

PARTICIP.AGE PROJECT

Supporting community participation and social inclusion of Ageing People
with Intellectual Disabilities

Stakeholder Analysis Report



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Abstract

This report provides a summary of the methodology and results of a stakeholder analysis on barriers and facilitators of social inclusion and community participation from the perspectives of both ageing people with intellectual disabilities and staff who support this population. The stakeholder analysis sought to examine the relevance of identified key barriers and facilitators through the exploration of lived experiences in both these populations.

The stakeholder analysis survey was developed in partnership with six project organisations: University of Galway (Ireland), European Platform for Rehabilitation (Belgium), Medea (Italy), Panagia Eleousa (Greece), Mariaberg e.V. (Germany) and Spain (Fundación Intrás). Data was collected by the project's partnership organisations across five different European countries: Greece (Panagia Eleousa), Germany (Mariaberg e.V.), Spain (Fundación Intrás) and Ireland (Rehab Group), with results being analysed by the University of Galway (Ireland) team. The stakeholder analysis was conducted over several European countries to identify the importance of certain barriers and facilitators, and explore the similarities and differences across countries, so that a clearer understanding of the topic could be developed.

Literature Review

Over the past three decades, advancements in medical care, therapeutic interventions and growing social support has allowed for a remarkable shift in the life expectancy of Ageing People with Intellectual Disabilities. With the exception of Down Syndrome, the collective increase in life expectancy has been substantial, nearly aligning with that of the general population (Coppus, 2013). A longitudinal cohort study by Patja (*et al.*, 2000) lends further support to this trend, revealing that individuals with mild intellectual disability (ID) exhibit a life expectancy on par with the general population. Conversely, those with severe and moderate ID experience decreased life expectancies relative to the general population, which is presumably linked to severe neurological deficits and associated disorders (Patja *et al.*, 2000).

Yet, in tandem with these encouraging developments, the concept of age and ageing within this community has given rise to a series of novel challenges. Due to limited attention, the response framework to ensure optimal health and social care for Ageing People with Intellectual Disabilities in their later years remains lacking (Holland, 2000). Many factors contribute to this, including ageism and negative attitudes (David *et al.*, 2015), diagnostic overshadowing and the resultant healthcare disparities (Bishop *et al.*, 2013), the risk of age-related physical health issues, mental disorders and dementia (Sinnai *et al.*, 2012), alongside the nuanced responses of caregiving staff to age-associated health changes for those with ID (Webber *et al.*, 2010). These factors collectively impede the process of ‘successful’ ageing within this demographic. As the life expectancy of Ageing People with Intellectual Disabilities continues to approach that of the general population, it is imperative to develop and implement policies and resources designed to optimise quality of life (QoL) for this population.

The ageing process among individuals with intellectual disabilities

The longevity experienced by individuals with ID carries a substantial burden of age-related disorders, spanning from dementia and mental disorders such as depression, to cataracts, hearing disorders, diabetes, hypertension, and osteoarthritis (Sinai *et al.*, 2012). For example, a study by Shooshtari (*et al.*, 2011) reported that there is a significantly higher risk of dementia among those with ID, estimated to be four to five times greater than the general population. This study also reports a 2.6 times greater risk for depression in older adults with ID in comparison to older adults without ID. Moreover, the challenges are compounded for those with Down Syndrome, where individuals often exhibit an earlier onset of symptoms related to mortality, dementia, or cognitive decline (McCallion & McCarron, 2004).

In contrast to such heightened risks, the concept of successful ageing, which is commonly used in the general population, appears more nuanced within the context of ID and age. A comprehensive review of successful ageing indicators among the general population revealed consistent markers such as non-smoking status, higher physical activity levels, and absence of conditions like arthritis, depression and diabetes (Depp & Jeste, 2006). Chronic diseases and multiple disabilities tend to manifest early in life for many with ID, such as sensory impairments, epilepsy, gastrointestinal issues, congenital heart conditions, musculoskeletal disorders and diabetes (Evans *et al.*, 2013). The transition to old age for individuals with ID is marked by functional constraints, multimorbidity, lifestyle disparities, limited cardiovascular risk detection, and overlooked medical conditions, all of which contribute to the trajectory of poorer health for this population (Sinai *et al.*, 2012).

Considering these differences, the relevant factors for successful ageing for Ageing People with Intellectual Disabilities should be considered separately to the general population. A review conducted by Reppermund and Troller (2016) explored the concept of successful ageing for those with ID. They recommended that key indicators such as sound physical and

mental health, healthy lifestyles, robust social interactions, life satisfaction, and access to quality healthcare, should be considered in the development of health policies and resources tailored to the specific age-related needs of individuals with ID. Moreover, it is crucial to recognise the inherent heterogeneity among Ageing People with Intellectual Disabilities, spanning diverse cognitive abilities and encompassing biological, psychological, and social backgrounds. This heterogeneity underscores the inadequacy of adopting a ‘one-size-fits-all’ model to successful ageing, necessitating tailored strategies that accommodate the unique dimensions of each person’s aging process.

Social inclusion as a key component of quality of life

Shalock’s (1990) QoL model contains three overarching factors contributing to one’s QoL which are linked to eight subdomains: Independence (personal development, self-determination), Inclusion (interpersonal relations, social participation, rights) and Wellbeing (emotional wellbeing, physical wellbeing, material wellbeing). Within the framework of Shalock’s QoL model, which has been validated for people with ID (Shalock *et al.*, 2011), social inclusion has been shown to be an essential element that has a significant impact on people’s general well-being and life satisfaction. Social inclusion has been commonly defined through a lens of conformity to prevailing societal norms, which typically is measured through productivity and independent living (Hayes *et al.*, 2008). However, this is inappropriate for those with severe disabilities and promotes an ableist view that social inclusion is limited to the measure of one’s participation in community-based activities. Cabigo (*et al.*, 2012) advocate for an evolved understanding of social inclusion – one that adopts a proactive stance, respects individual experiences outside the dominant group, embraces a developmental perspective where social inclusion improves with increased opportunities, and encompasses a sense of belonging and well-being.

Within this perspective, the significance of social inclusion is underscored by contrasting the experiences of Ageing People with Intellectual Disabilities with those without intellectual disabilities. It becomes evident that while social engagement is an integral part of the human experience, Ageing People with Intellectual Disabilities often face a higher likelihood of exclusion from social networks and community activities (LaPlante, 2014). This disparity in inclusion not only causes feelings of isolation but also has a cascading impact on various dimensions of well-being (Emerson & Hatton, 2008). Although Ageing People with Intellectual Disabilities report moderate levels of contentment with life in their old age (Lehmann *et al.*, 2013), many suffer significant social network losses when they move to/within residential services (McCausland *et al.*, 2016). A systematic review (Schepens *et al.*, 2019) highlighted the importance of supporting social inclusion by maintaining, strengthening, and building supportive social networks in this population to experience a higher QoL. Exploring the determinants, barriers, and facilitators of social inclusion for this population provides the foundation for developing targeted interventions, resources, and policies.

Gaps in social inclusion for Ageing People with Intellectual Disabilities

The pursuit of social inclusion for Ageing People with Intellectual Disabilities is marked by many gaps and inequities, emphasising the need for theory-driven and population-motivated policies. The distinctive trajectory of Ageing People with Intellectual Disabilities ageing process can make them prone to marginalisation and exclusion from society. While policy and legislation can be tailored towards specific populations, there is an unfortunate tendency to overlook the diversity within the Ageing People with Intellectual Disabilities population, therefore limiting the QoL improvements which could be reached by promoting social inclusion (Turner & Cooper, 2015).

Previous qualitative research focusing on the perspective of individuals with ID on social inclusion highlight a variety of perceived barriers and facilitators. Abbott and McConkey

(2006) identified four prominent barriers: lack of necessary knowledge and skills, role of support staff and service managers, location of house and community factors such as amenities and the attitudes of key groups. Participants in this study also suggested several solutions, for example, increasing access to appropriate skills training, being listened to by staff, increased support to access activities available locally and promoting volunteering to accompany individuals with ID in community activities. The Irish Longitudinal Study on Ageing (McClausland *et al.*, 2016) explored predictors of social contacts for Irish Ageing People with Intellectual Disabilities. Residence, level of ID and age were all significant factors determining social contact, with those in institutional residence, older respondents (> 50 years) and those with severe ID having the lowest level of contact. Importantly, Ageing People with Intellectual Disabilities who lived in a community setting had greater social contact than those residing in institutions.

Ageing People with Intellectual Disabilities can oftentimes feel socially excluded and are therefore less likely to engage in community-based activities which negatively affects social well-being (McConkey & Collins, 2010). Of interest, recent evidence suggests that interventions aimed at enlarging social networks by getting fellow APWIF to come together as a group is not effective, instead interventions should be tailored to include pre-existing social networks to promote significant enlargement of external social networks (Kruithof *et al.*, 2018). Research also supports the importance of urban design being viewed through the lens of social infrastructure so that diverse community-care support is promoted (Carnemolla, 2022). A comparative study of rural and urban living for Ageing People with Intellectual Disabilities (Nicholson & Cooper, 2013) suggested that adults with ID who lived in rural areas had better daytime opportunities and lived in less deprived areas than those who resided in urban areas. However, they may not hold positive or close relationships. Much of the research in this area has been conducted with Ageing People with Intellectual Disabilities who are in paid formal

services (Amado *et al.*, 2013), and it is therefore important to consider the influence of staff relations in the context of social inclusion.

The role of support staff

Support staff have a pivotal role in promoting social inclusion and enhancing QoL for Ageing People with Intellectual Disabilities. Staff have a significant influence over the experiences, interactions, and opportunities that shape the daily life of Ageing People with Intellectual Disabilities. Research focusing on staff who support Ageing People with Intellectual Disabilities has highlighted the need for proactive planning, individualised care, and teamwork in providing the best possible care in services (Doody *et al.*, 2013). The collaborative efforts between family, client and healthcare professionals are essential for providing quality care. Furthermore, it is recommended that staff adopt a leading role in this collaboration and planning of care, as it allows for the implementation of professional, individualised care through the development of realistic, proactive and responsive strategies.

However, there appears to be a lack of appropriate training programmes to address the complexities of ageing in people with ID (Alborz *et al.*, 2003; Wilkinson *et al.*, 2005). Additionally, research suggests that training programmes developed without soliciting input from support staff often fall short of achieving intended objectives. Of note, there exists a widespread lack of involvement from staff in shaping the content and direction of training programmes. (Whitworth *et al.*, 1999).

In qualitative research, a Delphi project was conducted focused on the impact of ageing on the support provided by disability workers, and what training was required to address the identified areas (Wark *et al.*, 2014). Five themes were developed: generic training such as on attitudes, medical issues including the complexity of comorbid health conditions, the increased burden in understanding of different support which emerges at different stages of ageing, the

need for additional training regarding mental health and lastly the inadequate acknowledgment of QoL as a focus in training. Innes *et al.* (2012) conducted a systematic review and concluded that the current frameworks for care and support for Ageing People with Intellectual Disabilities are largely inadequate; there is lack of appropriate services and accommodation, and they recommended that staff, who are advocates, collaborators, and facilitators for social inclusion, are trained in specialist knowledge for the unique needs of Ageing People with Intellectual Disabilities.

Research aims

This research focuses on identifying the pivotal barriers and facilitators to social inclusion for Ageing People with Intellectual Disabilities. Moreover, this study includes the perspectives of the support staff who play a central role in the lives of Ageing People with Intellectual Disabilities. Exploring the role and significance of key barriers and facilitators of social inclusion for Ageing People with Intellectual Disabilities from these two unique perspectives, will allow for the design and implementation of online educational resources to improve social inclusion and therefore enhance QoL. This project was conducted in collaboration with teams based in Greece, Spain, Italy, Ireland, and Germany, allowing for comparison of diverse perspectives and contextual variations. This stakeholder analysis has two research objectives:

1. To conduct an exploratory analysis of each national partner's individual data and an overall sample of the key barriers and facilitators for social inclusion in the Ageing People with Intellectual Disabilities population as perceived by both the staff responsible for supporting and Ageing People with Intellectual Disabilities themselves.
2. To conduct a comparative analysis between each national partner's data on the key barriers and facilitators for social inclusion in the Ageing People with Intellectual Disabilities population as perceived by both the staff responsible for supporting and Ageing People with Intellectual Disabilities themselves.

Research Method

Design

This was a multi-site collaborative research project using a mixed methods approach. Data was collected through a mixed-methods survey with both closed and open-ended questions. The survey was available in both an online and a paper-and-pen version. The survey aimed to prioritise key barriers and facilitators that were identified through both a literature review and preliminary stakeholder meetings with the project partners. The survey went through three revisions using the feedback from topic experts and project partners, before being sent to partners for translation and dissemination. Two separate surveys were designed; one which investigated the perspectives of Ageing People with Intellectual Disabilities and the other investigated the perspectives of staff who support Ageing People with Intellectual Disabilities.

Participants

Eligible participants were recruited online or in-person through each organisation's professional networks. The first sample consisted of Ageing People with Intellectual Disabilities, who were required to be the minimum age of 50 years and have a formal diagnosis of ID. There were no exclusion criteria which referred to socioeconomic status or cultural background. As this is a population with cognitive difficulties, caregivers of the sample were asked to provide any required assistance to the participants when completing the survey form. The second sample consisted of staff who support Ageing People with Intellectual Disabilities, who were required to be the minimum age of 18 years and to be formally employed in a support role for Ageing People with Intellectual Disabilities. There were no exclusion criteria which referred to socioeconomic status or cultural background. Staff and Ageing People with

Intellectual Disabilities were recruited exclusively from four organisations: Panagia Eleousa (Greece), Mariaberg E.V. (Germany), Fundación Intrás (Spain), and Rehab Group (Ireland).

Measures

Survey 1 (Ageing People with Intellectual Disabilities). The form consisted of two separate sections. The first section sought to examine the relevance of 10 identified barriers to social participation. Each barrier had a code for the research team, such as “limited functional independence,” which corresponded to an easy-to-read statement that the participant saw in the form (e.g., “It’s hard for me to do things on my own.”). The second section sought to examine the relevance of 10 identified facilitators of social inclusion. As before, each item had a relevant code, for example “co-residential friendships,” which corresponded to an easy-to-read statement (e.g., “I can make friends with the people I live with.”). Across both sections, participants were asked to choose either Yes, Maybe or No to indicate if a statement related to their own experience of social inclusion. There was an additional open text box at the end of each survey, where participants were invited to share any additional comments or feedback.

Survey 2 (Staff). The form consisted of a 17-item survey which sought to examine the relevance/prioritisation of barriers and facilitators of promoting social inclusion for Ageing People with Intellectual Disabilities. Participants were not informed whether an item was considered a barrier or facilitator and were instead asked to rate if they considered an item as a barrier or facilitator themselves on a 7-point Likert Scale (-3=Strong Barrier; -2=Intermediate Barrier; -1=Weak Barrier; 0=Not Applicable; +1=Weak Facilitator; +2=Intermediate Facilitator; +3= Strong Facilitator). There was an additional open text box at the end of each survey, where participants were invited to share any additional comments, [Appendix A](#).

Data Analysis

An interpretive approach to the data was applied to address the research aims. Responses from each project partner were sent to the University of Galway team, alongside a short questionnaire on data methodology (sample sizes, survey procedure and data exportation). These responses were exported into Excel for analysis, so that identified barriers and facilitators could be ordered by relevance (most relevant to least relevant). In addition, all project partners' data was added into a master excel file so that the overall sample data could be analysed. In order to compare the results from each national sample and the overall sample, a narrative comparative analysis was conducted based on the results presented from the first research objective. Following a collaborative discussion, the key topics that will be further addressed in Work Package 2 will be selected.

Results

A target of 120 participants per sample group ($N = 240$) was established based on Key Performance Indicators for the grant. However, the final sample sizes for both sample groups were larger than preliminary expectations. Information for each national partner's sample size can be seen below in *Table 1*.

Table 1.

Sample sizes across the sample groups and project partners.

	Panagia Eleousa	Mariaberg E.V.	Fundación Intras	Rehab Group	Total sample
Country	Cyprus	Germany	Spain	Ireland	
Aging People with Intellectual Disabilities STAFF	40	57	20	16	133
STAFF	55	50	20	20	145
Total sample	95	107	40	36	278

Research Objective 1: Aging People with Intellectual Disabilities

Calculated values for each factor were based on multiplying sample sizes per the attributed value of a possible response. For both the barriers and facilitators, ‘No’ was given a value of -1, ‘Maybe’ was given a value of 0, and ‘Yes’ was given a value of +1. Factors were then sorted by total relevance (least to most relevant).

Individual organisation information is provided in [Appendix B](#).

Barriers					
	<i>Panageia</i> <i>n=40</i>	<i>Mariaberg</i> <i>E.V.</i> <i>n=57</i>	<i>Fundación</i> <i>Intras</i> <i>n=20</i>	<i>Rehab</i> <i>Group</i> <i>n=16</i>	<i>FULL</i> <i>SAMPLE</i> <i>N=133</i>
1. Type of residence (residential) and living arrangements.	9	20*	-8	-3	18*
2. Limited freedom to choose meaningful activities.	0	-21	1	-10	-30*
3. Difficulty in finding activities due to co-morbidity of other illnesses/disorders.	-1	21	-5	-7	8
4. Social inclusion policies which do not consider the diversity in the population.	-4	12*	5	-2	11*
5. Limited functional independence.	-5	32*	-5	-4	18*
6. Limited interaction with the community.	-8	-22	-2	-13	-45
7. Active exclusion from the community.	-15	-26*	-16	-9	-66*
8. Service user/ Ageing People with Intellectual Disabilities values not listened to.	-16	-14	-5	-9	-47*
9. Service user/ Ageing People with Intellectual Disabilities preferences not taken into account.	-19	-17*	-3	-6	-42*
10. Limited choice/social opportunity to develop fulfilling friendships.	-22	-11	-3	-12	-48*

Note. * = incomplete response, whereby the full sample size did not all answer the item.

Facilitators

	<i>Panageia</i>	<i>Mariaberg E.V.</i>	<i>Fundación Intras</i>	<i>Rehab Group</i>	<i>FULL SAMPLE</i>
	<i>n=40</i>	<i>n=57</i>	<i>n=20</i>	<i>n=16</i>	<i>N=133</i>
1. Freedom to choose meaningful activities.	11	26*	13	14	64*
2. Social inclusion policies which were developed with the population.	18	18*	20	9	65*
3. Skill development from active engagement with the community.	27	18*	20	14	80*
4. Willingness to attend community-based activities.	31	29*	9	13	82*
5. Openness of the community.	34	44*	20	14	112*
6. Co-resident friendships.	34	11*	16*	4	62*
7. Trust to confide in staff.	37	49*		15	121*
8. Greater connection with the staff.	37	51*	19	15	122*
9. Social support from staff.	38	34*	20	15	107*
10. Emotional support from staff.	38	54*	18	13	123*

Research Objective 1: Staff

Calculated values for each factor were based on multiplying sample sizes per the attributed value of a possible response. For this survey values were established as: Strong Barrier (-3), Intermediate Barrier (-2), Weak Barrier (-1), Not Applicable (0), Weak Facilitator (+1), Intermediate Facilitator (+2), Strong Facilitator (+3). Factors were then sorted by total relevance (least to most relevant).

Individual organisation information is provided in [Appendix C](#).

Factors staff considered Barriers					
	<i>Panagaia Eleousa n=55</i>	<i>Mariaberg E.V. n=50</i>	<i>Fundación Intras. n=20</i>	<i>Rehab Group n=20</i>	<i>TOTAL N=145</i>
1. Staff feelings that they lack the skills/competence to support the social inclusion of Ageing People with Intellectual Disabilities.	-72	-51*	-33		-153*
2. Staff member's fear of trying new strategies or approaches that could support social inclusion.	-83	-52	-30	-4	-169
3. Negative beliefs/stereotypes about Ageing People with Intellectual Disabilities.	-98	-57*	-40	-3	198*
4. Lack of local policy to guide social inclusion policies.	-121	-95*	-40	-14	271*
5. Staff exhaustion/burnout from providing care for many complex health needs.	-132	-123	-48	-24	-327
6. Limited financial support to support inclusion activities.	-134	-98	-47	-29	-308
7. Understaffing/staff shortages.	-134	-137	-49	-27	-349
8. Increasing demand for services while financial support is decreasing.	-135	-119	-43	-22	-319
9. No specific legislation in place to enshrine Ageing People with Intellectual Disabilities rights to be socially included.	-145	-38*	-45	-18	-246*

Factors staff considered Facilitators

	<i>Panagaia Eleousa</i> <i>n=55</i>	<i>Mariaberg E.V.</i> <i>n=50</i>	<i>Fundación Intras.</i> <i>n=20</i>	<i>Rehab Group</i> <i>n=20</i>	<i>TOTAL</i> <i>N=145</i>
1. Teamwork.	104	48*	44	38	264*
2. Awareness of the principles of inclusivity.	135	42*	0	16	193*
3. Increased flexibility during the planning and delivery of services.	137	10*	35	33	215*
4. Staff training regarding appropriate social interaction with Ageing People with Intellectual Disabilities.	139	52*	36	3	243*
5. Proactive planning for social inclusion activities.	140	51*	38	16	261*
6. Increasing staff networking skills/ competencies and ability to manage the interface between Ageing People with Intellectual Disabilities and community.	141	58*	29	18	246*
7. Inter-disciplinary training (e.g., from a mental health professional).	144	59*	35	13	251*
8. Client-focused/individualised care.	149	2*	40	32	223*

Note. * = incomplete response, whereby the full sample size did not all answer the item.

Research Objective 2: Narrative Comparison

This narrative comparison focused on exploring the most relevant barriers and facilitators for improving social inclusion for Ageing People with Intellectual Disabilities from the dual perspectives of the Ageing People with Intellectual Disabilities themselves and the staff supporting them. Data was collected through two surveys across four organisations located in Greece, Germany, Spain, and Ireland. Each survey provided unique insights into the challenges and opportunities related to facilitating social inclusion. It is essential to acknowledge that while the results offer valuable insights, they may not present an exact representation due to variations in sample sizes and potential comprehension issues that surfaced during the translation process. Furthermore, incomplete response may have influenced specific results.

The examination of Ageing People with Intellectual Disabilities experiences sheds light on both common and distinct challenges and opportunities they face. Ageing People with Intellectual Disabilities consistently face barriers that encompass limited choices, exclusion from their communities, and limited opportunities to engage in activities that match their preferences and values, often leading to feelings of isolation and exclusion. Staff, too, offer critical perspectives as they grapple with challenges such as understaffing, increasing demand upon services, and the absence of specific legislation to safeguard Ageing People with Intellectual Disabilities rights for social inclusion. Common facilitators for the social inclusion of Ageing People with Intellectual Disabilities include trust in staff, emotional support from staff, and greater staff connections. For staff, inter-disciplinary training, proactive planning for activities that facilitate social inclusion, and teamwork play crucial roles in overcoming the barriers they face in supporting Ageing People with Intellectual Disabilities.

Ageing People with Intellectual Disabilities - Barriers. Active exclusion from the community is the most pervasive and significant barrier across all countries (score of -66

in the full sample). The results reveal a common challenge in which Ageing People with Intellectual Disabilities values and preferences are oftentimes disregarded, highlighting a lack of personal agency and recognition of their individual choices and needs. This, in turn, hampers their opportunities for developing fulfilling friendships, significantly affecting their QoL. Interestingly, Ireland was the sole organisation reporting all results with negative values, while the other organisation had some variables with positive values, indicated that the surveyed participants did not see the barrier in a negative light, but rather positively. For instance, residential and living arrangements were seen as facilitators rather than barriers in Germany and Greece, potentially indicating that residential care could facilitate Ageing People with Intellectual Disabilities social inclusion depending on specific policies in place in different countries. Many variables across all organisations were scored 0, indicating a lack of consensus on these issues, which may be due to conflicting perspectives within the sample.

Ageing People with Intellectual Disabilities - Facilitators. Across the board, each facilitator was viewed positively, with scores varying from weak to strong in their role in promoting social inclusion. Notably, scores in this section were considerably higher, with the weakest score in the full sample being 62 (out of a maximum of 133). A strong emphasis is placed on the relationship between the Ageing People with Intellectual Disabilities and the staff supporting them, as evidenced by the results from each organisation. **Trust in staff, emotional support from staff, and a greater connection with staff members play critical roles in Ageing People with Intellectual Disabilities experiences of social inclusion.** It is important to consider these findings, as such variables enable a supportive relationship that helps build a sense of security and contributes to a nurturing environment. Variables such as ‘skill development from active engagement with the community,’ scored higher in Ireland and Spain than in Greece and Germany, potentially indicating differences in the quality of care and

activities implemented for Ageing People with Intellectual Disabilities cross-nationally. These variations emphasise the importance of considering country-specific circumstances.

Staff - Barriers. It is noteworthy that all organisations, except for the Irish one, rated the barriers within a moderate to high range, while scores from Ireland fell into a weak to moderate range. This variance may be attributed to translational difficulties or cultural, societal, and structural variables. **Understaffing emerged as the most prevalent issue across all locations**, whereby staff shortages directly affect their capacity to meet the needs of Ageing People with Intellectual Disabilities effectively. Results indicate that this can result in a high level of burnout and exhaustion, exacerbated by limited financial support to facilitate activities and the ever-increasing demand for services while financial support decreases. Overall, this suggests that while there are individual differences in staff experiences, there is a general lack of funding and adequate support provided to those who work in this sector. Staff members appeared confident in their competency and knowledge of specific workplace strategies, as both of these variables were perceived as low-ranking facilitators. This indicates that providing support, helpful resources and improving working conditions may be more crucial than focusing solely on staff training. All organisations ranked a lack of legislation and local policy as moderate facilitators, signifying that legal protection and clear policies are necessary to guide the efforts of staff and organisations in promoting social inclusion for Ageing People with Intellectual Disabilities.

Staff - Facilitators. Overall, the range of scores varied across organisations, with Greece and Spain having the highest number of facilitators with moderate to high relevance, while Germany and Ireland had scores ranging from low to moderate relevance. This highlights location-based differences, supported by the overall scores falling within a moderate range due to these discrepancies. The variables in this section exhibited the most variation across

organisations, with stronger-ranked facilitators like **teamwork, inter-disciplinary training and proactive planning for activities** falling anywhere from the most to the least relevant facilitators. These findings underscore the importance of considering specific cultural, societal, and structural environments to provide a holistic approach in supporting collaboration and coordination amongst staff members, creating a supportive environment benefiting Ageing People with Intellectual Disabilities. The results also demonstrate that improving staff's knowledge of concepts like the principles of inclusivity or staff training in appropriate social interactions with Ageing People with Intellectual Disabilities may not necessarily lead to significant changes, as staff are aware of such concepts from their academic and professional development.

Discussion

The results presented in this study provide valuable insights into the experiences and perspectives of both Ageing People with Intellectual Disabilities and the staff who support them in the context of social inclusion. The study involved multiple organisations across different countries, highlighting the diversity of challenges and opportunities in promoting social inclusion for Ageing People with Intellectual Disabilities. While these results offer significant contributions, it is essential to acknowledge that variations in sample sizes, translation issues, and incomplete responses may have influenced specific findings. Nonetheless, this research serves as a foundation for understanding the complexities of social inclusion for Ageing People with Intellectual Disabilities and the critical role of staff in facilitating this process.

Ageing People with Intellectual Disabilities perspective: barriers and facilitators

The findings in the Ageing People with Intellectual Disabilities section highlight both common challenges and variations across organisations and countries. Active exclusion from the community emerged as a significant and pervasive barrier, underscoring the issue of marginalization faced by Ageing People with Intellectual Disabilities. However, some differences between organisations, such as the perception of residential care as a facilitator rather than a barrier in some countries, indicate that cultural and contextual factors play a substantial role in shaping the experiences of Ageing People with Intellectual Disabilities. The study suggests that Ageing People with Intellectual Disabilities consistently face barriers related to limited choices, exclusion, and constraints on activities aligning with their personal preferences and values. It is vital that a nuanced approach, where both general and specific

experiences within different cultural and societal contexts, is acknowledged so that QoL can be enhanced.

Trust in staff, emotional support, and greater staff connections are identified as crucial facilitators for social inclusion. This suggests that the human element plays a pivotal role in the journey of Ageing People with Intellectual Disabilities towards social inclusion. It is not merely about providing choices and activities; rather, it's about creating an environment that fosters trust, emotional well-being, and meaningful activities. Overall, it appears that the freedom to choose meaningful activities, while important, is not as critical as the openness of the community and the willingness of Ageing People with Intellectual Disabilities to participate in community-based activities. This implies that active inclusion within the existing social circle holds more significance in facilitating social inclusion than the diversity of available activities. These common facilitators underscore the importance of empowering Ageing People with Intellectual Disabilities and ensuring that the communities, policies, and support systems are inclusive, diverse, and responsive to the unique needs and perspectives of this population. Fostering a sense of belonging and trust within the community, coupled with promoting emotional well-being, can significantly contribute to enhancing social inclusion for Ageing People with Intellectual Disabilities.

Staff perspective: barriers and facilitators

One prevailing issue identified by staff is the widespread problem of understaffing, a concern pervasive across all organisations. This structural and organisational shortfall has a detrimental impact on the quality of care and services extended to Ageing People with Intellectual Disabilities. In addition, staff members grapple with financial constraints, particularly in terms of limited support for social inclusion activities. This financial constraint is further compounded by the increasing demand for services and a simultaneous reduction in financial

support, creating a challenging environment for staff to provide optimal care. This highlights the need for addressing these barriers by not solely focusing on staff training but by providing them with additional support and resources. Furthermore, a moderate barrier identified by staff is the absence of specific legislation designed to protect the rights of Ageing People with Intellectual Disabilities with respect to social inclusion.

On the facilitator side, a few key elements shine through in supporting staff members as they endeavour to overcome these barriers. Teamwork emerges as a significant asset, promoting collaborative efforts and shared responsibilities among staff. Interdisciplinary training (e.g., from a mental health professional) also plays a vital role, equipping staff with a broader skill set that allows them to better address the diverse needs of Ageing People with Intellectual Disabilities. Proactive planning for activities further enhances the capabilities of staff members, ensuring a well-structured and inclusive approach to social inclusion initiatives. The collective experiences of staff, as revealed in this survey, underscore the importance of addressing these barriers to ensure that Ageing People with Intellectual Disabilities receive the care and support necessary for leading inclusive and fulfilling lives. Furthermore, the findings highlight that staff member's experiences differ significantly across organisations, and the individual experiences of staff significantly contribute to the successful social inclusion of Ageing People with Intellectual Disabilities. Recognising and leveraging these differences can be instrumental in tailoring support and resources to enhance the quality of care provided by staff.

Additional qualitative commentary by staff highlights three important points for consideration. Firstly, that there were challenges in implementing surveys, particularly for Ageing People with Intellectual Disabilities with limited verbal communication abilities. Alternative methods for data collection should be considered in the future, and the involvement

of family members or guardians may be beneficial. Secondly, staff emphasised the need for professional support for both families and caregivers. Collaborating with these groups is crucial for enhancing social inclusion for Ageing People with Intellectual Disabilities. Lastly, staff stressed the importance of a holistic approach involving society, governments, communities, organisations, and individuals to eliminate barriers and create an inclusive and accessible environment.

Dual perspective: barriers and facilitators

A dual perspective is indispensable in the endeavour to foster social inclusion for Ageing People with Intellectual Disabilities. The narrative analysis of Ageing People with Intellectual Disabilities and staff viewpoints elucidates the barriers and facilitators present in their respective experiences. Ageing People with Intellectual Disabilities face challenges such as active exclusion from the community and the neglect of their values, emphasizing the need for a more inclusive society. Conversely, staff members encounter barriers like understaffing and financial constraints, emphasizing the importance of support and resources. Notably, trust in staff, emotional support, and enhanced staff connections are essential facilitators. The synthesis of these dual perspectives highlights the need for a holistic and collaborative approach to advance social inclusion effectively and compassionately for all.

Summary of Findings

- The study reveals diverse challenge and opportunities in promoting social inclusion for Ageing People with Intellectual Disabilities across different organisations and countries.
- It is essential that both a general and specific perspective is taken into account, there are both similarities and differences that are shared across locations, but also disparities.
- A dual perspective which takes account of the lived experiences of Ageing People with Intellectual Disabilities and the staff who support this population is essential when addressing social inclusion.
- Common barriers for Ageing People with Intellectual Disabilities include limited choices, active exclusion, and constraints on personal preferences and values in inclusion activities. However cultural and contextual factors play a significant role in shaping Ageing People with Intellectual Disabilities experiences, leading to variations across regions.
- Crucial facilitators for Ageing People with Intellectual Disabilities social inclusion are trust in staff, emotional support from staff and improved staff connections.
- Staff commonly face challenges due to understaffing which negatively affects quality of care, and additional financial constraints, including limited support for inclusion activities, further complicate matters. Furthermore, high staff competency and knowledge emphasize the need for additional support and resources rather than just training.
- Teamwork, interdisciplinary training, and proactive activity planning are key facilitators for staff in overcoming barriers.
- These findings underscore the importance of taking a holistic, collaborative approach to enhancing social inclusion.

References

- Abbott, S., & McConkey, R. (2006). The barriers to social inclusion as perceived by people with intellectual disabilities. *Journal of intellectual disabilities, 10*(3), 275-287.
- Alborz, A., McNally, R., Swallow, A., & Glendinning, C. (2004). From the Cradle to the Grave: A literature review of access to healthcare for people with learning disabilities across the lifespan. *National Institute for Health and Care Research*.
- Amado, A. N., Stancliffe, R. J., McCarron, M., & McCallion, P. (2013). Social inclusion and community participation of individuals with intellectual/developmental disabilities. *Intellectual and developmental disabilities, 51*(5), 360-375.
- Bishop, K. M., Robinson, L. M., & VanLare, S. (2013). Healthy aging for older adults with intellectual and development disabilities. *Journal of Psychosocial Nursing and Mental Health Services, 51*, 15–18.
- Carnemolla, P. (2022). Apartment Living and Community Care: Experiences of People With Intellectual Disability, Their Families, and Support Staff. *Urban Planning, 7*(4), 398-408.
- Cobigo, V., Ouellette-Kuntz, H., Lysaght, R., & Martin, L. (2012). Shifting our conceptualization of social inclusion. *Stigma Research and Action, 2*(2), 75-84.
- Coppus, A. M. (2013). People with intellectual disability: what do we know about adulthood and life expectancy?. *Developmental Disabilities Research Reviews, 18*(1), 6-16.
- David, N., Duvdevani, I., & Doron, I. (2015). Older women with intellectual disability and the meaning of aging. *Journal of Women & Aging, 27*, 216–236.
- Depp, C. A., & Jeste, D. V. (2006). Definitions and predictors of successful aging: a comprehensive review of larger quantitative studies. *The American Journal of Geriatric Psychiatry, 14*(1), 6-20.

- Emerson, E., & Hatton, C. (2008). Self-reported well-being of women and men with intellectual disabilities in England. *American journal on mental retardation*, 113(2), 143-155.
- Evans, E., Bhardwaj, A., Brodaty, H., Sachdev, P., Draper, B., & Trollor, J. N. (2013). Dementia in people with intellectual disability: Insights and challenges in epidemiological research with an at-risk population. *International Review of Psychiatry*, 25(6), 755-763.
- Hayes, A., Gray, M., & Edwards, B. (2008). Social Inclusion-Origins, concepts and key themes.
- Holland, A. J. (2000). Ageing and learning disabilities. *British Journal of Learning Disability*, 176, 26-31.
- Innes, A., McCabe, L., & Watchman, K. (2012). Caring for older people with an intellectual disability: a systematic review. *Maturitas*, 72(4), 286-295.
- Kruithof, K., Suurmond, J., & Harting, J. (2018). Eating together as a social network intervention for people with mild intellectual disabilities: a theory-based evaluation. *International Journal of Qualitative Studies on Health and Well-Being*, 13(1), 1516089.
- LaPlante, M. P. (2014). Key goals and indicators for successful aging of adults with early-onset disability. *Disability and Health Journal*, 7(1), S44-S50.
- Lehmann, B. A., Bos, A. E. R., Rijken, M., Cardol, M., Peters, G. J., Kok, G., & Curfs, L. M. G. (2013). Ageing with an intellectual disability: the impact of personal resources on well-being. *Journal of Intellectual Disability Research*, 57(11), 1068-1078.
- Doody, C., Markey, K., & Doody, O. (2013). The experiences of registered intellectual disability nurses caring for the older person with intellectual disability. *Journal of Clinical Nursing*, 22(7-8), 1112-1123.
- McCallion, P., & McCarron, M. (2004). Ageing and intellectual disabilities: A review of recent literature. *Current Opinion in Psychiatry*, 17(5), 349-352.

- McCausland, D., McCallion, P., Cleary, E., & McCarron, M. (2016). Social connections for older people with intellectual disability in Ireland: Results from wave one of IDS-TILDA. *Journal of Applied Research in Intellectual Disabilities*, 29(1), 71-82.
- McCausland, D., McCallion, P., Cleary, E., & McCarron, M. (2016). Social connections for older people with intellectual disability in Ireland: Results from wave one of IDS-TILDA. *Journal of Applied Research in Intellectual Disabilities*, 29(1), 71-82.
- McConkey, R., & Collins, S. (2010). Using personal goal setting to promote the social inclusion of people with intellectual disability living in supported accommodation. *Journal of Intellectual Disability Research*, 54(2), 135-143.
- Nicholson, L., & Cooper, S. A. (2013). Social exclusion and people with intellectual disabilities: a rural–urban comparison. *Journal of Intellectual Disability Research*, 57(4), 333-346.
- Patja, K., Iivanainen, M., Vesala, H., Oksanen, H., & Ruoppila, I. (2000). Life expectancy of people with intellectual disability: a 35-year follow-up study. *Journal of Intellectual Disability Research*, 44(5), 591-599.
- Reppermund, S., & Trollor, J. N. (2016). Successful ageing for people with an intellectual disability. *Current Opinion in Psychiatry*, 29(2), 149-154.
- Schalock, R. L. (1990). *Quality of life: Perspectives and issues*. American Association on Mental Retardation, 1719 Kalorama Rd., NW, Washington, DC 20009.
- Schalock, R. L., Keith, K. D., Verdugo, M. Á., & Gómez, L. E. (2011). Quality of life model development and use in the field of intellectual disability. *Enhancing the quality of life of people with intellectual disabilities: From theory to practice*, 17-32.
- Schepens, H. R., Van Puyenbroeck, J., & Maes, B. (2019). How to improve the quality of life of elderly people with intellectual disability: A systematic literature review of support strategies. *Journal of Applied Research in Intellectual Disabilities*, 32(3), 483-521.

- Shooshtari, S., Martens, P. J., Burchill, C. A., Dik, N., & Naghipur, S. (2011). Prevalence of depression and dementia among adults with developmental disabilities in Manitoba, Canada. *International Journal of Family Medicine*, 2011 (-).
- Sinai, A., Bohnen, I., & Strydom, A. (2012). Older adults with intellectual disability. *Current Opinion in Psychiatry*, 25, 359–364.
- Turner, S., & Cooper Ueki, M. (2015). Current policy and legislation in England regarding older people—what this means for older people with learning disabilities: a discussion paper. *British Journal of Learning Disabilities*, 43(4), 254-260.
- Wark, S., Hussain, R., & Edwards, H. (2014). The training needs of staff supporting individuals ageing with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 27(3), 273-288.
- Webber, R., Bowers, B., & McKenzie-Green, B. (2010). Staff responses to age-related health changes in people with an intellectual disability in group homes. *Disability & Society*, 25, 657–671.
- Whitworth D., Harris P. & Jones R. (1999) Staff culture and the management of challenging behaviours in people with learning disabilities. *Mental Health Care*, 2, 376–379.
- Wilkinson H., Kerr D. & Cunningham C. (2005) Equipping staff to support people with an intellectual disability and dementia in care home settings. *Dementia*, 4, 387–396.

Appendix A

Additional Commentary

Both surveys (Ageing People with Intellectual Disabilities and Staff) featured an optional section for participants to provide further comments and feedback. This additional commentary offers valuable insights into the real-life experiences of the participants and provides further perspectives on the structure, design and implantation of this study.

Panagia Eleousa. Participants did not provide any additional feedback.

Mariaberg E.V. Staff members who assisted Ageing People with Intellectual Disabilities in completing their surveys raised several noteworthy points. They highlighted time and location constraints, as the surveys had to be implemented on a one-on-one basis outside of normal care routines, which placed an additional burden on staff members with limited capacities. Staff also expressed the view that service users with higher support needs require additional staff resources, which can pose challenges when integrating them into the community or implementing activities. Concern was raised regarding the appropriateness of the survey as a tool to collect Ageing People with Intellectual Disabilities perspectives, particularly for those with limited verbal communication abilities. Additionally, staff commented that the participating Ageing People with Intellectual Disabilities found it difficult to grasp and assess political and legislative circumstances, suggesting that future research should consider examining the perspectives of relatives and legal guardians.

Fundación Intras. Staff members shared additional feedback after participating in the survey. They emphasised the importance of professional support for both families and caregivers as a significant variable of interest. Collaboration with these groups is crucial not only to facilitate but also to enhance the social inclusion of Ageing People with Intellectual

Disabilities. One staff member drew attention to a primary concern expressed by some of the Ageing People with Intellectual Disabilities they have worked with, who have voiced that they oftentimes do not receive the respectful treatment they deserve in care. Overall, it was emphasised that a holistic approach is needed, involving cooperation between society, governments, communities, organisations, and individuals, to eliminate barriers and create an inclusive and accessible environment for all individuals.

Rehab Group. One of the Ageing People with Intellectual Disabilities participants found the survey statements confusing, expressing that the answer choices of ‘yes,’ ‘maybe,’ and ‘no’ were sometimes counterintuitive to their initial understanding. Additionally, several staff members highlighted the significant role played by the availability of local transportation and amenities in supporting suitable activities for Ageing People with Intellectual Disabilities to engage in. Furthermore, it was observed that some service users are reluctant to acknowledge their age and may decline to join support groups like active retirement groups as they perceive themselves as too young. Another staff member pointed out a lack of community awareness in rural and isolated areas. Many staff members strongly emphasised the fundamental role of state support and identified understaffing and staff burnout as critical barriers. They also noted an unfortunate cycle of staff shortages, recruitment, training of new hires, and subsequent turnover, creating a continuous build-up of pressure on the remaining staff.

Appendix B

Research Objective 1: Aging People with Intellectual Disabilities

Detail of each of the surveys per organisation follows.

Panagaia Eleousa. A total of 40 Ageing People with Intellectual Disabilities participated in the study, with possible scores ranging from -40 to 40. Informed consent was obtained at the start. Data was collected on paper forms in-person with the help of a member of the organisation, such as a social worker or occupational therapist.

Table 2.

Panagaia Eleousa: *Barriers and facilitators of social inclusion as identified by people with an intellectual disability, organised by least to most relevant.*

Ageing people with intellectual disabilities (n=40)				
Barriers		Facilitators		
	Score		Score	
	9	Freedom to choose meaningful activities.	11	
2. Limited freedom to choose meaningful activities.	0	Social inclusion policies which were developed with the population.	18	
3. Difficulty in finding activities due to co-morbidity of other illnesses/disorders.	-1	Skill development from active engagement with the community.	27	
4. Social inclusion policies which do not consider the diversity in the population.	-4	Willingness to attend community-based activities.	31	
5. Limited functional independence.	-5	Openness of the community.	34	
6. Limited interaction with the community.	-8	Co-resident friendships.	34	
7. Active exclusion from the community.	-15	Trust to confide in staff.	37	
8. Service user/Ageing People with Intellectual Disabilities values not listened to.	-16	Greater connection with the staff.	37	
9. Service user/ Ageing People with Intellectual Disabilities preferences not taken into account.	-19	Social support from staff.	38	
10. Limited choice/social opportunity to develop fulfilling friendships.	-22	Emotional support from staff.	38	

Mariaberg E.V.: A total of 57 Ageing People with Intellectual Disabilities participated in the study, with possible scores ranging from -57 to 57. Several items are marked as ‘incomplete responses,’ whereby only 53-56 responses were collected due to a lack of understanding. Data was collected on paper forms in person with the help of a staff member or a project partner. The results (see *Table 3*) were then exported into an Excel spreadsheet.

Table 3.

Mariaberg E.V.: *Barriers and facilitators of social inclusion as identified by people with an intellectual disability, organised by least to most relevant.*

Ageing people with intellectual disability (n=57)				
Barriers			Facilitators	
		Score		Score
1.	*Limited functional independence.	32	*Co-resident friendships.	11
2.	Difficulty in finding activities due to co-morbidity of other illnesses/disorders.	21	*Social inclusion policies which were developed with the population.	18
3.	*Type of residence (residential) and living arrangements.	20	*Skill development from active engagement with the community.	18
4.	*Social inclusion policies which do not consider the diversity in the population.	12	*Freedom to choose meaningful activities.	26
5.	*Limited choice/social opportunity to develop fulfilling friendships.	-11	*Willingness to attend community-based activities.	29
6.	*Service user/ Ageing People with Intellectual Disabilities preferences not taken into account.	-14	*Social support from staff.	34
7.	*Service user/ Ageing People with Intellectual Disabilities values not listened to.	-17	*Openness of the community.	44
8.	*Limited freedom to choose meaningful activities.	-21	*Trust to confide in staff.	49
9.	Limited interaction with the community.	-22	*Greater connection with the staff.	51
10.	*Active exclusion from the community.	-26	*Emotional support from staff.	54

Note. * = incomplete response, whereby the full sample size did not all answer the item.

Fundación Intras: A total of 20 Ageing People with Intellectual Disabilities participated in the study, with possible scores ranging from -20 to 20. Item 8 for facilitators is marked as a ‘incomplete response,’ whereby only 18 responses rather than 20 responses were collected due to a lack of understanding. Informed consent was obtained at the start. Data was collected on paper forms in-person with the help of a health care professional. The results (see Table 4) were scanned into a PDF file, then exported into an Excel spreadsheet.

Table 4.

Fundación Intras: Barriers and facilitators of social inclusion as identified by people with an intellectual disability, organised by least to most relevant.

Ageing people with intellectual disability (n=20)				
Barriers			Facilitators	
		Score		Score
1.	Social inclusion policies which do not consider the diversity in the population.	5	Willingness to attend community-based activities.	9
2.	Limited freedom to choose meaningful activities.	1	Freedom to choose meaningful activities.	13
3.	Limited interaction with the community.	-2	*Co-resident friendships.	16
4.	Limited choice/social opportunity to develop fulfilling friendships.	-3	Emotional support from staff.	18
5.	Service user/ Ageing People with Intellectual Disabilities preferences not taken into account.	-3	Greater connection with the staff.	19
6.	Service user/ Ageing People with Intellectual Disabilities values not listened to.	-5	Social support from staff.	20
7.	Difficulty in finding activities due to co-morbidity of other illnesses/disorders.	-5	Openness of the community.	20
8.	Limited functional independence.	-5	Social inclusion policies which were developed with the population.	20
9.	Type of residence (residential) and living arrangements.	-8	Skill development from active engagement with the community.	20
10.	Active exclusion from the community.	-16	Trust to confide in staff.	20

Note. * = incomplete response, whereby the full sample size did not all answer the item.

Rehab Group. A total of 16 Ageing People with Intellectual Disabilities participated in the study, with possible scores ranging from -16 to 16. Informed consent was obtained at the start. Data was collected through a Microsoft Form with the help of a member of the organisation. The results (see *Table 5*) were then exported into an Excel spreadsheet by the research team for data analysis.

Table 5.

Rehab Group: *Barriers and facilitators of social inclusion as identified by people with an intellectual disability, organised by least to most relevant.*

Ageing people with intellectual disability (n=16)				
Barriers			Facilitators	
		Score		Score
1.	Social inclusion policies which do not consider the diversity in the population.	-2	Co-resident friendships.	4
2.	Type of residence (residential) and living arrangements.	-3	Social inclusion policies which were developed with the population.	9
3.	Limited functional independence.	-4	Emotional support from staff.	13
4.	Service user/ Ageing People with Intellectual Disabilities preferences not taken into account.	-6	Willingness to attend community-based activities.	13
5.	Difficulty in finding activities due to co-morbidity of other illnesses/disorders.	-7	Freedom to choose meaningful activities.	14
6.	Active exclusion from the community.	-9	Openness of the community.	14
7.	Service user/ Ageing People with Intellectual Disabilities values not listened to.	-9	Skill development from active engagement with the community.	14
8.	Limited freedom to choose meaningful activities.	-10	Social support from staff.	15
9.	Limited choice/social opportunity to develop fulfilling friendships.	-12	Trust to confide in staff.	15
10.	Limited interaction with the community.	-13	Greater connection with the staff.	15

Full Sample. The total Ageing People with Intellectual Disabilities sample consisted of 133 participants, with possible scores ranging from -133 to 133. Various databases from each partner were exported into one master database on Excel for analysis (see results in *Table 6*). Certain items are marked as incomplete responses due to some participants not answering in full due to a lack of comprehension and other reasons.

Table 6.

Full Sample: *Barriers and facilitators of social inclusion as identified by people with an intellectual disability, organised by least to most relevant.*

Ageing people with intellectual disability (N=133)				
Barriers			Facilitators	
		Score		Score
1.	*Limited functional independence.	18	*Co-resident friendships.	62
2.	*Type of residence (residential) and living arrangements.	18	*Freedom to choose meaningful activities.	64
3.	*Social inclusion policies which do not consider the diversity in the population.	11	*Social inclusion policies which were developed with the population.	65
4.	Difficulty in finding activities due to co-morbidity of other illnesses/disorders.	8	*Skill development from active engagement with the community.	80
5.	*Limited freedom to choose meaningful activities.	-30	*Willingness to attend community-based activities.	82
6.	*Service user/ Ageing People with Intellectual Disabilities preferences not taken into account.	-42	*Social support from staff.	107
7.	*Limited interaction with the community.	-45	*Openness of the community.	112
8.	*Service user/ Ageing People with Intellectual Disabilities values not listened to.	-47	*Trust to confide in staff.	121
9.	*Limited choice/social opportunity to develop fulfilling friendships.	-48	*Greater connection with the staff.	122
10.	*Active exclusion from the community.	-66	*Emotional support from staff.	123

Note. * = incomplete response, whereby the full sample size did not all answer the item.

Appendix C

Research Objective 2: Staff

Panagaia Eleousa. A total of 55 Staff participated in this study, with possible scores ranging from [-165 to 165]. Informed consent was obtained at the start. Data was collected on paper forms in-person, and a staff member was present for any possible clarifications needed.

Table 7.

Panagaia Eleousa. *Barriers and facilitators of social inclusion as identified by staff, organised by least to most relevant.*

Staff Responses (n=55)			
Factors staff considered Barriers		Factors staff considered Facilitators	
No.		Score	
			Score
10.	Staff feelings that they lack the skills/competence to support the social inclusion of Ageing People with Intellectual Disabilities.	-72	Teamwork.
11.	Staff member’s fear of trying new strategies or approaches that could support social inclusion.	-83	Awareness of the principles of inclusivity.
12.	Negative beliefs/stereotypes about Ageing People with Intellectual Disabilities.	-98	Increased flexibility during the planning and delivery of services.
13.	Lack of local policy to guide social inclusion policies.	-121	Staff training regarding appropriate social interaction with Ageing People with Intellectual Disabilities.
14.	Staff exhaustion/burnout from providing care for many complex health needs.	-132	Proactive planning for social inclusion activities.
15.	Limited financial support to support inclusion activities.	-134	Increasing staff networking skills/competencies and ability to manage the interface between Ageing People with Intellectual Disabilities and community.
16.	Understaffing/staff shortages.	-134	Inter-disciplinary training (e.g., from a mental health professional).
17.	Increasing demand for services while financial support is decreasing.	-135	Client-focused/individualised care.
18.	No specific legislation in place to enshrine Ageing People with Intellectual Disabilities rights to be socially included.	-145	-

Mariaberg E.V. A total of 50 Staff participated in the study, with possible scores ranging from [-150 to 150]. Items 6-17 are marked as ‘incomplete responses,’ whereby only 48 responses rather than 50 responses were collected due to a lack of understanding. Data was collected online, through Umfrage Online, where links were shared with managers who then shared the survey with their employees. The results (see *Table 8*) were exported into a Word File.

Table 8.

Mariaberg E.V. *Barriers and facilitators of social inclusion as identified by staff, organised by least to most relevant.*

Staff Responses (n=50)				
Factors staff considered Barriers		Factors staff considered Facilitators		
No.	Score		Score	
1.	*No specific legislation in place to enshrine Ageing People with Intellectual Disabilities rights to be socially included.	-38	*Client-focused/individualised care.	2
2.	*Staff feelings that they lack the skills/competence to support the social inclusion of Ageing People with Intellectual Disabilities.	-51	*Increased flexibility during the planning and delivery of services.	10
3.	Staff member’s fear of trying new strategies or approaches that could support social inclusion.	-52	*Awareness of the principles of inclusivity.	42
4.	*Negative beliefs/stereotypes about Ageing People with Intellectual Disabilities.	-57	*Teamwork.	48
5.	*Lack of local policy to guide social inclusion policies.	-95	*Proactive planning for social inclusion activities.	51
6.	Limited financial support to support inclusion activities.	-98	*Staff training regarding appropriate social interaction with Ageing People with Intellectual Disabilities.	52
7.	Increasing demand for services while financial support is decreasing.	-119	*Increasing staff networking skills/competencies and ability to manage the interface between Ageing People with Intellectual Disabilities and community.	58
8.	Staff exhaustion/burnout from providing care for many complex health needs.	-123	*Inter-disciplinary training (e.g., from a mental health professional).	59
9.	Understaffing/staff shortages.	-137	-	-

Note. * = incomplete response, whereby the full sample size did not all answer the item.

Fundación Intras. A total of 20 Staff participated in this study, with possible scores ranging from [-60 to 60]. Informed consent was obtained at the start. Data was collected online through a Google Form that was sent to key departments within the organisation. The results (see Table 9) were then exported into an Excel spreadsheet.

Table 9.

Fundación Intras. Barriers and facilitators of social inclusion as identified by staff, organised by least to most relevant.

Staff Responses (n=20)				
Factors staff considered Barriers			Factors staff considered Facilitators	
No.		Score		Score
1.	Staff member’s fear of trying new strategies or approaches that could support social inclusion.	-30	Awareness of the principles of inclusivity.	0
2.	Staff feelings that they lack the skills/competence to support the social inclusion of Ageing People with Intellectual Disabilities.	-33	Increasing staff networking skills/ competencies and ability to manage the interface between Ageing People with Intellectual Disabilities and community.	29
3.	Negative beliefs/stereotypes about Ageing People with Intellectual Disabilities.	-40	Increased flexibility during the planning and delivery of services.	35
4.	Lack of local policy to guide social inclusion policies.	-41	Inter-disciplinary training (e.g., from a mental health professional).	35
5.	Increasing demand for services while financial support is decreasing.	-43	Staff training regarding appropriate social interaction with Ageing People with Intellectual Disabilities.	36
6.	No specific legislation in place to enshrine Ageing People with Intellectual Disabilities rights to be socially included.	-45	Proactive planning for social inclusion activities.	38
7.	Limited financial support to support inclusion activities.	-47	Client-focused/individualised care.	40
8.	Staff exhaustion/burnout from providing care for many complex health needs.	-48	Teamwork.	44
9.	Understaffing/staff shortages.	-49	-	-

Note. * = incomplete response, whereby the full sample size did not all answer the item.

Rehab Group. A total of 20 Staff participated in the study, with possible scores ranging from [-60 to 60]. Informed consent was obtained at the start. Data was collected through an online Microsoft Form. The results (see *Table 5*) were then exported into an Excel spreadsheet by the research team for data analysis.

Table 10.

Rehab Group. *Barriers and facilitators of social inclusion as identified by staff, organised by least to most relevant.*

Staff Responses (n=20)			
Factors staff considered Barriers		Factors staff considered Facilitators	
<i>No.</i>	<i>Score</i>		<i>Score</i>
1. Negative beliefs/stereotypes about Ageing People with Intellectual Disabilities.	-3	Staff feelings that they lack the skills/competence to support the social inclusion of Ageing People with Intellectual Disabilities.	3
2. Staff member's fear of trying new strategies or approaches that could support social inclusion.	-4	Inter-disciplinary training (e.g., from a mental health professional).	13
3. Lack of local policy to guide social inclusion policies.	-14	Awareness of the principles of inclusivity.	16
4. No specific legislation in place to enshrine Ageing People with Intellectual Disabilities rights to be socially included.	-18	Proactive planning for social inclusion activities.	16
5. Increasing demand for services while financial support is decreasing.	-22	Increasing staff networking skills/competencies and ability to manage the interface between Ageing People with Intellectual Disabilities and community.	18
6. Staff exhaustion/burnout from providing care for many complex health needs.	-24	Client-focused/individualised care.	32
7. Understaffing/staff shortages.	-27	Proactive planning for social inclusion activities.	32
8. Limited financial support to support inclusion activities.	-29	Increased flexibility during the planning and delivery of services.	33
9. -	-	Teamwork.	38

Full Sample. The total Staff sample consisted of 145 participants, with possible scores ranging from [-435 to 435]. Various databases from each partner were exported into one master databased on Excel for analysis (see results in *Table 11*). Certain items are marked as incomplete responses due to some participants not answering in full due to a lack of comprehension and other reasons.

Table 11.

Full Sample. *Barriers and facilitators of social inclusion as identified by staff, organised by least to most relevant.*

Staff Responses (N=145)			
Factors staff considered Barriers		Factors staff considered Facilitators	
<i>No.</i>	<i>Score</i>		<i>Score</i>
1. *Staff feelings that they lack the skills/competence to support the social inclusion of Ageing People with Intellectual Disabilities.	-153	*Awareness of the principles of inclusivity.	193
2. Staff member's fear of trying new strategies or approaches that could support social inclusion.	-169	*Increased flexibility during the planning and delivery of services.	215
3. *Negative beliefs/stereotypes about Ageing People with Intellectual Disabilities.	-198	*Client-focused/individualised care.	223
4. *No specific legislation in place to enshrine Ageing People with Intellectual Disabilities rights to be socially included.	-246	*Staff training regarding appropriate social interaction with Ageing People with Intellectual Disabilities.	243
5. *Lack of local policy to guide social inclusion policies.	-271	*Increasing staff networking skills/competencies and ability to manage the interface between Ageing People with Intellectual Disabilities and community.	246
6. Limited financial support to support inclusion activities.	-308	*Inter-disciplinary training (e.g., from a mental health professional).	251
7. Increasing demand for services while financial support is decreasing.	-319	*Proactive planning for social inclusion activities.	261
8. Staff exhaustion/burnout from providing care for many complex health needs.	-327	*Teamwork.	264
9. Understaffing/staff shortages.	-349	-	-

Note. * = incomplete response, whereby the full sample size did not all answer the item.