

How to improve the quality of life of elderly people with intellectual disability:

A systematic literature review of support strategies

## **Abstract**

**Background:** The increased life expectancy of people with intellectual disability (ID) intensifies the need for age-specific support. Research on the effects of support strategies on the quality of life (QoL) of these people remains scattered. **Methods:** A systematic search of peer-reviewed publications since 1995 was performed, with participants having ID and being aged  $\geq 50$  years. Studies include experimental, observational and exploratory designs that analysed the links between support strategies and QoL outcomes. We adopted a narrative approach. **Results:** We found 73 articles, assessed their quality, thematically categorised the interventions into 12 themes, and listed them with their stated relationships to the elderly persons' QoL. **Conclusions:** The studies indicated the importance of funding, provision and organisation of services/personnel, education, and cooperation among different systems of support. The provision of good housing or activities, support when these provisions change, provision of (mental) health care, dementia care and end-of-life care, life story work, future planning and support for (instrumental) activities of daily living ((I)ADLs) are crucial.

*Keywords:* ageing, elderly people, intellectual disability, quality of life, intervention, systematic review

## **People with Intellectual Disability during Ageing**

People with intellectual disability (ID) are living into old age for the first time in history (Bigby, 2004). Their changing needs challenge caregivers, who aim for the best quality of support. Compared to elderly people without lifelong ID, ageing people with ID have experienced very different life course trajectories, and many have been excluded from society (Bigby, 2002; Foster & Boxall, 2015; Laplante, 2014). Few persons with ID have children to care for them, and many continue to be supported by very old parents. When these parents move to elderly care or die, it can lead to crisis moves, inappropriate placement, sudden loss of lifelong networks and a process of grieving (Bigby,

1996). Some of these people with ID have lived since childhood in residential services, where they rely on often-changing professional support workers for their daily care (Foster & Boxall, 2015).

Although elderly persons with ID report being quite content in their old age (Lehmann et al., 2013), they do suffer great losses in their networks when they move to or within residential services, leaving preferred activities or well-known caregivers behind (McCausland, McCallion, Cleary, & McCarron, 2016). Their abilities decline, and many experience limitations in going out (Evenhuis, 2012). Most retirees have not worked in regular, well-paid jobs and do not have savings or regular pensions (Bigby et al., 2014). They often depend on others for transportation, the organisation of their lives, activities, finances and housing (Bigby, 1996).

Similarly, while many elderly persons with ID age in a healthy manner, a disproportionate number show more age-specific deficits at younger ages. Early frailty arises due to impairments as consequences of lifelong disability or new (advanced) age-related problems (Schoufour et al., 2014). These problems are caused by biological and environmental factors, such as unhealthy lifestyles or inadequate access to (preventive) health care (Fesko, Hall, Quinlan, & Jockell, 2012; Janicki, 2010; World Health Org., 2001).

The aforementioned needs pose specific threats to the quality of life (QoL) of elderly people with ID. This systematic literature review is the first to examine and to provide an overview of the QoL-supporting strategies and their effects on QoL of this targeted group.

### **Quality of Life: An Operational Model**

What, then, is good quality of life? To discover its building blocks, we first examined the gerontologic concept of active or successful ageing (Fesko et al., 2012); the World Health Organisation declared that ID policies in developed countries should focus on 'productive or successful ageing' (World Health Org., 2001).

Active ageing means that, after retirement, ageing people (with ID) continue to lead a meaningful active life within their communities (Fesko et al., 2012). Bowling and Dieppe (2005), Depp and Jeste (2006) and Laplante (2014) described how elderly people need to feel safe, determine

what they want to do, be involved in meaningful leisure activities and continue to learn or challenge themselves. They want to contribute to their communities, maintain important relationships and networks, and age in a preferred place in a healthy manner. They like to be relatively free from emotional stress or disease and to experience increased longevity, QoL and life satisfaction whilst remaining functionally able. Physical, psychosocial, material and existential aspects are part of this concept. As such, 'active ageing' at this time combines elements of productive ageing, mental and physical well-being and quality of life (Walker, 2015).

Second and complementary to the concept of successful ageing, this review adopts the QoL model proposed by Schalock and colleagues (Schalock, 2004). The model has major benefits: it is discernibly linked to existing needs theories and the concept of active ageing; it is multidimensional; and it matches the current supports paradigm. The model has been well described, researched and validated in the field of support for people with ID (Deci & Ryan, 2000; Gómez, Peña, Arias, & Verdugo, 2014; Tay & Diener, 2011). We upheld the eight QoL domains to further organise QoL outcomes (Buntinx & Schalock, 2010; Schalock, 2004; Schalock et al., 2010). The domains are emotional, physical and material well-being (elements of the Well-being Factor); personal development and self-determination (elements of the Independence Factor); and interpersonal relationships, social inclusion and rights (elements of the Social Participation Factor). Additionally, we explored the relevance of a possible domain of 'Existential/spiritual Well-being' (Power, Quinn, Schmidt, 2005; Raphael, Brown, & Renwick, 1999; Renwick & Brown, 1996), which is said to be particularly important for ageing people, who examine their past lives and ask questions about the afterlife (Marcoen, Grommen, & Van Ranst, 2006).

### **Where Does Support Fit in? A Programme Logic Model**

With ageing and to attain good QoL, (lifelong) support for people with ID must change in nature and frequency (Simões & Santos, 2016; Simões & Santos, 2017). Support influences QoL outcomes in many complex ways. A so-called 'programme logic model' presents these outcomes, factors and their relationships (Wasserman, 2010). Our review co-opts the simplified scheme proposed

by Claes (2011) to organise the results. The model includes input variables, process variables, and short-term and long-term effects.

Input variables are personal characteristics or contextual factors that do not easily change (e.g., age, severity of ID and adaptive behaviours, support needs or having family alive). They influence the support needed and QoL outcomes.

The review focuses on QoL-influencing process variables (throughput factors): resources, support strategies, interventions, and organisational services. These processes have short- and long-term effects and are comprised of governmental decisions (macro level), organisational strategies (meso level) and individual support (micro level). The patterns and intensity of support should be adequately fitted to the support needs of a person to achieve QoL (Buntinx & Schalock, 2010). QoL outcomes should in turn steer the interventions that caregivers undertake (Schalock & Bonham, 2003; Schalock et al, 2018).

The increase in lifespan has challenged the development of QoL-enhancing support by paid and non-paid caregivers as new issues arise. What preferences do older people with ID have regarding their later lives? How do they transfer well from working life to a retirement lifestyle, and what types of activities do they want to engage in? How can they remain part of their social network or become part of a new one? What (mental) health issues arise, and how will they pay for their support? Where is the best place to age, and how can dementia care and end-of-life care be organised in the best way possible (Bickenbach et al., 2012)?

### **What Works?**

The Graz Declaration on Disability and Ageing states that, given the “predicted growing numbers of elderly people with ID, we can expect similar augmentation in support needs” (Weber & Wolfmayr, 2006). Nonetheless, families and disability services remain ill prepared for the ageing of their relatives or clients, as it is with the regular elderly care when old persons with ID arrive and the legislation that, in most parts of the world, delineates strictly separated paths for either disability or elderly care (Bigby, 2002; Brown, 2012; Foster & Boxall, 2015; Innes, McCabe, & Watchman, 2012;

Weber & Wolfmayr, 2006). The World Health Organisation recommends not ignoring this growing group since it challenges governments and non-governmental organisations to rethink policies, funding, planning and specialty care programmes for elderly people (World Health Org., 2001).

At this time, evidence has expanded on the specific changing needs of elderly people with ID, as well as on the building blocks of QoL. The programme logic model clarifies that specific, good-quality support strategies are crucial for QoL, but little is known about the specific strategies that have impact on particular QoL outcomes of these elderly people. What support strategies are effective to improve their quality of life (QoL)? An overview of the empirical research performed on this subject would provide much needed answers for practice and policy.

The main research question of this review was therefore: “Which support strategies and support interventions can be identified and classified as having influences on QoL outcomes for elderly people with ID?”

## **Methods**

We adopted a pragmatic research approach (Savin-Baden & Major, 2013) and collected data through a systematic literature review (Boland, Cherry, & Dickson, 2014; Matheson, Jesson, & Lacey, 2011; Moher, Liberati, Tetzlaff, & Altman, 2009).

## **Inclusion and Exclusion Criteria**

Articles were included if they met the following criteria.

- Participants in the study had an ID, defined as an IQ < 75 or required ‘lifetime support because of difficulties with learning and adapting’ (<http://aaid.org>).
- Participants in the study were  $\geq 50$  years of age. The original, gerontology-derived criterion of  $\geq 65$  years old ( $\geq 50$  years old when Down syndrome or Profound Intellectual Multiple Disabilities (PIMD)) was lowered since the large body of (older) research uses this relatively low age-criterion. Without including these articles, much of the relevant literature would have been omitted. Furthermore, few researchers distinguish between ageing people with or without Down syndrome or with different levels of ID.

- An explicit and strict link was made between variables of (quality of) care/support and QoL outcomes. On the ‘support-side’, strategies or interventions were considered in the broadest sense. Strategies are all practices or policies that caregivers or policy makers implement for ageing people with ID (Schalock et al., 2010). On the ‘outcome-side’, QoL was defined by the eight domains that Schalock (2004) described, plus an additional domain of ‘Existential/spiritual Well-being’. In addition, concepts such as ‘healthy ageing’, ‘subjective well-being’, ‘health-related well-being’ or ‘active ageing’ were considered QoL outcomes. Similarly, we included articles mentioning heightened or lowered mortality rates since medical interventions rarely discuss QoL in itself, and at death, one’s QoL disappears.
- The articles presented original, peer-reviewed, English, Dutch, German or French research, all with English abstracts and keywords.
- The articles were published between January 1995 and August 2017.

### **Search Strategy**

The ERIC OvidSP, MedLine OvidSP, Sage Journals online, Elsevier Science Direct, Elsevier Scopus, Proquest, and PubMed databases, all Ebsco databases and Web of Science (including Social Sciences Citation Index and Conference Proceedings Citation Index – Social Sciences & Humanities) were searched. LIMO, the electronic search platform of KU Leuven, served as the direct entry to the databases. The search combined keywords on: a) ‘ageing’ (aging, old, elderly, later life); b) ‘intellectual disability’ (mental/developmental/learning disability, mental handicap, learning difficulty, retardation); and c) ‘quality’ (of life, of care, well-being, active/successful/healthy ageing, frailty). No keywords referring to ‘intervention’, ‘strategy’ or ‘programme’ were used: a pre-search revealed that few articles explicitly mentioned such keywords.

Systematic reviews, expert opinions, and reports from symposia, although excluded, were read during the assessment for the eligibility phase, yielding 14 additional, possibly relevant articles found via their references (11 articles during the 2015 search, 3 during the 2016 and 2017 searches). Of these 14, we included 3 additional articles (Carmeli, Merrick, & Berner, 2004; Craig & Bigby, 2015; Hermans & Evenhuis, 2012).

Since the first search was performed in 2015 (61 articles included), a second search on July 26, 2016, and a third between July 5 and 12, 2017, retrieved another 66 eligible articles for August 2015 to July 2017, of which we included 12 and were not able to find one full text. In total, we included 73 articles. Figure 1 presents the search flow.

[Insert Fig. 1]

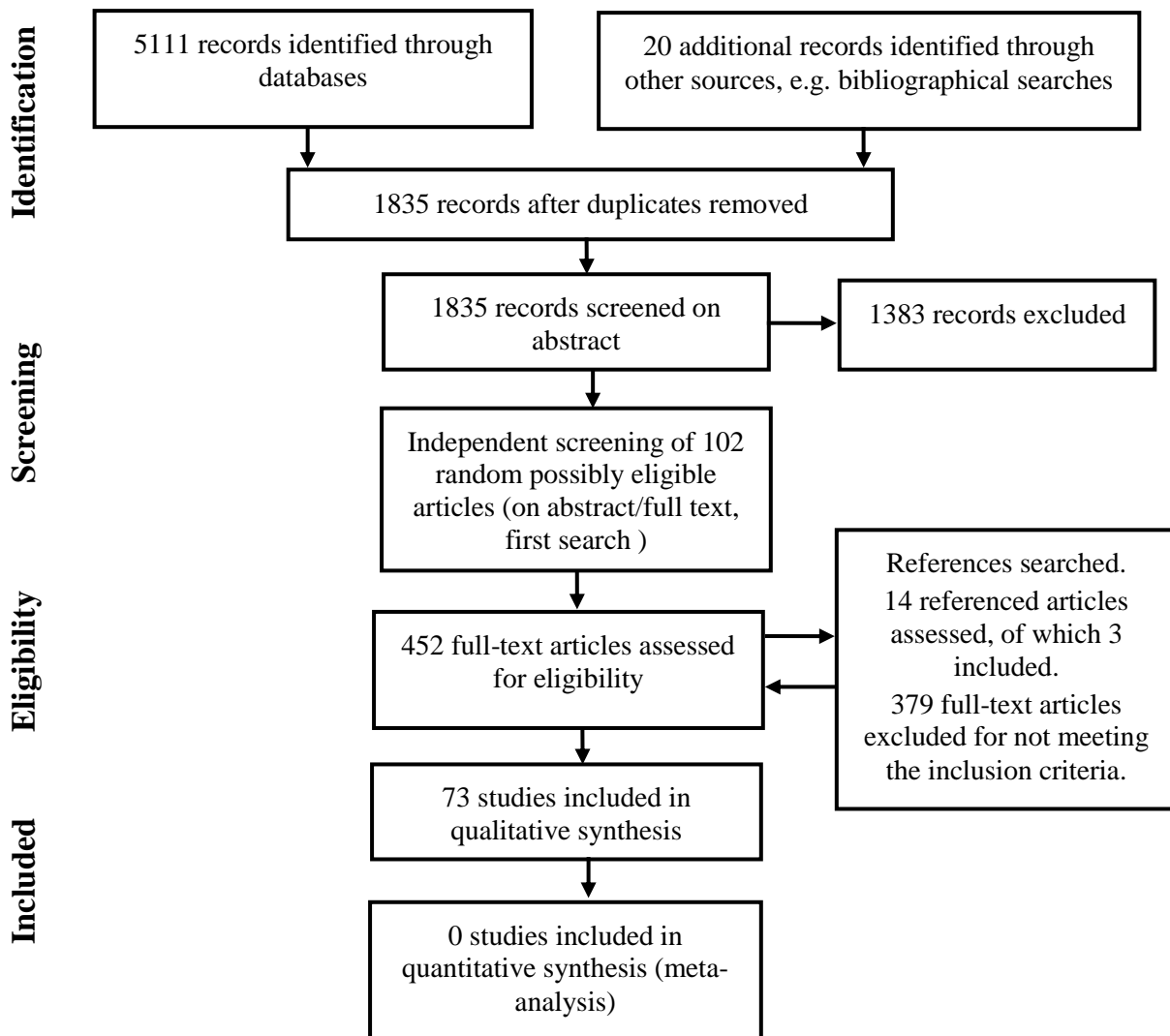


Fig. 1. Flow diagram of the literature search (PRISMA, Moher et al., 2009)

### Quality Assessment (QA)

To evaluate the studies' quality, we consistently used the Evidence Based Library (EBL) Critical Appraisal Checklist (Glynn, 2006), supplemented with criteria from seven similar checklists.

The resulting scale, which is available from the first author, was used to weigh the differences in evidence for all of the articles' methods (quantitative, qualitative or mixed) and study designs, judging each on its own merits (Bibby, 2012; Boland et al., 2014; Bradshaw, Playford, & Riazi, 2012; Deeks et al., 2003; Furlan, Pennick, Bombardier, & Van Tulder, 2009; Heyvaert, Maes, & Onghena, 2013; Mays, Pope, & Popay, 2005; Pluye, Gagnon, Griffiths, & Johnson-Lafleur, 2009; Thomas & Harden, 2008).

The list included five sections: a general section, a population section, a data collection section, a study design section and a results section. It included 31 quality indicators for qualitative research, 34 indicators for quantitative research, 1 additional indicator for mixed methods research and an additional 6 indicators for comparative research. Every quality indicator was phrased as a question in such a way that a 'Yes' score indicated good quality. All of the items were rated as 'Yes', 'No', 'Unclear' or 'Not Applicable' (non-relevant). We strictly reserved the 'Yes' scores for items that could be answered clearly and positively based on the study report, after having defined the criteria with our research team and an independent reviewer. We rated the items as 'No' when the article contained information indicating that the criterion was not met, and 'unclear' when information pertaining to the criterion was lacking in the article (not per se in the research done). To assess inter-rater reliability for the quality assessment, an independent reviewer checked the quality of 10 randomly selected articles. Both attained a degree of similarity of 85.2%.

To generate a quality score, the number of positively scored items was divided by the total number of applicable items (according to the type of research). We grouped the scores in quartiles, providing a rough indication of the reliability and validity of the information presented in each article. According to Glynn (2006), research with a Yes/Total score  $> 75\%$  (or  $\text{No} + \text{Unclear} / T \leq 25\%$ ), could safely be seen as valid.

### **Data Extraction and Coding**

A thematic analysis was performed to identify and arrange the different types of interventions in an intuitive, yet systematic, fashion (Mays et al., 2005; Savin-Baden & Major, 2013). A first



reading of the articles familiarised us with the type(s) of interventions and the outlines of the QoL outcomes mentioned. In a second reading, we highlighted with line-by-line coding: a) study characteristics; b) participants' characteristics; c) detailed description(s) of the intervention(s) reported; d) QoL outcomes per intervention; and e) other variables influencing the outcomes (Thomas & Harden, 2008). These data were summarised using a pre-devised, piloted Microsoft Office Excel 2016 (Microsoft Corporation, Redmond, USA) worksheet. We classified QoL-outcome descriptions under the most relevant corresponding QoL domain. In this manner, 'autonomy', '(in)dependency', 'choice-making', 'decision-making' and 'ownership' were classified under Self-determination and 'network' and 'friends and family' under Interpersonal relationships. 'General QoL' consisted of no further detailed compilations of QoL domains or indicators. The first author scored the outcomes in the relevant domains as 'enhancing QoL' (+), 'deteriorating QoL' (-) or 'no influence on QoL' (0).

All of the retrieved interventions were roughly categorised into provisional types of support strategies. Interventions with a similar content were then clustered under emerging descriptive (sub)themes, such as 'Macro Making Policy' or 'Micro Assisting with (instrumental) activities of daily living ((I)ADL) – driving, transport' (Thomas & Harden, 2008; Wiese, Stancliffe, Balandin, Howarth, & Dew, 2012). We repeated this process several times, revising and (re-)naming (sub)themes and reorganising interventions under the most relevant, refined theme. We then linked every intervention to its corresponding QoL outcome and organised all of the data in Tables 2 and 3.

### **Results**

Table 1 presents an overview of all of the included articles, the results of the QA and information about the study and participants' characteristics.

Methods of research are identified as quantitative, qualitative or mixed; quantitative study designs as experimental or observational, and qualitative study designs by their approach, data collection or analysis (Deeks et al., 2003; Savin-Baden & Major, 2013). The direction of the relationship between strategies and outcomes was not always clear. Depending upon design, the reader

should interpret the quality assessment scores, reliability and validity, and relationships between support and outcome factors more or less cautiously (Veerman & van Yperen, 2007).

[Insert Table 1]

### **Quality Assessment Results**

The methods sections of the articles did not always clearly present methods of research or provide information about research limitations, while the results presented did not always match the data collection methods mentioned.

Mixed methods designs supplemented quantitative data mainly with qualitative interview data. Qualitative explorative research most frequently conducted semi-structured interviews and focus groups, which were then analysed with (variations on) thematic analysis, following a Grounded Theory approach. A wide variety of data collection instruments were used, validated only in 22 articles. Only one research design used regularly collected statistics, and the HA-ID study articles presented the data collection and analysis methods in the most extensive, accurate way.

Participant samples in general contained fewer than 100 persons, with the exception of some larger studies; they seemed relevant to the subjects studied and were relatively well presented with basic descriptive statistics. Recruitment was largely performed through contact with service providers, partner organisations or community groups, with only Bigby (1996) intensively seeking 'hidden' elderly persons with ID. Only 12 studies presented study samples 'representative of all actual and eligible users' and sufficient for precise estimates. Despite generally low non-response bias, participant selection was seldom justified and was in most cases purposive and thus possibly biased. Control groups were not often used.

Some of the included articles did not mention ages but clearly focused on age related subjects, such as end-of-life care. When participants were of mixed ages, we focused on the results of those  $\geq 50$  years old; the same practice applies to mixed disabilities, for which we focused on ID. Questioned participants with ID typically had borderline, mild or moderate levels of ID or could understand and coherently answer interview questions, with or without prompting. Research on people with

severe/profound ID was always performed through proxies, raising the issue of possible differences in appraisals between parties (Verdugo, Schalock, Keith, & Stancliffe, 2005). Family, friends and other non-paid caregivers were questioned in nine studies, all in small numbers.

### **Data Extraction Results**

We organised the interventions into twelve themes, some with subthemes, and we describe the QoL outcomes per subtheme or intervention in Tables 2 and 3. In Table 2, we present the actions undertaken, programmes implemented or strategies provided, whereas Table 3 presents data on the lack of interventions.

For reasons of conciseness, we only once mention interventions that could fit two (sub)themes, without referring to the other possible (sub)themes.

The articles presented a broad range of QoL outcomes, some of which were readily defined into one of Schalock's QoL domains. Other articles presented them as one broad category or clearly described, but did not define, them. Several articles examined or presented outcomes in the domains of Emotional well-being (n=41), Physical well-being (n=37), Personal development (n=32), Interpersonal relationships (n=33), Social inclusion (n=26) and Self-determination (n=27). Material well-being (n=16) and Rights (n=10) were examined far less.

Effects of interventions on Physical well-being were examined with the highest quality standard of research. The experiments of Carmeli et al. (2002, 2004, 2005, 2008) demonstrated the direct impacts of the interventions on Physical well-being, and the HA-ID studies (Bastiaanse, Mergler, Evenhuis, & Echteld, 2014; de Winter et al., 2012a; 2012b; 2014; 2015; 2016; Hermans & Evenhuis, 2012; Van de Wouw, Evenhuis, & Echteld, 2013; van Schijndel-Speet, Evenhuis, van Wijck, van Empelen, & Echteld, 2014) suggested that health interventions have direct consequences on this domain. In most of the presented experimental research, the effects of the interventions on Emotional well-being, Interpersonal relationships and/or Social inclusion appeared together.

The domain of (respect for) rights was not directly examined for elderly people with ID; the presented evidence was derived from observational or exploratory research. Two articles explicitly

reported on the support of spiritual well-being, which is not a domain included in the model from Schalock at this time.

[Insert Table 2]

[Insert Table 3]

## **Discussion**

This systematic review of empirical research presents a methodical and thematic overview of what caregivers and organisations (can) do to support the population of elderly people with ID and of the possible QoL outcomes of these actions. We first focus on the conclusions about support strategies that can be identified as having an influence on the QoL outcomes of elderly people with ID (Table 2) and second on the effects of lacking or halted interventions (Table 3). Additionally, we highlight patterns in the QoL outcomes, differentiation in support according to client characteristics, the importance of variables on the macro level and the impact of strategies on caregivers. Finally, the limitations of this review are discussed.

### **When Caregivers Act (Well)**

**Strategies important to all elderly persons with ID.** Support strategies specific to the place where elderly people with ID live, related to all QoL domains, and all of the living environments had pros and cons. Most settings quite easily increased ADL assistance and provided adaptive environments, with mixed effects. Good support in communication might counter the risk of decreased self-determination or personal development when removing self-help skills from the elderly person's hands. Further, our results confirmed that having older people with ID 'ageing in place' seems to have positive effects on their material and emotional well-being and relationships. Supervisors with a strong ageing in place philosophy (Webber, Bowers & McKenzie-Green, 2010b) prove that this goal might be achievable, although they did report the elderly people's physical health as a challenging factor. To honour this principle, funding, planning, re-organising and cooperating should coincide with a strong vision and profound effort. If relocation is necessary, preparation in consultation with the ageing

person and his or her family, active network building and using reminiscence interventions can counter the negative consequences of such changes.

Moving away from long-stay hospitals shows mixed results for ageing people with ID, of which some levelled out, and others only gained strength after several months. Community inclusion is not automatically achieved by moving itself but is significantly influenced by level of ID, gender and age. Physical and emotional well-being declines when a small staff organises work too strictly. The question might arise of whether this outcome also applies to elderly people who did not recently move.

When moving to regular elderly care is promoted as a good ‘community alternative’, the results reveal better physical support and higher use of technical/digital methods (Webber, Bowers & Bigby, 2014), but in contrast, the results also support the worldwide critical questions posed regarding the QoL effects of limited specialised ID care in these (benevolent) services. Special attention should be paid to persons younger than 65 years old entering regular elderly care because they face long years of living among much older, frail people at an age at which they might prefer to be active.

Establishing the best support is possible when all partners communicate and cooperate in policy making, daily practice and research (Heller, Gibbons, & Fisher, 2015; Walker, 2015). Families, ID and regular elderly care staff, and medical and palliative care specialists voiced this need to share information and to work together. Good QoL effects seem to be gained by appointing a co-operating ‘key person’ who knows the elderly person well and for a long time: he or she is a source of information and, as trustee and spokesperson, can flexibly react to changes in care and plan ahead. Such support planning has positive effects on several QoL domains, whether in the form of appointing this person or in the planning of networks, future support, hospital discharge or end-of-life care.

Policy, financing and organisational strategies, such as increasing staff numbers, prevention of waiting lists, provision of waking night staff and respite care, are beneficial to the emotional and/or physical well-being of elderly people with ID. When, in contrast, staff must work within strict financial restraints or according to fixed daily schedules, while at the same time having to support

clients outside one's own group, the elderly person's chances for participation in (inclusive) activities are hampered.

**Strategies especially important for healthy ageing persons.** Ageing people with ID might like to take things slightly slower after retiring, but they unanimously expressed a desire for attractive, enjoyable, fun or interesting leisure-time activities, educational programmes and the opportunity to do things together with staff, friends, family or (new) acquaintances. Staff overloading the daily schedule, conversely, could impede personal development, inclusion and one's own choice making.

Few working ageing people with ID had a clear idea of what awaits them after retirement, and they feared the loss of companions or even their homes. The provision of education and leisure-oriented lifestyle programmes, emphasising skills to maintain satisfying relationships, is necessary, as is flexible cooperation with volunteers, mentors and community organisations. Bigby et al. (2014), Wilson et al. (2013) and Stancliffe, Bigby, Balandin, Wilson and Craig (2015) demonstrated the possibilities of their Transition-to-Retirement and Mentoring programmes.

Life story work, talking about life and death, and spiritual and end-of life care had, despite sometimes troubling the elderly person when he or she recalled difficult life events, overall positive effects on several QoL domains.

**(Preventive) strategies especially important for the (pre-)frail elderly.** Many elderly persons with ID live sedentary lives (de Winter, Bastiaanse, Hilgenkamp, Evenhuis, and Echteld, 2012b), are at high risk for falling, eat unhealthy foods and are given high doses of different medications (Flood, 2016). Antipsychotics can possibly cause metabolic syndrome (Chitty et al., 2016). Overweight or obesity, cardiovascular problems, diabetes, long periods of disease and early death are the direct consequences. Several elderly people suffered from depression or anxiety, as they experienced many negative life events. It is clear that not all ageing persons with ID age 'actively' (Coppus, 2013; Deb et al., 2009; Dykens, 2013; Fesko et al., 2012; Gangadharan, Devapriam, & Bhaumik, 2009; Singh, 2016; World Health Org., 2001).

Several strategies prevent frailty and deteriorating QoL outcomes at advanced ages and would be best started before the age of 65 years old or before 50 years old for persons with Down syndrome

or severe/profound ID. Brown, Jacobstein, Yoon, Anthony, and Bullock (2016) and Kiani et al. (2014) encouraged governments to promote access to general health care and preventive screening, to gather health information and to coordinate care. The studies presented by Carmeli et al. (2002, 2004, 2005, 2008) and Van Schijndel-Speet et al. (2014) demonstrated the feasibility and positive effects of adapted, attractive training programmes. A planned and coordinated approach to prevention, with attention to timely screening, healthy living education and careful, QoL-orientated prescribing of psychotropic medication (Deb et al., 2009), is feasible and should be promoted by all supporting staff (Brown et al., 2016; Heller & Sorensen, 2013; Krahn, Hammond, & Turner, 2006; Ouellette-Kuntz, Coe, Cobigo, & Wilton, 2015). Hermans and Evenhuis (2012) pleaded for good monitoring and prevention of negative life events.

The importance of recognising health issues, quality pain relief, treatment of diseases, adaptation of environments, mental health support and dementia care increases with the ageing of this fragile population and is quite well achieved in generic elderly care (Webber et al., 2014). Good quality dementia and end-of-life care require good organisation of educated, cooperating personnel, early detection and good physical care, adapted, pleasant environments and aids, careful planning and support for existential needs. Acute decisions, especially those regarding moving the elderly person, are detrimental to physical and emotional QoL.

Since many elderly people and their caregivers reported negative hospitalisation experiences, the need for hospitals to develop specific ID-care support is crucial and, as Elwell and Hallas (2016) reported, feasible. Educational curricula for health-care workers should contain ID-specific courses, ID specialists should be taught to recognise and support health issues (Brown et al., 2016), and all partners should cooperate. Adapting hospital policies and communicating with staff or family on the needs of the elderly person do have positive effects on physical well-being.

### **When Caregivers Do Not Act (Well)**

The reviewed articles not only reported interventions that were realised, but they also highlighted the QoL consequences of a lack of strategies, the falling away of support or the poor execution of interventions, of which Table 3 provides an overview. The characteristics of the elderly

person, his or her caregivers and environment, and a lack of interventions are clearly interrelated. Unfit housing, networks falling apart, reluctant attitudes, insufficient staffing and high turnover weighed heavily on several QoL domains, even after deinstitutionalisation, as did a lack of planning and psychosocial support.

Although the provision of activities seems QoL enhancing, caregivers often favour health, housing or (I)ADL support, so the loss or lack of meaningful activities was frequently mentioned. Older family cannot go out as much as before, relocation disrupts favourite activities, and staff decides how free time will be organised. In regular services for elderly people, this population has difficulty fitting in with even less frequent activities. Ageist ideas, transportation or money difficulties and caregiver shortages can impede participation in highly valued (inclusive community) activities or educational courses -- even more so for elderly people with severe or profound ID. Negative effects were not only reported on personal development but also on emotional well-being, relationships, inclusion, physical well-being and self-determination.

The data on regular elderly care reveal not only the need for the organisation of more ID-appropriate activities but also the demand for communication with neighbouring ID services, educating personnel, investing in contact with (professional) caregivers outside the service and providing of opportunities to build or continue relationships. To complement these needs, ID services voiced a wish for better organised physical health care and education. In an environment in which doctors, nurses or hospitals do not support these needs, there are serious negative QoL effects and not only on physical well-being. de Winter et al. (2012a; 2015; 2016) and other reviewed authors explicitly pointed out the careless prescription of medication, the mis- or underdiagnosis of disease or pain, the lack of mental health care and health education and the risks of a lack of screening, e.g., for diabetes, when the person is anxious and vice versa. Untimely utilisation of healthcare, inadequate pain relief, lack of communication, poor post-discharge and end-of-life planning cause extended suffering, maltreated conditions, and even premature death.

### **Patterns in QoL Outcomes**



QoL outcomes were outlined in different ways, as Tables 2 and 3 detail, and few clear-cut patterns were discernible. Many of the suggested strategies and pursued outcomes fit into an active ageing model (Bowling & Dieppe, 2005; Depp & Jeste, 2006; Fesko et al., 2012; Foster & Boxall, 2015; Laplante, 2014; Reppermund & Trollor, 2016). Nevertheless, we assert that the model presented by Schalock (2004) is sufficiently broad to incorporate multidimensional concepts and goals, providing room for intertwined or negative outcomes.

When strategies are (well) executed, QoL effects are often, but not always, positive. When interventions are lacking, fall away or are badly executed, the effects on QoL are without exception negative or (at best) non-existent. Many caregivers and organisations make substantial efforts to optimise the lives of elderly people with ID and to prove that positive results are achievable. Additionally, in general, these elderly persons do feel content about their lives, even when they have objectively less qualitatively good living conditions (Bowling & Dieppe, 2005; LeRoy, Walsh, Kulik, & Rooney, 2004). The frequent mention of ‘lack of...’, ‘diminished’ or ‘insufficient’ support in the literature emphasises this objective lack of positive interventions and the seemingly evident logic that it is the actual implementation of interventions that makes or breaks positive QoL consequences.

When examining the link between specific strategies and specific outcomes in Tables 2 and 3, we conclude that interventions focusing on a specific QoL domain often have the intended or expected effects. Several articles in Table 2 revealed that the provision of (accessible) housing, ageing in place and deinstitutionalisation increase material well-being, that personal development is improved with the provision of good activities, that self-determination, social inclusion and relationships are ameliorated by the assessment of levels of choice making, participating in community activities and the building of networks and, finally, that physical well-being does not automatically improve by the elderly person being active but requires specific physical training programmes and quality medical care. Similarly, a lack of good physical treatment leads to worsened disease or pain, and the restriction of learning programmes results in less personal development (Table 3).

Strategies might intend to change a specific domain but often have broader or unexpected effects on other QoL domains. Ageing in place positively affects material well-being and makes the

elderly person feel better and keep relations intact. Living independently or with family might – perhaps unexpectedly -- lead to worse housing and more conflicts, but one’s rights seem more respected, while support by residential services seems to reduce self-determination or community inclusion. Chosen, meaningful and preferably inclusive leisure activities, such as a community membership programme or a well-balanced physical training programme, ameliorate not only personal growth but also how one feels, if one can make one’s own choices or relate to others. Conversely, such activities do not necessarily lead to better physical well-being.

As such, orchestrated strategies of different sorts are sometimes needed to exert positive effects on a specific QoL domain. When the goal of moving elderly people with ID is to gain real and positive changes in social inclusion, additional efforts will be minimally required, such as carefully choosing an age-adapted, accessible environment, actively building networks (Shogren, Wehmeyer, Lassmann, & Forber-Pratt, 2017), offering behavioural and health promotion programmes, changing staff attitudes and preventing high staff turnover.

Further research on the significance of support in a QoL domain of spiritual/existential well-being/experiencing meaning in life is needed. Since many people with ID are reported to understand issues of ageing, disease and dying, communication about these themes and spiritual and end-of-life care should be provided (Newberry, Martin, & Robbins, 2015). The existential support and end-of-life care interventions explicitly highlighted broad, positive QoL effects and revealed the importance of the act of ‘giving meaning to one’s life’ (which is linked to but transcends emotional well-being), while caregivers often reported feeling incompetent to answer the clearly expressed spiritual needs of dying elderly people (Bekkema, De Veer, Hertogh, & Francke, 2016; McCarron, McCallion, Fahey-McCarthy, & Connaire, 2010). As other QoL models suggest, future research might examine the extension of the bio-psycho-social model with ‘existential’ or ‘spiritual’ elements (Dezutter, 2017; Liégeois, 2014).

Within this context, far more attention should be paid to strategies improving the rights and self-determination of these elderly people. Replacement of or within (age-adapted) residential settings, for example, is rarely undertaken in consultation with the ageing person, is too frequently experienced as a

negative life event, especially when undertaken in crisis, and it can lead to anxiety or depression and loss of preferred activities and important relationships. Throughout the review, the lack of choices or co-planning and the imposing of important decisions by caregivers are striking, as the title of the article -- "I always do what they tell me to do" -- resonates (Treece, Gregory, Ayres, & Mendis, 1999).

### **Influence of Client Characteristics on the Effectiveness of Support Strategies**

The severity of ID or the presence of a specific syndrome calls for different interventions. Independently living people require support with entertaining relationships, (I)ADL skills, choice making, planning their future lives and healthy living and eating (de Winter et al., 2012b). Especially vulnerable to non-action are elderly people with severe or profound disability levels. They require health-related interventions, support in communication, in peer interactions, and in self-determination, and adaptation of environments (Maes, Lambrechts, Hostyn, & Petry, 2007). Many people with Down syndrome require early support in ageing and possibly with Alzheimer disease (Brown, 2012; Crook, Adams, Shorten, & Langdon, 2016).

The questioning of older women with ID by LeRoy et al., (2004) and their plea to pay attention to (the effects of) their specific life courses and health problems answered an explicit request of the WHO (Walsh & Le Roy, 2000). For these women, the strategies presented are even more important QoL-securing interventions.

### **Complementary Strategies, Effects and Risks**

While not the crux of this article and thus not described in the tables, the included articles did mention the relevant effects of strategies on the governmental level, as well as QoL effects for caregivers, which we briefly discuss and substantiate with the literature because they supplement or contextualise the aforementioned results.

**Strategies on the macro level.** Several articles pointed out the negative QoL outcomes caused by the lack of a good and accessible organisation of competent ministry services, care system integration, intersystem collaboration and (simple) explication of the available options (Hole, Stainton, & Wilson, 2013; Wark et al., 2015; Webber et al., 2010b). Governments and organisations would do

well to create coherent policies to assemble into one framework all of the services that support this ageing population (Watchman et al., 2017). Outlining a national disability policy (Kåhlin, Kjellberg, & Hagberg, 2015) and unifying pathways between care systems could help to prevent the double jeopardy of being old and having ID. Walker and Walker (1998), Bigby (2002), Weber and Wolfmayer (2006), Innes et al. (2012) and Higgins and Mansell (2009) warned against this problem as well.

Regrettably, several articles identified the QoL effects of governments or organisations worldwide reducing funds (Buys, Aird, & Miller, 2012a; Hole et al., 2013; Kåhlin et al., 2015; LeRoy et al., 2004; Thompson, Ryrie, & Wright, 2004; Wark et al., 2015). Decisions in policy, in financing, as well as in provision of services, trickle down to almost every meso- and micro-intervention and thus effect QoL-outcomes. Due to a lack of (government) funding, services are hampered in the organisation of essential support strategies, sufficient and flexible staffing or age-related adaptations to housing. Some authors linked the reported lower general quality of regular services for the elderly directly to the poorer funding of the sector (Bradshaw et al., 2012). Staff training stagnates, and valued activities cannot be organised. After retirement, elderly people who cannot be left alone for several hours must move, so insufficient funding negatively influences 'ageing in place'. Fewer staff must accomplish a vast number of tasks, with no time to sit and talk with residents, and the staff members change jobs quickly. An overload of work, strict schedules and ageist ideas lead to strict, overprotective, and sometimes infantilising reactions. Busy staff does not oversee the work, forgets health screenings or has no time to get clients in or out bed on a timely basis. Clients live in large groups as non-chosen co-residents in residential services, where conflicts can cause depression and anxiety. Families are overburdened and cannot adapt their homes, while respite care is not flexibly available. In rural areas, financing for this support is even more at risk. The reviewed articles confirmed the poverty of ageing people with ID, rendering transportation or activities unaffordable. This lack in turn hampers the community participation, choice making, personal development and physical well-being of ageing people with ID (Lehmann et al., 2013; Murphy, Cooney, Shea, & Casey, 2009; Van Campen & Van Santvoort, 2013).

**Caregiver outcomes.** Several authors reported caregiver-outcomes. The provision of respite care, training in dementia care and in end-of-life care, active mentoring and cooperation between services diminish caregiver stress (Hole et al., 2013; McCarron et al., 2010; Wiese et al., 2012; Wilson et al., 2013). Crisis transfers, stopping of fluids and food at the end of life, and the lack of clear information, of adequate pain detection and of resources frustrate or sadden them (Hole et al., 2013; McCarron et al., 2010; Wilkinson, Kerr, & Cunningham, 2005). Similarly, in daily practice, the strategies' effects on the QoL of the elderly person should be carefully weighed against the effects on caregivers' or co-residents' QoL, as these outcomes do not always run in parallel. Having the elderly age in place might have negative outcomes for these people's co-residents, and the intense effort to care for a person with dementia or to support the elderly in hospital can exhaust caregivers (Webber, Bowers & Bigby, 2010a; Wilkinson et al., 2005).

### **Methodological Issues and Further Research**

Noteworthy and pertinent to further research is the shortage of articles directly researching the QoL domain of rights. The themes of sexuality (Turner & Crane, 2016) and behavioural problems are missing: Do the frequently reported problems of their younger counterparts disappear with ageing, are they ignored, or are all the right supports in place? In addition, information from African, South American or Eastern researchers is lacking, with the exception of Hong Kong and Israel, so the proposed interventions will require further research and adaptations to non-Western regions. Furthermore, although the use of technical devices seems to be promising, articles on the effects of new assistive technologies remain scarce.

Like Innes et al. (2012) and Verdugo et al. (2005), we established a lack of robust evidence and of research directly addressing ageing people with ID. Since published results are the starting point of this review, there might be a bias against studies reporting null effects of interventions or policies (publication bias). Such information would nevertheless be highly informative for the overview presented and the conclusions drawn. Furthermore, we mixed the results of research of different designs and qualities, which might have limited the validity and reliability of the presented

results. That said, while randomised, controlled trials (RCTs) are regarded as the gold standard of research, they might not be representative of the complexity of daily work (Veerman & van Yperen, 2007). In addition, including different research methods provided us with a much larger body of research questions and data relevant to practice, policy and research (Heyvaert, Maes, & Onghena, 2011). To counter this first limitation of possible biases, we included research since 1995, we presented the studies' designs, we provided a QA and we clearly distinguished levels of evidence in Table 1. Further research might test whether the presented interventions have the supposed effects, for whom and under what circumstances, while also reporting null effects. The causal relationships between strategies and outcomes are seldom clear (Schalock et al., 2018).

The reading, quality assessment and data extraction were mainly performed by the first author. We overcame this second limitation by thoroughly discussing the search protocol, the processing of the evidence, the thematic analysis and the presentation of the results with the second and third author and the research team. Double-checking of randomly selected articles showed sufficient degrees of similarity.

Third, the limitation of using a non-validated quality assessment tool was countered by its construction from a broad combination of existing, validated or thoroughly discussed tools (Furlan et al., 2009; Glynn, 2006; Pluye et al., 2009). Although we assessed more than 30 items per article, the overall Yes/Total score provides only a rough indication of the quality of each article. Moreover, the quality score was based on the information presented in the article, which did not per se reflect the quality of the research performed. We did not calculate section scores, which would be indicative of gaps in the research done, nor did we weigh 'No' and 'Unclear' differently. The QA scores should be interpreted with caution, but they do provide the reader with some guidance on the overall validity of an article.

### **Conclusions**

This review bundles QoL-influencing interventions, strategies and methods and thus presents possible ideas for future policies and support strategies at the governmental, organisational and

individual levels. The twelve themes presented in Tables 2 and 3 answer our question regarding the ways in which caregivers can improve the QoL of elderly people with ID.

These tables clarify that this ageing group of persons with ID can be supported in positive, active ways, with specific interventions adapted to their age, as well as to the level of ID and individual needs. Specific risk factors include their very different life course trajectories, ageist prejudices, networks falling apart, unprepared retirement or crisis relocation, and specific age-related health problems.

The participants in the included studies reported several strong points of services and the enormous commitment of caregivers to provide good-quality support. Conversely, many reported that problems in supporting older people with ID do occur and require attention, as well as solutions. With many improvements required, this overview points out positive pathways to practice and policies to attain the best quality of life and care.

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**Table 1. Overview of author(s), year of publication, country, quality assessment quartile score, aim, participants, study design and level of evidence.**

Nr	Author(s) (Publ). Country	QA (%)	Aim	Examined persons with ID and informants	Study approach / design / methods / analysis	Level of evidence of correlations
1.	Ager et al. (2001). UK.	]50,75]	To examine levels of social integration for individuals resettling into community after closing a long-stay hospital.	n=76 with ID. 18/76 ≥60y (35%). Mean age 53y; range 21-93y. Some severe behaviour problems, different levels of dependency. Comp. between < and ≥ 60y, before and after. Inf.: elderly and/or staff.	Quant. Obs.: cross-sectional, partly before-and-after.	Tested / observed
2.	Bai et al. (2014). Hong Kong.	]50,75]	To develop a training protocol of Life Story Work and examine its effects on enhancing mood, socialisation, and QOL.	n=60 with ID. 32 intervention group + 28 control group. Mean age 55.84y; SD 4.63. Male + female. Mild-to-moderate ID, no severe psychiatric disorder or behavioural problems. Comp. between groups.	Quant. Exp.: non-rand. trial./ quasi-exp.	Tested / observed
3.	Bastiaanse et al. (2014). Neth.	]50,75]	To obtain insight into bone quality in older adults with ID.	n=768 with ID [of n=1050 (Hilgenkamp et al., 2011)]. Mean age 61.1y; SD 8.2; range 50-94y. Male + female. Mild, moderate, severe IQ. All res. support. Down Syndrome or not + res. status. Comp. with non-part. of HA-ID study. Inf.: staff.	Quant. Obs.: cross-sect.	Explored
4.	Bekkema et al. (2016). Neth.	]75,100]	To explore important care relationship dimensions of end-of-life care.	n=33. Mean age 58y; range 21-84, 76%>50y. Male and female. Mild ID. Not receiving end-of-life care. All supported by ID care service. Inf.: part. with ID.	Qual.: nominal group technique + thematic analysis	Explored
5.	Bigby (1996). Aus.	]25,50]	To obtain insight in parents' future planning for their middle-aged child with ID and the short and longer term effects.	n= 62 with ID. Mean age 65y; range 55y-82y. Male + female. Most living in generic aged care, 6 in ID care, 16 in private home with support. 33 known to ID-care, 21 using ID services. Inf.: n=51 elderly with ID + 49 non-paid inf. + 13 staff.	Mixm. Obs.: Quant.: case series + Qual.: constant comp. anal.	Explored
6.	Bigby and Knox (2009). Aus.	]50,75]	To explore everyday lives of older people with ID using disability services, to inform practice and service development.	n=16 with ID, in triad with caregivers. Mean age 62y; range 52-80y. ID and communicating verbally. Inf.: n=48: 16 elderly with ID + 16 non-paid inf. + 16 staff.	Qual.: social constructionism, exploratory.	Explored
7.	Bigby et al. (2011). Aus.	]50,75]	To understand and increase inclusion of retirees from supported employment in community organisations.	n= 6 + 6 with ID. Age: over 45y. Male + female. ID or other dis. All supported employees. Inf.: n=35: 12 elderly with ID + 7 staff disability service + 6 staff ID service + 4 non-paid inf.	Qual.: exploratory, focus group design.	Explored
8.	Bigby et al. (2014). Aus.	]50,75]	To explain the components of the Transition-to-Retirement program.	n=24 with ID. Mean age 57.5y; range 46.0y–72.2y. Male + female. 17 primary ID, 7 with other primary disabilities. Supported employees.	Mixm. Obs.: Quant.: before-and-after + Qual.: content anal.	Explored
9.	Bigby and Craig (2017). Aus.	]50,75]	To explore qualities of friendship between a person with severe ID and a person without + support factors sustaining the friendship.	n= 1 with ID. Age 50y, female, severe ID, Rett syndrome, not communicating verbally, unable to walk, epilepsy. Day care centre. Inf.: 4 without ID interviewed (friend, sister, staff) + several staff, community members observed.	Qual.: social constructionism, case study, grounded coding.	Explored
10.	Bishop et al. (2013). USA.	]0,25]	To describe health care challenges for older adults with IDD and advice for nurses.	n=1 with moderate ID, woman, 56y old, limited verbal ability.	Qual.: case study. Caution validity!	Explored
11.	Bland et al. (2003). UK.	]50,75]	To identify an ID population ≥65y, their health problems, sources and types of support, ratings of care staff satisfaction.	n= 94 with ID. Mean age 72.77y; SD 6.86; range 65-93y. Male + female. Mostly in residential services. Low levels of inclusion. High prevalence of psychological, behavioural and physical problems. Inf.: staff.	Quant. Obs.: cross-sect.	Explored
12.	Brown et al. (2016). USA.	]75,100]	To investigate adherence to health screening guidelines for people with ID + barriers and facilitators of community prevention.	n=444. Mean age 59y; range: 42y-90y; 92.8% >50y. Male and female. Severe / profound ID > mild / moderate ID. 80% African American. In Intermediate Care Facilities, independent living or home care. None in family home. All under court monitoring. Comp. between groups.	Quant. Obs.: cross-sect.	Explored



## IMPROVING QUALITY OF LIFE, ELDERLY PEOPLE WITH ID

13.	Buys et al. (2012a). Aus.	]50,75]	To identify service providers' experiences, views of active ageing among older adults with ID. To better understand what active ageing might entail.	n=16. Age 52-80y. Male and female. ID + capacity to communicate verbally. Some working, some retired, some attending day program. Inf.: staff members.	Qual.: thematic analysis	Explored
14.	Buys et al. (2012b). Aus.	]50,75]	To know to what extent family members and others act as facilitators of active ageing and to know the obstacles in fulfilling this role.	n=32. Age 52-80y. Male and female. ID + capacity to communicate verbally. Living in supported accommodation or in private dwellings. Some working, some retired, some attending day programs. Inf.: 16 elderly with ID + 16 key caregivers.	Qual.: phen. approach: thematic analysis	Explored
15.	Carmeli et al. (2002). Israel.	]75,100]	To evaluate effects of a 6-month treadmill walking program on leg muscle strength of institutionalized elderly with Down Syndrome.	n= 26 with ID, 16 in exp. walking group + 10 in control group. Mean age 63y; range 57-65y. Male and female. Down Syndrome, living in foster home for over 4 years. Comp. between groups.	Quant. Exp: RCT.	Tested / observed
16.	Carmeli et al. (2004). Israel.	]50,75]	To evaluate two 6-month muscle strength and balance training programs for individuals with ID.	n= 27 with ID, 14 balance group + 13 muscle strengthening group. Age range 55-77y. Male and female. Mild ID. No Down syndrome, no loss of visual acuity. Comp. between groups, before and after.	Quant. Exp.: non-rand. trial / quasi-exp.	Tested / observed
17.	Carmeli et al. (2005). Israel.	]50,75]	To evaluate effects of physical training emphasizing balance and muscle strength on locomotor performance and well-being.	n=22 with ID, 10 in exp. group + 12 in control group. Age range 54-66y. Male and female. Mild ID. Requiring minimal ADL support. No Down syndrome, all able to answering questionnaire, no loss of visual acuity. Comp. between both groups.	Quant. Exp: non-rand. trial / quasi-exp.	Tested / observed
18.	Carmeli et al. (2008). Israel.	]50,75]	To research the relationship between perception of well-being and maintaining physical training among adults with ID.	n=60 with ID, 31 in exp. group + 31 in control group - 2 drop-outs. Mean age 56.5y; range 47-67y. Male and female. Mild ID, requiring minimal ADL supervision. No Down syndrome. Living for ≥5 years in residential service. Comp. between groups.	Quant. Exp: non-rand. trial / quasi-exp.	Tested / observed
19.	Craig and Bigby (2015). Aus.	]50,75]	To identify pathways to active participation in community groups, explore enabling or constraining factors and consider implications.	n=5 with ID. Ages 48, 54, 58, 59, 62y. Moderate ID. All interested in joining a community-based activity + members of community groups. Inf.: 11 mentors and group leaders.	Qual.: participant obs. study, critical realist anal.	Explored
20.	Crook et al. (2016). UK.	]50,75]	To test effects of life story books and rummage boxes on elderly with Down syndrome and dementia.	n=5. Age range 55-63y. Male and female. Moderate ID (age-equivalent scores). Down syndrome and Alzheimer. Day care centre. Comp. between conditions.	Quant. Obs: rand. single case series.	Tested / observed
21.	Dag et al. (2017). Sweden.	]50,75]	To explore experiences with eating aid Bestic, a small, robotic arm with manoeuvrable spoon controlled by user, in increasing autonomy.	n=6, 2 with ID. 29y male, moderate ID, in service home with assistants, communicative abilities + 60y female, severe ID, in group home, no communicative abilities. Needing help in meal-situations. Inf.: 29y male + 4 assistants of both.	Qual.: pilot study, descriptive.	Explored
22.	Dagnan et al. (1995). UK.	]25,50]	To describe effects on QoL, community access, integration of de-institutionalization to community-based homes.	n=36. Persons with ID: mean age 61y at the time of second data collection. Male and female. Moving from hospital site to 12 community homes. Inf.: staff.	Quant. Obs.: before-and-after.	Tested / observed
23.	Dagnan et al. (1998). UK.	]50,75]	To describe longitudinal changes in QoL after resettlement from a long-stay hospital to community-based ID services.	n=29 with learning disabilities. Mean age 61y; SD 12.9; range 39-93y. Male and female. Having lived in hospital for a mean of 31.8y (SD 13.0, range 13-67y). Moving to 16 community homes for 3 or 4 persons, 24h staffing. Inf.: staff.	Quant. Obs.: before-and-after.	Tested / observed
24.	de Winter et al. (2012a). Neth.	]50,75]	To investigate the prevalence of overweight, obesity and body fat percentage, and associations with participant and treatment characteristics.	n=945 with ID [of n=1050 (Hilgenkamp et al., 2011)]. Mean age 61.5y; range 50-93y. Male and female. All levels of ID. All supported by three care provider services. Comp. with non-part. of HA-ID study.	Quant. Obs.: cross-sectional.	Explored
25.	de Winter et al. (2012b). Neth.	]50,75]	To determine the prevalence of cardio-vascular disease risk factors, correlates and new diagnoses found.	n=980 with ID [of n=1050 (Hilgenkamp et al., 2011)]. Mean age 61.5y; range 50-93y. Male and female. All levels of ID. All supported by three care provider services. Comp. with non-part. of HA-ID study + with general Dutch pop.	Quant. Obs.: cross-sectional.	Explored

## IMPROVING QUALITY OF LIFE, ELDERLY PEOPLE WITH ID

26.	de Winter et al. (2014). Neth.	]50,75]	To determine the prevalence of chronic kidney disease in older people with ID / in the sarcopenic group. To identify correlates of renal dysfunction.	n=635 with ID. 82 in sarcopenic group [of n=1050 (Hilgenkamp et al., 2011)]. Mean age 61.7y; range 50-92y. Male and female. All levels of ID. All supported by three care provider services. Comp. with non-part. of HA-ID study.	Quant. Obs.: cross-sectional.	Explored
27.	de Winter et al. (2015). Neth.	]50,75]	To explore the relationship between symptoms of anxiety and depression, and cardiovascular risk factors in older people with ID.	n=990 with ID [of n=1050 (Hilgenkamp et al., 2011)]. Mean age 61.1y; SD 8.2. Male and female. All levels of ID. All supported by three care provider services. Comp. with non-part. of HA-ID study.	Quant. Obs.: cross-sectional.	Explored
28.	de Winter et al. (2016). Neth.	]50,75]	To study incidence & symptoms of cardiovascular morbidity, interventions undertaken, predictability of risk factors on morbidity and mortality.	n= 790 with ID [of n=1050 (Hilgenkamp et al., 2011)]. Mean age at baseline 62y; SD 8; range 50-93y. Male and female. All levels of ID. All supported by three care provider services. Comp. with HA-ID part., Down or not. Follow-up of HA-ID study.	Quant. Obs.: prospective follow-up.	Tested / observed
29.	Gómez et al. (2014). Spain.	]50,75]	To examine the influence of different types of human services on QoL of their users + personal and organizational variables.	n=11,624 !with and without ID!. Mean age 59.37y; females mean 66.7y; males mean 50.49y; !range 16-111y! Male and female. 42% elderly. 45.5% ID; 10.8 mental health problems; 9.9% phys. dis.; 21.9% chemical dependency. Inf.: staff.	Quant. Obs.: cross-sectional.	Tested / observed
30.	Hahn (2014). USA.	]50,75]	To describe the most central nursing interventions and to determine if a specific set of interventions are essential to a preventive model.	n=80 with ID. Mean age 51.7y; median age 53y; SD 10; range 29-86y. Male and female. Mild to moderate ID. 25% in independent housing, 25.25% in single-family housing, 17.5% in 24h staff group homes, 3.75% in rented/ boarding room, 1.25% in retirement home. Inf.: Staff: advance practice registered nurses.	Quant. Obs.: descriptive data analysis + market basket analysis.	Explored
31.	Hamilton and Atkinson (2009). Ireland.	]25,50]	To collect and disseminate life stories of elderly clients with ID.	n=11 with ID. Aged over 60y. Male and female. Criteria for inclusion: >69y, able and willing to take part in the project.	Qual.: narrative.	Explored
32.	Hermans and Evenhuis (2012). Neth.	]50,75]	To investigate exposition to (negative) life events, accuracy of observers' judgement of burden, associations with depression and anxiety.	n=988 with ID [of n=1050 (Hilgenkamp et al., 2011)]. Mean age 61.07y; SD 8.16. Male and female. All levels of ID. All supported by three care provider services. Comp. with non-part. of HA-ID study.	Quant. Obs.: cross-sectional.	Explored
33.	Herron and Priest (2013). UK.	]50,75]	To explore support workers' knowledge of mental health needs and dementia, their ability to identify signs of dementia and their responses.	n=14 support workers on hypothetical vignette of person with ID: male, 72y of age, moderate ID, dementia (three stages described), living in a supported house, who cannot speak but communicates well with facial expressions & gestures.	Qual.: vignette study, thematic analysis.	Explored
34.	Heyne (1996). USA.	[0,25]	To illustrate success of a Community Membership Project. Contribution of Thomas., B.A.	n=1 with ID. Age 59y. Male.	Qual.: case study. Caution validity!	Explored
35.	Higgins and Mansell (2009). UK.	]50,75]	To compare the QoL of people with and without ID in ID-group homes and regular older people's homes.	n=59. 20 without ID + 19 with ID in older people's residential home + 20 with ID in ID residential home. Age: over 50y. Male and female. Comp. between three groups. Inf.: staff.	Quant. Obs.: cross-sectional.	Tested / observed
36.	Hole et al. (2013). Canada.	]25,50]	To explore self-advocates' and family members' plans, hopes and concerns regarding future supports and services.	n=22. Persons with ID: age over 50. Male and female. Mild-moderate ID and verbally communicating. Inf.: 11 self-advocates with ID + 11 family members.	Qual.: descriptive method, thematic analysis.	Explored
37.	Jones and Gallus (2016). USA.	]50,75]	To investigate families' experience of important aspects of deinstitutionalisation, their relatives with ID moving to community living.	n=23 parents and siblings. Persons with ID: Mean age 52.31y; SD 10.03y; range 35-70y; 14>46y. Male and female. Moderate, severe, profound ID. All deinstitutionalised from 2 large state-run institutions to community homes.	Qual.: phen. approach, seven step analysis.	Explored

## IMPROVING QUALITY OF LIFE, ELDERLY PEOPLE WITH ID

38.	Kählin et al. (2015). Sweden.	]50,75]	To explore ID-group homes' staff experiences of age-related challenges for the residents in regard to participation.	n=15. Persons with ID: mean age 62y; range 39-90y. Male and female. Mild to profound level of ID, with additional dis. Living in group homes, access to communal activities. 24-hour staff support. Inf.: 15 direct care staff.	Qual.: thematic analysis.	Explored
39.	Kiani et al. (2014). UK.	]25,50]	To give an overview of available literature on lung cancer in persons with ID + case analysis of a patient with lung cancer.	n=1. Age 56y. Profound ID, brain damage at birth and a history of epilepsy. Living in a residential home for 14 years. Died of undiagnosed lung cancer.	Qual.: case study.	Explored
40.	Leroy et al. (2004). USA + Ireland.	]50,75]	To explore the life experiences of older women with ID.	n=29. Mean age 60.1y; all over 50y. 9 women from Ireland, 20 from USA. Different levels of ID, all able to understand and answer interview questions. 48.1% living in group home, 22.2% in own home, 18.5% in family home, 11.1% other, 21% alone.	Qual.: pilot study, thematic analysis.	Explored
41.	Lifshitz and Klein (2013). Israel.	[0,25]	To explore applicability and effects of Mediation Intervention for Sensitizing Caregivers (MISC) on persons with ID and Alzheimer.	n=1. Age 54y. Male. Down syndrome, Alzheimer. Moved to sheltered residence.	Qual. Obs.: case study. Caution validity!	Explored
42.	Mahon and Goatcher (1999). Canada.	]50,75]	To assess the impact of a leisure education-based later-life planning model for older adults with ID.	n=20 with ID. 10 in intervention group + 10 in control group. Analysis on 9+7 participants. Intervention group: mean age 58y. Control group: mean age 62y. Male and female. Persons 'in need of retirement planning'. Comp. between groups.	Mixm. Exp: Quant.: non-rand. trial / quasi-exp + Qual.: content analysis.	Tested / observed
43.	McCarron et al. (2010). Ireland.	]25,50]	To explore concerns of caregivers in supporting persons with ID and advanced dementia.	n=57. Persons with ID: no ages mentioned. All with advanced dementia + end of life care. Male and female. Inf.: 50 direct care staff from six ID service providers + 7 staff from Specialist Palliative Care.	Qual.: descriptive design, thematic analysis	Explored
44.	McCausland et al. (2010). Ireland.	]50,75]	To identify areas in which elderly persons with ID have needs and to compare self-reported needs across levels of disability.	n=75 (of 176) with ID. Mean age 57.6y; SD 5.4; range 50-72y. Male and female. 37.3% mild ID, 46.7% moderate ID, 16% severe or profound ID. Living in residential settings or independently + day care centre. Comp. between levels of ID.	Quant. Obs.: cross-sectional.	Explored
45.	McCausland et al. (2016). Ireland.	]75,100]	To examine the frequency & predictors of social contacts between older people with ID, family and friends, and compare with general population.	n= 753 with ID; 474 with ID comp. to non-ID, random sample from TILDA-(IDS). Age range 40-90y, 64% >50y. Male and female. All levels of ID. 45.3% residential care, 34.1% community group home, 5% (semi-) independently, 11% supported by families. Comp. between matched groups, all >50y. Inf.: clients + proxy.	Quant. Obs.: cross-sectional.	Explored
46.	Murphy et al. (2009). Ireland.	]50,75]	To identify determinants for QoL of elderly persons with a disability living in the community and to construct a model to explain these.	n=122, !24 with ID! Age: <65y - >85y. Participants with phys. dis.: stroke (n=20) & arthritis (n=20); with sensory dis. (n=20); with mental health dis.: depression (n=20) & dementia (n=18); with ID (n=24). 82 living at home, 18 in residential care.	Qual.: Grounded Theory, constant comp. anal. + review.	Explored
47.	Neville et al. (2005). UK.	]25,50]	To design and test an effective educational program in peritoneal dialysis therapy.	n=10. 5 with ID + 5 temporary learning dis. due to uremia. 5 Exp. Group (3 ID), median age 73y; range 72-80y + 5 Control group (2 ID), median age 67y; range 61-75y. All renal failure, trained for peritoneal dialysis. Comp. between groups.	Mixm. Exp.: Quant.: quasi-rand. trial + Qual.: theme identification.	Tested / observed
48.	Nøttestad et al. (2000). Norway.	]50,75]	To compare frequencies of psychiatric / behavioural disorders + utilisation of psychiatric health services before and after de-institutionalisation.	n=23 of 29 originally (1987) studied persons. Mean age in 1995: 67y; range 58-75y; 6 part. >70y. Male and female. 1 moderate ID, 16 severe ID, 4 profound ID, 1 PIMD. Moved from central institution to six local communities. Inf.: caretakers.	Quant. Obs.: prospective cohort without control.	Tested / observed
49.	Ouellette-Kuntz et al. (2015). Canada.	]75,100]	To compare Ontarians with/without IDD screened for colorectal cancer; to explore influencing characteristics.	n= 807,583. 15,791 Ontarians with IDD + 791,792 without IDD. Age range 50-64y. Male and female. IDD: ID, Autism Spectrum Disorder and Fetal Alcohol Spectrum Disorder. Comparison between groups.	Quant. Obs.: routine-data-based.	Explored

## IMPROVING QUALITY OF LIFE, ELDERLY PEOPLE WITH ID

50.	Parsons et al. (1997). USA.	]50,75]	To determine the most effective choice offering strategy for older adults with severe ID, specifically in leisure activities.	n=7 with ID. Age range 49-67y. Male and female. Profound ID, ambulatory, 3 using wheelchair/walker for long distances, 3 impaired vision. Attending a Senior Program at a residential facility for people with severe ID.	Quant. Exp.: non-rand. trial / quasi-exp.	Explored
51.	Rogers et al. (1998). USA.	]25,50]	To explore perceptions of leisure of elderly with ID + feelings of empowerment in choosing personal leisure preferences.	n=29 with ID, of 47. Age ≥50y. Male and female. Mild ID: 18, moderate ID: 5, severe ID: 2, unspecified ID: 4. 2 in community employment, 14 in sheltered workshop, 9 retired with adult activity program, 4 retired without day program.	Qual.: constant comparative analysis.	Explored
52.	Rourke et al. (2004). Ireland.	]50,75]	To identify satisfaction of elderly with ID and their caregivers with the current living arrangement across different types of residential options.	n=195. 92 with mild / moderate ID. Mean age 58y; !60 in range 40-49y!; 32 ≥ 50y. 103 staff / guardians of persons with all levels of ID. !68% in range 41-49y!; 32% ≥50y. Male and female. 26% in residential village campus; 32% in community based group home; 41% with family / guardian / independently; 1 in nursing home.	Quant. Obs.: cross-sectional.	Explored
53.	Smith and Carey (2013). Ireland.	[0,25]	To describe a person-centred care plan + an essential lifestyle plan to maintain skin integrity of a person with ID.	n=1. Age 68y. Male. In residential facility for people with ID, with 5 other men. Severe ID, unspecified mental illness. Severe skin condition, psoriasis, ulcer on right leg. Pre-occupied with routines and rituals.	Qual.: single case study. Caution validity!	Explored
54.	Stancliffe et al. (2015). Aus.	]50,75]	To examine feasibility and effects of supporting attendance to mainstream community groups. Transition-to-retirement program.	n=58, 29 interv. group. Mean age interv. group 57.4y; range 46.0 –72.2y. Male and female. !40 with ID (mild or moderate ID)! Elderly supported employees of a Disability Enterprise (ADE). Inf.: self-report + by proxy. Comp. between groups.	Quant. Obs.: before-and-after + concurrent cohort.	Tested / observed
55.	Thompson et al. (2004). UK.	]25,50]	To explore the placement of people with ID in residential services for elderly persons: n, reasons, activities and opportunities.	n=530 with ID. Age unclear, possibly <50y. Average age at entry: 64.8y (SD 11.5); range 17–88 years. 40% placed before 65y. Male and female. 215 currently in homes for elderly, the others having been in contact / having lived in home.	Mixm. Obs.: Quant.: cross-sectional + Qual. case study.	Explored
56.	Treece et al. (1999). USA.	]50,75]	To describe circumstances and effects of choice-making opportunities on QoL.	n=2. Ages 69y. Severe learning difficulties. Living in a 3-bedroom house in the community. Supported by non-profit agency for direct care services.	Qual.: case study, thematic analysis.	Explored
57.	Van Allen et al. (1999). Canada.	]25,50]	To obtain longitudinal outcome information on the natural life course of adults with Down Syndrome.	n=38. 18 middle-aged; mean age at chart review or death: 36.2y; range 30-43y. 20 elderly; mean age 59y; range 50-68y. Male and female. All Down syndrome. All residing in one residential centre. All severe / profound ID. Comp. between groups.	Quant. Obs.: case series.	Explored
58.	van de Wouw et al. (2013). Neth.	]50,75]	To investigate sleep parameters and problems, and associated factors.	n=301 with ID [of n=1050 (Hilgenkamp et al., 2011)]. Mean age 62.13y; SD 8.45; range 50-92y. Male and female. All levels of ID. All supported by three care provider services. Comp. with non-part. of HA-ID study.	Quant. Obs.: cross-sectional.	Explored
59.	van Gennep (1995). Neth.	]25,50]	To explore differences in deterioration according to age, level of adaptive behaviour, quality of care.	n=40 with ID. Mean age in 1989: 65y; SD 9; range 50-90y. 50-59y: n=15; 60-69y: n= 16; ≥70y: n=9. No info on gender. 16 'lower level' + 24 'higher level'. 20 in residential groups + 20 in socio-homes. Comp. between groups.	Quant. Obs.: longitudinal, concurrent cohort.	Explored
60.	Van Puyenbroeck and Maes (2009). Bel.	]50,75]	To examine effects of a narrative reminiscence group work program on subjective well-being.	n=41 with ID. Mean age 62.7y; SD 7; range 50-78y. Male and female. Mild or moderate ID. Living in six care facilities. Comp. of sub-samples. Inf.: elderly + staff.	Mixm. Exp.: Quant.: non-rand. trial / quasi-exp + Qual.: program evaluation.	Tested / observed
61.	van Schijndel-Speet et al. (2014). Neth.	]50,75]	To explore preferences for, participation in, facilitators and barriers to physical activity.	n=40 with ID. Aged ≥50y; range 50-80y. Male and female. Mild (n=28) and moderate ID (n=12). Working in one of seven day-care centres. n=29 using no walking aid; n=7 using a walking aid; n=4 using a wheelchair. Link HA-ID study.	Qual.: clustering of codes.	Explored
62.	van Schijndel-	]75,100]	To analyse effects of a combined physical activity and physical health education program.	n=150 with ID: 81 intervention, 70 control. Mean age intervention: 58.2y; range 44-83y. Male and female. Mild, moderate, severe ID. Working in day care centre. Comp. between groups.	Quant. Exp: RCT.	Tested / observed

## IMPROVING QUALITY OF LIFE, ELDERLY PEOPLE WITH ID

	Speet et al. (2017). Neth.		Program description: Van Schijndel-Speet et al. (2013)			
63.	Wagemans et al. (2017). Neth.	]50,75]	To clarify deliberation process and pitfalls of non-emergency Do-Not-Attempt-Resuscitation Decisions for persons with ID at end-of-life.	n=52 without ID: ID physicians, trainees, experts (of which 4 relatives) responsible for DNAR-decisions. No ages, gender, levels of ID mentioned. Theme: end-of-life care important to elderly people with ID.	Qual.: Grounded Theory, constant comparative analysis.	Explored
64.	Walker and Walker (1998). UK.	]25,50]	To explore age discriminatory attitudes and supports ('ageism') in ID and elderly care.	n=222 with ID. Two surveys. In 1991/92: n=102 with ID; mean age 48.7y; 42% ≥50y. All resettled from long-stay hospital. In 1995/96 follow-up: n=60 resettled + n=60 since long in the community. 49% over 50y. Male and female. Comp. before and after resettlement. Inf.: 41 relatives + all staff.	Mixm. Obs.: Quant.: before-and-after, cross-sectional + Qual.: case study.	Explored
65.	Wark et al. (2015). Aus.	]50,75]	To examine issues of ageing, service facilitators and barriers, support-enhancing practices in rural areas.	n=34; 17 with ID. Age range 54-79y. Male and female. All in rural area, in own home, in drop-in or support unit, in group home, retirement village or aged-care facility. Inf.: 17 with ID + 17 caregivers.	Qual.: thematic analysis.	Explored
66.	Webber et al. (2010a). Aus.	]50,75]	To explore group home staff and family members' views on hospital experiences of group home residents + support strategies.	n=55, clustered round n=17 with ID. Age range of persons with ID: 49-81y at first interview. Male and female. No levels of ID. Living in group homes or moved to elderly care. Group home staff have basic first aid training. Inf.: staff + family.	Qual.: Grounded Theory, dimensional analysis, longitudinal.	Explored
67.	Webber et al. (2010b). Aus.	]25,50]	To explore group home staff's views and supports of age-related health changes of residents + reasons for relocation to aged care.	n=10 supervisors. No info on age, gender, level of ID of persons with ID. Elderly in ID-group homes with rostered day staff + night-staff, being relocated to aged care. Inf.: supervisors of group homes.	Qual.: Grounded theory, dimensional analysis.	Explored
68.	Webber et al. (2014). Aus.	]50,75]	To examine positive and negative effects on health and social inclusion of moving from an ID-group home to residential aged care.	n=31, clustered round n=10 with ID. Persons with ID: mean age 64y; range 48-85y. Male and female. In 9 elderly care services. Limited communicative abilities, some frail. Inf.: 9 family + 10 staff ID group home + 12 staff elderly care.	Qual.: Grounded Theory, dimensional analysis.	Explored
69.	Wiese et al. (2012). Aus.	]50,75]	To examine the current status of palliative care and dying of elderly people with ID.	n=33 staff. Persons with ID: age ≥40 y, in ID-community group homes. Staff: male and female. 64% cared for client who had died. 27% participants received formal training in end-of-life care and dying. Inf.: staff.	Qual.: Grounded Theory, constant comparative analysis.	Explored
70.	Wilkinson et al. (2005). UK.	]25,50]	To explore staff training, support and wider needs in dementia care + good practices in care home provision.	n=50, clustered around n=18 with ID and dementia. Persons with ID: age: 1 ≥40y, 11 ≥50y, 6 unknown. Male and female. Some Down syndrome. All in residential care home. Inf.: 32 staff + 13 co-residents + 5 family.	Qual.: case study, analysis of interviews.	Explored
71.	Williams (1998). USA.	]25,50]	To analyse effects of a phenylalanine-restricted diet for an elderly person with phenylketonuria.	n=1. Age 73y. Male. Nonverbal, profound ID. Phenylketonuria. Dry skin, unwilling to hold materials, refusals to be touched, severe spasticity and ataxia, severe self-injurious behaviour.	Quant. Exp.: non-rand. trial / quasi-exp. Single case.	Tested / observed
72.	Wilson et al. (2013). Aus.	]50,75]	To examine mentors' experiences of Active Mentoring a person with ID, participating in community group.	n=14 mentors. Persons with ID: mean age 57.5y; range 46.0y-72.2y. Male and female. Long-term dis., mostly ID. Supported employees of a Disability Enterprise (ADE). Inf.: mentors.	Qual.: constant comparative analysis.	Explored
73.	Young and Ashman (2004). Aus.	]50,75]	To monitor changes in skills, life circumstances, QoL after de-institutionalization and relocation to community homes.	n=97. Persons with ID: mean age 47y; range 21-84. 61% ≥40y. Male and female. n=15 mild ID; n=26 moderate ID; n= 63 severe/profound ID. 50% additional dis., ≥50% challenging behaviours. High support needs. All relocated. Comp. between groups (age, level of ID groups, before-and-after). Inf.: Staff.	Quant. Obs.: before-and-after, longitudinal, trend analysis.	Tested / observed

**Note: Abbreviations:** Publ. = year of publication. Aus. = Australia. Neth. = the Netherlands. Bel. = Belgium. QA = Quality Assessment. [x,y]= all numbers between x and y, including x, y; ]x,y]= all numbers between x and y, excluding x, including y. Serv. = service. Res. = residential. ID = Intellectual Disability. Dis. = disabilities. IDD = Intellectual and Developmental Disabilities. Y = year. Inf. = informants. Part. = participants.

## IMPROVING QUALITY OF LIFE, ELDERLY PEOPLE WITH ID

Vs = versus. Interv. = Interview. Interv. = intervention. Pop. = population. Quant = quantitative. Qual. = Qualitative. Mixm. = Mixed Methods. Obs. = observational. Exp. = Experimental. Them. Anal. = Thematic Analysis. Constant comp. anal. = constant comparative analysis. Rand. = random. Cross-sect. = cross -sectional. Phen. = phenomenological. Comp. = Comparison. Rand. = randomized.

IMPROVING QUALITY OF LIFE, ELDERLY PEOPLE WITH ID

**Table 2. Overview of themed support strategies and QoL-outcomes (well) executed**

Theme and subtheme	Interventions	Gen QoL	Phys WB	Mat WB	Em WB	Ex WB	Ri	Int Rel	Soc Incl	Pers Dev	Self Det
<b>Living arrangement / housing</b>											
Provision of housing / living arrangement	<b>Provision of a living place</b> in itself (be it residential, community based group home, with family, guardians or independently, or in a nursing home) (52)			+	+						
	<b>Provision of smaller socio-homes</b> which offer a better physical environment, person-oriented management and organisation of community participation than large institutions (59)									+	
	<b>Independent living / living with family</b> (compared to residential care / group living ) (3; 45; 52)	+ / -	+	+ / -	-		+	+			+
	Family looking for and finding <b>secure and stable living arrangements</b> (14; 36; 44)	+									
Accessibility and quality of surroundings	Provision of <b>comfortable, homely</b> , not jam-packed <b>residence facilities</b> , own room, good meals (52)			+							
	Provision of <b>aids, equipment</b> and adaptations for physical changes, mobility devices (wheelchair, walker, ...), cognitive devices (timer, time schedules with pictures,...) (38; 40; 46; 52). Home nurses adapting the environment for fall prevention and self-care assistance (30). Good physical environment, aids and adaptations provided for health problems (11; 68)		+	+	+				+		+
	Provision of <b>accessible community environment</b> : nearby bus stops or shops, churches, restaurants, canteens, work on the site or nearby (46, 52)							+	+ / 0		+
	<b>Adaptation</b> of environment to <b>dementia</b> (70)		+	+	+						
Support by family / community when living in family home / independently	<b>Family / close-knit community support</b> of (I)ADL, going out, problem solving (14; 65)							+		-	+ / -
(Residential) ID-care specific support	<b>Support by ID-service</b> (35; 29), over a long period of time (40)		+	+			-	+/-	+/-	+	-
	Organisation of <b>homogeneous groups</b> (level of ID and age) (52)							+			
	<b>Staff and co-residents</b> providing the most important <b>support and company</b> (6; 40)							+/-	-		
	<b>Staff organising daily life</b> (14)										-
	Leaving clients long time in bed (late getting up, early being put to bed) in <b>residential central ID-facility</b> (58; 68)		-								

IMPROVING QUALITY OF LIFE, ELDERLY PEOPLE WITH ID

Support by regular service for elderly people	<b>Support by regular service for elderly people</b> (29; 35; 55; 64)	-		-	-		-	-	+/-	-	-	
	Attempting to <b>make elderly feel at home</b> , consulting family and some former group home on this matter (68)				+			+				
	<b>Being placed before 65 years in regular elderly care</b> (55)				-							
'Ageing-in-place' philosophy and strategies	'Ageing-in-place'-dedicated supervisors <b>explore all options</b> to keep the resident in place, <b>promote slow relocation</b> or try to prevent it, plan for the future (67)			+	+			+				
	<b>Re-allocate or seek additional resources</b> in an effective way, while navigating care systems (67)			+	+			+				
	<b>Reorganise staffing patterns</b> for older residents; identify flexible personnel and seek staff with aged care or medical experience (67)			+	+			+				
	<b>Adapt homes</b> and residences in more effective way (67)			+	+			+				
	Encourage families and friends to <b>install buddy systems</b> , and to regularly pass by those elderly that stay home alone (67)			+	+			+				
	<b>Teach</b> older residents the <b>skills</b> to stay home alone (67)			+	+			+				
	Send personnel to <b>training programs</b> , courses (67)			+	+			+				
	Organise <b>alternative activities</b> for the elderly with ID (67)			+	+			+				
Moving	'Active engagement'-dedicated supervisors build special homes and support quick <b>moves out of the group home</b> (67)							-	-		-	
	Frequent or crisis moving, decided by supervisors, staff, family (6; 39; 51; 67).	+/-			-			-			-	
Moving from long-stay hospital	<b>Moving from long-stay hospital</b> to community-based homes for people with ID, to live with family or independently, to elderly care (1; 22; 23; 37; 48; 64)	+/-	+/0	+	+			+	+	0/-	+/0	+
	Deinstitutionalisation leading to <b>more favourable staff:resident ratio</b> for smaller groups in smaller, more normal environment with better living conditions. <b>More stable staff</b> , in closer, more equal relationships (22; 37; 48; 73)	+	+/0	+	+			+	+	+	+	
	<b>Provision of more (community) leisure activities and teaching of new skills</b> ; staff and clients doing things together after deinstitutionalisation (22; 23; 37)	+		+	+					+	+	
	<b>More opportunities provided to express choices and make decisions</b> , less governed by imposed routines and more decisions made on a day-to-day basis (22; 23; 37)										+	+
	<b>Support of meaningful relationships and giving time to adapt to change</b> (37)				+							
	<b>Extensively organised work and leisure time and maintaining of daily schedules</b> after deinstitutionalisation, with high occurrence of interactions with personnel (48)		-		-							



IMPROVING QUALITY OF LIFE, ELDERLY PEOPLE WITH ID

	Staff ageist beliefs causing elderly to be <b>significantly more moved to large units</b> (22; 73).									-	-	-
<b>Work / Daily activities</b>												
Provision of activities	<b>Provision of a range of age and ability appropriate activities</b> , including organisation of holidays and <b>maintaining lifelong passions</b> (6; 13; 14; 32; 36; 40; 44; 52)									+	+	+
	Provision of meaningful <b>socialisation activities</b> (36; 52)									+	+	+
Activities in ID-care	Staff focusing on <b>active lifestyle and active ageing</b> : filling daily schedule with activities, schooling, routines, maintaining habits and skills (6; 13; 14; 38; 46; 67)	+								+/-	+/-	-
	Staff and elderly <b>doing things together</b> : communicating and interacting, watching TV or having coffee together, playing games or singing songs (38)									+		
Retirement	<b>Retirement planning</b> , providing education and development of leisure oriented life-style, skills and satisfying relationships (7; 14; 36)									+/-	+	+
	<b>Transition-to-retirement program</b> and <b>active mentoring</b> (8; 19; 54; 72)									+	+	+
	<b>Community Membership Project</b> , with a community builder supporting activities and developing networks (34)		+							+	+	+
	After retirement: provision of <b>daily activities, adapted retirement lifestyle, transport, moving to integrated living arrangement</b> (38; 51)									+	+	+/0
	<b>Tacit retirement policy</b> in ID-care services (64).											-
Physical activities, physical therapy and sports	Treadmill <b>walking program</b> (15), physical balance and muscle strength <b>training programs</b> (16; 17; 18), <b>physical training</b> and physical health education (62), <b>physiotherapy</b> (46)		+/0							+	+	
	<b>Strategies facilitating participation in physical activities</b> , e.g. coffee and cigarette breaks, routine organisation, receiving rewards or positive feedback (46; 61)		+							+		
(I)ADL support	<b>Increasing support of (Instrumental) Activities of Daily Life</b> (ADL and IADL) (14; 40)		+/-								+	+/-
	<b>Involvement of elderly person in daily tasks</b> (35)											+
	Use of <b>eating aid Bestic</b> (21)			0		+						0
	<b>Support of communication</b> (38; 44)											+
	<b>Others budgeting money</b> (14; 40; 44; 56).											-
<b>Psychosocial support</b>												
Existential supports	<b>Talking about ageing</b> , future life and death (13; 43)											+
	<b>Involving peers in rituals</b> around death and dying (43)											+/-

IMPROVING QUALITY OF LIFE, ELDERLY PEOPLE WITH ID

	Giving <b>spiritual care</b> to anxious elderly dying (43)		+		+	+					
	<b>Performing individual Life Story Work</b> , creating life history documents, rummage box, Story to Tell Project (2; 20; 31; 38)		+		+/0		+	+	+	+	+
	<b>Group reminiscence work</b> , 'narrative storytelling' (60)				+/0			+			
Support of Self-determination	<b>Strategies fostering independence:</b> keeping focus on residents' wishes; promoting choice and self-determination in future planning; providing alternatives to choose between; trying to interpret non-verbal signs when giving choice (36; 38; 52; 55)							+	+		+
	<b>Assessment of level of choice-making</b> of clients with severe ID (50)										+
	<b>Facilitating preferred, desired, meaningful activities, and activity trial and rejection</b> (13; 51)				+					+	+
	<b>Staff quickly taking over (I)ADL-activities (38).</b>								-	-	-
	<b>Staff or family making (present- focused) decisions on behalf of elderly with ID:</b> choosing menu, moving, retirement, day program, holidays, where to live. Non-consultation of elderly (6, 38).	-							-	-	-
	<b>Care providers choosing</b> diversional, passive, group managed activities and daily routines, <b>fit into management schedules (51; 56).</b>				0/-					-	-
Support of Social Inclusion	<b>Staff organising inclusive support by volunteers:</b> hospitable, appreciative environment, prioritising long-term engagement, regular volunteer gatherings, volunteer manager, making volunteers feel at home, opportunities for both meaningful activity and personal growth (9)				+		+	+	+		
	Staff, families, friends, key-person, clubs, churches <b>planning and taking part in shared or community activities</b> , participating in (individualised) shared activities (9; 14; 36; 40; 46; 65)				+		+	+	+	+	
	Volunteers, familiar persons, close knit communities <b>bridging service and non-service worlds</b> (38; 65)	+							+		
Support of Interpersonal Relations	<b>Active monitoring and support of contact with co-residents</b> (32; 38)				+			+	+		
	<b>Support of contact with staff:</b> staff and residents doing communal activities (38). Elderly care staff building contact (training volunteers, participation in social programs) (68)							+	+		
	<b>Maintaining, strengthening of existing, or building new supportive social networks. Establishing relationship and network building strategies. Supporting meaningful contact</b> with friends and volunteers over time in an <b>individualised, personalised planning and decision-making process</b> , while handling potential tensions. Involving family, friends, volunteers <b>in and via activities</b> (6; 9; 36; 67)				+			+	+		
<b>Planning of support</b>											
Planning of support	<b>'Leisure-education-based later-life planning model'</b> (42)			0	+		+/0			+	+

IMPROVING QUALITY OF LIFE, ELDERLY PEOPLE WITH ID

	<b>Person-centred care and an essential lifestyle plan</b> (53)		+						+		
	<b>Parents planning future transition-of-care:</b> key person succession plans; financial and legal plans; residential plans (5; 14; 36)			+	+				+		+
	<b>Planning of sleep-over respite care and supported holidays</b> (13; 36)				+			+/0			+/0
	<b>Advanced end-of-life care planning:</b> honouring last wishes, Do-Not-Attempt-Resuscitation decisions (4; 63)		+		+						+
<b>Dementia and end-of-life care</b>											
Dementia Care	<b>Personal, qualitative (physical, psychosocial, spiritual) sensitive caring</b> (43; 70)		+	+	+				+		
	<b>Early detection</b> of dementia (33)		+		+						
	<b>Peaceful, beautiful, quiet, familiar, supportive environment.</b> Preferably aging-in-place in adapted environment (43)		+		+						
	<b>Who:</b> Committed, trained, familiar staff. Extra shifts, waking night staff. Supervisors monitoring staff stress levels (70)		+		+				+		
	<b>Acute decisions and non-planned transfer</b> to hospital, <b>moving in end-stage (43). Also in End-of-life Care.</b>	-	-		-						
End-of-life care	<b>Treatment of physical issues:</b> pain, insomnia, dehydration, infections, secretions or nausea, lack of appetite. Adequate nutrition and hydration, sedation, PEG or hand feeding (39; 43)	+	+		+						
	<b>Collaboration</b> between all involved services (43)		+		+						
	Clear <b>procedures</b> , end-of-life <b>planning</b> and clear Do Not Reanimate / Resuscitate-codes, and Ethic Committee present (43; 63)		+		+						
	<b>Supporting the person nearing end-of-life:</b> last wishes, practical, emotional, spiritual and social support (4; 43)				+	+			+		+
	<b>Where:</b> preferably at place of client's choice, enough room and space (43; 69; 70)				+/-				+		+
	<b>Who:</b> support by familiar, prepared staff (69)				+/-				+		
	<b>Quality post-death caring:</b> focus on clients, staff, family. Capturing grief responses, rituals (peers!), attending to funeral. Use of palliative care expertise in this matter (43; 69)				+						
<b>Mental Health / Behaviour Support</b>											
Medication + psychotherapy	Correct diagnosis and treatment by <b>thorough review of medical, medication &amp; behavioural history</b> (10; 11)		+		+				+		+

IMPROVING QUALITY OF LIFE, ELDERLY PEOPLE WITH ID

Managing difficult behaviour	<b>Medical assessment of residents with 'disruptive' behaviours, treatment of causes, trials on analgesia, management of behaviour</b> , in elderly care (68)		+									
	<b>Behaviour management</b> by home nurses (30)		+									
<b>Physical Health Support</b>												
Health Screening	<b>(Preventive) health screening</b> (11, 30, 40; 68). Specifically for persons with <b>Down syndrome</b> (57). Specifically for <b>cardio-vascular disease risk</b> (25) and <b>chronic kidney disease</b> (26)		+									
Diagnosis and treatment	<b>Regular contact with GP</b> (primary care patient enrolment model) <b>or with health care resources</b> leads to better participation in ColonCancerCheck Program (49)		+									
	Taking <b>precautions to prevent choking and aspirating</b> (68)		+									
	<b>Early and correct diagnosis</b> , e.g. by review of medical history; <b>health and pain assessment</b> (10; 13, 68)		+		+			+			+	
	<b>Clear information from healthcare professionals</b> (46), seeking / receiving <b>specialist advice</b> (11, 68)		+									
	<b>Monitoring and treatment</b> of physical problems (11; 13; 68). <b>Provision of medication and diets</b> (68)		+									
	<b>Administering of phenylalanine-restricted diet</b> (71)		+		+			+			+	
	<b>Accommodation of erratic sleep schedules + monitoring of night activities</b> (68)		+									
	<b>Strategies to minimise consequences of non-treatable conditions</b> (68)		+									
	<b>Nursing support, physiotherapist support</b> (46)		+									
Medication	Administration of <b>anticonvulsant drugs</b> (3)		-									
	Administration of ( <b>sedative</b> ) <b>antipsychotics</b> (58)		+									
	<b>Changing of medications</b> to decrease fall risk, night waking and faecal incontinence (68)		+									
	<b>Managing polypharmacy by home nurses</b> (30)		+									
Health education	<b>Training on peritoneal dialysis</b> (47)		+		+			+			+	+
	<b>Nutrition and weight management, and health education</b> by home nurses (30)		+									
Hospitalisation	<b>Adaptations</b> of hospital policies, resources, systems, communication, training and partnering (66)				+							
	<b>Staff / family using strategies to overcome negative experiences:</b> providing information package, partnering, advocating (66)		+	-	+/-							



## IMPROVING QUALITY OF LIFE, ELDERLY PEOPLE WITH ID

**Note: Abbreviations:** QoL-outcomes: Gen. = General influence, not specified per domain. PhysWB = Physical Well-being. MatWB = Material Well-being. EmWB = Emotional Well-being. ExWB = Existential Wellbeing. Ri = Rights. IntRel = Interpersonal Relations. SocIncl = Social Inclusion PersDev = Personal Development. SelfDet = Self Determination. + = positive effect on QoL. - = negative effect on QoL. **0**: no effect. +/-: positive and negative effects on QoL. Pop.= Population. Vs = versus.

IMPROVING QUALITY OF LIFE, ELDERLY PEOPLE WITH ID

**Table 3. Overview of QoL-outcomes of themed support strategies lacking, falling away or executed in a non-qualitative way**

Theme, subtheme, level of intervention	Interventions	Gen QoL	Phys WB	Mat WB	Em WB	Ex WB	Ri	Int Rel	Soc Incl	Pers Dev	Self Det
<b>Living arrangement / housing</b>											
Accessibility and quality of surroundings	<b>Bad group home design and organisation</b> , providing too small, non-adapted rooms, lack of storage room, noisy, too small housing (14; 38; 52; 65).			-	-				-	-	
Support by family / community when living in family home / independently	<b>Disintegrating support by networks dissolving</b> (40; 45).				-			-			
Support by regular service for elderly people	<b>Reluctance to provide support for (younger) elderly with ID in elderly care</b> (64).			-			-		-		
Moving from long-stay hospital	Staff ageist beliefs and organisational issues causing personnel to <b>invest less in support of external relationships and activities (in the community)</b> (1; 64).									-	-
	<b>Lack of / decreased mental health care</b> after deinstitutionalisation (48).				0/-						
	<b>Low care consistency, high turnover</b> of staff after deinstitutionalisation, caused by staff shortages, low wages, lack of adequate training and high stress. Low staff-to-individual ratio (37; 64).							-			-
<b>Work / Daily activities</b>											
Provision of activities	<b>Lack of or loss of activities</b> , going out (especially when severe disabilities!) (14; 32; 36; 44; 52).				-			-		-	
Activities in ID-care	<b>Staff not supporting participation</b> in indoor or outdoor (social) activities (6; 11; 14; 38).				-			-	-	-	-
	<b>Staff not organising activities</b> out of ageist expectations or lack of responsibility (64).									-	
Activities in regular service for elderly people	<b>Limited provision of ID-suited activities</b> , not available at weekend. Discontinuation of former preferred activities (35; 55; 64; 68).				-			-	-	-	
Retirement	After retirement: provision of <b>meaningless activities, no supporting of old / building of new network, lack of money and transport, lack of options, moving/relocation</b> to nursing home (7; 51; 65).	-			-			-	-	-	-
	<b>Ill-prepared or non-self-chosen retiring</b> (32; 51).				-			-	-	-	-
Physical activities, physical therapy and sports	<b>Lack of activation</b> of low levels of <b>physical activity</b> and of healthy lifestyle (3; 24; 40).		-								
	<b>Strategies reducing participation in physical activities</b> : not replacing activities by more appropriate ones, staff discouraging elderly to being active, difficulties with transportation and staff shortages (46; 61).		-					-	-		

IMPROVING QUALITY OF LIFE, ELDERLY PEOPLE WITH ID

(I)ADL support	<b>Lack of specific support</b> of daytime activities, money budgeting, transport and communication <b>for elderly with severe / profound disability levels</b> (44).	-									
	<b>Lack of support for / provision of transport</b> (44; 46).			-					-	-	-
<b>Psychosocial support</b>											
Support of Self-determination	<b>Self-determination-obstructing attitudes:</b> being strict or impatient, overprotecting, infantilising; not viewing ‘fostering independence’ as staff role; providing less opportunities to normal ways of living or empowering of independence, out of ageist, lower expectations (51; 52; 64).				-						-
	<b>Busy staff losing track of things important to the elderly</b> (by limited funding or staff availability) (38).								-		
	<b>Disruption</b> of usual patterns <b>of leisure activities, with fewer opportunities for decision making;</b> no searching of new meaningful activities <b>after relocation to elderly care</b> (51).								-	-	-
Support of Social Inclusion	<b>Lack of provision of community involvement and participation opportunities,</b> e.g. family not taking their relatives out anymore, because of own high age, visiting stopped (13; 35; 40). <b>Especially in elderly care.</b>				-				-	-	-
Support of Interpersonal Relations	<b>Discontinuation of attempts for social interaction development in elderly care,</b> e.g. by moving residents to private rooms (68).				-				-		
	<b>Staff, family not entertaining existing important contacts,</b> because of lack of transport, high age, health, staff or money shortages or daily schedules (13; 40). <b>In elderly care:</b> stop of former staff visiting, limited contact with external professionals, staff not feeling responsible (55; 68).				-				-	-	
	Breaching contact by <b>changing staff or key worker</b> (32).				-						
<b>Planning of support</b>											
Planning of support	<b>Lack of future planning, present-focused orientation of staff</b> (6).	-									-
	<b>Lack of monitoring and preventing (negative) life events</b> (32).				-						
<b>Dementia and end-of-life care</b>											
Dementia Care	<b>Lack of pain detection</b> and management (70).				-						
	<b>Lack of resources,</b> trained staff, end-of-life care plans (43; 70). Also in End-of-Life Care.				-						
End-of-life care	<b>Restrictions, untimely interventions</b> of coroner, disagreement on rituals (43; 69).				-						
<b>Mental Health / Behaviour Support</b>											



## IMPROVING QUALITY OF LIFE, ELDERLY PEOPLE WITH ID

Medication + psychotherapy	<b>Non-specialised (psychological) advice and treatment</b> by general practitioners and nurses, <b>misdiagnosis, prescription of unnecessary medication</b> , caused by lack of education or lack of attention for emotional and psychological needs (10; 11; 44).		-		-					
	<b>Lack of screening for diabetes, when anxiety, and vice versa</b> (27).		-		-					
	<b>Uncareful prescribing</b> atypical antipsychotics (24; 28).		-/0							
<b>Physical Health Support</b>										
Diagnosis and treatment	<b>Mis- or underdiagnosis of disease, pain</b> (10; 28; 39; 66).		-		-		-		-	-
Health education	<b>Lack of support of, and education on healthy eating and physical activity</b> , especially for elderly shopping for groceries independently (24; 25; 40).		-							
Hospitalisation	<b>Lack of ID-specific support of elderly people with ID in hospitals</b> (39; 66).		-		-		-		-	-
	<b>Inadequate treatment or pain management of elderly people with ID in hospitals</b> (39; 66).		-		-		-		-	-
<b>Services</b>										
Provision of personnel	<b>Insufficient staffing</b> , staff shortages and high turnover (32; 36; 38; 40; 52). Also in elderly care (55).		-		-		-		-	-
	Diminished <b>availability of local medical personnel / services</b> , causing difficulties to access health care (65).		-		-					
	<b>Scarce contact</b> organised with social worker or case manager, community nurse, psychiatrist / psychologist, ID-professional, in elderly care (55).						-			-
<b>Education</b>										
Education of elderly people with ID	<b>Lack of lifelong learning programs</b> , basic education classes (especially for severe / profound ID) (13; 44).		-						-	-
	<b>Restriction of training opportunities</b> by ageist staff (64).								-	-
<b>Cooperation</b>										
Cooperation with hospitals	<b>Lack of cooperation</b> between ID- or elderly care staff, families and hospitals (66).		-		-					-

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