



# Transition to Retirement for Older People with Intellectual Disabilities— Staff Descriptions of the Process and Roles

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RESEARCH



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## ABSTRACT

Our study examines how staff in housing and day activity centres describe the transition of people with intellectual disabilities (ID) to old-age retirement. The data comprise the staff's written responses to open-ended questions included in an online questionnaire. The data were analysed using content analysis, followed by further analysis using the concept of the script. We identified two main scripts in which the staff outline the transition process. According to the person-centred script, the role of the person with ID in transition is an agent with initiative and the staff are seen as enablers and supporters. In the system-driven script, the role of the person with ID is a passive object adapting to changes, while the staff seems to implement routines. This study shows inequality among aging people with ID. Their opportunities to make decisions from retirement depends on which script is followed in their municipality's disability services and service-provider organisation.

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The global phenomenon of the aging population also affects people with intellectual disabilities (ID), especially in developed countries (WHO 2001: 259). The longevity of disabled people means that they also experience old-age life-course transitions, like retirement (Leahy 2021: 3). By transition, we refer to a movement or change in one's life course (see e.g., Grenier 2012: 5). The transition to retirement is associated with an exit from work-life, which raises the question of the nature of the retirement processes of ageing persons with ID. Only a small minority of people with ID is typically engaged in paid employment, while the majority attends various work and day activities organised for them on a daily basis (e.g., McGlinchey et al. 2013; Vesala, Klem & Ahlsten 2015). Often people with ID have been able to attend the same activity centre for a very long time, even their entire adult life. Thus, their work roles and social networks are usually formed in these milieus. Consequently, the majority of people with ID do not experience the transition to old-age retirement as a termination of paid work (cf. Brotherton et al. 2016; Lawrence & Roush 2008). Instead, the transition in this population often involves no longer going to the activity centre (Bigby et al. 2011: 167; Engeland, Kittelsaa & Langballe 2018: 77; Judge et al. 2010: 298).

Such practices have been challenged by Bigby (2004: 134), who asks if the transition to retirement without a work history is a replication of disadvantageous norms from the normalization perspective and if it is driven more by the system than individual needs. Indeed, empirical studies have found that this transition can be problematic to persons with ID. Judge et al. (2010) found that some people with ID felt disempowered and did not want this anticipated change; they did not want to 'retire' from their current life. In a study by Bigby et al. (2011), retirement was seen as a risky proposition. The risk of inactivity and losing social contacts made retirement undesired.

However, life in retirement is not always experienced in negative terms. Old age can also be a time of increasing wellbeing for a person with ID (Buys, Aird & Miller 2012; Dew, Llewellyn & Gorman 2006; Engeland, Kittelsaa & Langballe 2018; Judge et al. 2010; Kåhlin, Kjellberg & Hagberg 2015). With appropriate support, a person with ID can discover new interests, learn new skills, adapt to the housing community, and become more independent after retirement (Bigby 2004: 49). At the same time, there is a risk that without planning, the everyday life of an older person with ID is diminished after retirement (Johansson et al. 2017). It seems that the opportunities for participation and an active life for old people with ID depend largely on the activities of close relatives or the housing unit's staff (Buys, Aird & Miller 2012; Kåhlin, Kjellberg & Hagberg 2015).

In this paper, we approach the transition of older persons with ID to retirement in terms of 'cultural scripts' (Quinn & Holland 1987; Schank & Abelson 1977), which guide actions and interpretations in different situations, such as major life-course transitions (Miettinen 2006; see also Löfgren-Mårtenson & Ouis 2019). By scripts, we refer to information structures that describe an appropriate chain of actions within a particular context (Schank & Abelson 1977). They involve information about what usually happens in those situations and in what order. They also describe the kind of roles different agents are expected to adopt when the script is enacted. By conceptualising these structures as cultural scripts, we emphasise that while they are learned and utilised by individuals, these structures are at the same time part of the shared culture of a community (Quinn & Holland 1987). In other words, they are social constructs that are bound to time and place.

More precisely, the aim is to find out the kinds of cultural scripts the staff of intellectual disability services currently rely on when planning and organising the transition. This issue is explored in the context of the Finnish system of ID services. In Finland, only 2% of adult persons with ID are in paid work, two-thirds participate in work activities, and one-third participate in day activities (Vesala, Klem & Ahlsten 2015: 7). Work activities involve work-like tasks, and a small reimbursement is paid for participating in those activities. However, work activities are differentiated from paid work in the sense that they do not involve employment contracts or salaries. In turn, day activities are directed at people who due to their disabilities are not able to participate in work activities. Day activities are more rehabilitative and stimulative in nature. Both forms of activity are usually organised at special activity centres (Vesala, Klem & Ahlsten 2015).

Current Finnish legislation on work and day activities does not set limits to participation based on a person's chronological age. The municipalities, who organise these services, can thus decide whether to restrict the participation to these services in this way or not. At the same

time, the question of the way in which persons with ID should retire is becoming ever more urgent in Finland due to the increasing lifespan of people with ID. The life expectancy has grown in this group even faster than that of the rest of the population in recent decades (Sauna-aho 2019: 11; Westerinen 2018: 84). A recent multi-registry study found that there are about 8,800 persons with ID over 65 years of age in Finland, which is 0.75% of the Finnish population over 65 (Westerinen 2018: 84).

There are national guidelines on how the services for a person with ID should be organised issued by Finnish Advisory board for Housing for People with ID (Kehitysvamma-alan asumisen neuvottelukunta [KVANK] 2011; 2017; 2018). These guidelines set quality criteria for services but are not age specific. The criteria are based on a model of person-centred life planning that has been adapted from international models, such as the Irish New Direction model. The criteria for work and day activities (KVANK 2017) underline that the support and services in the transition phase of a person with ID should be based on a transition plan that the service provider develops together with the service user from the user's viewpoint. While the guidelines are not legally binding, they can have an impact on the scripts that are attached to the transition of older persons with ID to retirement. The analysis presented later in this article will shed light on what kind of impact they have had in Finland and what kind of cultural scripts are in use.

## RESEARCH PROCESS

The research was conducted with the staff at three service-provider organisations in February and March 2021. The organisations were chosen so that they have a lot of service users from different municipalities and are located in different parts of Finland, representing both private and public disability service providers in cities and rural areas.

The data were gathered with a questionnaire targeted at staff of work and day activities and housing services for people with ID. These services were chosen because they are the two central actors for adult persons with ID in their everyday life in Finland. In the following, we use the term 'daytime activity services' to refer to both work and day activities, differentiating these from supported work and other forms of paid work.

The first author emailed the invitation to participate in the study to the service managers of each organisation that granted the research permit. The managers forwarded the e-mail message to their staff. The invitation included a link to the Microsoft Forms questionnaire and answering instructions. The respondents were instructed that responding was anonymous and no data on the respondent or their employer would be gathered. The instructions underlined the importance of the respondents' own experience, observations, and operation models in the process of the transition to retirement.

The questionnaire had a total of 10 questions, including a background question on whether the respondent works in daytime activities, housing services, or another service. To add understanding and get descriptive data on the transition process, we used both closed and open-ended questions. The closed questions were: 'Will planning for the future be done?', 'Will the cooperation with elderly services be done?', and 'Has the Covid-19 pandemic affected the transition to retirement?' Each of these was followed with a more descriptive 'what kind of question (when answering yes) or causal 'why' question (when answering no). In addition, the questionnaire included the questions 'What other practices are involved in the process of disengagement from day and work activities?' and 'What kind of development ideas do you have regarding the transition?'

Altogether 36 staff members from different disability service producer units responded to the questionnaire. Of the respondents, 21 worked in housing services, 13 in daytime activity services, and two in other services for people with ID. The Finnish Advisory Board on Research Integrity (Tutkimuseettinen neuvottelukunta [TENK]) guidelines have been carefully followed both in the data collection and the analysis stages. This research did not involve any elements that according to TENK (2019) guidance require ethical committee approval.

For the purposes of this paper, the data was analysed to identify the scripts the respondents utilised in describing the retirement process of their clients. Atlas.ti software was used for coding and organising the contents of the responses to the open-ended questions. Six group codes were created to represent the process and roles of the transition script. These were:

1) initiative to transition, 2) realisation of transition (divided into preparations and actions), 3) daily activities and relations in retirement, 4) staff, 5) municipal disability services, and 6) the person with ID.

After labelling the data with these codes, the content of the coded data sections was further examined. At the same time, previous research findings were studied to deepen the understanding. In this way, we were able to identify two main categories into which all the coded parts of the responses fell. These were conceptualised as the system-driven transition script and the person-centred transition script. In these scripts, the transition to retirement proceeds through divergent chains of events, in which people with ID, and staff of service units and municipality's disability service receive different roles.

We will describe the scripts in detail in the following section. The summary of the contents of the main scripts can be found in [Tables 1](#) and [2](#). Due to the gender neutrality of the Finnish language used in the data, we use 'they/them' as gender-neutral singular pronoun in the following text.

## RESULTS

The person-centred script and the system-driven script were used by an almost equal number of participants in describing the transition of a person with ID to retirement. Altogether 26 participants described the process in a way that fits the person-centred transition script and 24 participants in a way that fits the system-driven script. Some participants drew on both scripts in their responses. The questionnaire requested descriptions of both practices in units and development ideas for the future, which allowed the presence of both scripts in the responses of the same participant. Most of the development ideas followed the person-centred script, while descriptions from practices were divided almost equally among the person-centred and system-driven scripts. There were also responses where the transition was described as starting according to the system-oriented script but changing as the process progressed towards the person-centred script. Respondents in daytime activity services described practices pertaining more to the person-centred than system-driven transition script, whereas the system-driven script was more common among housing services.

### THE SCRIPT OF PERSON-CENTRED TRANSITION

The essential feature of the person-centred transition script is that the wishes of the person with ID guide the process from beginning to end. The transition begins with the person's own wish for a change in daytime activities. This is linked to the person's impaired functional capacity, increased fatigue, or experience of becoming old. It may also be associated with the person's desire for a change and to retire, or a lack of interest in leaving home. According to the person-centred script, the initiative for the transition is not associated with a specific chronological age, as evidenced by the following description of a staff member at a day activity centre: 'We listen to the wishes of people with intellectual disabilities; not everyone retires at 65 [...] In my unit, there are many over that age' (Respondent 29, Daytime Activity Services).

The daytime activity and housing services staff described that they listen to the wishes of people with ID to reduce the amount of day or work activity or to retire, and they also convey these wishes to a representative in municipal disability services. Some of the responses describe a joint meeting discussing the importance of change, planning the transition in practical terms, and thinking about possible service needs after retirement. The meeting's participants were described to include the person with ID, a family member or other person close to them, a representative from the municipal disability service, and staff members from the daytime activity and housing services. The goal of this cooperation is to ensure that the person with ID can continue to have a meaningful and satisfying life after the end of daytime activities, as described in the following quote:

'In addition to cooperation with the client, we closely cooperate with both city officials and home/housing unit. The most important thing is that the client is not left to "hang about", but meaningful and stimulating activities during daytime continue in their everyday life' (Respondent 24, Daytime Activity Services).

In planning the future, the transition process was described to be planned as either gradual or total. At the same time, consideration was given to whether there is a need for new activities or daytime content, whether there is sufficient social interaction (e.g., meeting friends), and whether the change will cause an economic impact in the life of the person with ID. There may exist an underlying, previously made plan, which has been regularly (e.g., semi-annually) updated. This is evident, for example, in the response of the following daytime activity services staff member:

‘We make an individual plan with each client, in which we also mark down the transitional steps. The plan is updated at least twice a year and, if necessary, more often’ (Respondent 25, Daytime Activity Services).

Proactive planning ensures awareness of the person’s wishes even in those transitional situations, which begin with the rapid deterioration of the person’s functional capacity. Wishes to make such plans in a timely fashion stood out in the answers. When planning is carried out proactively and plans are updated regularly, extensive meetings are not required when the transition to retirement is topical. A staff member’s announcement to the representative of the municipal disability services was described to be enough to ensure that the person-centred transition script is enacted. Sometimes also a staff member can take the initiative for the transition based on the previous plan.

For the respondents drawing on the person-centred script, everyday life after retirement involves developing new routines according to the person’s wishes, as well as experiments with new activities. Supporting the continuation of an active life outside the home was seen as important, given that this is the wish of the person with ID. Some respondents had helped their clients to apply for a support person or a personal assistant. There were also reports about clients being granted pensioner activities by municipal disability services. The following quote exemplifies this:

‘They say what they would like to do when getting more free time because of retirement. We make plans together, like applying for a support person with whom to do interesting things’ (Respondent 16, Housing Services).

However, maintaining the functional capacity of a person with ID is also considered important in the transition. The concern for maintaining the functional capacity can create some tension in following the person-centred script. According to this script, retirement can occur quickly if the person with ID so wishes. However, the respondents worried that an abrupt end of daytime activities could lead to the severe deterioration of the client’s functional capacity, and at least one had witnessed this scenario becoming the reality. Consequently, the respondents also recounted finding ways to maintain the functional capacity of the person with ID within the boundaries of the person-centred script, as the following quote exemplifies:

‘The client had wished for retirement. However, the client was still able to function. We discussed together the reasons they wants to stay at home. We had the conversation and encouraged them to leave the home, so that their functional capacity would not get weaker. Decided together with the client about part-time retirement, meaning more home days. Earlier they went to the work centre five days a week; we have now decreased the workdays little by little according to the client’s wishes. At first the client worked for four days a week, now for three days a week. We also had a discussion about this with the work centre’ (Respondent 3, Housing Services).

In such a situation, the staff member, perhaps unlike the person with ID, described thinking about the best interests of the individual from the viewpoint of maintaining their functional capacity. In joint reflection, a new plan was described as being created that in some respects still reflects the wishes of the individual while also aiming to secure their wellbeing. In general, the person-centred script of the transition to retirement involves the remarkable flexibility of plans and solutions. This is illustrated, for example, in the following quote, where even reversing the retirement decision was made possible, respecting the person’s wishes:

‘When the client wants to move from the work centre to the day activity, we make it possible. The second customer “retired” completely, but after a year, wanted to go back to the work centre—we enabled that too’ (Respondent 28, Daytime Activity Services).

At the same time, the previous two quotes raise the question of whether continuing daytime activities really was in this case the only way to maintain the functional capacity of the individual (the written response do not mention if other solutions were considered). This implies shortages in support services, at least in some locations, which limit the ways in which a person-centred transition can be realised. After all, a fully person-centred transition requires a range of options that ensures it is possible to create both a meaningful and wholesome lifestyle in retirement. For example, a discussion group for peers was cited as a supporting method in daytime activities for people with ID, respondents described the group as a way to come to terms with aging. In addition, a retirement club for people with ID had been organised.

To sum up, the person-centred transition is described as hearing the wishes of the person with ID and those close to them at various stages of the process, as well as providing trial opportunities and support for the decisions and choices ahead. In the person-centred transition script, the person with ID plays the role of an active agent. Staff members of daytime activities and housing services appeared to be supporting persons in the process and enablers in practical matters. The role of the municipality’s disability service representatives seems to be to grant required support services.

ACTOR AND ROLE	INITIATIVE	PREPARATION	ACTIONS	IN RETIREMENT
The aging person with ID: active agent	Own wishes and decisions determine how the transition happens	Reflecting on the meaning of change with close relatives and staff	Decision to proceed or retire gradually or immediately; experiments with new activities if wanted	Upon choosing, activities independently or with the support of housing staff or a personal assistant; cancellation of the decision also possible
The staff members of daytime activity and housing services: supporting person and enabler	Telling the person’s wishes to municipal disability services; based on a previous plan, they can also take the initiative if the person is unable to do so	Considering the matter together with the person with ID and their close relatives and giving support in decision making; searching for alternative leisure activities	Make adaptations to the duration and content of daytime activities; present new options, apply for a support person for leisure activities when needed	Individual support for the person with ID in a new situation; enables the return to daytime activities when the person so chooses
Municipality’s disability service: funder and organiser of necessary support	Asks and listens to the wishes of the person with ID	Participating in the negotiations on the phases of transition	Modify service commitments when needed	Asks and listens to the wishes of the person with ID and modifies service commitments when needed

**Table 1** The script of person-centred transition, the phases of the process, and the roles of people affected. The leading agent in the process is presented in the first row.

## THE SCRIPT OF THE SYSTEM-DRIVEN TRANSITION

In the system-driven script, the transition to old-age retirement proceeds on the terms of the system. The term ‘system’ refers to the guidelines and activities of staff in service-provider organisations and the municipal disability service. Within the system-driven script, we also found the subscript of everlasting daytime activity, in which the transition to old-age retirement does not happen at all. Central to the system-driven transition script is that the person with ID is not able to genuinely influence how things proceed.

The system-driven transition script contains several options for starting the transition. A typical incentive for the transition was described to be the chronological age of the person with ID; the age limit is determined by the municipal disability services. The most common age limit was 60 years, after which daytime activities are no longer granted. When this age is reached, the daytime activities end without exceptions, as evidenced by the following quote:

‘Municipalities have different ways to determine until what age clients are provided daytime activities through disability services, for example in our municipality this age is 60 years. Consequently, people with ID over 60 years of age are no longer granted daytime activities and are therefore left without them, even if their functional ability would allow participation’ (Respondent 23, Other Services).



Based on the system-driven script, the transition can also start before the age limit is reached. According to some respondents, the staff takes the initiative for the transition, as there is a lack of adequate resources in daytime activities to meet the person's changed needs. As one of the housing services staff members describes:

'The initiative comes from the daytime activity services or municipal social work. The customer requires a lot of resources, or the municipality terminates the payment commitment' (Respondent 13, Housing Services).

The Covid-19 pandemic has brought up other system-driven practices related to retirement. In some day activity centres, it resulted in organising daytime activities in smaller groups and prioritising the needs of younger persons. In this situation, it was suggested that older persons with ID should retire. As one housing services staff member describes: 'Jobs and inclusion activities have decreased considerably, and this has brought up the need for "retirement" as younger people need activities in small groups' (Respondent 18, Housing Services).

In the system-driven script, the staff is allowed to try to influence people's opinions when they do not agree on quitting daytime activities. For example, the respondent indicated that the Covid-19 pandemic was used as an excuse to leave daytime activities: 'Citing Covid-19, it's easier to talk the client/resident into staying at home, making retirement more likely' (Respondent 2, Housing Services). Efforts to influence the client's opinion also emerged in the direction of the continuation of daytime activities, even if a person had expressed a desire to transition to retirement (see the subscript of everlasting daytime activity).

Preparation for the transition to retirement and specific transitional activities are carried out as a collaboration between staff in housing and daytime activities and the municipal disability service. According to some respondents, the person with ID is informed of the forthcoming change, and it will be discussed with them, but they cannot influence the timing or the process. Sometimes the end of daytime activities can happen abruptly and come as a surprise. As one respondent noted: 'The plan is not made well in advance, but the end of daytime activities often occurs at short notice or without notice' (Respondent 5, Housing Services). For the staff in daytime activities, the transition routine was described to include organising a farewell coffee gathering.

As to life in retirement, the system-driven script does not include individual planning or planning the future together with the retired person. If in these descriptions some activities are planned, they are planned by the staff without the person with ID. One of the housing staff member states: '[There are] No substitutive activities, only hanging around in the unit' (Respondent 17, Housing Services). Some staff members felt that supporting residents' daytime activities is not the responsibility of housing services, as is evidenced by the following quote:

'We need to discuss this topic more in housing units. We can't have the resident's lack of activities becoming an additional burden to the housing unit by increasing our duties' (Respondent 15, Housing Services).

In the system-driven transition script, the guiding role is played by the municipality's disability services and the staff in housing and daytime activity services. When older people themselves cannot influence the practices prevailing in the system, they are mainly left with the role of passive objects who adapt to the changing situation. According to the following quote, in the script of the system-driven transition, the change goes well for some people, but not so well for others:

'Emptiness when others leave for work, and they do not. The money stops coming in, mates disappear, because there won't be contact with the co-workers as much. Some are relieved when they don't have to get up so early in the mornings. Some enjoy it and for some staying at home is terrible and brings big problems' (Respondent 18, Housing Services).

### The Subscript of Everlasting Daytime Activity

In the accounts of three respondents, one can distinguish a particular variation of the system-driven script called here as the subscript of everlasting daytime activity. In this subscript, no transition process is described nor the need for it identified. All residents are taken to daytime

activities for as long as they can leave home. The person with ID does not have a say if they attend or not. An example of this is seen in the following quote: ‘The perception we have is that they will not “retire” from daytime activities because also the older ones are taken to daytime activities, however, within the limits of their capability’ (Respondent 14, Housing Services).

The script of everlasting daytime activity is possible in organisations that produce both daytime activities and housing services. As the everlasting daytime activity script guides the thinking of the staff, the individual wishes of the person with ID are ignored:

‘Too rarely one actually listens to the client’s own opinion. Too much pressure is put on continuing daytime activities, even if the client’s own wish is to already “retire” and live a peaceful home life. Workers often feel that people with ID are supposed to be in work/day activities five days a week on an old-age pension. It doesn’t matter if the functional capacity or age is calling for retirement’ (Respondent 26, Daytime Activity Services).

In the subscript of everlasting daytime activity, the staff member’s role is to execute routines and await instructions. The decisions made by people in managerial positions guide the activities, as evidenced by the following quote: ‘This is exactly what we have been pondering in our daytime activities, when someone can be retired from daytime activities. [...] We haven’t received a response from management yet’ (Respondent 34, Daytime Activity Services). The role of a person with ID is to adapt.

ACTOR AND ROLE	INITIATIVE	PREPARATION	ACTIONS	IN RETIREMENT
Municipality’s disability service: Supervisor of the transition process	Determines the time of transition		Decides if substitute services are funded or not	Same support services for everybody in the same age group
The staff member of daytime activity and housing services: executor of routines, waiting for instructions from managers	System-based initiative, seeks to influence the opinion of the person with ID when needed	Staff plan and inform the time of transition to retirement or plan actions for everlasting daytime activity services	Phased or direct transition / no transition (everlasting daytime activity); arrange farewell coffees	Same support for all residents in housing, no special activities during daytime for the retired
The aging person with ID: passive object	Cannot affect the time of the transition or if there will be any transition	Is informed about their own retirement or continues in daytime activity services like before	Adaptation to transition or continuing in daytime activity	Adaptation to retirement or no transition to retirement

**Table 2** The script of system-driven transition, the phases of the process, and the roles of people affected. The leading agent in the process is presented in the first row.

## CONFLICTING SCRIPTS

Sometimes different actors follow different scripts, resulting in conflicts. An example of such a clash of scripts is the situation in which staff working with a person with ID would like to follow the person-centred transition script, but it is not possible due to the municipal disability services’ system-driven script. The quote below describes one such situation:

‘In the retirement of our clients who attend daytime activities, individual needs are not taken into consideration by those paying for the services, but every client retires on the day they turn 60. This is an automatic operating model that we have tried to influence a few times (taking into account the client’s level of activeness), but municipalities (service funders) have not consented to this. Municipalities are also not very keen to pay for pensioner activities for people with ID over the age of 60; participation by pensioners often remains paid for by the person themselves. Clients often cannot afford to participate in pensioner clubs, in which case they drop out of all activities’ (Respondent 31, Daytime Activity Services).

Respondents who experienced conflicting situations like this criticised the disability services’ system-driven script on the grounds that the chronological age of the person with ID does not tell the whole truth, and therefore more attention should be paid to the person’s physical and mental capacity to function when decisions are made. Some of the clients exceeding the age limit want to continue in daytime activities if they are capable of doing so. The respondents



emphasise that withdrawing daytime activities simply because the client has reached a certain age is against the person's right to self-determination. They implied that only economic considerations guide the decision-making.

A commitment to the person-centred transition script can be seen behind such criticism. However, at the same time the staff point out that the buyer of services ultimately determines the resources and modes of operation. In other words, scripts at higher levels of the system restrict the implementation of the person-centred script, even if the staff is otherwise prepared to follow it.

Differences of view could be seen also between the staff in housing and the staff in daytime activity services regarding which script to follow in the person's transition to retirement. In the following quote, a daytime activity services staff member expresses their disagreement in relation to the manner observed in housing units when some of the clients are retiring:

'Too often the decision to end daytime activities comes from the housing unit without genuinely hearing the client' (Respondent 35, Daytime Activity Services).

As shown in the previous quote, the main controversy is whose opinion should guide the transition. The respondent expresses the view of the person-centred script that the opinion of the person with ID should settle the matter. At the same time, they point out the different point of view in the housing unit, and that the housing unit plays a dominant role.

Based on the responses, it seemed that sometimes the person-centred transition script is only followed by one operator, such as the daytime activity or housing services staff, while the rest of the environment operates according to the system-driven script. In this case, the person-centred script cannot in practice be implemented, because in order to realise it, the script should involve all levels involved in the organisation of services.

## **INDIVIDUAL ABILITIES AS A PRECONDITION OF A TRANSITION SCRIPT**

In addition to the structural restraints described above, it seems that the perceived abilities of the older person with ID also steer which transition script will be followed. If the person has good functional capacity, the person-centred script is more probably used, and their day programme will be planned together with the housing staff:

'In the work community, the resident's day programme is planned if they is retired from day or work activities. Depending on the client's abilities, they is also involved in the planning if they is capable.' (Respondent 7, Housing Services)

The system-driven script is often seen as a valid way to realise the transition to retirement especially for individuals with significant restrictions in their cognitive and communicative abilities. In these cases, the inclusion of the person in decision-making can become a challenge, and, in the worst case, the person will not be heard at all. The quote below describes such a situation:

'Another customer's ability to function deteriorated to the point where [they] practically sleeps all day in their wheelchair. Speaks only a few words. Speech is not always comprehensible. Does not necessarily recognise where they are. They is also blind. It was agreed with the parents and day activity center that the customer will stay at home because the day activities were not seen enjoyable for them. The client is in a state where they does not understand any more the activities/where they is. There was no discussion with the customer' (Respondent 3, Housing Services).

This shows that people with more significant restrictions in their cognitive and communicative abilities are at greater risk of being excluded from the planning of the transition to retirement than people with mild ID. However, the system-oriented transition script can also be applied to a person with mild ID if their capacity to function rapidly deteriorates and the transition has not been prepared beforehand (see the person-centred transition script section). It is remarkable that the respondents do not mention the use of alternative and augmentative communicative methods to ascertain the person's wishes in such situations. The exclusion from planning the retirement process was not problematized in the responses from the perspective of self-determination.

Our interest in this study was to increase understanding about the transition to old-age retirement of people with ID. Qualitative data was collected from staff in housing and daytime activity services and the concept of the script was used as a tool to analyse descriptions of operating transition models. The study showed that the expected roles and activities of people with ID and staff differ significantly depending on whether the transition process progresses according to the person-centred or the system-driven script.

The person-centred script emphasises individuals' rights to choose, control, and direct the decisions in the retirement process. The central role of the person with ID in planning and decision making as well as the staff's supporter and enabler roles are well-known and distinguished principles in international best practice (Ouellette-Kuntz et al. 2019) and Finnish quality criteria for services (KVANK 2011; 2017; 2018). In other words, this script can be seen to reflect the impact of these ideas.

In turn, the system-driven script presents a more conventional way of organising the transition of retirement of older persons with ID, diverging from the aforementioned principles. In relation to potential changes in an aging person's life, the municipality's disability services and staff in service units play the leading role.

Chronological age proved to be the key determinant of the timing of transition in the system-oriented script. The age limit is determined by municipal disability services, which finance the services. Bigby (2004: 156) and Watchman (2019: 246) have criticised this, pointing out that chronological age is more of a discriminatory principle than a useful indicator of the age-related needs of persons with ID. The timing and effects of the aging process are contingent on the syndrome behind the ID, and the life course of persons with ID differs significantly from the norm. While some would benefit from retirement planning already at the age of 40, others might be able and willing to continue their habitual everyday activities far beyond 65 years of age (Lawrence & Roush 2008, 248).

Our findings regarding the system-driven script have some commonalities with the findings of studies conducted by Engeland, Kittelsaa, and Langballe (2018), in which people with ID themselves were not involved in deciding the date or manner of their transition to retirement. In the system-driven script, the person with ID adapts to the system and does not make choices or influence the course of events.

Interestingly, we found that this script can also be realised in the form that was defined in this study as the subscript of everlasting daytime activity. In this script, the older person with ID continues daytime activity services without retirement discussions and within the limits of their capability to participate. Staff members are waiting for the manager's decision on retirement. This script was not used as often as the other scripts by the participants of this study. It may be linked to specific situations, such as when the municipal disability services buy 'the whole package' from the service producer without a separate financial commitment to daytime activities and housing services.

The subscript of everlasting daytime activity denies the older person with ID the opportunity to experience what social gerontologist Laslett (1994) has defined as the 'third age'. This refers to 'free from duties' senior life, which is highly valued among people in general. Kåhlin, Kjellberg, and Hagberg (2016: 7) noticed in their study that the third age does not exist in the way home staff understand and discuss ageing in people with ID. People with ID were seen as ageless (see also Buys, Aird, & Miller 2012: 1141) and the staff mainly discussed old age in people with ID in relation to frailty and an increasing need for support, typical to Laslett's (1994) 'fourth age'. Such findings are in line with the subscript of everlasting daytime activity that was found in this study.

Even when the system-driven script involves a transition to retirement, it lacks an approach for supporting an active and fulfilling senior life. Instead, it seems to involve confusion about whose responsibility it is to provide support for new activities for persons with ID after they have retired from work and daytime activity centres. Similar observations have been made by Kåhlin, Kjellberg, and Hagberg (2016: 7), who pointed out that ageing among people with ID is an unarticulated phenomenon in group homes.

In contrast, the person-centred script involved considering compensation for lost roles, social relationships, and activities in the transition to the retirement phase. However, as Lawrence and Roush (2008: 249) have argued, if person-centred plans are not made at all or in time, it may be difficult for a person with ID to make their voice heard in the later stages due to a reduced ability to function. In this situation, a lack of means to consult those who are unable to talk about their wishes for retirement represents a further obstacle. In some cases, communicating desires is successful with augmentative and alternative communication methods, such as pictures, even if the ability to speak is poor. Should these be excluded as well, there is still a whole spectrum of various embodied expressions of will available (Miettinen 2021).

In this way, the person-centred transition script could in principle be applied in some form to situations where aging is combined with constrained communication and cognition. However, in the staff's responses, these constraints were seen as a justification for introducing a system-driven script, which indicates that alternative ways of hearing the person with ID are still poorly known. The low functional capacity of people with ID has been found to increase the likelihood of them being subjected to passive and object roles instead of being self-defining subjects with initiative (Teittinen & Rapo 2021: 251).

In sum, our study showed the existence of multiple and conflicting scripts around the transition to retirement of older persons with ID in Finland. This indicates that ageing people with ID do not have equal opportunities to realise their own transition to old-age retirement, but this depends on which script is followed in their municipality's disability services and service-provider organisations. However, changing the transition script is very difficult if it is not supported by the surrounding system of services. Enabling a person-centred transition to retirement requires the system to be able to adapt to the individual needs of the ageing person with ID. This can be achieved, for example, through diversifying daytime activities and using personal budgeting (Bigby 2004; see also Wahl, Iwarsson, & Oswald 2012).

In this study, the data was collected via an internet questionnaire. Open questions in the questionnaire produced free-form descriptions of the transition process by staff members. Some weaknesses with this method include short answers by some respondents and the inability to ask focused additional questions. The results of the article are based only on the staff's perspective, so to gain more understanding of the transition to the old-age retirement phase, the experience of persons with ID and management level decision-makers are also needed. The recognition of the existence of diverging transition processes and practices offers important understandings for further research.

## DATA ACCESSIBILITY STATEMENT

Certain sections of data are available in Finnish on request from the corresponding author but are not publicly available due to the procedure agreed in the research permits.

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## COMPETING INTERESTS

The authors have no competing interests to declare.

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