Review

Caring for older people with an intellectual disability: A systematic review

Anthea Innes [a,*], Louise McCabe [b], Karen Watchman [c]

[a] School of Health and Social Care, Bournemouth University, Royal London House, Christchurch Road, Bournemouth, BH1 3TS, UK
[b] School of Applied Social Science, University of Stirling, Stirling, FK9 4LA, UK
[c] University of Edinburgh, Edinburgh, UK

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ABSTRACT

This review critically evaluates the available research literature on aging among people with an intellectual disability. 42 papers meeting the review inclusion criteria are presented under three themes: studies with a service user perspective (13), studies of carers of older people with ID (14) and studies of service provision for older people with ID (15). User view specific findings relate to concerns about accommodation; experiences of services; and perceptions of aging; with a common underlying finding from all user focused themes that of unmet need. Carer specific findings relate to fear of the future; experiences of older carers; and planning for the future. Services themes reflect the debate over specialist or generalist services as people age; accommodation; retirement from day services; and staff training. Overall this review reveals a lack of robust research evidence concerning the lives of older people with ID and a need for more research that directly engages with older people with ID and their carers.

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* Corresponding author. Tel.: +44 0 1202 961632.
  E-mail addresses: ainnes@bournemouth.ac.uk (A. Innes), louise.mccabe@stir.ac.uk (L. McCabe), k.watchman@ed.ac.uk (K. Watchman).

1. Introduction

For the purpose of this review the definition of intellectual disability (ID) is taken from the World Health Organisation as meaning '*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.*' [1]. The term intellectual disability is preferred to the UK specific term learning disability, in recognition of its international usage.

The circumstances and expectations of people with an intellectual disability have evolved over recent decades, largely as a result of change in practice and policy. In practice, we have seen a more person centred approach to support with an emphasis on inclusion and community living. In many countries the closure of large institutions has been instrumental in the change in quality of life for people with intellectual disabilities. This change reflects policy supporting choice and giving more control to people with intellectual disabilities. For example in Scotland 'The Same as You?' [2] recommended the development of life plans for people with intellectual disabilities who live with their parents to prepare for a time when parents may no longer be able to provide care. This is reflected elsewhere internationally for example the Macau Declaration on Ageing for Asia and the Pacific and the Plan of Action on Ageing for Asia and the Pacific recognize the changing needs of older people with ID [3]. In Australia, ageing in people with ID is recognised as a national priority [4] whilst the English report 'Valuing People' [5] identified those living in the family home with carers aged over 70 as a priority group. Although this raises expectations of positive developments and opportunities as people with intellectual disabilities age, questions remain about support for current and future generations of older people with an intellectual disability. An increase in health screening and medical intervention gives a greater awareness that people will live for longer, yet without a corresponding evidence base of how support will be provided as people age.

The purpose of this review is to critically evaluate available research literature on aging among people with an intellectual disability. The low number of countries included (7) is indicative of poor recognition of the requirements of older adults with ID internationally. This bias is recognised, along with the knowledge that nations vary in the status afforded to, and provision for, people with ID generally regardless of age. Additionally, some countries in Europe are supporting a population aging with ID for the first time due to actions of the third Reich [6]. Whilst the early stages of the review showed an abundance of condition specific or disability specific articles in relation to aging, for example in Down syndrome, other types of ID were notable by their absence, for example aging with autism and the gender differences associated with this.

It is also important to remain aware of different life markers; we are not comparing like with like when looking at the aging experiences of people with an intellectual disability in relation to aging in the general population. People with an intellectual disability will have different experiences of childhood, education, relationships, employment and retirement [7]. Generally, although not exclusively, people with an intellectual disability are not married, or parents, and have not been in paid employment. The debate will be explored between age related needs as distinct from the existing intellectual disability – a distinction that is not reflected in service provision or policy.

2. Methods

2.1. Search strategy

Six databases (PsychInfo, Web of Knowledge, CINAHL, Medline, EMBASE and Sociological Abstracts) were searched between 2nd January and 12th January 2012. The search terms for all databases were (intellectual disability or learning disability*) and carers. The asterisk indicates that all terms beginning with this root were searched. The term carer covered both formal (paid) and family carers.

The original date from 1980 was revised to 1990 onwards due to the availability of online resources. As a result, the international search was of English language studies published between 1990 and 2011. Further criteria were set in the advanced search terms to include articles with participants aged 40 and over.

2.2. Inclusion and exclusion criteria

Only peer review published articles were considered. Grey literature such as conference proceedings, position papers, editorials and dissertations were excluded. Inclusion criteria were people aged 40 and over with ID, carers of people aged 40 and over with ID, and providers of services for older adults with ID.

2.3. Findings

The database search originally identified 532 research articles for review. This was reduced to 451 after the exclusion of gray literature and articles that were not peer reviewed. Health or disability specific papers were removed resulting in 154 abstracts; these abstracts were reviewed by two researchers and adjudicated by a third. This stage saw the exclusion of health related papers: diabetes, epilepsy, cancer, depression, oral health, cognitive behavioural therapy and condition specific papers such as Prader Willi syndrome, autism and Down syndrome. The rationale for this exclusion was to present an overview of aging generally with an intellectual disability. The inclusion of condition specific papers would have distorted the findings due to known health issues for older adults with specific forms of intellectual disability, such as dementia in people with Down syndrome, seizures in Angelman syndrome and sleep disorder in Prader Willi syndrome.

A further three existing literature reviews were added at this stage to provide international context and background information. 157 papers were then reviewed with 102 excluded for not including any older adults (aged over 40) within the sample size. Clinical studies and research into supported employment settings were also excluded at this stage. The majority of the papers (8 in service user, 3 in service provision and 12 in carers sections) were not specific about the youngest age within their range, or began the age span of their sample group before the age of 40. These papers were included on the basis of their upper age range being appropriate.

Despite being aware that this is not a heterogeneous group, we have been unable to account for the level of individuality that is essential in practice and instead have divided the remaining 42 papers into three topics: studies with a service user perspective (13), studies of carers of older people with ID (14) and studies of service provision for older people with ID (15). These 42 papers met the inclusion criteria and are included in this review of caring for older people with an intellectual disability. A further 7 papers provided background information and are included in the introduction for this purpose.

Studies are grouped in Table 1 by topic along with country, theme, method of data collection, sample and key findings.

2.4. Findings

2.4.1. Studies with a user view focus

Thirteen papers in this review discussed aspects of aging with an intellectual disability (ID). The majority (9) of studies used an interview for data collection with 1 [8] of these also collecting data via a carers questionnaire; 2 used focus groups [9,10]; 1 used case studies of people with ID along with carer interviews [11] and one involved a secondary analysis of randomized trial of hand held patient records [12]. The research design of the user views studies reflects the relatively small sample sizes, the smallest having 11 participants who were adults with intellectual disability [9], the largest sample was 201 adults with intellectual disability and their carers who had been participants in the randomized trial [12]. Countries where this user focused research had taken place were UK (Scotland and England), Australia, Republic of Ireland and the US. A common limitation in the reporting of user focused research for our purposes was the lack of detail given about the age of the sample size, therefore the studies we include below included samples with participants from 18 to 62 [9], as well as samples with a mean age of 62.5 [13]. Therefore the limited number of studies we identified with a user view focus, coupled with small sample sizes and often large age ranges suggests that there is an acute lack of attention in the research literature to older adults with an intellectual disability.

The three key themes user focused themes are, concerns about accommodation (5 studies); experiences of services (5); and perceptions of aging (8). A common underlying finding from all user focused themes is that of unmet need.

2.4.2. Concerns about accommodation

Adults with intellectual disability were concerned about current [8,14] and future [15–17] housing placements. Experiences of different types of accommodation varied, with those living at home with family members happier but lonelier [8] but in another study more than half those living in a family home wanted to move out to obtain more independence [14]. Satisfaction in living arrangements included the physical features of an environment, activities available and the staff [8], with a garden and a pet [14] particularly important features for participants in one study. Bowey and McGlaughlin [16] found that older adults with ID were less likely to want to move out of the family home than younger adults with ID and that reciprocity was a feature of these adults living arrangements with older carers. This suggests a need for more focused engagement with older adults with ID rather than wide age range studies. Anxiety about moving into a home in the future rather than maintaining independence at home was reported [15] with more information required to enable both the adult with ID and their carers to make informed decisions and plan for the future [16,17]. The lack of attention to choice and providing information about future options suggests a lack of engagement with the needs of older adults with ID living arrangements.

2.4.3. Experience of services

The primary reported reason for adults with ID to visit the GP was pain [12], however GP service use was less than expected and linked to the age, gender and type of carer who would instigate consultations with GPs reflecting the importance of the carer in the use of services discussed above and below.

One study reviewed focused on adults with ID experience of hospital services [9] they report feelings of anxiety in both the adult with ID and their carers in attending hospital either for day appointments, or for stays in wards that may have practical limitations, perceived stigma and negative comments from hospital staff were also reported, highlighting that for this sample hospital service experience is one of anxiety. The authors argue for an increased use in specialist ID staff to support hospital staff in providing services to adults with ID and improved communication between staff, carers and adults with ID when in hospital.

Judge et al. [15] report on the views of 16 services users as they move from a learning disability day centre as they move towards 'retirement age'. The potential loss of continuity and loss of support was a source of anxiety to service users who were unclear about the change in the service provision they would experience when they moved from the category of adult to older adult.

One study reports on the drawbacks for service users who were moved from a home to the community [11], the aspiration was that adults with ID in the community would be integrated into society and have more opportunities however the reality was that service users had very small social networks due to less contact with family members, and failure to form new relationships in place of those they had in the home.

McCausland et al. [18] report on a range of unmet service and support needs for adults with ID in urban Ireland. They report a lack of basic education and monetary budgeting information and a lack of transport to access available services. Areas where needs were met related to food and daytime activities, however those with more complex forms of ID had more unmet needs. They argue for more lifelong learning for older adults with ID to help them plan and cope with the changes 'retirement' will bring as they move from adult to older adult status for service provision purposes.

2.4.4. Perceptions of aging

Concerns about retirement and the age distinction between 'adult' and 'older adult' in relation to service provision [18] and housing [16,17] are reflected in studies examining perception and understanding of retirement in adults with ID. Judge et al. [15] demonstrate the impact of the perception of aging in adults with ID as being exclusion from previous day care and the risk of moving to a group home rather than remaining independent at home.

Buys et al. [19] explored active aging with older adults with ID and found four levels of understanding of aging; no conception, awareness of physical effects of aging, awareness of need for some preparation for older age and an overall good understanding. They explored awareness of aging and engagement with learning but found no strong relationship between the two. Their conclusion was that more learning opportunities are required to meet different understandings of aging helping to prepare older adults with ID for new challenges ahead. Boulton-Lewis et al. [20] also examined conceptions of aging and impact on hopes for the future. They had similar distinctions of aging to Buys et al. [19] with one additional level of limited awareness. An interesting conception of aging reported by Brown and Gill [10] was that aging was associated with increased disability and ill health. They suggest that a lack of health promotion and awareness needs to be addressed to help people prepare and cope with older age [13]. Different care approaches are advanced by Bigby and Knox [13] who found that older adults with ID wanted to remain active and connected with other people but that being 'retired' reduced their ability to join previous activities.

Table 1

Study, country and key theme(s)	Study method and sample	Major findings
Service user focused studies		
Bigby (2008), Australia Experience of services, unmet need	24 people moving from home to community. Interviews with staff, 20 family telephone interviews and 11 intensive case studies (via repeated visits) with sub-sample of residents. Age 39–68, mean 50.1	• Residents did not form new relationships when moved to community, • Regular contact with family members reduced for some people, • People with ID had very small sized social networks.
Bigby and Knox (2009), Australia Perceptions of aging	Interviews with 16 participants mean age of 62. 5 attending day care programmes	• Being connected with other people and valued by staff and other service users; • Importance of keeping active and doing things, but some had stopped activities they valued as 'retired'. • Participants had sense of purpose but activities decided by others
Boulton-Lewis et al. (2008), Australia Perceptions of Aging	Interviews with 16 older people (mean age 62) and persons care workers/family members.	• 5 conceptions of aging identified: no conception; limited awareness; awareness of aging effects; aging as requiring preparation and overall understanding. • Also examined engagement with learning – low, medium and high and looked at conceptions of aging in relation to engagement with learning. –no strong partnerships between conception and engagement. • Males more active with computers than females.
Bowey and McGlaughlin (2005), UK Accommodation, perceptions of aging	Interviews (service users questionnaire with pictures to enhance involvement) with 41 adults with LD, 51% male, 49% female, age range 20–82. Mean age 44. 50% of respondents aged 40–49.	• Participants aware of future need for alternative housing and support and express concern for family carers (death or ill health) which impacts on willingness to plan for the future or to move. • 83% helped out at home – mutual support, blurring of boundary between carer and cared for. • Fewer want to move compared with study of younger people – most want to stay at home
Brown and Gill (2009), US Perceptions of aging	34 women participated in focus groups. Age 30 or older	• Aging associated with disability by participants.
Buys et a; (2008), Australia Perceptions of aging	Interviews with 16 older people with ID, and carers (family and paid)	• Awareness of some effect of aging (physical) • Requiring preparation (aware of need for future prep e.g. funeral)
Gibbs et al. (2008), UK Experience of services, experiences of older carers	Focus groups (7) – 11 adults with ID (age 18–62), 9 parents and 5 paid carers.	• Feelings of anxiety and fear of hospital and what takes place there, • Difficulties in relation to practicalities of being in (single or shared wards) or attending hospital (admission and discharge) and fear of getting lost, • Perceived discrimination and negative comments from hospital staff
Gorfin and McGlaughlin A (2004), UK Accommodation, perceptions of aging, unmet need	Semi-structured interviews using a housing needs questionnaire with 41 service users aged between 20 and 82 (average age 44). All carers were over 70.	• Services users concerned about future inability to care or death of carers. • Existing mutually supportive relationships continue and some service users start to take on more. • Less service users had a desire to move than in younger groups. Users know they need to plan for future but few have concrete plans – many wanted more independence
Judge et al. (2010), UK Accommodation, experience of services, perceptions of aging	16 semi-structured interviews with older people with LD who were moving from LD day centre	• Importance of being active and day centre provided a social hub • Retirement concept confusing for people who had never worked, desire for continuity rather than change when hit 65 • Desire to remain independent at home rather than be moved into a home when day care stops
McCausland et al. (2010), Ireland Experience of services, perceptions of aging	Used CANDID-S to identify health needs of 75 people with ID over 50. Compared people according to mild, moderate and severe/profound ID. Key workers assisted with interview and completing question for 19 of the sample	• Unmet needs – basic education and monetary budgeting. Also transport • Met needs – food and daytime activities • Higher degree of ID meant more unmet needs
McGlaughlin et al. (2004), UK Accommodation, unmet need	Database from 1996 of 816. Random sample of 120 selected in different settings. In 44 cases proxy respondents were used.	• More than half in family home wanted to move out, while just under half wanted more independence. • Having a garden and pet and proximity to the day centre were all important. • Clear sense of people wanting their own home but given little or no choice with decisions made by others.
O'Rourke et al. (2004), Ireland Accommodation, planning for the future	92 interviews with over 40s about their views of living arrangements. Questionnaire to 103 carers.	• Satisfaction liked to physical features of arrangements, activities and staff. • Dissatisfactions linked to staffing issues e.g. Staff restricting independence, impatience and shortages. • People living with family happier but also lonely.
Turk V et al. (2010), UK Experience of services	Secondary analysis of data from stratified random sample, of adults with ID taking part in randomized trial of hand held patient records. Separate interviews for people with ID and their carers using identical or adapted questions. 201 people with ID and/or carers took part.	• Carers reporting health problems and pain reported by people with ID were factors affecting the consultation to GPs. • Consultation rates were low, 3.2% per annum for women and 2.2% for men. • Increased age, gender (women) and type of carers (paid) were all associated with increased consultations.

Table 1 (*Continued*)

Study, country and key theme(s)	Study method and sample	Major findings
Carer focused studies		
Bigby et al. (2002), Australia Specialist versus generalised care (service theme) Planning for the future	Semi structured interview with random sub set of 20 people with ID and parallel interview with each person's case manager. Telephone survey with random 10 of 99 who attended community education session within the programme. 4 interviews conducted with personnel who designed the programmes.	• Pro-activity seen as important as was a dual emphasis on maintenance and change for the carers and adult with ID. • A significant outcome of the programme was the preparation for the future, planning for separation from carers and their subsequent letting go which was important as availability of accommodation and a move happen in a very short space of time.
Bowey et al. (2005), UK Planning for the future	Five focus groups with professionals and carers, one focus group with older carers, aged over 65.	• For all carers and professionals, risk was the biggest concern when considering independent housing. • Relationships between carers and professionals and between professionals could cause barriers. • Suggestion that older carers had better knowledge of services and that they believed family member would not want to leave family home.
Bowey and McGlaughlin (2007), UK Planning for the future	Interviews with 56 older carers (aged over 70) of adults with ID and 6 more completed a survey	• 34–55% of older carers unable/willing to make plans for the future. • There was a lack of confidence in housing options.
Carmeli and Merrick (2010), Israel Planning for the future	Focused on people with ID aged 40+ with special attention to DS. Data collected on 794 people with ID from formal services and carers including 20 in-depth interviews with key informants. 3 × 6 h long multidisciplinary focus groups including family carers.	• As person with ID ages less family contact. • ID severity linked to lower ADL • Leisure activities decline for older ID
Dillenburger and McKerr (2010), UK (Northern Ireland) Planning for the future, experiences of older carers	Semi-structured interviews with open ended questions with 29 carers of people with LD followed by GHQ-12. Average carer age 65.17, average age of people with LD 33.48 (range 12–59)	• Themes in findings were: everyday positives and everyday challenges; caregivers physical and psychological health; family social and agency support; futures planning. • Few relied on non-family for help, day care most common service. • Few had made concrete plans for the future. • Aging of carer a problem and concern for future.
Eley et al. (2009), Australia Fear of the future	Mixed methods: open ended survey questions (146 carers and 156 ID) and semi structured interviews with adults with ID and their carers. ID mean age 37.2 but 18–79 range. 10 carer interviews and 10 ID interviews, then 'saturation' reached. No age given for those interviewed. Only 19 over 50 in total sample.	• Family environment important from carer point of view. • Living away from home transition difficult, level of care good if competent staff, bad if low staffing levels and training needs
Gilbert et al. (2008), UK Fear of the future, planning for the future	28 unstructured interviews with main family carer or carers if two involved in caring (over 65). Person with ID may also be present (ages not given).	• Findings suggest a need for information about housing options, a lack of practical support and feelings of marginalization. • Carers who are still coping don't make provision for the future, those who have experienced ill health made more aware of need for planning. • Mixed views of professionals, mainly negative views of residential care. Levels of support decline over time.
Llewellyn et al. (2010), Australia Experiences of older carers	Conversational style interviews with 64 older carers in their own homes, in addition participants completed scales: Health status (using SF-12), caring stress (CADI) and coping strategies (CAMI) and a demographics questionnaire as well as analysis of social support network and care-load. Average of people with LD was 38	• Health status did not differ from population norms except for carers 55–64 years who reported significantly poorer mental health. • Better health associated with having a partner, a larger and close network of support and a lower care-load. • Carers identified stresses and satisfactions of caring. Common sources of stress were loss of control and poor professional support.
Mansell and Wilson (2010), UK Fear of the future	Members of a parent/carer federation were sent a semi-structured questionnaire and 151 out of 647 responded. Aged 25 – over 64 (19.2%). Age of those they cared for ranged from 4 to 67. Two focus groups with 15 carers who had completed the questionnaire. Age 25–75	• Issues identified as important by carers: help accessing services or professional help, respite care, independence for person with ID, anxiety about the future, other and problems with educational provision. • Focus groups dominated by discussion on anxiety about the future. • Fears were about: inappropriate placements, financial concerns and what will happen when I am no longer here to care.
McConkey and McCullough (2006), UK (Northern Ireland) Retirement (service theme) Planning for the future	Individual and group interviews with over 100 people with ID and from carers completing self completion questionnaires. (Not clear about ages covered)	• Carers less able to accompany on holidays as they age. –or at least not the type of holidays that people with ID want. • Those carers who did not get a break had poorer mental health.
McConkey (2005), UK (Northern Ireland) Planning for the future, experiences of older carers	Survey completed by member of staff deemed to know family best about 1584 people with ID over 20 years of age.	• Older people with ID may be under-counted in Northern Ireland • Over half of carers report a degree of ill-health and 71% of carers had no other dependents at home • Indication that older carers (over 75) have less access to day care but more use of domiciliary care
McGrother et al. (1996), UK Experiences of older carers	Data is from interviews undertaken by health authority when individuals register on the Learning Disabilities register. Paper includes data from interviews conducted between 1987 and 1993 including 2117 adults with ID.	• Numbers of people of different ages living at home or in residential care - older people were more likely to be in residential care. • Fairly consistent prevalence of older people with ID in the UK since 1960s is shown.

Table 1 (*Continued*)

Study, country and key theme(s)	Study method and sample	Major findings
Prasher et al. (1995), UK Experiences of older carers	Secondary analysis of existing data from learning disability register. Study population was individuals living in family home and aged 10 years or older from 1985 to 1993 and included over 2800 people with ID.	• People living with a single carer were significantly older than those living with two carers. • Most single older carers are women. • Suggest that day services more appropriate for older people but not clear from data presented.
Prosser and Moss (1996), UK Experiences of older carers	Semi-structured interviews with the main carers of 32 people with LD over the age of 40 (mean age 46.7) who lived at home or had very recently moved (within the past month) Ave age of carers was 74.	• Siblings seldom provide personal or household support unless they are the main carer or main carer is ill. • Most people with ID attended day care and carers had some contact with a social worker. • Carers found to be very independent and proud of this. Some evidence on mutual support between carer and person with ID
Service focused studies Bigby et al. (2008), Australia Accommodation needs	Survey of 826 directors of residential aged care facilities seeking info about residents with ID. 286 responded. – 35% response rate.	• Residents with ID in generic aged care were younger than general population, and remained there for longer. • 60.7% were classed as having high care needs and came to care home from the family home suggesting a reliance on care homes earlier in life cycle than other older people. • Concerns raised about service offered, inability to fit in with older residents, lack of participation in activities and lack of meaningful relationships.
Cleaver et al. (2008), Canada Accommodation	Proxy response telephone survey with 128 people who knew person aged 45+ with ID well.	• People with mobility problems had 3.6 times greater chance of living in high support settings • High prevalence of walking problems in high support settings • Inverse relationship between behavioral problem and mobility limitation
Cooper (1997), UK Staff training	134 participants from the Leicestershire Learning Disabilities Register aged 65 and over. Random sample group also of 81 adults aged 20–64. Semi-structured psychiatric assessments	• Older people received less day care and less respite care, were less likely to have a social worker, less likely to receive health service input than younger group. • Needs were better assessed by services for those in residential care. • In learning disability settings morbidity attributed to old age, in aged care setting s it was due to the person having ID
Dodd et al. (2009), Ireland Specialist versus generalised services	Two part study using the National Intellectual Disability database to look at the number and characteristics of older people outside (2668 people aged 30+ (*n*=43) services. Second stage was questionnaire to look at contact and assessment procedures with those listed as not requiring specialist service	• 2780 (10.4%) individuals can be classified as being outside services. • Two thirds have been outside services for at least five years • For these not accessing any services, poor assessment practices were highlighted including significant periods of time passing between contacts with the individual and limited contact regarding service planning.
'Hogg et al. (2007), UK Accommodation	142 children and adults surveyed in 1993 in one Scottish region, data collected using postal questionnaire. This was followed up in 2003 after period of significant policy change.	Findings noted in relation to older people: • 21% had died. • In line with policy all those in institutions had left, some to community others to care or nursing homes. Proportion living at home increased from 33% to 40%, group homes from 6.3% to 15.5%.
Jenkins R (2009), UK Specialist versus generalised service	Case studies developed around 6 older people with ID, at least one from the age band 44–54, 55–64, 65–74. 75+ followed by 2 focus groups with learning disability and mental health nurses, 17 nurses in total	• Some services are not prepared for older people with ID, not are services appropriate. • Little specialist provision for older people with ID • Little clarity in policy over planning for people aging with ID
Lawrence and Roush (2008), Ireland Retirement	Postal survey with closed and open questions from each ID service in Ireland (8 health board regions. Of 144 organisations, 22 were excluded as they did not provide services for adults with ID. 59% response rate	• Clear ongoing demand for retirement related ID services but lack of clarity over the concept of 'retirement' for people with ID. • Lack of knowledge base in how best to support the development of a retirement policy • Lack of retirement and pre retirement educational programmes for older people with ID.
Lin et al. (2011), Taiwan Specialist versus generalised services	54 institutional managers in Taiwan, self competed structured questionnaire. The managers all worked in educational setting, training centres, workshops, residential care and rehabilitation centres.	• More than 90% saw early onset ageing in people with ID • Government policy considered inadequate to meet needs • Existing institutions and services did not meet need satisfactorily and that their institution did not meet their needs appropriately.
Maes and Van Puyenbroeck (2008), Belgium Accommodation	Questionnaire completed by 66 staff in services for people with ID, supporting 310 (27%) people with Down syndrome aged 40 and over, and 833 (73%) people with ID (not DS) aged 55 and over.	• Changes in accommodation (modification) and management were evident in two thirds of respondents. • Staff/client ratio required to be higher as clients aged • Only 20% of staff had received training in caring for older people with ID
Merrick et al. (2010), Israel Staff training	National survey of all residential care centres for people with ID aged 40 and over, 2283 individuals were included	• Many people with ID live with older families who are also experiencing age relate decline. • Older people with ID have same age -related health needs as others but differences in communication can delay intervention • Social, housing, work and medical needs should be addressed

Table 1 (*Continued*)

Study, country and key theme(s)	Study method and sample	Major findings
Powrie (2003), UK Staff training	Postal survey of 17 practice nurses in Grampian area of Scotland in June 2001.	• Communication barriers exist preventing access to health screening and treatment for some people. • Ethical issues found over supporting people in the community over lifestyle choices such as overeating or alcohol consumption • Primary care providers would benefit from closer working relationship with ID specialist staff
Shaw et al. (2011), Australia Accommodation	Focus group and individual interviews with 15 people with ID who work in supported employment and with 10 family carers	• Carers and people with ID expressed preference to live close to, or with, peers as they age • Living alone, or in smaller community groups, as not a preferred option for the majority of carers who preferred larger groups • Carers maintained that general residential aged care was not an appropriate service
Webber et al. (2010), Australia Specialist versus generalised services	10 group home supervisors were interviewed for between 30 and 60 min. Open questions initially with structured at end of interview. Some had responsibility for more than one home.	• Belief that at some point residents would need more skilled care as they aged. • Residents were not included about decision whether to move or not – it was assumed that they did not want to move. Group home supervisors were primary decision makers. • Additional equipment and staffing were reported to be the most important resource to enable people to age in place.
Bigby et al. (2002), Australia Also in carers Specialist versus generalised services	Evaluation report of twp pilot programmes for older families, 44 of 55 clients responded. Semi structured interview with random sub set of 20 to look at expectations, experiences and satisfaction. Parallel interview with each person's case manager. Telephone survey with random 10 of 99 who attended community education session within the programme. 4 interviews conducted with personnel who designed the programmes. (Aging carers and 'middle aged' children)	• Dual emphasis on future changes for the carers and adult with ID. Maintenance of the current situation involved reducing stress on carers • A significant outcome of the programme was the preparation for the future, planning for separation from carers and their subsequent letting go including replacing parental role with external services. • The quality, availability and accessibility of out of home services was crucial to ling term planning
McConkey and McCullough, Ireland, (2006) Also in Carers Retirement	209 postal questionnaires returned Individual and group interviews with over 100 people and carers plus self completion questionnaires (Ages not specified)	• Carers are less able to accompany their adult child with ID on holidays as they age – or at least not the type of holidays that the person with ID wanted. • Carers who did not get a break had poorer mental health. • Carers reported more benefits to person with ID in later years of the project as both parties aged.

Their participants had a sense of purpose and desire to remain active but the decision about activities were made by others.

2.4.5. Unmet need

Unmet need is a common theme underpinning the user focused research included in this review. Adults with ID were often given limited or no choice in where they might live now [14] and also a lack of attention given to help adults with ID prepare for where they might live in the future as they approach the service defined 'old age' or 'retirement age' category [17]. A similar lack of attention to choice is illustrated in experiences of service provision with adults with ID being moved from a home to a community setting [11] due to changes in policy promoting community based services that actually led to isolation and lower levels of social engagement for service users. This reflects an apparent lack of concern of service providers with matching accommodation to the needs and preferences of adults with ID despite carers and adults with ID having clear concerns and views about future living arrangements.

2.4.6. Carers of older people with ID studies

Fourteen studies reported on the views of carers of people with ID. A range of data collection approaches were included, many utilising mixed methods, including: interviews (2); interviews with surveys (5), focus groups (1) or psychometric scales (2); surveys (1), surveys with focus groups (1); focus groups (1); and secondary analysis of existing data sets (1). A range of sample sizes were reported from large scale studies looking at populations in a given area with sample sizes of 2000 and above [21] to smaller studies where a sample of carers were interviewed, for example, 28 in Gilbert et al. [22]. The majority of studies were undertaken in the

UK (10) including 3 from Northern Ireland, the other studies were from Australia (3) and Israel (1). It was not always clear what the ages of participants were as these were either given as a range such as 12–59 [23] or an average age [24]. Most papers (10) reported the experiences of older carers, usually those over 60 or 65 but did not give the age of those they were caring for [23,25] while other research (2) reported the views of younger carers about the future [26,27].

Three key themes emerged from the literature: fear of the future (3 studies), experiences of older carers (6 studies) and planning for the future (8 studies).

2.4.7. Fear of the future

Carers, of all ages, of people with ID do express uncertainty and fear about the future [26,27]. These fears include financial concerns, fear of inappropriate placement for the person with ID and fear of what will happen when they are no longer there to provide care [27]. Eley et al. [26] review accommodation needs for people with ID in Australia and stress the need for the government to recognise the changing needs of people with ID as they age, they identify a need to ensure people are supported to be independent, as nursing homes are deemed inappropriate by carers. Transitions from the family home into residential or supported living often occur at a time of crisis for people with ID, following the death or illness of their main carer [22,28].

2.4.8. Experiences of older carers

Three studies report on the demographics of older carers and show that people with ID living with a single carer were older than those living with two carers, and most single older carers

were women [29,30]. It was also found that people with ID are increasingly likely to live in residential accommodation as they age [21].

Llewellyn et al. [24] found that older carers did not have poorer health than population norms and found that better health was associated with having a partner and a large and close support network as well as a lower care load. Older carers were found to be self-reliant and reported experiences of poor professional support [24,31]. However, other studies such as McConkey [31] find older carers have high levels of ill-health, over half of the sample in their study.

Older carers face both stress and satisfaction with caring with both affecting their own health [23]. Professional support and available services also added or reduced to the stresses of caring [24]. As Llewellyn et al. [24] point out, older carers are often very self-reliant and find support from other family members. Older carers are proud of their caring role and very independent [31]. Research focusing on user views finds that older carers provide crucial support for those they care for. Gibbs et al. [9] highlight their importance during hospital visits. Prasher et al. [29] call for wider recognition of the contribution of older carers who may have health problems or disabilities themselves.

2.4.9. Planning for the future

Older carers were often found to be unwilling or unable to make plans for the future or just simply had not got round to it especially those who were still coping well [23,32]. There is a suggestion that those who have experienced ill health are more aware of the need to plan ahead [22]. Many were fearful of what may happen in the future. Other studies suggest that older carers believe the person with ID would prefer to stay at home as they have lived there a long time [25]. Another reason for not planning ahead was a lack of confidence in the housing options available, perhaps after a poor experience during respite for the person with ID [8,22,32]. Risks associated with independent living were a concern for carers and professionals when planning for the future [25].

Research suggests there is a lack of available information about housing options and not enough practical support to raise awareness of options among older carers for those that they care for [22]. Older carers reported negative experiences of professional support that could add to the stresses of caring and cause barriers to change [24,25]. In one study it was suggested that older carers had more access to domiciliary care but made less use of day services [30] but in others more use of day services was found [23,31]. One paper suggested that older carers may have better knowledge of available services due to the length of time they had been caring [25]. Most older carers rely on other family for support [23]. Older carers may be less able to provide support for activities such as holidays as they age although still benefit from respite when offered [33]. Studies call for more tailored services for people with ID and their carers [33,34].

Older carers need proactive support with planning for the future [22,32]. Bigby et al. [28] describe a successful programme that supports transition for people with ID out of the family home. The programme provides proactive support for the carer and the person with ID to plan ahead and prepare for the separation, for example, through using taxi vouchers and having weekends away.

2.4.10. Service provision focused studies

15 papers in this review discussed issues from a service provider perspective. The majority (9) used a postal survey for data collection, with one additionally collecting data from a national disability database [35]. 3 involved focus groups, 1 in addition to semi-structured interviews [36] and 1 in addition to case studies [37]. 2 used telephone surveys [28,38]; 1 used psychiatric assessments [39] and 1 used face to face interviews [40]. The predominance of

postal surveys reflects the larger sample size with number ranging from 10 participants [40] to over 2000 [6,41]. 9 articles had a sample size of over 100. 3 articles defined the age range of older adults with ID as beginning under 40 [35,39,42]. These were included as their sample range spread from 30 or 39 to over 60 in each paper, again suggesting a lack of attention to the definition of an older adult with ID. Countries represented by the service provider focused research are USA, UK (England, Scotland and Northern Ireland), Belgium, Republic of Ireland, Taiwan, Israel and Australia. The range of staff interviewed included key workers and managers from group homes and supported accommodation (6), nurses (2), carers (3), health board managers (1), social work care managers (1) with 2 papers taking data from an existing disability register or national database.

The four key themes that emerged from the research literature about services for adults aging with an intellectual disability are: the debate over specialist or generalist services as people age (5), accommodation (5), retirement from day services (2) and staff training (3).

2.4.11. Specialist versus generalized services

In 1997 Hogg [43] questioned whether if, by the early 21st century, we may see less need for ID specific services as the effects on inclusion would mean that people with ID were less visible as a separate group with specialist needs. Research literature suggests that the opposite has happened with seven papers supporting a specialist service for people aging with an intellectual disability [8,9,28,35,37,39]. Jenkins [37] extended this to specialist services within hospitals to address not only health related needs but also the social and emotional experience for the older person with ID in a hospital setting. Without such specialist services, changes experienced as part of the aging process were attributed to 'old age' in ID settings whereas in generic older people services it was consider to be due to the person having an intellectual disability.

The similarity or difference in the aging process for people with ID compared to older people generally remains open to debate. This was discussed by a further 2 articles [39,41] both maintaining that some of the biological process of ageing is similar whether the person has an intellectual disability or not, with the exception of specific associate conditions such as the aforementioned dementia and epilepsy. Lin et al. [44] reported a different aging process and experience to that of the general population. Where there is consensus is over the planning that is required for later life care. This includes the importance of understanding individual perspectives and the role that leisure has in facilitating a healthy lifestyle.

The move towards specialist services has occurred in the face of an increasing trend of independent living and community inclusion suggesting that such an approach may need reassessed if it is to meet the needs of people with ID as they age.

2.4.12. Accommodation

The dilemma over the future accommodation of people with ID has not been satisfactorily resolved. Seven articles make suggestions including the family home, supported group living, independent living with outreach support and generic care for older people. The location varies from dispersed communities to out of town care homes and urban settings although with consistency over the need for age related adaptations [8,11,42,44,36,45,46]. For many older people with ID a crisis point is reached in their forties or fifties after the death or illness of a family carer.

Aging in place, the option to remain in the person's home of choice with appropriate support, is seen a crucial in Australia for people with ID as they age [11] recognizing that many people move prematurely to a facility for older people. This is viewed as an inappropriate placement for older people [42] often remaining there for longer due to their younger age on admission.

Literature highlighting the service provider perspective does not focus on how much choice the person with ID or their carer has over their accommodation or any planned changes.

2.4.13. Retirement from day services or activities

2 papers reflect a concern about the lack of daytime activities after a person with ID reached retirement age [34,47]. Despite increased knowledge of this aging population, there is no preparation evident for this eventuality. Even the term retirement itself is not clearly understood in relation to people with ID, it is often more associated with declining ability rather than age, which means some are 'retiring' at a considerably younger age than others. If someone is not in employment they will be not be officially retiring, yet people with ID are still placed in this category despite not having access to older people's services generally.

2.4.14. Staff training

The importance of staff training, and the provision by staff of relevant age related information, was emphasised in 5 articles [8,9,34,39,46]. Specific issues included the importance of staff training alongside environmental adaptation as people aged, changing staff attitude to support people to age in their own accommodation. Powrie [48] featured the importance of training for hospital based staff specifically and the need for a closer partnership between heath and ID services.

3. Discussion

It is clear that the needs of older people with ID are not well met within current frameworks for care and support. This is due to a number of factors: first, there is a lack of appropriate services and accommodation; second, staff lack specialist knowledge of the needs of older people with ID; and third, the somewhat artificial concept of retirement for this group who may lose access to services, particularly day services, when they retire.

Evidence from service focused literature coupled with findings about the fears of older carers suggests that current services, particularly residential placements for older people with ID are not appropriate. Older people with ID may be placed in generalist homes for older people that may not meet their needs [42]. There is some evidence that staff within generalist settings may assume that aging processes are part of the ID therefore the individual may not get appropriate care and treatment [37]. Health services were particularly neglected within the literature and one study on hospital services [9] highlighted the fears of people with ID and their carers. There is also a need to develop better accommodation choices for older people with ID that allow them to live among peers [36] and close to family and friends. There are calls within the literature for more specialist services for older people with ID and their carers [34].

When someone with ID reaches an older age, relationships with carers are long standing and have often evolved into mutually supportive relationships that are valued by individuals and their carers [31]. Both people with ID themselves and their family carers report fears for the future as they age, these fears are often about what will happen when carers are no longer able to care and are exacerbated by a perception, that current service options are not appropriate [32]. These fears along with a lack of professional support often result in a lack of forward planning. Transitions, therefore, often occur at a time of crisis such as the death of the main carer. Proactive support is called for to help people plan for future changes in living situations. There is also a need to further recognize and support the contribution of older carers.

Staff need more training to prepare for working with older people in the context of 'aging in place' to enable them to

support people with ID and continue to meet their changing needs as they age. Older carers report negative experiences of professional support that can cause barriers to change as people age [24]. It is not only professionals that need training and support as education and information for carers and people with ID about getting older is also needed [10]. People with ID vary in their understanding of the ageing process and its impact on their lives [19].

For many people with ID retirement is a meaningless concept as they have never been in employment, instead this may mean a loss of day time activities as they move from adult to older adult services [47]. People with ID report anxiety about retirement relating to a loss of continuity and uncertainty about what changes will take place [15]. McCausland et al. [18] suggest more lifelong learning opportunities are needed for people with ID to help them plan for the future. For those living in community settings following retirement there will be a need to support social networks to avoid loneliness and isolation.

Further research is needed that engages directly with older people with ID and their carers including those from under-represented groups such as black and ethnic minority communities and people with profound and multiple ID. There is also a lack of evidence based research and evaluation of different service settings; health care is an area where the evidence base is particularly sparse. Within the literature reviewed there is a lack of adequate sample definition and small sample sizes limit the strength of reported findings.

In conclusion, older people with ID experience a range of unmet needs within current service and support models. Most services reported within this paper do not respond to the needs of older people with ID and their carers although there are emerging models of good practice that could be built upon. Key needs identified include providing support and education for forward planning and offering more appropriate choices for accommodation in later life. The literature reviewed further demonstrates that there is a lack of robust research evidence concerning the lives of older people with ID and a need for more research that directly engages with older people with ID and their carers.

Contributors

Anthea Innes reviewed abstracts and papers, contributed to conceptualization of paper outline, contributed to writing including overall integration. Louise McCabe reviewed abstracts and papers, contributed to conceptualization of paper outline, contributed to writing. Karen Watchman conducted database search, reviewed abstracts and papers, contributed to conceptualization of paper outline, contributed to writing.

Competing interest

The authors confirm that they have no competing interests to declare.

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