSPITALS NETWORK** <http://a2anetwork.co.uk/> Accessed 7th February 2011. This is a national forum for people interested in improving access to acute hospital care for people with learning disabilities.

**AMERICAN ASSOCIATION OF MENTAL RETARDATION** <http://aamr.org> Accessed 7th<sup>th</sup> February 2011. AAIDD promotes progressive policies, sound research, effective practices, and universal human rights for people with intellectual and developmental disabilities

**BILD** (The British Institute of Learning Disabilities) <http://www.bild.org.uk/> Accessed 7th February 2011. BILD is a national that aims to improving the life of people with a learning disability by influencing policy-makers and other decision-makers, encouraging improved practice and helping people with a learning disability in many aspects. Also carry out research and publish research.

**CHALLENGING BEHAVIOUR FOUNDATION** <http://www.thecbf.org.uk/> Accessed 7th February 2011. The following citation from the Foundation web home page states its aims as “The Challenging Behaviour Foundation exists to demonstrate that individuals with severe learning disabilities who are described as having challenging behaviour can enjoy normal life opportunities when their behaviour is properly understood and they receive appropriate individualised support. The CBF will support families, professionals and other stakeholders through education, information, research and partnership working to enable this to happen and will work strategically to influence national policy and practice.” There is a N. Ireland link in this site that offers excellent advice in relation to people who challenge.

**CHILD BEREAVEMENT** <http://childbereavement.org.uk/> Accessed 10th<sup>th</sup> February 2011. This organisation aims to make a real difference to bereaved families through providing accessible quality support and information to all affected by the death of a child or when children are bereaved, and accessible quality training for the professionals who work with these families and children.

**CRUSE** <http://crusebereavementcare.org.uk/> Accessed 10th<sup>th</sup> February 2011. Cruse is the UK’s largest bereavement charity. It promotes the well-being of bereaved people and enables anyone bereaved by death to understand their grief and cope with their loss. As well providing free care to all bereaved people, the charity also offers information, support and training services to those who are looking after them.

**DEPARTMENT OF HEALTH** <http://dh.gov.uk/> Accessed 7th February 2011. Official website of UK Department of Health, the government department responsible for public health issues. Provides up to date material and reports on health issues related to people with intellectual disability as well as the general population.

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### **FOUNDATION FOR PEOPLE WITH LEARNING DISABILITIES**

<http://www.learningdisabilities.org.uk/> Accessed 7th February 2011. Promotes the rights and quality of life for people with learning disabilities and their families by research, promote human rights of, service improvements and knowledge provision.

**GENTLE TEACHING INTERNATIONAL** <http://gentleteaching.com> Accessed 10th<sup>th</sup> February 2011. This site provides useful information about international conferences, resources and international site relating to gentle teaching approaches.

**IN CONTROL** <http://www.in-control.org.uk/> Accessed 7th February 2011. **In Control is a national charity that advocates for a fairer society for all who need additional support** because of their age, health status, disability or social disadvantage. They also aim to provide support for families of those who need additional support.

**INTERNATIONAL ASSOCIATION FOR THE SCIENTIFIC STUDY OF INTELLECTUAL DISABILITIES** <http://www.iassid.org/> Accessed 7th February 2011. The International Association for the Scientific Study of Intellectual Disabilities (mental retardation and related developmental disabilities) is an international and interdisciplinary scientific non-governmental organization with official relations with the World Health Organization. It promotes worldwide research and exchange of information on intellectual disabilities.

### **INSTITUTE OF HEALTH RESEARCH, LANCASTER**

<http://www.lancs.ac.uk/shm/dhr/research/learning/intro.htm> Accessed 7th February 2011. This is the Division of Health Research at Lancaster University, one of the leading research centres in the UK in the field of learning disabilities. They undertake research and development that is directly relevant to supporting the inclusion and quality of life of children and adults with learning disabilities in the North West, nationally and internationally.

**JESSICA KINGLEY PUBLISHER** <http://jkp.com> Accessed 10th February 2011. Independent publishers of accessible books that make a difference. Recognised as the leading publisher on autism and Asperger syndrome, publish in a range of areas including social work, education and arts therapies.

**LEARNING DISABILITY COALITION** <http://www.learningdisabilitycoalition.org.uk/> Accessed 7th February, 2011. This is a coalition of 14 organisations that are each influential in supporting people with learning disabilities and their families, they are:

- **Association for Real Change (ARC)** - [www.arcuk.org.uk](http://www.arcuk.org.uk)
- **BILD (British Institute of Learning Disabilities)** - [www.bild.org.uk](http://www.bild.org.uk)
- **Downs Syndrome Association** [www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk)
- **Foundation for People with Learning Disabilities** [www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)

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- **Mencap** - [www.mencap.org.uk](http://www.mencap.org.uk)
- **National Autistic Society** - [www.NAS.org.uk](http://www.NAS.org.uk)
- **People First** - [www.peoplefirstltd.com](http://www.peoplefirstltd.com)
- **Real Life Options** - <http://www.reallifeoptions.org/>
- **Sense** - [www.sense.org.uk](http://www.sense.org.uk)
- **The National Forum for People with Learning Difficulties** - [www.nationalforum.co.uk](http://www.nationalforum.co.uk)
- **National Family Carer Network** <http://www.familycarers.org.uk/>
- **Turning Point** - [www.turning-point.co.uk](http://www.turning-point.co.uk)
- **United Response** - [www.unitedresponse.org.uk](http://www.unitedresponse.org.uk)
- **Voyage** - [www.voyagecare.com](http://www.voyagecare.com) The coalition aims to provide a Provide a unified focused approach in supporting many areas of life for people with learning disabilities.

**MENCAP** <http://www.mencap.org.uk/> Accessed 7th February 2011. A useful sight to access a range of information on laws and services, issues around prejudice and other aspects that help support people to make life choices.

**MIND FOR BETTER MENTAL HEALTH** <http://www.mind.org.uk/> Accessed 10th February 2011. Promoting and protecting good mental health for all, this organisation provides information and support, and campaigns to improve policy and attitudes and, in partnership with independent local Mind Associations, develop local services.

**NATIONAL ASSOCIATION OF DUAL DIAGNOSIS** <http://nadd.org/> Accessed 10<sup>th</sup> February 2011. This is a useful website that focuses on mental health issues in people with intellectual disabilities.

**NATIONAL CHIDRENS BUREAU** <http://www.ncb.org.uk/> Accessed 7th February 2011. This leading charity supports children, young people and families and those that work with them. It aims to improve the well-being of children and young people across every aspect of their lives.

**NATIONAL DEVELOPMENT TEAM FOR INCLUSION** <http://www.ndti.org.uk/> Accessed 7th February 2011. The National Development Team for Inclusion (**NDTi**) is a not-for-profit organisation which works to promote inclusive lives for people who are most at risk. It is concerned with promoting inclusion and equality for people who risk exclusion and who need support to lead a full life. They have a particular interest in issues around age, disability and mental health.

**NATIONAL ELECTRONIC LIBRARY FOR LEARNING DISABILITIES** <http://minervation.com/ld> Accessed 7th February 2011. Provides evidenced based

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health care information. Each month the newsletter details the latest learning disabilities evidence (guidelines, systematic reviews, policy documents, statistics, patient information and news).

### **NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE (NICE)**

<http://www.nice.org.uk> Accessed 10th February 2011. NICE is an independent organisation responsible for providing national guidance on promoting good health and preventing and treating ill health.

### **NHS EVIDENCE - LEARNING DISABILITIES**

<http://www.library.nhs.uk/learningdisabilities/> Accessed 7th February 2011. This site provides access to key documents and evidence for health professionals. including links to key publications.

### **NORAH FRY RESEARCH CENTRE** University of Bristol

<http://www.bristol.ac.uk/norahfry/> Accessed 7th February 2011. A Centre that focuses on research, and also provides academic courses.

### **PAVILLION PUBLISHING** <http://pavpub.com/> Accessed 10th February 2011.

Pavilion is the leading publisher and even organiser for professionals delivering public services, whether they work in the public, private or voluntary sectors. Their objective is to share best practice through the dissemination of high-quality training materials, exhibitions, conferences and magazines.

**SOCIAL CARE ONLINE** <http://www.scie-socialcareonline.org.uk/> Accessed 7th<sup>th</sup> February 2011. This site provides information on various aspects of social care including for mental health and learning disabilities.

**SPEECHMARK PUBLISHING** <http://www.speechmark.net/> Accessed 10th<sup>th</sup> February 2011. Publish high-quality, practical resources for teachers, health professionals and parents. Resources include books, games, posters, cards, assessments and CD-Rom resources in the areas of Autism, Behaviour Management, Elderly Care, Emotional and Mental Health, Speech and Language Therapy to name just a few.

**TIZARD CENTRE** <http://ukc.ac./tizard/> Accessed 10<sup>th</sup> February 2011, The Tizard Centre is one of the leading UK academic groups working in learning disability and community care. The Centre provides short courses and degree and diploma programmes at the University of Kent, taught at both the Canterbury and Medway campuses, and also undertakes an extensive programme of consultancy and research - both nationally and internationally. The primary aims of the Tizard Centre are: to advance knowledge about the relationship between the organisation of community care services and their outcomes, and to help service agencies (both purchasers and providers) develop their own competence to provide and sustain high quality, comprehensive community care services.

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**UK YOUTH** <http://ukyouth.org/> Accessed 7th February 2011. UK Youth is a leading national youth work charity supporting over 7th50,000 young people, helping them to raise their aspirations, realise their potential and have their achievements recognised via non-formal, accredited education programmes and activities.

**UNDERSTANDING INTELLECTUAL DISABILITY & HEALTH** St George's University, London <http://www.intellectualdisability.info/> Accessed 7th February 2011. Information on health, mental health and disability & resource for health professionals and students in the healthcare sector.

## Themes Identified from Consultation Analysis

### Behaviours that challenge

#### Gaps in service

- *A huge difficulty for families with severe CB is that there is no rapid response when a breakdown occurs. What little there was, is now likely to be an admission to an assessment unit and there is talk of respite centres taking on the need but can they manage?*
- *Lack of family support – if parents can see the signs and know the signs they can act earlier and get help before it becomes a crisis.*
- *Why is there not more awareness of people with challenging behaviour who also have mental illness?*
- *There should be early intervention when the risks are known, e.g. higher likelihood of behaviours that challenge with certain behavioural phenotypes.*
- *If a crisis arises out of hours somebody gets in touch with the Doctor who has little expertise or time to devote to this so the person ends up in a LD hospital. This is very disruptive to people's lives and a lot of work is needed to get them back home.*
- *Environmental adaptations due to challenging behaviour – no agreed criteria where OTs can go in and make an assessment for that. There is only clear guidance for physical disability and OTs are trying to interpret that for people with ID and CB. It is much more cost effectiveness to keep families in the home.*

#### Perpetuating traditional practice

- *I have not seen a major shift away from placing people in congregated residential settings. How do we make those settings better able to manage behaviours? A lot of people in these homes are having to put up with agency staff and it's only a containment of challenging behaviours.*
- *There is still an expectation of treating everyone the same and that does not allow for individual differences.*

#### Efficiency

- *Cost effectiveness will be greater if we look at these behaviours at an early age. Family dynamics will improve and they will have a healthier living style*

#### Integrated approach

- *Planned services – it has to be multi agency there is no one service that can meet the family's needs. The issue is not solely education or health.*
- *If you look at the level of agency and temporary cover there is often not continuity of staff. It is often continuity of staff that prevents breakdown.*

## APPENDIX 2: CONSULTATION

### Effective services

- *Our Trust has the lowest number of hospital admissions in the province. We created 3 CB respite beds in 2 units; some are respite beds and some crisis beds so the service user gets some form of respite. There is a behaviour support plan for the individual so there is some continuity when you get a crisis. There is also a contingency plan when a crisis arises that involves the co-ordinator or Dr. Instead of having to admit that person to hospital they can go to the respite bed. There is continuity of staff and also behaviour support plan and families trust you to work with that. We have done work looking at how effective that is and it's quite cost effective. Supporting families in this way is less traumatic for them.*
- *In smaller settings there's more dependence on staff thinking outside the box. Good staff can adapt to those individual differences when the managing of behaviours is broken down into small steps.*
- *Active support needs to be provided by staff.*
- *Person-centred day opportunities, plan and refocusing on people with CB. Work placements, social firms, colleges are so much better than putting them in a nursing home. People need to be in ordinary houses in the community based around an individualised approach.*

### Suggested developments/research need

- *There are innovative models happening – let's compare how they function, what are the procedures and outputs and compare that with another model which could be the hospital model then it is possible to do a comparison - are the behaviours any different being coped with within each setting and what's the impact? Would this work help to transform some of the services/resources that we currently spend? Different interventions can be effective and maintain people e.g. in school. Rather than expect the children to change we need to change systems in order to maintain the most challenging – 2 were hospitalised for 1 ½ years although they are now back in school. We have to look at the situation, skills and staff.*
- *The numbers of admissions to hospital are higher from residential homes than from family homes. Leadership and management of behaviour in residential/nursing homes is lacking. Staff need to be more person-centred. Service providers should have a holistic approach with a key worker.*
- *It's a no brainer - if you are putting people in nursing homes with CB and something happens then other residents are bound to be affected. So it's not surprising the homes can't manage that population.*

## APPENDIX 2: CONSULTATION

- *Parents could be in a position to teach other parents. Parents learn more from other parents. Parent organisations should evaluate the impact (and cost-effectiveness) of their support to families.*
- *There needs to more R&D around service improvements (as per Bamford Review).*

### Failing to use evidence

- *A lot of literature says these techniques are effective but no-one use these interventions.*
- *We are letting it go too late to intervene. It should when the child has been diagnosed and it's not the child it's the family that should be the focus. It should be a change of life strategy. As a parent you have to search for things. It would be easier if the focus was on the parents, it's to allow them to know what to expect and how to approach things. There's enough research around what the trust does ... [but we need research] to change the services that we have. We are not going to get additional money and we have to do better with what we have.*

## APPENDIX 2: CONSULTATION

### Ageing

#### Apprehension about the future

- *Fear in carers of what's going to happen. Parents' biggest worry is what happens after they are gone. It's a terrible thing when people are saying they'd be happy if their child should die before them.*
- *[Apprehension begins from birth and may be life-long for carers] At initial diagnosis of child with LD it's like bereavement, your whole life has to change and have to build a new picture. After the amount of energy and emotional investment you have made in this baby there is a sense of hopelessness as you face into old age.*

#### Planning for the future

- *Difficulty in getting older parents to talk about succession planning and looking into the future. Denial- people don't want to talk about the future.*
- *There's a feeling in NI that we should look after our children until whatever age...*
- *Is there work that can be done before the carers are too old, after all you are asking carers to consider their own mortality. If we were doing work earlier that it was normal for people with ID to leave home and to have moved out and more opportunities for that to happen. It's all about transition and managing transitions.*
- *Clinicians must start asking questions about succession planning. Advice is needed on setting up legacies, trust arrangements and beneficiaries. Legal advice required for that, but good advice is not always available. Mencap can advise you.*

#### Difficulties

- *Some service programmes are out there for older persons but are they really "as-advertised"? There may be lovely brochures but the programmes that go on may not exist. People are just sitting there.*
- *There's a problem with crossing Trusts to get services. It shouldn't be like that. It restricts people's freedom of movement. But then again, people move to trust areas to get better services; to be where they have perceptions that the services will meet their needs better. I know a few families like that. People Vote with their feet!*
- *There are barriers to making adaptations to the home environment. It's the systems that have to change. Too much red-tape.*

#### What helps?

- *Has it something to do with the care-plans? The care-plan changes as they change. And family and key person should work towards a common care plan.*
- *This is where family support comes in to tell you what options are available. If people had more options people would be more willing to talk about the future.*

## APPENDIX 2: CONSULTATION

- *Older carers would benefit from having someone to come into the house to support us e.g. cooking and dressing.*
- *Need an individualised structured programme.*
- *[Being open and working together] When succession plans are in place and work well - what is it that makes them work well. For the parent and families you have to test it for a period to make sure it's working properly. The service user themselves may sometimes think "oh my parents they are wanting to getting rid of me". There has to be openness among everyone involved.*

### Gaps in service

- *There are not many options within a rural area. Lack of transport – you have to transport relative yourself but what happens when you can't drive?*
- *There's a sub-section of LD population that don't see professionals at all. What happens to them if a family crisis arises?*

### Developments or research

- *There's a huge need that professionals require training in terms of sensitive handling as to how they talk to people and how they talk to families. The terms they use. People who are dealing with them don't have the skills in my experience.*
- *The skills of the staff, they should have good management even in attending centres.*
- *Carer assessments and direct payments are not being offered by trusts.*
- *Are carers neutralising the carer's assessment? This is an assessment that the carer is entitled to. Puts your needs in front of the trust. Delegated statutory functions have to offer the assessment. Parents don't see themselves as a carer [with] a right to have an assessment done.*
- *Social workers and key workers are not acknowledging the carers assessment or direct payments. If direct payments are talked about with people, then they are talked about in such a way that people are made to feel "Oh, you don't want to be doing this do you?" Families get put off this, for example by people saying "oh you'll become an employer" and all. People are actively being discouraged by this. Social workers either don't know about direct payments or don't want to tell people about them. I say to people well they worked for me!*

### The Troubles

- *There was an expression from the group that people with ID have been impacted upon by the troubles here, but few particular examples could be given and the impacts are perhaps similar to others. An example of comments made are as follows:*
- *People have been traumatised by specific instances as they have happened.*
- *There has been imprisonment (of father) ... and when released ... years later and back in the home that's when the behavioural problems started for the child.*
- *Families have had to move out of their home due to the noise of troubles – child had autism.*
- *Reluctance to take child out in public transport because of the troubles and social connections got lost.*
- *If services are perceived to be located in the area of another other community some parents are reluctant to use those services.*
- *We are an inclusive organisation but some parents will not let their children go to the [city location where the other community live] to go bowling, we do find that happens.*

## Appraisal of the quality of qualitative studies (CASP - Critical Appraisal Skills Programme)

This tool presents a number of questions that deal broadly with some of the principles of qualitative research.

### 10 questions to help you make sense of qualitative research

How to use this appraisal tool

Three broad issues need to be considered when appraising the report of qualitative research:

- **Rigour:** has a thorough and appropriate approach been applied to key research methods in the study?
- **Credibility:** are the findings well presented and meaningful?
- **Relevance:** how useful are the findings to you and your organisation?

The 10 questions on the following pages are designed to help you think about these issues systematically.

The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions.

A number of italicised prompts are given after each question to remind you why the question is important.

**1. Was there a clear statement of the aims of the research?** Yes [ ] No [ ]

*Consider:*

- what the goal of the research was
- why it is important
- its relevance

**2. Is a qualitative methodology appropriate?** Yes [ ] No [ ]

*Consider:*

- if the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants

**Is it worth continuing?**

### **Detailed questions**

(Notes or comments can be made after each question if desired)

#### **Appropriate research design**

**3. Was the research design appropriate to address the aims of the research?**

*Consider:*

- if the researcher has justified the research design (e.g. have they discussed how they decided which methods to use?)

#### **Sampling**

**4. Was the recruitment strategy appropriate to the aims of the research?**

## APPENDIX 3: CASP GUIDE FOR APPRAISAL OF QUALITATIVE STUDIES

Consider:

- if the researcher has explained how the participants were selected
- if they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- if there are any discussions around recruitment (e.g. why some people chose not to take part)

### Data collection

#### **5. Were the data collected in a way that addressed the research issue?**

Consider:

- if the setting for data collection was justified
- if it is clear how data were collected (e.g. focus group, semi-structured interview etc)
- if the researcher has justified the methods chosen
- if the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, did they use a topic guide?)
- if methods were modified during the study. If so, has the researcher explained how and why?
- if the form of data is clear (e.g. tape recordings, video material, notes etc)
- if the researcher has discussed saturation of data

### Reflexivity (research partnership relations/recognition of researcher bias)

#### **6. Has the relationship between researcher and participants been adequately considered?**

Consider whether it is clear:

- if the researcher critically examined their own role, potential bias and influence during:
  - formulation of research questions
  - data collection, including sample recruitment and choice of location
- how the researcher responded to events during the study and whether they considered the implications of any changes in the research design

### Ethical Issues

#### **7. Have ethical issues been taken into consideration?**

Consider:

- if there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- if the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- if approval has been sought from the ethics committee

### Data Analysis

#### **8. Was the data analysis sufficiently rigorous?**

- if there is an in-depth description of the analysis process
- if thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
- whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- if sufficient data are presented to support the findings

## APPENDIX 3: CASP GUIDE FOR APPRAISAL OF QUALITATIVE STUDIES

- to what extent contradictory data are taken into account
- whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

### Findings

#### 9. Is there a clear statement of findings?

Consider:

- if the findings are explicit
- if there is adequate discussion of the evidence both for and against the researcher's arguments
- if the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst.)
- if the findings are discussed in relation to the original research questions

### Value of the research

#### 10. How valuable is the research?

Consider:

- if the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature?)
- if they identify new areas where research is necessary
- if the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

**Note there is no rating or scoring of studies with this tool. We made a judgment on the study and how it meets the three initial criteria i.e. Rigour, Credibility and Relevance based on the 10 questions. Based on answers to these questions we decided to include or exclude the study from the review. This may be a subjective decision so if unclear discussion with team took place. In addition one question such as question 10 'Value of the research' could lead us to reject the study if it is considered to have little value. We also cross rated these studies with the Weight of Evidence – high, medium, low as per the framework in Table 4, p. 24.**

**APPENDIX 4: BEHAVIOURS THAT CHALLENGE – LIVING OPTIONS**

| Author & Date  | Sample  | Methods   | Main Findings  | Rating |
|----------------|---|---|--|--------|
| Kim et al 2001 | Behavioural outcomes of deinstitutionalisation for people with intellectual disability: a review of US studies conducted between 1980 and 1999. | 38 studies were reviewed and coded by the authors according to research design, outcomes reported, and direction and magnitude of the findings.   | <ul style="list-style-type: none"> <li>-In terms of adaptive behaviour, 19 studies showed significant improvements and two studies showed significant decline</li> <li>- In terms of challenging behaviour, 5 studies found significant improvements while 2 studies found a significant worsening</li> <li>- Of the remaining studies where change was not significant, 8 reported a trend towards improvement while 6 reported a trend towards decline</li> </ul>  | 3      |
| Lemay 2009     | Canadian study reviewing international literature around the deinstitutionalization of people with ID   | Examines literature on the move of a minimum of five adults from institutions to community residences through pre–post data gathering, basic demographic information, and measurements of adaptive and/or challenging behaviour. Used a computer search of PSYCHINFO and ERIC databases, a manual review of ID journals and a review of article bibliographies for the period January 1999 to October 2007. | <ul style="list-style-type: none"> <li>-People, irrespective of their degree of disability, are apt to do better in the community</li> <li>-Notes considerable debate about deinstitutionalization and challenging behaviours.</li> <li>-Studies show that deinstitutionalization leads to improvements in quality of life and to concomitant improvements in adaptive behaviours</li> <li>-A common argument against deinstitutionalization is that challenging behaviour will deteriorate when the person moves but this was not supported by the literature.</li> <li>-Studies showed mixed results on the Impact of deinstitutionalization on challenging behaviour, however the author concludes that people “do no worse” and argues that community services may be underperforming due to lack of training on how to deal with challenging and self-injurious behaviour.</li> </ul> | 3      |
| Mansell, 2006  | Literature & policy review of services in North America, Europe   | The effects of deinstitutionalisation are summarised and emerging   | <ul style="list-style-type: none"> <li>- studies show that community-based services are superior to institutions</li> <li>-evaluation of services is difficult because of variation in</li> </ul>  | 3      |

**APPENDIX 4: BEHAVIOURS THAT CHALLENGE – LIVING OPTIONS**

| Author & Date                                  | Sample   | Methods  | Main Findings  | Rating |
|--|--|--|--|--------|
|  | and Australasia by a UK based author.  | problems identified. The changing context of different welfare-state models and paradigms in disability and public administration are outlined.  | service delivery and this undermines the consensus supporting deinstitutionalisation and community living.<br>-Effective responses to challenging behaviour require organisation and management of services as a system of interdependent components, in which there are many different options  |        |
| Mansell et al 2001                             | 35 individuals aged 13-39 with extremely challenging behaviour, originally destined for institutional care in South East England.                                  | Development and evaluation of residential care in specialised staffed houses offering ‘active support’. Placement outcomes are noted and residents quality of life was measured by direct observation with time-sampling and data collected using a hand-held computer | -22 Placements were established and 13 were maintained<br>-the specialised residential care services had similar costs to specialised institutional care.<br>- support from local managers and professionals was recognised as crucial but this was not always forthcoming<br>- All participants showed an increase in the overall level of participation in meaningful activity after transfer to staffed houses<br>- Average social interaction remained low & whereas average level of major & minor challenging behaviours were lower after transfer, this was not statistically significant and showed great variability among individuals.<br>-no major negative effects were noted in co-tenants without challenging behaviour but this is noted as a priority for future research. | 3      |
| National Development Team for Inclusion (2010) | A guide by the National Development team for Inclusion (NDTi) to help commissioners to implement Government policy on how to commission cost and outcome effective | Based on evidence collected and analysed by studying locations that have made good progress in supporting people who challenge in ways similar to those envisaged in the Mansell Report  | Seven broad areas of evidence are identified<br><br>1)Basing all decisions on a clear vision and set of values<br>2)Strong, knowledgeable and empowered leadership<br>3)Strong relationships and a ‘no-blame’ culture<br>4)An evidence-based Service Model<br>5)Having skilled providers and support staff<br>6)Evidence Based Commissioning   | 2      |

**APPENDIX 4: BEHAVIOURS THAT CHALLENGE – LIVING OPTIONS**

| Author & Date        | Sample  | Methods  | Main Findings   | Rating |
|----------------------|---|--|---|--------|
|                      | services for people with learning disabilities described as 'challenging services'.   |  | 7) Other commissioning actions such as upfront investment & flexible contracting systems  |        |
| Perry et al 2011     | 19 adults with severe challenging behaviour   | <p>To evaluate the quality of life consequences arising from the resettlement of adults with challenging behaviour severe enough to be deemed to require continuing healthcare from a traditional learning disability hospital to new purpose-built bungalows. Pre-move measures were taken and followed up at three different time points during resettlement.</p> <p>Measures used: Participant descriptors; setting descriptors and quality of care: objective lifestyle indicators and lifestyle satisfaction.</p> | <p>The authors conclude that quality of care and quality of life outcomes in new community settings were generally equivalent or superior to previous hospital levels.</p> <p>Staff hours per service user were lower in the community</p> <p>Improvements over time were included greater family contact and reduction in staff-reported challenging behaviour.</p> <p>The authors suggest a need for a longer-term follow-up study to identify whether improvements in the early stages of the move are maintained or enhanced.</p> | 2      |
| Robertson et al 2005 | Comparison of procedures employed to treat and manage challenging behaviours in 25 people with ID living in noncongregate community settings where the minority of residents have | <p>A longitudinal matched groups design.</p> <p>Data were collected for each participant at two points in time (10 months apart).</p> <p>Information was collected on adaptive behaviours &amp;</p>  | <p>-Co-locating people with behaviour disorders in community- based supported accommodation was associated with more physical restraint and reliance on medication to manage behaviour.</p> <p>-Additionally, the specialist nature of congregate settings appears to be limited to more staff being trained in control and restraint, and an increased reliance on this a means to control behaviour.</p> <p>- In both types of settings, behaviour disorders were</p>   | 3      |

**APPENDIX 4: BEHAVIOURS THAT CHALLENGE – LIVING OPTIONS**

| Author & Date   | Sample   | Methods  | Main Findings  | Rating |
|---|--|--|--|--------|
|   | challenging behaviour and 25 people with ID congregate community settings where the majority of residents have challenging behaviour   | additional impairments (ABS), psychiatric status (PAS-ADD Checklist) & the nature & severity of challenging behaviour of participants using both questionnaire measures (ABC) & nonparticipant direct observation. | stable over a 10-month period and there were few ABA technologies in place to reduce behaviour (<15% of service users).<br>-The data regarding change over time suggest that this approach may not be effective in reducing challenging behaviour, with results indicating no significant improvements in challenging behaviour over time for either staff reported or observational measures of challenging behaviour.  |        |
| Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists, 2007 | The report focuses primarily on adults with moderate to severe learning disabilities, although the broad principles outlined are applicable to children and adults of all degrees of intellectual disability | This report is the result of a joint interdisciplinary working group. It aims to have relevance to all professionals who work with people with ID to inform and guide policy, service provision and commissioning. | <ul style="list-style-type: none"> <li>- An emphasis on the design of effective environments</li> <li>- Services that are unnecessarily restrictive of an individual's freedom could be in breach of the European Convention on Human Rights.</li> <li>-seclusion, defined as 'supervised confinement in a room, which may be locked'' should not be used outside the mental health act</li> <li>-Assessment and treatment units should be used only for this purpose</li> <li>-Professional support for placements</li> <li>- The appointment of an independent mental capacity advocate if there is to be a change in the provision of accommodation to a service user.</li> <li>-Mechanisms should be in place to ensure that out-of-area placements reflect individual choices.</li> </ul> | 3      |
| Slevin et al 2008a  | 48 people with ID in an assessment and treatment unit in Northern Ireland  | Purposely designed pro forma to obtain demographic information from community- and unit-based staff about the persons with ID, combined with a within-subject comparison design using two                          | <p>The analysis found significant reductions in challenging behaviours and mental health problems following admission to the unit</p> <p>success of coordinated onsite multidisciplinary working with close involvement of service users (90%) in their own care plans</p>   | 3      |

**APPENDIX 4: BEHAVIOURS THAT CHALLENGE – LIVING OPTIONS**

| Author & Date      | Sample  | Methods  | Main Findings  | Rating |
|--------------------|---|--|--|--------|
|                    |   | structured assessment scales that were completed on those admitted at three time intervals. The two assessment scales were the Mini psychiatric assessment schedule for adults with a developmental disability (PAS-ADD) and the aberrant behaviour checklist (ABC). | This study concludes that short-term assessment and treatment units for people with learning disabilities can have a valuable contribution to make to practice.  |        |
| Taggart et al 2007 | 37 young people with mild to moderate ID living in state care in Northern Ireland | Case-file survey, social worker questionnaires and/or interviews. The Strengths and Difficulties Questionnaire was completed by social workers with regard to each young person.   | <p>-21 young people (56.8%) lived in residential care, 13 (35.1%) within non-relative foster care and another three young people (8.1%) in relative foster care.</p> <p>- more than 90% of placements were deemed “long-term” and it is likely that the majority of these young people will require further supported accommodation in adulthood</p> <p>- 77.1% of the young people scored within the abnormal range of the Total Difficulties Score of the SDQ indicating potential mental health problems/the presence of a psychiatric disorder which may impact on their capacity to be fully integrated into their communities as adults.</p> | 2      |

**APPENDIX 5: BEHAVIOURS THAT CHALLENGE – DAY OPPORTUNITIES**

| Author & Date                         | Sample   | Methods  | Main Findings   | Rating |
|---------------------------------------|--|--|---|--------|
| Didden et al. 2006                    | Eighty articles were examined.   | <p>Meta-analysis on the effectiveness of behavioural and psychotherapeutic treatments for challenging behaviours and individuals with mild ID.</p> <p>Articles were identified through searches of PsychInfo, Eric, and Medline electronic databases. Also, journals that had been published between 1980 and 2005 and references mentioned in the identified articles. Finally, unpublished studies were considered if enough information was provided.</p> | <p>Findings indicated that behavioural interventions for challenging behaviours are effective with people with mild ID</p> <p>It was recommended that future research should extend this literature to these under researched populations, challenging behaviours, and settings to assess whether or not the findings reported here are applicable to adults, older adults, and to family and day care settings.</p>                                  | 3      |
| DoH Report 2007. Chaired by J Mansell | An update of the DoH 1993 Mansell Report on BC based on evidence from literature | A chaired report based on consultation and review of a substantial amount of literature.   | <p>The main findings were:</p> <ul style="list-style-type: none"> <li>- Services that follow the principles of Valuing People</li> <li>- Direct payments always be considered in planning for individuals and be made more widely available</li> <li>- Improved service models for housing &amp; day care, family short breaks (reduce residential school placements); commissioning of more local smaller individualised services needed;</li> </ul> | 3      |

**APPENDIX 5: BEHAVIOURS THAT CHALLENGE – DAY OPPORTUNITIES**

| Author & Date                            | Sample  | Methods  | Main Findings  | Rating                  |
|--|---|--|--|-------------------------|
|  |   |  | <p>more specialist multi-disciplinary support teams &amp; 24 hours a day, seven days a week access; appropriate mental health services with access that meets the needs of ID people.</p>  |                         |
| <p>Grey, Hastings &amp; McClean 2007</p> | <p>Studies using staff report methods to evaluate the impact of different training methods to train staff</p> | <p>Editorial on staff training and challenging behaviour.</p>      | <p>Issues that need to be explored in future research:</p> <ul style="list-style-type: none"> <li>- How changing staff cognitions or emotions will benefit service users' challenging behaviour directly.</li> <li>- Development of research that includes observable outcome measures for staff and service user behaviour.</li> <li>- Need for a functional analysis of staff behaviour so that training interventions for staff are following evidence-based practice in treating CB</li> <li>- Training interventions should be individualised for staff rather than applied using the same model to all staff or to groups of staff at one time.</li> <li>- Building of an evidence base on the processes by which staff training has an impact on outcomes for service users.</li> </ul> | <p align="center">1</p> |
| <p>Meyer &amp; Evans, 2006</p>           | <p>Searches from 1988 to 2005</p>   | <p>Meta-analytic - methods for the review were consistent with</p> | <p>This report summarises the processes, approach, and findings of a review of the literature and knowledge</p>  | <p align="center">3</p> |

**APPENDIX 5: BEHAVIOURS THAT CHALLENGE – DAY OPPORTUNITIES**

| Author & Date               | Sample  | Methods   | Main Findings  | Rating                  |
|-----------------------------|---|---|--|-------------------------|
|                             |   | <p>international standards for conducting more traditional literature reviews as well as specific recommendations for carrying out meta-analyses: (a) review articles; (b) references located within studies; (c) the computerised bibliographic databases Educational Resources Information Clearinghouse (ERIC) and Psychological Literature (PsycLIT) databases; and (d) making contact with relevant experts in this area for contemporary information.</p> | <p>base regarding severe challenging behaviour in children and young people with developmental disabilities. It is focussed on effective educational and support services for children and youth whose behavioural challenges accompany a diagnosis of intellectual disability, developmental delay, severe learning difficulties, severe traumatic brain injury, or autistic spectrum disorder (ASD). Key findings outline best practice in behavioural interventions, evidence of intervention effectiveness and recommended levels of behavioural support.</p>  |                         |
| <p>McConkey et al 2004b</p> | <p>A substantial audit of published literature on ID. (Chapter 4 related to BC)</p> | <p>Audit review conducted by members of the Developmental &amp; Intellectual Disability Research Centre in the UU. Based on a robust review of literature.</p>  | <p>Day opportunities:</p> <ul style="list-style-type: none"> <li>- The existing model of day centre provision needs to be radically reviewed in order to meet the needs and aspirations of the service user.</li> <li>- Mainstream agencies should be persuaded by the HSS to accept their responsibilities with regard to the ordinary needs of this client group.</li> </ul> <p>Further Education:</p> <ul style="list-style-type: none"> <li>- Further developments are required in order to bring it in line with practice in Great Britain</li> <li>- In order to enable young people with a disability to take part in the workforce preparations for this must be made throughout their education.</li> </ul> | <p align="center">3</p> |

**APPENDIX 5: BEHAVIOURS THAT CHALLENGE – DAY OPPORTUNITIES**

| Author & Date                              | Sample   | Methods                     | Main Findings  | Rating                  |
|--|--|-----------------------------|--|-------------------------|
|  |  |                             | <p>Employment:</p> <ul style="list-style-type: none"> <li>- Greater commitment is required from the Department of Employment and Learning and closer working relationships need to be established with Health and Social Services agencies. Consistency in approaches between ID community staff and family carers</li> </ul>  |                         |
| <p>McGill, Tennyson &amp; Cooper 2006a</p> | <p>Parents of children attending residential schools</p> | <p>Postal questionnaire</p> | <p>This paper reports the findings of a survey of parents whose children attended 52-week residential schools. Seventy-three parents completed a postal questionnaire which asked questions about three main areas: support and services received prior to their child’s entry into residential education; perceptions of the quality of care and education provided by residential schools; and concerns for their child’s future care and welfare. Telephone interviews were conducted with 14 parents, to obtain additional information on the topics addressed by the questionnaire. Parents were critical of services and support received prior to their child’s entry into residential education and reported high rates of exclusion from local services. Residential schools were generally perceived as providing a good quality of service, though considerable concern was expressed about their geographical distance from the family home, and this had a significant impact on the frequency of visits. Parents expressed high levels of concern about the future care and support needs of their children. Further research is required to understand the relationship between the availability and quality of local services and the need for 52-week residential schools. The impact of distant residential education on parent–</p> | <p align="center">2</p> |

**APPENDIX 5: BEHAVIOURS THAT CHALLENGE – DAY OPPORTUNITIES**

| Author & Date                        | Sample  | Methods   | Main Findings  | Rating |
|--------------------------------------|---|---|--|--------|
|                                      |   |   | child relationships and on future demand for residential care is considered.   |        |
| Probst, Jung, Micheel & Glen 2010    | 1 child with autism living in a residential home and 3 adults in a day care and vocational setting  | Synthesis of two TEACCH-based intervention studies. Individual subject design | The synthesis of these two studies provides tentative support for the efficacy and effectiveness of TEACCH based interventions across different ages and life settings within the social context examined.   | 2      |
| Rose, Saunders, Hensel & Kroese 2005 | The files of 200 clients who had most recently left the supported employment agency were reviewed   | Retrospective analysis  | Staff assessed motivation after two weeks on the scheme was found to be the only significant predictor of employment outcome. Motivation levels decreased for all groups of participants while at the agency, irrespective of work outcome. This study highlights that a greater emphasis on motivation within employment agencies may increase the changes of people with intellectual disability finding work.   | 3      |
| Stephens, Collins, Dodder 2005       | Data were obtained from an existing data set of all known persons receiving services from the Developmental Disabilities Division of the Oklahoma Department of Human Services (N = 2,760). | Longitudinal study  | Results indicated that as people moved to employment, scores on adaptive skills increased, that as people moved from employment, adaptive skills decreased, and that as employment status remained constant, adaptive skills also remained unchanged. No consistent impact was found on challenging behaviours. Type of employment (sheltered, supported, and competitive) was then examined, and the same pattern of changes in adaptive skills was found; i.e., changes in employment to more/less competitive was accompanied by more/less adaptive skills. This suggests that employment itself, especially work in the competitive workforce, may be a significant source of enhancing adaptive skills for people with developmental disabilities and, thus, greatly adding to the success of community living. | 3      |
| Symes,                               | 19 home-based   | Interviews  | This study identified facilitating factors and barriers that   |        |

**APPENDIX 5: BEHAVIOURS THAT CHALLENGE – DAY OPPORTUNITIES**

| Author & Date                   | Sample   | Methods        | Main Findings  | Rating |
|---------------------------------|--|----------------|--|--------|
| Remington Brown & Hastings 2006 | behavioural intervention therapists with various service providers in the South of England   |                | <p>therapists considered to influence their capacity to deliver early intensive behavioural intervention to young children with autism.</p> <p>Findings indicated that in general, responses represented opposite poles of the same construct. For example, child factors such as compliance and competence were considered to facilitate instruction, whereas challenging behaviour and lack of progress were perceived to hinder it. These issues are considered in the light of previous research on staff behaviour in related contexts. The factors identified suggest specific avenues for questionnaire and experimental research to validate these findings, have implications for routine service provision and may help improve the outcomes of children receiving early intensive behavioural intervention.</p> | 2      |
| Watson 2009                     | Principals in mainstream schools, special schools and Applied Behavioural Analysis Education Centres and parents of children with ID and PDD | Postal surveys | <p>Findings outlined:</p> <ul style="list-style-type: none"> <li>- how teaching professionals' capacity to meet the needs of some pupils is deemed inadequate by many principals.</li> <li>- Universal mainstream provision of services requires health and teaching professionals to attain competence in special education provision &amp; culture.</li> <li>- Universal enrolment therefore pleads universal training. It is imperative that pre-service training incorporates module(s) and preferably work experience in special education to provide staffs</li> </ul>   | 3      |

**APPENDIX 5: BEHAVIOURS THAT CHALLENGE – DAY OPPORTUNITIES**

| Author & Date | Sample | Methods | Main Findings   | Rating |
|---------------|--------|---------|---|--------|
|               |        |         | <p>with competency.</p> <ul style="list-style-type: none"> <li>- Disabilities awareness and an understanding of the capabilities of pupils and how to manage areas of difficulty would greatly improve the habit's of teachers and ultimately the pupils' access to education.</li> <li>- Finally, access to effective mainstream education provision requires government commitment to the provision of economic capitals in the form of accessible occupational, physical and speech and language therapies to support pupils' needs and to provide relevant cultural capital for their educators.</li> <li>- The provision of psychological services requires expansion to meet the needs of all schools and of all pupils within them.</li> <li>- Currently, there is little effective provision of auxiliary supports, particularly in the mainstream system.</li> </ul> |        |

**APPENDIX 6: BEHAVIOURS THAT CHALLENGE – FAMILY SUPPORT**

| Author & Date                         | Sample   | Methods  | Main Findings   | Rating |
|---------------------------------------|--|--|---|--------|
| DoH Report 2007. Chaired by J Mansell | An update of the DoH 1993 Mansell Report on BC based on evidence from literature   | A chaired report based on consultation and review of a substantial amount of literature.   | <p>The main findings were:</p> <ul style="list-style-type: none"> <li>- Provide more local services and reduce out of area placements</li> <li>- Services that follow the principles of Valuing People</li> <li>- Direct payments always be considered in planning for individuals and be made more widely available</li> <li>- Improved service models for housing &amp; day care, family short breaks (reduce residential school placements); commissioning of more local smaller individualised services needed; more specialist multi-disciplinary support teams &amp; 24 hours a day, seven days a week access; appropriate mental health services with access that meets the needs of ID people.</li> </ul> | 3      |
| Hudson et al 2008                     | <p>2,119 people were recruited – mothers = 1,551; fathers = 396; grandparents, foster carers, child care staff, and teacher aids = 172</p> <p>A total of N= 1790 families (Victoria Australia)</p> | <p>Delivery of the Signposts program for parents involving group, individual, telephone or self delivery. Pre-test post-test evaluation by various scales used to measure outcomes in parents, child</p> | <p>Positive impact on parents including sense of parenting efficacy, parenting satisfaction, and reducing daily hassles.</p> <p>Improvements noted e.g. depression measurements &amp; a high degree of satisfaction by parents.</p> <p>Positive impacts on the BC of the children.</p> <p>Dissemination of knowledge &amp; skills to undertake the Signposts program to 554 staff in schools, local agencies, community services &amp; private practitioners.</p>   | 3      |

**APPENDIX 6: BEHAVIOURS THAT CHALLENGE – FAMILY SUPPORT**

| Author & Date           | Sample   | Methods  | Main Findings   | Rating |
|-------------------------|--|--|---|--------|
|                         |  |  | Following training 203 practitioners (39%) were active in the ongoing delivery of the Signposts program at 6 months post study.   |        |
| Kenny & McGiloway, 2007 | 32 participants who were parents of a child <18 with an ID. All participants were living in the Greater Dublin area & recruited from friends or acquaintances of one of the authors. | Administration of a Caregiver Strain Questionnaire & A caregivers questionnaire that measured personal experience and practical aspects of providing care. | Almost 75% were worried about child's future.<br>BC were rated as the most difficult to manage.<br>Participants were mainly dissatisfied with formal care support i.e. nursing, social work, psychology and medical.<br>Participants were most satisfied with informal support i.e. those rated highest were spouse, other children, other family & friends.  | 1      |
| McConkey et al 2004b    | A substantial audit of published literature on ID. (Chapter 4 related to BC)   | Audit review conducted by members of the Developmental & Intellectual Disability Research Centre in the UU. Based on a robust review of literature.        | Family support should involve:<br><ul style="list-style-type: none"><li>- Person-centred approach</li><li>- Education and support for caregivers</li><li>- Consistency in approaches between ID community staff and family carers</li><li>- Support that involves provision of media to guide; group &amp; individual support; guiding parents to self-direction and underpinned by ABA principles.</li></ul> | 3      |
| McDonald et al, 2006    | 46 children with ID and 71 caregiving parents  | Survey of parents managing the care of their child & use of respite. Used questionnaires   | Children with BC did not access respite any more than other children. Parents identified management coping  |        |

**APPENDIX 6: BEHAVIOURS THAT CHALLENGE – FAMILY SUPPORT**

| Author & Date       | Sample  | Methods   | Main Findings  | Rating |
|---------------------|---|---|--|--------|
|                     | (43% response rate)   | completed by caregivers & offered completion in their home by interview if they wished.   | strategies as <ul style="list-style-type: none"> <li>- Setting aside free time M (male) &amp; F (females)</li> <li>- Use of humour (M&amp;F)</li> <li>- Not blaming their child (M&amp;F)</li> <li>- Develop routine and stick to it (F)</li> <li>- Try alternatives to find what works (F)</li> <li>- Gain as much information as possible (F)</li> <li>- Being positive in situation (M)</li> <li>- Accept the situation (M)</li> <li>- Self-belief about coping with situation (M)</li> </ul>   | 2      |
| McGill et al, 2006a | 73 parents of children with ID (& 14 from this for interview) who were mothers of children attending a 52-week residential school placement. All the children displayed BC<br>- on average 10.5 different forms of BC | A Likert-scale satisfaction questionnaire returned by 73 parents (34% response) & 14 from were interviewed over telephone on their views of services. | Before child's placement in school <ul style="list-style-type: none"> <li>- Lack of support for child's BC</li> <li>- Frequent breakdown of school and respite due to BC</li> <li>- Parents felt their child was neglected.</li> </ul> Views of current residential placement <ul style="list-style-type: none"> <li>- Positive views in most cases</li> <li>- But did express some concerns re: extent of staff turnover and the training; distance from home, which reduced contact with their child &amp; limited assistance or support from their local authorities (both education and social services) to maintain higher levels of contact with their child.</li> </ul> Parents expressed high concern for the future & limited | 2      |

**APPENDIX 6: BEHAVIOURS THAT CHALLENGE – FAMILY SUPPORT**

| Author & Date      | Sample  | Methods   | Main Findings   | Rating |
|--------------------|---|---|---|--------|
|                    |   |   | planning for this.  |        |
| McGill et al, 2010 | Interviews with 8 commissioners of ID services; in-depth consultation with 6 families & a literature review   | A scoping report involving interviews, consultation & literature. Aimed to identify future need & work required for individuals & families of people with BC & to inform commissioners. | <p>Families reported: Families reported: a lack of expertise by services; poor access; lack of support and training for themselves in their roles as carers &amp; lack of information that adversely impacted on their planning and mental health; not being included as essential partners</p> <p>Commissioners reported: little evidence of local work to implement recommendations of the revised Mansell report; difficulties with development of local services; poor coordination of adult &amp; child services; lack of confidence in local providers to provide good quality support for people with BC; lack of coordination and consistency between services/agencies &amp; lack of family preferences for specialist services.</p> | 2      |
| Rawson, 2009       | 13 siblings who had brothers or sisters with complex needs attending who were attending a residential school. | Interviews with young adult siblings with respect to future expectations when their brother/sister transitions to adult services  | <p>Support siblings suggested to inform them should they need to arrange care for their sibling:</p> <ul style="list-style-type: none"> <li>- Training in legal and monetary issues</li> <li>- Having a dedicated sibling support staff person within the organisation</li> <li>- A book containing pertinent information</li> <li>- A website for networking with other siblings.</li> </ul>   | 2      |

**APPENDIX 6: BEHAVIOURS THAT CHALLENGE – FAMILY SUPPORT**

| Author & Date            | Sample  | Methods  | Main Findings  | Rating |
|--------------------------|---|--|--|--------|
| Slevin et al 2007        | 145 community learning disability team (CLDT) members, 27 family caregivers and 21 people with ID (Slevin et al, 2007). | A satisfaction survey of CLDT members, family caregivers and people with ID                | Reported high levels of perceived effectiveness with the services provided by the CLDTs, but caregivers gave lower satisfaction ratings with 44% of them rating their satisfaction lower.  | 2      |
| Wodehouse & McGill, 2009 | Mothers (N=13) caring for children with behaviours that challenge (BC)  | Qualitative study using interviews with each mother following a phenomenological approach. | <p>1) Problems with services such as schools and GPs and ‘generic’ children’s or disability services.</p> <p>2) Poor access to specialist services for BC.</p> <p>3) When services were accessed mothers felt they offered little change. Suggested need for</p> <p>1) More proactive prevention interventions</p> <p>2) Specialist behavioural approaches/services that are more effective</p> <p>3) Increased understanding of the need for specialist support</p> | 1      |

**APPENDIX 7: BEHAVIOURS THAT CHALLENGE – INTERVENTIONS**

| Author & Date            | Sample  | Methods  | Main Findings   | Rating |
|--------------------------|---|--|---|--------|
| Ashvind et al, 2010      | Systematic review of 13 included studies                              | A systematic review of 13 studies that the focused on treatment for BS; a design of at least quasi-experimental; and involved ID people prescribed clozapine.  | Overall they found the outcomes to using clozapine to treat behaviours that challenge in people with ID inconclusive as according to global subjective assessments improvements were demonstrated; but studies that used more objective assessment check lists found less benefits.   | 2      |
| Beail, 2005              | 20 people with ID who had been referred for treatment with various BC | <p>Each person seen individual &amp; assessed. All had once weekly sessions -50 min duration with a therapist. Interventions involved e.g.: exploration of difficult feelings, early life experiences, current problem,&amp; past relationships, dreams, fantasies and so on. Aim – develop a shared understanding with client of latent meanings in their communications.</p> <p>A range of symptom &amp; problem scales were administered at onset of treatment &amp; at repeated times with ANOVA analysis.</p> | <p>Psychodynamic psychotherapy, in routine clinical practice, can:</p> <ul style="list-style-type: none"> <li>- produce significant reductions in psychological distress,</li> <li>- improve interpersonal functioning</li> <li>- increase self esteem in adults with ID</li> </ul> <p>But, caution is recommended as the study was conducted as part of a normal treatment facility and therefore was not controlled.</p> <p>No time limit was placed on interventions – average was 13.2 sessions.</p> <p>Attrition can be a problem initially sample was N=35, (n=5 could not consent to the research) 30 agreed but 10 people dropped out of treatment &amp; the study.</p> | 2      |
| Brylewski & Duggan, 2004 | A systematic review of  | A Cochrane Review of 9 RCTs of antipsychotic medication  | No evidence of whether antipsychotic medication benefits or harms adults with ID and challenging  | 3      |

**APPENDIX 7: BEHAVIOURS THAT CHALLENGE – INTERVENTIONS**

| Author & Date     | Sample   | Methods   | Main Findings  | Rating |
|-------------------|--|---|--|--------|
| (updated 2009)    | 9 RCTs   | use versus placebo.   | behaviour. Limited data & an urgent need for more research needed.   |        |
| Chan et al, 2010  | 132 studies were identified & 17 met the inclusion criteria for the review.                  | A systematic literature review of studies on the effectiveness of multisensory therapy as an intervention for behaviours that challenge in adults with an ID.   | <p>Positive effects on: communication; social behaviours; concentration and engagement, and relaxation.</p> <p>Limited evidence that these positive effects generalize to outside the multisensory environment.</p> <p>Limited evidence on reduction of behaviours that challenge.</p> <p>Supports original philosophy of multisensory therapy, i.e. activity for leisure &amp; psychological well-being but limited evidence in behaviour support.</p> <p>More research on the treatment impacts, if any of the intervention.</p> | 3      |
| Felce et al, 2008 | N=108 People with ID selected from 40 GPs practices within three health authorities in Wales | An experimental design in which sample was divided into groups – group 1 has health checks at designated times; group 2 did not but did have these at later date. Aim was to identify the optimum time for health checks. | <p>Found no significant difference in detection of health problems between groups at various times.</p> <p>However, did find that</p> <ul style="list-style-type: none"> <li>- 51 out of 75 participants in groups 1 and 2 combined (68%) had health needs newly identified 8 (11%) of a serious nature</li> <li>- average intervals between health checks were all above 12 months (the lowest 14 months) &amp; as a similar number of new needs were still found</li> </ul>  | 2      |

**APPENDIX 7: BEHAVIOURS THAT CHALLENGE – INTERVENTIONS**

| Author & Date        | Sample  | Methods   | Main Findings  | Rating |
|----------------------|---|---|--|--------|
| Heyvaert et al, 2010 | 80 articles identified, 30 used for statistical meta-analysis.<br><br>18 - biological, 13 – psychotherapeutic<br><br>9 - contextual | Statistical meta-analysis of biological, psychotherapeutic & contextual interventions that are applied to treat BC.<br><br>Each intervention applied alone or combined. | <p align="center">after this shortest interval annual health checking is recommended to detect problems.</p> <p>Interventions used: (number in brackets is studies)</p> <p>Biological – antipsychotic medications (risperdone and olanzapine) (9); typical antipsychotics (2); &amp; other biological interventions (5).</p> <p>Psychotherapeutic – behavioural (4); systemic (4); CBT (3); other (2).</p> <p>Contextual - interventions of multidisciplinary approach (6); changing the environment (2).</p> <ul style="list-style-type: none"> <li>- No significant differences between 3 intervention groups</li> <li>- Overall in these 30 articles there is evidence for the effectiveness of pharmacological, psychotherapeutic &amp; contextual approaches used alone or in combination as interventions for people who challenge.</li> </ul> | 3      |
| Marshall, 2004       | An Audit of 382 sets of notes   | An audit of medication prescribing in 382 sets of notes (89% of the case-loads) for a community intellectual disability service   | 102 (26.7%) of clients on medications because of BC<br><br>Antipsychotics main drugs prescribed for 98 (96%)<br><br>Average duration of treatment with the drugs = 5.3 years   | 2      |
| Mansell et al,       | 72 residential homes for  | Investigated organizational   | PCAS group rated most tasks e.g. promoting activities,   |        |

**APPENDIX 7: BEHAVIOURS THAT CHALLENGE – INTERVENTIONS**

| Author & Date | Sample   | Methods   | Main Findings  | Rating |
|---------------|--|---|--|--------|
| 2008          | people with ID (n=359) & n=354 staff in the homes. England | <p>variables impact on use of active support in community-based residential services. Managers in 36 settings were trained in person-centred active support (PCAS) by a number of workshop days. They in turned introduced PCAS to their staff and trained them in this (reg. coordinators provided backup). Data was collected on staff values, priorities, stress and job satisfaction, &amp; care practices. Extent of residents engaging in meaningful activity was observed. Behaviours that challenge were measured with adaptive behaviour scales.</p> <p>Study involved group comparison – settings where residents were supported by staff whose managers had been trained in active support X with settings where training was not provided. Groups</p> | <p>behavioural programmes, teaching &amp; helping as less difficult than the comparison group.</p> <p>Modest differences between PCAS and comparison groups: in meaningful activity, observed assistance &amp; active support. Active support found to result in higher engagement.</p> <p>Higher engagement in meaningful activity was significantly associated with reduced stereotyped behaviour by residents.</p> <p>PCAS group were more likely to attribute behaviours that challenge to lack of stimulation than control group.</p> <p>The control group were more likely to attribute behaviours that challenge as being learned negative behaviour.</p> <p>An unexpected outcome was that the control group showed more teamwork and were more satisfied.</p> | 3      |

**APPENDIX 7: BEHAVIOURS THAT CHALLENGE – INTERVENTIONS**

| Author & Date     | Sample  | Methods   | Main Findings  | Rating |
|-------------------|---|---|--|--------|
|                   |   | were comparable at baseline in terms of behaviours that challenge   |  |        |
| Mason, 2007       | Psychiatrist 274, n=90 (31%) responded; Psychologists 412, n=133 (33%) responded  | Survey perceived effectiveness of psychological therapy with ID people using perception questionnaire & vignettes   | Most important factors were: perceived competence of clinicians in delivering psychological therapy; the level of the client's ID (least effective with most severe ID); the influence of bias about co-existing mental illness.   | 2      |
| Murphy et al 2007 | N=15 men who had indulged in sexually abusive behaviour. Identified by CLDT & service managers in two ID services in south London | CBT over a 12-month period for two groups (1 <sup>st</sup> group n=7; 2 <sup>nd</sup> n=8). Measures = Sexual attitudes & knowledge scale; Attitudes Consistent with Sexual Offending; Sexual Offenders Self Appraisal Scale; Victim Empathy Scale-Adapted. Measures at base-line and during & after process. Interventions involved sessions on: examples - social rules & sexual relationships, legal issues, consequences of behaviour, talking about illegal sexual behaviours & coping, victim experiences, causes of their sexual behaviour, offence cycles & relapse, understanding choice, consent and age of consent | Significant improvements between the start of the group and the end of the group in terms of:<br>Sexual knowledge & attitudes and victim empathy<br>Most showed no further sexually abusive behavior, except one who indulged in public indecent exposure & masturbation a number of times<br>At 6-month follow-up none of the men had further convictions for sexual offences<br><br>3 engaged in further sexually abusive behaviour involving non-consensual sexual touching through clothing & the one continued to indulge in public indecent exposure & masturbation a number of times<br><br>Cognitive distortions remained unchanged. | 3      |

**APPENDIX 7: BEHAVIOURS THAT CHALLENGE – INTERVENTIONS**

| Author & Date                        | Sample  | Methods   | Main Findings   | Rating |
|--------------------------------------|---|---|---|--------|
|                                      |   |   | <p>Overall positive results in sexual knowledge and victim empathy but recommends a larger multi-site trial to analyse further.</p>   |        |
| Ozdemir, 2008                        | 3 children aged 7-9 years old with a diagnosis of autism. | Evaluation of individually designed Social Stories in reducing targeted behaviours that challenge using a single-subject, multiple-baseline design across subjects. (Stories 2-times per day for 9 weeks) | <p>Significant reduction of behaviours that challenge in all 3 children compared to the baseline measures.</p> <p>Following initial intervention stories were faded at two time points &amp; the behaviours increased somewhat but not back to baseline measures.</p> <p>Social Story interventions are effective in reducing problem behaviours that challenge, are an accepted approach to teachers for use in classrooms and are enjoyed by the children</p> | 3      |
| Reynhout & Carter, 2006              | 11 Peer-reviewed journal articles<br>5 Dissertations      | Review of the empirical evidence supporting social stories as an intervention, including meta-analysis of single-subject studies  | <ul style="list-style-type: none"> <li>- Present research on use of Social Stories for children with behaviours that challenge is inconclusive</li> <li>- Most studies focus on use with children with ASD</li> <li>- May have promise but further research is required.</li> </ul>   | 3      |
| Royal College of Psychiatrists, 2007 | Expert panel from RCP, BPS & RCSLT                        | Clinical and service guidelines Based on review of literature & policy by expert panel from   | <ul style="list-style-type: none"> <li>- Assessment should focus on person &amp; environment</li> <li>- Involve comprehensive functional assessment of behaviour leading to diagnosis &amp; a clear formulation of the presenting problem</li> </ul>  |        |

**APPENDIX 7: BEHAVIOURS THAT CHALLENGE – INTERVENTIONS**

| Author & Date               | Sample   | Methods   | Main Findings   | Rating |
|-----------------------------|--|---|---|--------|
|                             |  | Royal College of Psychiatrists,<br>British Psychological<br>Society and Royal College of<br>Speech and Language<br>Therapists                               | <ul style="list-style-type: none"> <li>- Proactive &amp; reactive strategies delivered in a person-centred context</li> <li>- Balance between best practice and pragmatic measures</li> <li>- Effective evaluations</li> <li>- Communication between professionals, carers and service users, and the timely sharing of information as an essential component at all stages of care</li> <li>- Creation of capable environments to support</li> <li>- Creative commissioning</li> </ul> | 3      |
| 180<br>Rush & Frances, 2000 | Expert panel publication.                                  | An expert panel that published guidelines based on published evidence & expert consensus in a special edition of the American Journal on Mental Retardation | Recommended individual and/or family education; ABA; managing the environment; CBT; counselling and psychotherapy. Agreed that the most highly recommended interventions in almost every situation were ABA, managing the environment, and individual and/or family education.<br><br>Medications found still to be highly used as a treatment for people with behaviours that challenge.   | 3      |
| Stancliffe et al, 2010      | N=41 people with ID in 9 group homes in an Australian city | Domestic activities, adaptive behaviour, behaviours that challenge, & depression measured with scales at pre-   | <ul style="list-style-type: none"> <li>- Significant increase in total scores on domestic participation from pre-test to post-test.</li> <li>- Significant improvements in adaptive behaviour total score</li> </ul>  | 3      |

**APPENDIX 7: BEHAVIOURS THAT CHALLENGE – INTERVENTIONS**

| Author & Date      | Sample  | Methods   | Main Findings   | Rating |
|--------------------|---|---|---|--------|
|                    |   | <p>test. Repeated measures following staff training &amp; implementation of Active Support - Post-test assessment 5–8 months after pre-test.</p> <p>Intervention for each resident involved:</p> <p>(1) Activity and Support Plan</p> <p>(2) Opportunity Goals</p> <p>(3) Protocols</p> <p>(step-by-step description of how to complete activity)</p> | <ul style="list-style-type: none"> <li>- Significant reduction in internalised behaviours that challenge (i.e. SIB, stereotypy, withdrawal) but no significant change in other behaviours that challenge although for total scores of behaviours overall there was significant reductions.</li> <li>- Significant reduction in total depression scores from pre-test to post-test (although pre-test scores were already quite low).<br/>(significant improvements at 6.5 months)</li> </ul>  |        |
| Unwin & Deb, 2008. | A review of literature on assessment scales 71 publications that identified use of 9 scales | Reviewed literature that had used assessment scales for BC & psychiatric disorders or a combination of these. Extracted articles that reported most psychometric properties.  | <p>Identified the 9 most commonly reported schedules for BC &amp; psychiatric symptoms in people with ID &amp; BC.</p> <p>List the scales and reports on the psychometric properties when this was available.</p> <p>Found there are sufficient number of scales available &amp; recommend for those who use these:</p> <ul style="list-style-type: none"> <li>- Select one (or more) that is fit for purpose</li> <li>- Check that scale/s selected are valid &amp; reliable</li> <li>- Is not difficult to use &amp; is not too time consuming</li> </ul> | 2      |

**APPENDIX 7: BEHAVIOURS THAT CHALLENGE – INTERVENTIONS**

| Author & Date | Sample                 | Methods   | Main Findings   | Rating |
|---------------|------------------------|---|---|--------|
|               |                        |   | <ul style="list-style-type: none"> <li>- Is reproducible &amp; could be used by a proxy</li> <li>- Can be used at regular intervals to supplement multidisciplinary assessments.</li> </ul>   |        |
| Willner, 2007 | A review of literature | Reviewed literature and identified 8 studies that used CBT (group or individual) for the management or treatment of anger in people with ID | <p>Significant improvements in the anger management by clients (intervention groups) in comparison to clients on waiting lists (control) in anger management</p> <p>Improvement maintained in intervention groups at 3-12 month follow-up</p> | 3      |

**APPENDIX 8: BEHAVIOURS THAT CHALLENGE – SERVICE MODELS**

| Author & Date                   | Sample   | Methods   | Main Findings  | Rating |
|---------------------------------|--|---|--|--------|
| Hassiotis et al, 2009           | 63 male and female service users with mild to severe ID & behaviours that challenge                                  | RCT single-blind controlled trial. Intervention group (n=32) received standard treatment plus ABA from a Community Challenging Behaviour Team. Control group received standard treatment from generic community team. | <p>Significant reductions in behaviours that challenge in the intervention group.</p> <p>Mental status improved in intervention</p> <p>Improvements were maintained over time, and at 6 months.</p> <p>There were no significant differences in the costs of each service.</p>   | 3      |
| Mackenzie-Davies & Mansell 2007 | <p>138 agencies 44 had an assessment and treatment unit &amp; 38 (86%) responded.</p> <p>333 people in units</p>     | Survey questionnaire sent to all agencies in England that had assessment & treatment units  | <p>333 in units, average age 36 &amp; 69% were male</p> <p>Number of units doubled since the 1990s</p> <p>Profile 85% of residents severe/profound ID in 1991 &amp; now 20% of the clients in 2007 severe/profound ID</p> <p>65% remaining &gt; 2-years in the early 1990s compared to the 2007 study where 25% &gt; 2-years in units</p> <p>Main advantage: knowledge and skills of the staff teams and the multidisciplinary support.</p> <p>Disadvantages delayed discharges, in-patient mix not always appropriate</p> | 2      |
| NHSCT, 2005                     | 42 Individuals and their carers who received input from an Adult Specialist Community Challenging Behaviour Service. | An evaluation of the service following first year it was established. Based on clients outcomes and service user expressed satisfaction   | <p>Reductions in frequency and severity of behaviours that challenge for clients</p> <p>Improved life-experiences for clients</p> <p>Prevented residential and/or day-care placement breakdowns for most clients.</p> <p>Carers' psychological wellbeing had improved and</p>  |        |

**APPENDIX 8: BEHAVIOURS THAT CHALLENGE – SERVICE MODELS**

| Author & Date     | Sample  | Methods   | Main Findings   | Rating |
|-------------------|---|---|---|--------|
|                   |   |   | <p>overall.</p> <p>Service users reported being very satisfied with the services they have received.</p>  |        |
| NHSCT, 2009       | 172 clients and their carers who received input from an Adult Specialist Community Challenging Behaviour Service.             | An evaluation of the service following first year it was established. Based on clients outcomes and service user expressed satisfaction | <p>Continued positive outcomes as reported for year one (NHSCT, 2005) including:</p> <p>A significant impact on maintaining placements that were identified as being ‘at risk’.</p> <p>A significant number of hospital admissions prevented</p>  |        |
| NHSCT/NEELB, 2009 | 73 children receiving input from a childrens challenging behaviour service (CCBS)   | An evaluation of the service following first year it was established. Based on clients outcomes and service user expressed satisfaction | <p>Behaviours that challenge reduced in children</p> <p>Improved children’s QoL.</p> <p>Psychological and attitudinal wellbeing of their carers have increased.</p> <p>Maintained, &amp; in some cases extended, the residential, respite and educational placements of children.</p> <p>Only one young person admitted to hospital during the year, for a period of only a week.</p>   |        |
| Kaehne, 2011      | 8 Professionals, 5 front line, 1 manager, 4 in CAMHS, 1 AMHS. Included manager, psychiatrists, clinical psychologists (Wales) | Semi-structured interviews related to transitions from CAMHS to AMHS  | <p>Poor coordination between CAMHS &amp; AMHS</p> <ul style="list-style-type: none"> <li>- Poor interagency communication of knowledge</li> <li>- Not being involved in transition planning</li> </ul> <p>Eligibility criteria for services that lead to people falling between gaps</p> <ul style="list-style-type: none"> <li>- Lack of clarity and agreement on adult age 16 or 18</li> <li>- Lack of clarity on what constitutes a severe and enduring mental health problem as opposed to something like Aspergers.</li> </ul> | 2      |

**APPENDIX 8: BEHAVIOURS THAT CHALLENGE – SERVICE MODELS**

| Author & Date                                | Sample   | Methods                                    | Main Findings   | Rating                  |
|--|--|--|---|-------------------------|
| <p>Alexander, et al<br/>2011<br/>England</p> | <p>138 people admitted to an inpatient service for offenders with mild ID. 77 were discharged &amp; 61 still inpatients (36 of these considered difficult to discharge).</p> | <p>An evaluation of treatment outcomes</p> | <p>All clients underwent 10-point treatment programme designed to help people with personality disorders that included: assessment and motivation work; interventions that are personality &amp; offense specific e.g. risk assessment, psychological formulation in partnership with client, medication, group psychotherapy and other interventions; relapse prevention &amp; discharge.</p> <p>Medium length of stay for discharged clients 2.8 years, but most move to lower security rather than community</p> <p>Long-stay clients have more criminal sections, restriction orders, history of abuse, property damage such as fire setting &amp; personality disorders.</p> <p>Need to focus on difficult to discharge clients.</p> | <p align="center">3</p> |

**APPENDIX 9: OLDER PEOPLE – HEALTH ISSUES & DEMENTIA**

| Author & Date      | Sample   | Methods   | Main Findings  | Rating |
|--------------------|--|---|--|--------|
| Ball, et al. 2006  | 55 older adults with Down syndrome                           | Longitudinal quantitative study, participants contacted at three time points – 1994, 18 months later and after a further 5 years. Medical history taken and assessment using Cambridge Examination for Mental Disorders in Older People CAMDEX and Cambridge Cognitive Examination (CAMCOG) | Early presentation of Alzheimer’s disease in people with Down syndrome is characterized by prominent personality and behaviour changes, associated with executive dysfunction. This suggests the functions of the frontal lobes may be compromised early in the course of the disease in this population.  | 3      |
| Burt, et al. 2005  | 78 adults with Down syndrome                                 | Two methods based on a large test battery and one method based on clinical judgment were used to diagnose dementia.   | Combinations of tests lead to increased levels of diagnostic sensitivity compared with single tests. When taken in combination with other investigations, results suggest that assessment for psychiatric disorders, delayed memory decline, adaptive behavior decline, and the presence of seizures are useful for the diagnosis of dementia and that dementia scales would provide additional useful information.        | 3      |
| Coppus, et al 2010 | 85 post-menstrual women with Down’s syndrome aged + 45 years | Prospective longitudinal cohort study. Participants followed for an average of 4.3 years. The effect of age at menopause on age at diagnosis of dementia and survival was estimated using correlation analysis and Cox Proportional Hazard Model.   | Findings show a significant correlation between age at menopause and age at diagnosis of dementia ( $\rho=0.52$ ; $p<0.001$ ), and between age at menopause and age at death ( $\rho=0.49$ ; $p=0.01$ ). Early age at menopause is associated with a 1.8 fold increased risk of dementia. The study suggests that age at menopause in women with Down syndrome is a determinant of age at onset of dementia and mortality. | 3      |

**APPENDIX 9: OLDER PEOPLE – HEALTH ISSUES & DEMENTIA**

| Author & Date            | Sample  | Methods  | Main Findings   | Rating |
|--------------------------|---|--|---|--------|
| Coppus, et al.<br>2006   | 506 people with Down's syndrome, aged + 45 years.   | A standardized assessment of cognitive, functional and physical status was carried out annually for 3 years. If deterioration occurred, the patients were examined and the differential diagnosis of dementia was made according to the revised Dutch consensus protocol and according to the ICD-10 Symptom Checklist for Mental Disorders. We compared our findings with those reported in the literature. | <p>The overall prevalence of dementia was 16.8%.</p> <p>Up to the age of 60, the prevalence of dementia doubled with each 5-year interval.</p> <p>Patients with dementia were more frequently treated with antiepileptic, antipsychotic and antidepressant drugs.</p> <p>The history of depression was strongly associated with dementia.</p> <p>Despite the exponential increase in prevalence with age, the prevalence of dementia in the oldest persons with DS was not higher than 25.6%.</p> | 3      |
| Cosgrave, et al.<br>2000 | 80 women with intellectual disabilities   | A five year follow-up study of prevalence of dementia, early clinical features of dementia and patterns of scoring on rating scales at diagnosis and end-stage dementia was completed.   | <p>Dementia was more common with increasing age.</p> <p>The earliest recognisable symptoms of dementia were memory loss, spatial disorientation and loss of independence especially in the area of personal hygiene.</p> <p>The authors suggest that the results of this study should facilitate earlier diagnosis of dementia in Down's syndrome.</p>  | 3      |
| Dalton, et al.<br>2002   | 336 individuals with an average age of 49.8 years, including an equal number of men and women, were participants in one or more of the five studies. There were 220 participants with | Synthesis five studies aimed at evaluating the usefulness, reliability, and validity of the Multidimensional Observation Scale for Elderly Subjects (MOSES) in the assessment of change in ageing persons with intellectual disability.  | Persons with Down syndrome + 40 years of age had statistically significant poorer scores than younger participants on the MOSES, with those + 50 years of age having the worst scores. Comparisons of adults with intellectual disability diagnosed with dementia of the Alzheimer type (DAT), using DSM-IV criteria, with or without Down syndrome, as well as comparisons of patients with clinically diagnosed depression, provided evidence that subtests of the MOSES were sensitive to      | 3      |

**APPENDIX 9: OLDER PEOPLE – HEALTH ISSUES & DEMENTIA**

| Author & Date        | Sample   | Methods  | Main Findings   | Rating |
|----------------------|--|--|---|--------|
|                      | Down syndrome, 81 persons without Down syndrome with intellectual disability, and 35 persons from the general ageing population who were clinically diagnosed with Alzheimer's disease using NINCD/ADRDA criteria. |  | DAT but less so to depression. These clinical groups also showed significantly poorer scores on the MOSES when compared with those of the normative sample. It was concluded that the MOSES is a behavioural observation scale that can provide useful information in clinical settings as well as in research.   |        |
| Davies, et al. 2002  | Total of 43 adults with intellectual disabilities<br>18 had diagnosis of dementia<br>4 under assessment for dementia<br>19 showing early signs of dementia   | Questionnaire to obtain information from key workers on the diagnostic status and presentation of dementia.  | Diagnostic services were patchy.<br>People with dementia were living in a range of residential settings.<br>Carers wished to care for their clients for as long as practically possible, but they required extra resources and training to do so.<br>Some individuals with an intellectual disability were excluded from elderly services   | 3      |
| Fahey-McCarthy, 2009 | 14 focus group interviews were conducted with staff across six ID services and one specialist palliative care provider in Dublin (Ireland)   | Qualitative descriptive analysis of focus group data was used to develop an educational intervention. Pre- and post-test questionnaires assessed responses to a pilot delivery of the educational intervention | The educational intervention was highly valued and addressed key training concerns. Training supported “aging in place,” and the preparation for a “good death” including support for staff, peers, and family in their grief and bereavement. An educational manual was produced to support cross-service, in-service training on issues of addressing advanced dementia in persons with ID. | 2      |
| Forbat, 2006         | Eight <i>key people</i>  | Semi-structured interviews   | Findings highlighted satisfaction and dissatisfaction in  |        |

**APPENDIX 9: OLDER PEOPLE – HEALTH ISSUES & DEMENTIA**

| Author & Date             | Sample   | Methods  | Main Findings  | Rating |
|---------------------------|--|--|--|--------|
|                           | involved in policy development and implementation around ageing and /or learning disability in England. Respondents identified as ‘key’ if actively involved in the development of recent policy, or currently involved in active implementation of policy at high levels, or if they held senior practice positions, with more than 20 years experience in learning disability and ageing. nationally as ‘experts’. | were conducted and a thematic analysis carried out.  | the connections between policy and practice. Areas for policy development and, crucially, ways of improving provision to people with a learning disability who develop dementia are highlighted.   | 2      |
| Hoekman, & Maaskant. 2002 | 329 adults affiliated with centres for people with intellectual disability in The Netherlands.   | Comparative study of three degree of consensus between 3 diagnostic instruments. The instruments are: the Dementia Questionnaire for Mentally Retarded Persons (DMR), the Checklist with Symptoms of Dementia (CLD) and the Delayed Match-to-Sample Test (DMTS).<br>The results were compared with the expert opinion of a physician/educational | The agreement between the expert opinion and the results of the tests was also found to be low. It was concluded that the instruments do not mutually agree upon which of the adults can be regarded as dementing or not dementing and they provide inconsistent agreement with the expert opinion when dementia is present. It was further concluded that it is not advisable to use a single instrument when attempting to diagnose dementia in people with intellectual disability. | 3      |

**APPENDIX 9: OLDER PEOPLE – HEALTH ISSUES & DEMENTIA**

| Author & Date           | Sample   | Methods  | Main Findings  | Rating |
|-------------------------|--|--|--|--------|
|                         |  | specialist/psychologist.   |  |        |
| Holland, 2000           | 75 people (32 females and 43 males) with Down’s syndrome, aged 30 + years living in one health district (population 280 000), were seen as part of an initial prevalence study ( <a href="#">Holland et al. 1998</a> ), were contacted again 18 months after the initial assessment. Together with their main carers, they were asked if they would be willing to take part in a follow-up study. This initial cohort makes up the prevalence wave of the present incidence study. | A modified version of the Cambridge examination for mental disorders of the elderly informant interview was used to determine the extent and nature of changes in memory, personality, general mental functioning and daily living skill 18 months after a similar assessment. | At the time of the first assessment, the initial changes reported were predominately in behaviour and personality. At the second assessment, overall estimated incidence rates for frontal-like dementia were high (0.24), mainly in the younger groups, with incidence rates of Alzheimer’s dementia, meeting both ICD-10 and DSM-IV criteria, of 0.04 predominately in the older groups. The authors have hypothesized that the observed personality changes and the high estimated incidence rates of frontal-like dementia in the younger groups may indicate that functions served by the frontal lobes are the first to be compromised with the progressive development of Alzheimer-like neuropathology in people with Down’s syndrome. | 3      |
| Janicki, & Dalton, 2000 | Population of adults with intellectual disabilities in one US state.   | Survey to identify prevalence, incidence and age at onset of dementia.   | Dementia was found in 3% of adults age 40+; 6%, age 60+; and 12%, age 80+. Among adults with Down syndrome, the rates were 22% for adults age 40+ and 56% for adults age 60+.  | 2      |

**APPENDIX 9: OLDER PEOPLE – HEALTH ISSUES & DEMENTIA**

| Author & Date | Sample  | Methods  | Main Findings   | Rating |
|---------------|---|--|---|--------|
|               |   |  | <p>Observed onset occurred in the mid-60s (early 50s for those with Down syndrome).<br/>Alzheimer-type dementia was the most frequent diagnosis.</p> <p>With the occurrence of dementia expected to rise proportionately with the increase of longevity among adults with intellectual disabilities, care systems will have to raise the “index of suspicion” among staff and families, become “dementia capable,” and improve their diagnostic and technical resources, as well as their care management supports designed to prolong the “aging in place” of adults affected by dementia.</p> |        |
| Kay, 2003     | 85 non-demented hospitalized adults with Down’s syndrome (DS) | <p>Quantitative studies<br/>Between 1985 to 1986 participants were interviewed using the Prudhoe Cognitive Function Test (PCFT).<br/>The Adaptive Behaviour Scale (ABS) was administered to carers.<br/>ID level was graded based on scores on the Stanford-Binet Intelligence Scale.<br/>The relationship between level of disability and performance on the PCFT and ABS was examined.</p> | <p>The PCFT provides a reliable quantitative measure of cognitive function in subjects with DS, and could be a useful adjunct to the diagnosis of dementia. However, the almost uniformly low scores obtained by those with high levels of ID suggests that its power to detect cognitive decline will be limited to those who are less disabled, while the ABS may be more useful than the PCFT in detecting deterioration in people with profound ID.</p>   | 3      |
| Prasher, 2004 | 150 adults with Down’s syndrome                               | The analysis of 5-year consecutive data developed a  | The Adaptive Behaviour Dementia Questionnaire (ABDQ) is a 15-item questionnaire, which is used to   |        |

**APPENDIX 9: OLDER PEOPLE – HEALTH ISSUES & DEMENTIA**

| Author & Date        | Sample  | Methods  | Main Findings   | Rating |
|----------------------|---|--|---|--------|
|                      |   | researched-based clinical screening tool for dementia in Alzheimer’s disease in adults with Down syndrome.   | detect change in adaptive behaviour. The scale has good reliability and validity, with an overall accuracy of 92%. It is the first clinical tool designed specifically to screen for dementia in Alzheimer’s disease in adults with Down syndrome.  | 3      |
| Schultz, 2004        | Groups of participants with and without a diagnosis of dementia matched on IQ, age, and presence of Down syndrome | Quantitative study comparing scales for sensitivity in distinguishing those with and without dementia. The Dementia Scale for Down Syndrome and Dementia Questionnaire for Mentally Retarded Persons were used tasks and also used the Reiss Screen. Logistic regression was conducted to assess which combination of tests discriminated best between groups. | Both dementia scales and both performance tasks discriminated between groups. The dementia scales were not related to premorbid IQ, age, or gender, whereas performance tasks were related to dementia and IQ but not age or gender. Various Reiss Screen subscales also discriminated between groups. Subscales of the screening instruments and performance tasks were significantly related, indicating congruent validity.  | 2      |
| Strydom, et al. 2009 | 281 adults with ID without Down syndrome (DS) aged $\geq$ 60 years.   | A two-staged epidemiological survey. Participants who screened positive with a memory task, informant-reported change in function or with the Dementia Questionnaire for Persons with Mental Retardation (DMR) underwent a detailed assessment. Diagnoses were made by psychiatrists according to international criteria. Prevalence rates were                | Dementia was more common in this population (prevalence of 18.3%, SMR 2.77 in those aged $\geq$ 65 years). Prevalence rates did not differ between mild, moderate and severe ID groups. Age was a strong risk factor and was not influenced by sex or ID severity. SMRs were higher for younger age groups compared to older age groups, indicating a relative shift in age-associated risk.<br><br>Criteria-defined dementia is 2–3 times more common in the ID population, with | 3      |

**APPENDIX 9: OLDER PEOPLE – HEALTH ISSUES & DEMENTIA**

| Author & Date               | Sample  | Methods  | Main Findings  | Rating                  |
|-----------------------------|---|--|--|-------------------------|
|                             |   | <p>compared with UK prevalence and European consensus rates using standardized morbidity ratios (SMRs).</p>  | <p>a shift in risk to younger age groups compared to the general population.</p>   |                         |
| <p>Strydom, et al. 2007</p> | <p>222 adults with intellectual disabilities but without Down's syndrome.</p> | <p>The Becoming Older with Learning Disability (BOLD) memory study is a two-stage epidemiological survey of adults with intellectual disability without Down syndrome aged 60 years and older, with comprehensive assessment of people who screen positive. Dementia was diagnosed according to ICD-10, DSM-IV and DC-LD criteria.</p> | <p>The DSM-IV dementia criteria were more inclusive. Diagnosis using ICD-10 excluded people with even moderate dementia. Clinical subtypes of dementia can be recognised in adults with intellectual disability. Alzheimer's dementia was the most common, with a prevalence of 8.6% (95% CI 5.2-13.0), almost three times greater than expected.</p> <p>Dementia is common in older adults with intellectual disability, but prevalence differs according to the diagnostic criteria used. This has implications for clinical practice.</p> | <p align="center">3</p> |

**APPENDIX 10: OLDER PEOPLE – AGEING IN PLACE**

| Author & Date                              | Sample   | Methods   | Main Findings   | Rating |
|--|--|---|---|--------|
| Barron et al. 2006<br>ROI and NI.          |  | Review of the databases in N. Ireland and ROI to determine the characteristics and living arrangements of adults with ID                  | More people with ID live with family carers in N. Ireland (4.35 per 1000) compared with the ROI (2.67 per 1000): prevalence rate is > 60% higher.   | 2      |
| Bigby 2008<br>Australia                    | 826 mainstream residential / nursing facilities          | Postal survey   | Found adults with ID who were admitted into these facilities were younger, had entered at an earlier age and remained longer than other non-ID residents.   | 2      |
| Black & McKendrick 2010<br>N. Ireland      | 36 ageing carers 50 yrs plus,                            | Face-to-face structured interviews exploring ageing family carers   | 81% female carers, 19% male carers, mean age 70 yrs, 58% lone parents (76% female)  | 2      |
| McConkey et al. 2003<br>N. Ireland         | N= 16,366 persons with moderate, severe and profound ID  | Review of databases examining prevalence of ID across N. Ireland, in long-stay hospitals, residential accommodation and ordinary housing. | 4107 people living in ordinary homes, 477 (12%) were aged 60 years plus. Approx. 1000 carers are aged 65 years and another 1000 carers are aged 75 years. Mothers were more likely to be the main sole carer. 1358 adults with ID living in some form of residential accommodation, 646 (47.6%) were aged 25-49 yrs, 712 (52.4%) were aged 50 years plus. | 2      |
| Taggart et al. current study<br>N. Ireland | N= 18 ageing family carers                               | Semi-structured interviews exploring ageing family carers   | Majority of carers were widowed (61.1%); four carers were married (22.2%), two carers divorced (11.1%) and one carer was not married (5.6%). Three quarters of ageing family carers were lone carers, mainly mothers.   | 2      |
| Thompson 2000<br>England                   | 230 people with ID living in residential / nursing homes | Questionnaires were sent the older care homes.  | 33% of the older people with ID came from their family home after their main carer had died; this group was younger compared to non-ID residents.   | 2      |

**APPENDIX 11: OLDER PEOPLE – FAMILY CARER SUPPORT FOR SUCCESSION PLANNING**

| Author & Date                            | Sample   | Methods  | Main Findings  | Rating |
|--|--|--|--|--------|
| Black & McKendrick 2010<br>N. Ireland    | 36 ageing carers 50 yrs plus,                                      | Face-to-face structured interviews exploring ageing family carers  | Third of carers reported having an emergency plan in place using family members; majority of carers wanted their relative to remain at home, then supported living, living with another family member, warden supported accommodation                                    | 2      |
| Dillenburger & McKerr 2009<br>N. Ireland | 29 older carers (mean age= 65)                                     | Structured interviews with using CADI & CAMI and GHQ 12  | Complex relationships of networks were reported, virtual absence of future planning was found. Carers were two times more likely to experience psychological ill-health compared to the non-ID population.   | 2      |
| Heller & Arnold 2010                     |  | Literature review 1970 – 2008; 23 relevant studies, siblings aged over 21 years                                  | Overall, these studies present a mix but generally a positive picture of psychosocial outcomes of having siblings with an ID; Siblings have long-lasting close relationships with their ID sibling and anticipate taking on greater supportive roles as they grow older. | 2      |
| Llewellyn et al. 2010 Australia          | 64 elderly family cares interviews                                 | 1-1 structured interviews that examined the health status and coping strategies of older cares of adults with ID | Better health was correlated with having a partner, support of family, friends and neighbours and a lower care load. Younger carers (55-64 yrs) reported to have more mental health issues.  | 2      |
| Magrill 2005<br>England                  |  | Older family carers initiative (OFCI)  | Family carers want to care for as long as possible and want to engage in future planning if the issue is dealt with sensitively and carefully  | 1      |
| McConkey 2006<br>N. Ireland and ROI      | 1568 family carers in NI (26% of estimated pop) versus a sample in | Using data bases to describe the demographics of older people with ID and their                                  | 35% of health staff in N. Ireland indicated the older people with ID will require a move within the next ten-years   | 2      |

**APPENDIX 11: OLDER PEOPLE – FAMILY CARER SUPPORT FOR SUCCESSION PLANNING**

| Author & Date                              | Sample   | Methods   | Main Findings   | Rating |
|--|--|---|---|--------|
|  | ROI  | ageing family carers  |   |        |
| Seltzer & Gidden 2011                      | International systematic literature review                                     | Family support interventions for families of adults with ID   | Family support emphasises the provision of information, emotional support and instrumental support to families in order to build on existing strengths  | 2      |
| Taggart et al. current study<br>N. Ireland | 18 ageing family carers  | Semi-structured interviews exploring ageing family carers   | Family carers reported that they suffered from chronic physical illnesses and also emotional ill-health (i.e. stress and anxiety, depression) from their caring roles.                                  | 2      |
| Thompson 2002                              | Editorial: informed by the GOLD Programme at the Foundation for People with ID |   | Most people with ID still live with their families. However, one estimate is that 25% people with ID do not become known to services until their family carer dies or is unable to look after them.     | 1      |
| Weeks et al. 2009<br>Canada                | 43 elderly family carers   | 10 pilot 1-1 interviews followed by 33 in-depth structured interviews exploring the current and future concerns of ageing family carers of older people with ID | Family carer expressed worry about the future, concerns about services funding in the future, having housing and care options and lack of provider understanding of the needs of their relative with ID | 2      |
| Williams & Robinson 2001<br>UK             |  | Role reversal , as people ID become carers for their parents  | Mutual care, although statutory services did not recognise this role  |        |
| Yamaki et al. 2009<br>USA                  | 206 older female family carers   | Caregivers completed a questionnaire on their health  | Arthritis, high BP, obesity, poor mobility, increased diabetes and cholesterol. But family carers want to continue caring.  | 2      |

**APPENDIX 12: OLDER PEOPLE – SUPPORT THROUGH FORMAL SERVICES**

| Author & Date                         | Sample   | Methods  | Main Findings   | Rating |
|---------------------------------------|--|--|---|--------|
| Bigby 2004<br>Australia               |  | A file audit and semi-structured interviews with older family carers   | Few differences were found, although mainstream older person services did not undertake outreach and community education functions. Models that build on the capacity of mainstream case management or carer support programmes to work with ageing family carers and target outreach more effectively are discussed. | 2      |
| Bigby & Balandin 2005<br>Australia    | <b>40 generic aged day activity and community leisure programmes used by older people</b>                              | <b>A survey was used to collect information on the extent to which such services are used by older people with an ID</b> | <b>More than half of these services are accessed by a small number of people with ID and overall there was a willingness to include this group in generic services.</b>   | 2      |
| Black & McKendrick 2010<br>N. Ireland | 36 ageing carers 50 yrs plus   | Caregivers completed a face-to-face structured interviews  | Many of the ageing family carers reported using respite care and domically support services   | 2      |
| McCarthy et al. 2009<br>Ireland       | 14 focus group interviews were conducted with staff across six ID services and one specialist palliative care provider | Focus groups were used to develop an education intervention for staff supporting people with ID and dementia             | Formal feedback from staff indicated that the educational intervention was highly valued and addressed key training concerns. They agreed that the training supported “aging in place,” and the preparation for a “good death” including support for staff, peers, and family in their grief and bereavement.         | 2      |
| McConkey et al. 2004b                 |  | Audit of ID literature   | Many older people in general enjoy an active social life and some take on new careers. However, for the older person with an ID few have opportunities to take part in leisure pursuits   | 2      |
| Reilly & Conliffe 2002<br>N. Ireland  | 31 older family carers   | Exploration of existing data sets in ROI and NI. Interviews with 31 older parents and older people with ID               | Formalised assistance is required as family carers continue to age for future planning is needed. Succession planning should also include quality of life. A planning instrument was developed ‘What the future holds’ for all focusing on health, financial, vocational, social, civil and                           | 2      |

**APPENDIX 12: OLDER PEOPLE – SUPPORT THROUGH FORMAL SERVICES**

| Author & Date                                       | Sample                  | Methods  | Main Findings   | Rating |
|---|-------------------------|--|---|--------|
| and ROI   |                         |  | residential well-being.<br>.  |        |
| Taggart et al.<br>(current study)<br><br>N. Ireland | 18 ageing family carers | Semi-structured interviews were employed to explore ageing family carers | Ageing family carers reported using a range of respite care, domiciliary support services and a few carers reported using a befriended scheme: results pending geographic region (i.e. urban / rural) | 2      |

**APPENDIX 13: OLDER PEOPLE – CONTRIBUTION OF MAINSTREAM SERVICES**

| Author & Date                    | Sample   | Methods  | Main Findings   | Rating |
|----------------------------------|--|--|---|--------|
| Adams 2001                       | A discussion paper   | Development for a multi-disciplinary pathway               | The education and training pathway should include knowledge and practice relating to the bio-psycho-social model, together with ethical and spiritual approaches. Psychosocial interventions should be utilised.  | 1      |
| Davies et al. 2002<br>N. Ireland | 37 adults with ID and dementia (aged 31–65 plus)                             | Survey of the support needs of adults with ID and dementia | The authors recommended multi-agency and multidisciplinary modes of support. The requirement for joint working between specialised ID and mainstream dementia services was seen as core to the development of services.   | 2      |
| Janicki et al. 2002<br>USA       |  | Survey of group homes for adults with ID and dementia      | A generic older people model can be adapted to the needs of older people with ID and dementia and focuses on: <ul style="list-style-type: none"> <li>• Early screening and diagnostics</li> <li>• Clinical supports</li> <li>• Environmental modifications</li> <li>• Programme adaptations</li> <li>• Specialised care</li> </ul>  | 2      |
| Kerr et al. 2006                 | Report of a study commissioned by Joseph Rowntree Foundation 'Home for Good' |  | Describes three models: <ol style="list-style-type: none"> <li>1) Ageing in place: the older person with ID and dementia remains within their own family home</li> <li>2) In place progression: environment developed to become increasingly specialised to provide care within an ID setting</li> <li>3) Referral out: move to long-term (usually nursing) facilities outside ID services</li> </ol> | 2      |

**APPENDIX 13: OLDER PEOPLE – CONTRIBUTION OF MAINSTREAM SERVICES**

| Author & Date                | Sample   | Methods   | Main Findings   | Rating |
|------------------------------|--|---|---|--------|
| King 2004<br>UK              | Examples of strategies used to implement policy directions on ageing                   |   | Specific funding for housing initiatives as part of 'Extra Care Housing and the FFPWLD Gold Project who funded a range of innovative projects between 1998 and 2002 that provided a series of programme exemplars leading to longer term service development (e.g. Birmingham Psychological Services for Older People). | 2      |
| Llewellyn et al. 2008        | 170 articles reviewed on diagnosis, needs and models of support and service provision. | A systematic literature review on dementia and ID   | The authors concluded that papers that focus either or in part on models of service models for older people with ID and dementia vary between the generic and the specific models as identified above.  | 2      |
| Maybin 2002<br>N. Ireland    | 44 ageing family carers  | Survey of ageing family carers of older people with ID and dementia and supports received                                 | Family carers reported that the most support they received was from a social worker and their GP. The majority of the carers reported they wanted accessible information on ID and dementia.  | 2      |
| McCarron et al. 2002<br>ROI  |  | A study on how staff in ID and dementia services adapt the Stress and Coping Model  | Developed the Caregiver Activity Survey (CAS-ID) to aid ID staff in identifying, planning and measuring care and resources for older people with ID and dementia throughout different stages of the dementia process.   | 2      |
| Parish & Lutwick 2005<br>USA | Literature   | A systematic review of the literature and a critical analysis of the emerging crisis in long-term care for adults with ID | Limited consensus about whether services for older people with ID should be integrated with older people services or whether specialist services are needed.  | 2      |
| Rosewarne 2001               |  | Development of a support group for older people with ID and dementia  | Outcomes reported were the maintenance of levels of verbal communication as well as evidence participants taking on new information. In addition the programme was found to have a motivating effect on support workers.  | 2      |

Table: Parental perceptions of perceived advantages and limitations of different type of respite options  
(cited in McConkey, 2010, p.34.)

| Type of service  | Advantages   | Limitations  |
|--|--|--|
| <b>Care provided by family and friends</b>   | Flexible<br>Provides time to complete small chores   | Short periods of 'babysitting' rather than care-giving<br>Not confident that persons could cope.<br>Reciprocation not possible<br>Fear of 'putting on' relatives<br>This option diminishes as child grows older  |
| <b>Home-based support from agency staff (e.g. social care/healthcare assistants)</b> | Chance to attend to household chores, shopping<br>Spend time with other children<br>Child taken out<br>Not asking a favour – it's a service<br>Can provide emotional and social support to mothers | Scheduled between treatments or when child is settled.<br>Not able/trained to provide care-giving for child<br>Outsiders coming to home adds to feeling of difference<br>Intrusion into family privacy<br>Increases family's workload<br>Changes the experience of parenting<br>Not acceptable in certain cultures |
| <b>Care provided by a host family in their home</b>                                  | Flexibility<br>Offers a trusted alternative family<br>Less costly option than residential care   | Not suited to medically complex children or those with severe challenging behaviours<br>Equipment needs to be provided.<br>Suitably qualified staff not available  |
| <b>Overnight home-based support</b>  | Time for parents to spend with other children<br>Time away from child  | Ambiguous rules – can staff attend to other siblings?<br>Can mothers take part in employment?<br>More flexibility in accessing service<br>The competences of relief/bank staff to deal with the child  |

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| <p><b>Overnight respite in dedicated facility</b></p> | <p>Rest for carers<br/>                 Opportunity to be a 'normal' family<br/>                 Chance to go on holiday<br/>                 Provides change in routine for child<br/>                 Easy access to health professionals<br/>                 Safer working environment for service staff than family home</p> | <p>Child away from the family –missing out<br/>                 Transport to distant centre<br/>                 Concern for the child's wellbeing</p> |
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**APPENDIX 15: INTERVENTIONS/MODELS THAT HAVE BEEN USED WITH YOUNG PEOPLE WITH ID**

| <b>Intervention approach</b>                                    | <b>Underpinning principles</b>  |
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| <i>Interventions in the Early Years (Birth – Age 7)</i>         |   |
| The Lovaas EIBI Model (Lovaas, 1987; McEachin, et al 1993)      | Uses discrete trail training (DTT) methods to reduce stereotypical autistic behaviours through extinction and the provision of socially acceptable alternatives to self-stimulatory behaviours.   |
| TEACCH (Sloper et al., 1971, 1995)                              | Providing structure to the person’s environment to suit his or her needs. Using structure as a means of directing behaviour into meaningful activities. Teaching appropriate skills & Communication training.   |
| Positive Behaviour Support (Horner, et al 2002)<br>(Carr, 2007) | This process uses a system to understand what maintains an individual’s challenging behaviour. It involves the identification, information gathering, hypothesis development, support plan design, implementation and monitoring. Recommends multi-element approaches & aims not only to reduce or prevent BC but improve QoL with respect to physical, social, emotional, psychological well-being while maintaining health and safety recreation and leisure, and empowering the individual in a person-centred approach. |
| Pivotal Response Treatment for Autism (Koegel and Koegel, 2006) | Derived from the principles of ABA this naturalistic intervention model, rather than target individual behaviours one at a time, targets pivotal areas of a child’s development such as motivation, responsivity to multiple cues, self-management, and social initiations. Underlying motivational strategies include child choice, task variation, interspersing maintenance tasks, rewarding attempts and the use of direct and natural reinforcers.   |
| The SCERTS Model (Prizant, et al 2003)                          | This educational model provides specific guidelines for helping a child become a competent and confident social communicator, while preventing problem behaviours that interfere with learning and the development of relationships. Focusing on building competence in <b>Social Communication, Emotional Regulation and Transactional Support</b> .   |
| Stepping Stones Triple P (Church, 2003)                         | An extension of the standard triple P ( <b>P</b> ositive <b>P</b> arenting <b>P</b> rogramme) focuses on the development of effective management strategies for dealing with a variety of childhood behaviour problems and development issue.   |

**APPENDIX 15: INTERVENTIONS/MODELS THAT HAVE BEEN USED WITH YOUNG PEOPLE WITH ID**

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| <p>Engaging Peers in Interventions during the Early Childhood Years (Hedeem, et al 1996)</p>                   | <p>Involving peers in the environment of someone with severe behaviour problems. Peers who know how to and can react constructively when problem behaviour occurs will not only be safe themselves but will help to ensure that the target child will receive appropriate feedback rather than be reinforced inadvertently. This is particularly important given that a core deficit of autism is social-communicative and a lack of appropriate social interactions.</p> |
| <p><i>Interventions in the Middle Years (Ages 8 - 12)</i></p>  |   |
| <p>Functional Communication Training (Carr and Durand, 1985; Durand, 1990).</p>                                | <p>Identifies the function or purpose of the child’s challenging behaviour then teaching an appropriate behaviour that will serve the same purpose for the child. This behaviour is referred to as replacement behaviour.</p>   |
| <p>Systems Oriented Approaches (Sugai et al, 2000)</p>   | <p>Positive Behaviour Support encompassing a school-wide approach to discipline that is consistent with regular education structures as well as being amenable to individualised adaptations to meet the needs of students whose repertoires challenge the overall disciplinary structures.</p>   |
| <p>Family Support and Involvement</p>  | <p>Support from parents and family members to supplement those educational services during the school day.</p>  |
| <p>Engaging Peers in Interventions during the Middle Years (Lord &amp; Hopkins,1986; Lee &amp; Odom, 1996)</p> | <p>Engaging same-age typically developing peers in interactions with children with autism at the same age. The intervention directly targets social initiations — not stereotyped behaviour — and is associated with an increase in the planned target but also a decrease in the challenging behaviour.</p>  |