Personalisation, self-advocacy and inclusion: An evaluation of parent-initiated supported living schemes for people with intellectual and developmental disabilities in the Netherlands

Comparative research suggests that individuals living in traditional institutions enjoy less choice (Stancliffe, 2001) and are less able to exercise self-determination (Stancliffe, 2001; Robertson et al., 2001) than those living in small-scale, community-based residences. Some research also suggests that individuals in community-based supported-living schemes have more opportunities for social inclusion (Abbott and McConkey, 2006). However, small community-based settings do not always facilitate personal choice and independence for people with disabilities . This research responds to Stancliffe's call (2001) for investigating specific environmental and structural factors of communal residences—in this case, parent-initiated supported living schemes—and their potential influence on personalisation, autonomy, choice and self-determination.

Personalisation can be defined as ensuring that people with disabilities who receive services are able to choose the type, form, and content of services, and make decisions about how, when and by whom these are delivered. Increased choice and autonomy for service users is positioned as delivering a 'less bureaucratic form of service which is on the side of the people needing services and their carers' (Department of Health, 2007: p.

1). Duffy (2007) lists six key areas in which work needs to be done to deliver full citizenship to adults with learning difficulties: self-determination, direction, money, home, support and community. Personalisation should ideally extend to all of these areas; accordingly, each has been considered in our findings.

However, as Lymbery (2012) and others have noted, self-determination and direction can be challenging for some service users, especially those with significant learning difficulties. Williams, Porter and Marriot (2014) highlight the role parents and support workers can play in supporting informed choices.

Parents can be caught between their 'duty' to provide care and the risk of perpetuating dependency. They risk being overprotective, and are prone to take decisions instead of facilitating the choices of the disabled person (Power, 2008). Therefore, this study explored tensions within and between control and care, and the extent of personalisation experienced by adults with developmental or intellectual disabilities living in parent-initiated supported living schemes.

Finally, this research placed these questions within the context of the Dutch state. The Netherlands is one of the last hold-outs in Europe regarding the UN Convention on the Rights of People with Disabilities (UNCRPD): ratification had not yet occurred when this article was written. (Van Balkom et al., 2015). Reasons for this continued delay are several, but have been summed up by the Coalition for Inclusion as "lack of insight in the prevalence and seriousness of human rights violations of persons with disabilities in our society and the lack of urgency and priority that the Dutch government assigns to

the realization of human rights of persons with disabilities" (van Wijnen, 2012). The UNCRPD states that people with disabilities should be able to choose where they live, and whom they live with (United Nations, 2006; Brown and Brown, 2009).

Two categories of reasons cited by van Wijnen (ibid.) are particularly relevant to the issue of personalisation: systemic incentives for congregate rather than individualised living and care, and limits applied via the personal budget (*persoonsgebonden budget*, PGB) system.

In the Netherlands, people with disabilities may receive a PGB in addition to other disability-linked benefits. Although the PGB was introduced in 1995 to facilitate personalisation, over the years administration of the scheme grew, and currently it contains rigidities that can limit meaningful personal choice (Van Haaster, *et al*, 2012). The PGB system was also originally intended as a means to save money on long-term care (The Health Foundation, 2011). Financial support is keyed to defined levels, as noted in the following section, rather than absolutely individually.

A PGB allows consumers to decide independently what kind of care services will be provided, and by whom, when and where these will be delivered (PerSaldo, 2009). Paid care providers must be registered with the appropriate state agency for billing purposes, and can be subject to a variety of bureaucratic requirements. This complexity incentivises choosing established care-provision companies rather than self-employed carers (*ibid.*).

To some extent, the parent-initiated supported living model was dictated by the Dutch care system, which makes it much easier to receive higher levels of services when living in specialist supported housing (College voor Zorgverzekering, op cit.) Parents stated that if they wanted to ensure that they and their son or daughter had the greatest extent of control over services received, initiating and running their own schemes presented an alternative to housing and care provided and organised by the state or by service providers.

Congregate housing is also incentivised over more independent alternatives, because efficiencies of scale can be achieved through pooling costs. However, parents noted that the PGB and other personal funds could not be used to cover the costs of shared spaces within the parent initiatives, so parents have to raise funds via sponsorship (for example, from a local carpentry firm or cinema) to pay for these.

In 2015 significant changes to the PGB system were introduced, including severe budget cuts, posing new challenges for people with disabilities (PerSaldo, 2015a). There is a greater emphasis on unpaid, unofficial care, which often devolves to parents of adults with intellectual or developmental disabilities. Insurers and local governments are directed to cover more costs for disabled people's care and support. Housing and support are now supposed to be delivered by different providers, except under specific circumstances. There are concerns that these changes may in future have a negative impact on adults with disabilities who live in specialist *wooninitaitives*, such as parent-

initiated supported living schemes (Per Saldo, 2015a). The potential additional human rights impact of these changes should be considered alongside our findings.

Parent-initiated supported living residences

In the Netherlands, parents have responded to deinstitutionalisation through initiatives that build and run small-scale residences for their sons and daughters with developmental or intellectual disabilities. The authors' comparison of 10 living schemes built by different parent initiatives revealed similarities in terms of their structure and level of organisation. About half of the parent initiatives rented and renovated parts of a building; in other cases parents hired social housing corporations to build a living space catering for the needs of adults with intellectual disabilities, which their offspring could later rent units in.

Commonly, each resident has his or her own apartment, equipped with a small kitchen and a personal bathroom. Additionally, each housing scheme has at least one common living room and kitchen where communal life takes place. Several of the 10 homes were already running, some for up to seven years, whereas others just had started or were in the process of moving into a new building.

Between six and 11 residents with intellectual or developmental disabilities live together in each project. With one exception, where coincidentally all residents were women, usually tenants of both sexes live together. Different levels of homogeneity were noted in terms of age and severity of disability. In the majority of schemes tenants'

ages ranged between 20-35, with exceptions where the youngest resident was in her early twenties and the oldest in his late fifties.

In the context of the Dutch care system, residents' care levels varied between standard residential care (*zorgzwaartepakket*, ZZP) levels 3 and 6 as specified for people with intellectual or developmental disabilities, which provides funding as follows (College voor Zorgverzekering, 2013):

- Level 3: *Residential care with some daily support and care*

- Level 4: *Residential care with some daily support and intensive personal care*

- Level 5: *Residential care with intensive daily support and intensive personal care*

- Level 6: *Residential care with intensive daily support and intensive personal care, with support specific to 'challenging behaviour'*

Level 7 is the highest level of care available, and corresponds to the care needs of people who need 24-hour care with individual staffing (PerSaldo, 2015b). Care and support needs are established through formal, individual evaluation by health and care professionals, in cooperation with clients. Parents or paid advocates may also be involved in this process. Each scheme chooses a care organisation and selects care and support workers independently (see *Findings* for more details.)

Methods

Our research objectives were to learn how well parent-initiated supported living projects for adults with intellectual or developmental disabilities supported independence,

enhanced participation, choice and self-advocacy for people with intellectual disabilities, and how research findings could be used to further personalisation and inclusive community building. To explore these questions, we analysed the structure and organisation of parent-initiated shared-housing schemes, as well as the dynamics between parents and tenants, particularly their impact on residents' autonomy, choice and self-advocacy. Areas of focus included the extent of residents' opportunities to exercise self-determination in major life decisions (e.g. with whom and where to live, recruitment and retention of care staff) and the housing schemes' potential to foster personalisation and community integration.

Qualitative data was obtained from 35 semi-structured interviews with parents, residents and staff. A manual thematic analysis was undertaken, with data contextualised and analysed through an in-depth literature review.

Parent initiatives in the province Noord-Brabant were contacted via email. Interviews were conducted in person by the lead researcher. Almost all were conducted in the resident's own home. One took place in a resident's workplace, and another at a parent's home. Overall, 35 people took part in semi-structured interviews: 15 tenants with an intellectual or developmental disability who reside in one of the shared-living communities, 17 parents of tenants, and three caregivers working in parent-initiated residences. This number of tenants corresponds to slightly more than 10 percent of the total number of adults living in the schemes contacted. The sample contained all residents, parents and staff who agreed to be interviewed.

Accommodations were used to both protect and include people with intellectual disabilities in the qualitative research process. Before each interview, participants were asked to indicate their preferences for the interview setting. Tenants could have someone accompany them during the interview for personal or communication support; this was usually a parent or caregiver. Hall (2013) indicates that when conducting qualitative research with people with intellectual disability, it is helpful to find multiple ways to ask the same question to enhance the understanding of the participant. Consequently, a number of guiding questions, including alternative formulations, were prepared. Hall also advises that concentration levels may decrease in a shorter period of time during an interview (ibid.). Accordingly, several interviews were kept to a length of about 30 minutes. However, the majority lasted 40 to 90 minutes.

All participants signed an informed consent form, and responses have been anonymised. This study was conducted in line with the ethical requirements set out in the "Disability Studies in Nederland Code of Practice for Researchers." This is available on request from the research organisation, and is compliant with the International Association for the Scientific Study of Intellectual Disabilities guidelines (Dalton and McVilly, 2004).

Interviews touched upon a wide variety of topics, covering all six areas of Duffy's framework (self-determination, direction, money, home, support and community, *op cit.*). Parents were far more likely to discuss money-related issues, such as the financial background of the projects or their son or daughter's financial arrangements regarding housing and care. Residents tended to focus on self-determination in activities of daily living and what defines "home" for them.

FINDINGS

In this section, our findings have been keyed to Duffy's six key areas for citizenship and personalisation (op cit.). In some cases areas have been combined to fit the data collected; money issues were covered in the introduction.

Self-determination and direction

Parent-initiated supported-living residences exhibited the greatest difference in comparison to traditional institutions in the way care was facilitated, organised and directed. Parents rent in care staff from companies that provide care services, and so can freely create a care package for and with their family member with intellectual or developmental disability to meet individual needs.

This characteristic reflects the parents' main motivation for starting such initiatives: having greater power to choose and decide. Parents criticised how little the opinion and wishes of the consumer are considered in classical institutions. Support staff also appreciate the difference. As one Caregiver A said:

> *Lines of communication are short [here]. If [a resident] has a problem, we can contact the parents. This is how we see it as professionals. If you work in a typical institution, you usually have to go through many steps to reach the same goal.*

Moreover, one tenant (C) expressed strong dislike toward living in a typical institution:

Father: *How would you have found it if we would have sent you to a typical institution?*

C: *I would have said no. I would have run away.(…) Those people* [clients in classic institutions] *have severe disorders. (…)They have lost their way.*

Consequently, the vast majority of the parents interviewed had never considered placing their child in such an environment.

The greatest degree of self-determination was seen in the area of daily occupations. Residents pursued personal interests such as hobbies and sport, and support workers individually facilitate these. This is in contrast to both traditional institutions and congregate day-centre provision.

Parents are free to choose any care organisation that seems to best suit the needs of their son or daughter. Once an organisation has been selected, parents typically interview potential carers and then present two or more candidates to their son or daughter, who can then make a choice. Personal care requirements are discussed between this personal caregiver, the parents and the tenant, and a care plan is created. However, not all parents give their son or daughter the opportunity to choose their personal caregiver.

According to the interviews, all homes attempt to implement a system of collaborative decision-making in which parents, caregivers and tenants form a triangle with equal participatory rights. Usually, parents decide on a few foundational rules. For example, they determine how the basic care is organised and coordinated, and whether a 'demoticon' (a warning system connecting the residence with a nearby care organisation that responds to emergency calls) replaces overnight care by on-site personnel. Other house rules are determined in agreement between the caregivers and residents.

Tenants hold regular meetings, accompanied by one or two caregivers, where they discuss and evaluate current issues and upcoming events. However, interviewees often indicated that the frequency of these meetings declined with time. Residents of some homes said that in the beginning they held meetings every two weeks; the majority of residents recalled that the first days and weeks after the move were both exciting and stressful. In that period, group meetings provided an opportunity to clarify issues and reduce stress factors, but also facilitated group bonding among the tenants. Later, with an established routine in place, residents ceased to participate, partially because they were not interested in the issues discussed, but also because they were less concerned about the group dynamics. Consequently, the decrease in frequency of meetings is not necessarily indicative of an enforced limitation of tenants' participation, but may reflect their desire for a more individualistic lifestyle within the group setting of the residences.

Home

The parent-initiated projects all shared in common that they were based on physical living environments: co-located apartments with some shared spaces.

Interviewees indicated that parents invested much energy towards providing their son or daughter with a new home. It takes Dutch parent initiatives up to seven years from the moment the initiators first meet until the actual move-in, with the search for prospective tenants, a suitable location and financial means representing the greatest obstacles in the set-up phase. Frequently, parents become discouraged during the process.

The involvement of residents during the set-up phase differed significantly between the homes. In one initiative, future residents met each other long before the actual inauguration of their new home. Their parents organised frequent meetings to facilitate group cohesion, which was considered essential for creating a sense of "home" by the parents as well as future tenants. As one parent said, "it is very important that there is a 'click' with the other residents." These residents participated in the search for prospective housemates, had a say in the conceptual planning of the communal space, and were actively involved in selecting staff. However, this high degree of participation represented an exception. More commonly, tenants only met each other on a few occasions before moving in.

During interviews, every resident indicated that privacy was one of the most important requirements for feeling "at home," and the few participants who had lived in classical institutions indicated that lacking private facilities for cooking, bathing and toileting had

been a source of discomfort. As resident J said: "What happens in my apartment [now] only concerns myself. No one else has a say in it."

Residents are free to decorate and furnish their personal apartments, restricted only by their budget and the housing corporation's rules. With assistance from their parents, tenants commonly chose paint colours and furniture. Visits to different apartments within the same homes revealed the high degree of individuality granted to the tenants: in one interview a resident proudly explained how he carefully planned the structure of his kitchen so that he could look through his window while preparing a meal, and picked the color of his tiles to match his wall. In a different living scheme, a resident happily mentioned that his brother is crafting a cupboard for him because he wanted his furniture to be as unique as possible.

Contrarily, the residents were given less or no say in the design of communal spaces. Parents explained that it would be time-consuming or cause too much tension if all tenants were involved. Parents added that residents lacked expertise, which motivated parents to make some major decisions regarding design; in one home, for instance, residents decided on the colour of the communal kitchen, but as one mother was a professional chef, it was she who determined the design of it.

Support

All three paid carers who participated in the research had followed a professional programme of education for care workers, and had previously worked in classical institutions. By the time of the interview, they had worked for almost a decade in

parent-initiated homes, and all stated that they preferred it to their former working environments.

Support and care staff noted that most parents still viewed the residents as their children, not wanting to accept advice from staff, although the tenant may act significantly differently in their new home. Caregiver A stated that under these circumstances, parents can present an obstacle to adult development, and that under different circumstances tenants could have already progressed further.

Staff, parents and residents work together to develop a care plan, **including** a daily agenda that **is** personalised for each resident. Parents are not usually present during interactions between residents and support workers, but they exert some measure of control through their participation in making care and support plans, and in subsequent meetings about day-to-day issues.

Therefore, the role of parent-(adult) child relationships was key to understanding the degree to which support was truly "personalised." Parents chose the company that would provide care in each residence, and also had a major role (and sometimes complete control) over the choice of personal carers for their son or daughter. And while parents stated that they wished for their son or daughter to become more independent, almost all admitted to have also struggled in the beginning, or to be still struggling, with offering more autonomy. One father explained that especially in the beginning it is hard for the parents to imagine that, through letting go, their son or daughter might eventually progress faster.

Some parents expressed very strong ideas about intellectual disabilities, which are likely to determine the extent to which they permit their son or daughter to direct their own support. The father of tenant L said, when asked about whether the romantic partner of a tenant would be allowed to stay over, that:

...for them "sleeping with each other" means something completely different. Just lying next to each other in bed.

During another interview with a tenant and his father, the resident was asked his age. He replied:

F: *26*

Father*: Yes, but how old are you really?*

F.: *Maybe 8 or so…*

The father then explained that F's capabilities are simply not comparable to those of other people of the same age. Without being specifically asked, F's parents gave detailed descriptions of his impairment, while he remained silent in his seat.

The lead researcher encountered several ways in which parents exerted control. For example, only parents' contact details were available from the parent-initiatives organisation, so parents were requested to ask residents about research participation. However, most did not wish to do so. Some parents stated that their son or daughter's

degree of disability wouldn't allow for an interview from which useful data could be obtained. Most interesting, however, was one father's explanation that "we [parents] are the voice of our children."

Several parents underlined the "missing or limited" capability of their children to make decisions. Furthermore, one father pointed out that too much choice could be overwhelming for tenants. He recounted a recent scenario when the whole team of caregivers was changed in a short amount of time, and parents were afraid to cause agitation among the residents by burdening them with choosing among all the applicants. Concerns about choice causing stress were more often repeated regarding residents with autism.

When the tenants were themselves asked in the interviews whether they felt restricted in their freedom and autonomy, none stated that his or her opinion was not considered enough. All residents said they perceived themselves as in charge of their life, and were grateful for the support received from their parents and caregivers. Additionally, some tenants said it was important to live near their family home. On average, tenants see one of their parents at least once per week; one mother stated that her son comes over on his bike almost every day. In cases where the father or mother is heavily involved with the parent-initiative organisation, he or she might be at the home daily.

Tenants and parents also stay in touch through texting and calling. Caregiver C said that tenants often seek the opinion and approval of their parent. She recounted one situation

where a female resident was going out to a party and sent a picture to her mother, asking whether she looked good.

Another interview held with a tenant and his father (P3) together portrayed how symbiotic the relationship between parents and their adult child can still be:

> Father (P3): *We are still behind: He doesn't like to hear it, but when it comes to domestic cleaning we help him. It is a form of coaching. Especially for his mother the laundry is very important: How do you separate coloured from white laundry? And with what else do you have to pay attention… Weekly, these tasks reoccur, and we also actively take action to help him. But we also let him think on his own.…This luckily works in harmony.… We provide this coaching so that at a certain moment he reaches a certain level of independence. As a consequence of his disability he needs to repeat things many times until they are ingrained in his routine.*

Community.

Next to greater participation, creation and safeguarding of a social network for their son or daughter was a primary reason that parents chose these supported-living schemes. Most expressed fear that their family member risked complete isolation from peers if they continued living in the family home. They explained that apart from family members, schoolmates and potentially their siblings' friends, the person with an intellectual or developmental disability had few social contacts. Once school ended and siblings left home, this circle contracted.

Most homes have a strong focus on the generation of communal life and a group feeling. A father (P7) explained how the group animates and supports his son in increasing his social network. He stated that before moving to the home, his son would have found it hard to meet friends on his own:

> *What bar, where should he go? He would be standing on the side alone. He needs to go with other people, otherwise he stands alone.*

> [People with intellectual disability] *function on a lower level. They start to ramble. Therefore they only have short contact with other people. Peers are thus not interested in him.*

> *K would make it for some time on his own. But clearly not as long as it is here the case. Here he can check at the board, who is home tonight? Oh, then I can go there to watch a video.*

Attendance of dinners held in the common rooms is mandatory in all homes for most days of the week. Moreover, parents urge caregivers to organise group activities and create certain rituals, such as a coffee hour after dinner, to stimulate interaction among tenants. At intervals, excursions (e.g. to a festival) are planned, or festive occasions – Easter, Christmas and important public holidays such as King's Day in the Netherlands – are taken as an opportunity to organise gatherings among residents and potentially their families.

The social networking efforts, however, are not restricted to strengthening the in-group. Energy is also spent on integrating tenants into the neighborhood of the residence. Almost all homes organised open days to which families, friends and neighbors were invited. Some residents volunteer in places close to their home; for example M. works next to her day centre as a waitress in a restaurant within an elderly care home. Local festivities are also used to create and strengthen social contacts outside of the residential care facilities and to find individuals a place in the surrounding community. For instance, a neighboring home for the elderly elected two residents as prince and princess during Carnival a few years ago, and they now hold a space in the historic gallery of elected couples.

Most tenants stated that their number of social contacts had increased since their move-in, whereby contact with their housemates constituted a significant part of their social network. Several tenants also had friends from sport clubs or holiday camps. It is important to note that most friends mentioned by interviewees also had disabilities: social contacts with non-disabled people were still largely restricted to encounters with family and care staff.

However, parental emphasis on community-building revealed areas of tension regarding self-determination and direction. Conversations with tenants and caregivers revealed mixed attitudes towards the parents' encouragements to socialise, and related regulations in the residences. First, there are differences in personality: a significant number of tenants found mandatory attendance of communal dinners an annoyance, a

compromise of time they would have preferred to spend on their own. However, other residents expressed their desire for more social interaction with their housemates. Notably, these were residents who also seemed to be more socially engaged outside of their homes and in possession of a greater friendship circle.

Finally, there are differences between parents' expectations and the tenants' visions of what the supported-living residence should embody. C. explained that when he was younger he wanted to live completely independently, until he eventually acknowledged that he is in need of some support. He said care staff enable him to live as independently as possibly. However, he doesn't see the need to socialise with his housemates if all he wants is to live in his personal apartment. Parents also noted that a strong focus on the group can have a negative impact on individual well-being, and causes dilemmas in respect to care issues.

Several parents noted that residents with autism in particular prefer spending more time in their rooms, and it is crucial that this freedom is also given to them. Moreover, Caregiver B pointed out that a resident who is capable of cooking for himself is at risk of losing this skill, since communal dinners are mandatory. This was one of the clearest examples of how an exaggerated emphasis on group-forming can potentially hamper individual development, self-determination and direction, and by extension can impact personalisation.

DISCUSSION

This study confirms the findings of other research (Stancliffe, 2001; Wehmeyer and Bolding, 2001) that small-scale communal living schemes have at least some positive impact on personalisation, choice and self-advocacy opportunities for people with intellectual and developmental disabilities.

However, parent-initiated schemes were not fully compatible with guidelines set out in the UNCRPD (2006). Some display rigidities in their structure that hamper full realisation of the goals described in the UNCRPD, which may limit residents' development. There are also many areas where personalisation is limited, both by structural issues such as benefits rules, and through the increased parental control that characterises parent-initiated schemes.

First, tenants cannot freely choose with whom they would like to live. Though residents of new initiatives meet each other beforehand, there is a high pressure to find someone to quickly fill any new openings. If a resident moves out, most parent initiatives struggle to compensate for the financial deficit, and less attention is paid to compatibility of new tenants with the group. One tenant remembered that because his father found a home that already existed, he was able to move in after a fairly short time, without having been much in touch with the current residents. Considering the cuts to personal care budgets introduced by the Dutch government in the beginning of 2015 (PerSaldo, 2015a), external circumstances do not necessarily support moving towards the ideal.

Budget restrictions can impact residents' participation and choice in even minor decisions. Eating together saves costs, so parents prefer it if residents take their meals communally.

Moreover, living with a romantic partner in all homes but one is impossible and would require the resident(s) to move out. The ability to age in place is also not catered for. Consequentially, it is questionable how suitable these types of group homes are for the residents' personal development in the long run.

However, limitations were in most cases not conscious decisions by parents: social housing corporations implemented rules about number of residents per unit, and the benefits system presented financial constraints.

The data evidences the complexity of a parent-child relationship involving disability, and the determinant role parents' behavior and beliefs about intellectual or developmental disability plays in their child's development towards self-determination, direction, and greater independence. The greatest struggle lies in the process of "letting go," which is determined by the parents' accreditation of staff and tenant competence. Parent initiatives seemingly have one big advantage, the ability to generate greater say in care questions. However, it was not always clear exactly who gained greater involvement: parents or residents. The data gives evidence for Goodley's statement:

> *Just as we respect the fact that all people have the right to decide what they*
> *want from life, then we must remember that the most well-meaning, helpful,*

sensitive and committed advisor will never be able to do the job of self-

determination as effectively as a well-prepared, well-trained self-advocate

(in Worrel, 1988, p. 13).

Strong attitudes about the capacity of people with intellectual disability expressed by some parents perpetuate a state of affairs in which people with intellectual disabilities are not empowered to define their own identity, but where outsiders tell their stories. These dynamics could be fatal to the development of positive adult identities, when considering Shakespeare's proposal of the concept of identity as narrative (1996). He argues that identity formation is an aspect of the stories we tell ourselves and others, and negative self-identities result from oppressive social relations. These parental attitudes, openly expressed in front of their adult son or daughter, exemplify how people with disabilities are socialised to think of themselves as inferior, and demonstrate one way that the dominant discourse portrays strong messages of difference and deficit to individuals with impairments. The same oppressive dynamics were reflected in one father's description of the tenants having a different understanding of the term "sleeping with each other." This perpetuates the stigma of people with intellectual disabilities being childlike and incompetent, depriving them of their sexuality (Shakespeare et al., 1996). The belief of some parents that they are "the voice of their children" can undermine the participation and self-advocacy of tenants.

Parents of children with disabilities are often valorised within education and healthcare as "experts on their child" (for example, De Geeter, Poppes and Vlaskamp, 2002; Solomon and Chung, 2012), but this can have negative repercussions when their child

grows up. Caregivers interviewed noted that parents often refuse to accept their advice, and can hinder independent skill development.

The literature suggests that dedicated care staff can potentially strengthen participation and self-advocacy in individuals with disabilities (McConkey and Collins, 2010). In our research, one support worker described challenges facing tenants in parent-initiated supported living residences regarding participation: "There are tenants who aren't used at all to it [making decisions] and who call their parent multiple times per day to get the confirmation that they make the right choice." She emphasised that having time and space to find one's own solutions is important, and mistakes are a learning opportunity.

This is consistent with self-advocates with intellectual and developmental disabilities who defined being supported to live in the community as follows:

> *We are supported to take risks, even if others don't approve. It is not a big deal when one of us makes a mistake. We get support to carry out a plan even when a provider does not agree with the decision being made. Service providers support us to get non-biased information when making decisions.* (Durbin-Westby, Ne'eman and Topper, et al., 2009: p. 9).

A person's dignity is an essential element of personalisation, as Turnbull (2014) states it is 'a consequence of how not only others regard but also, and more significantly, how they respond to the person' (p. 292). The dignity of risk presented here stands in direct contrast to parents' tendency to be overprotective.

A turn towards interdependence.

However, at what point is parental behavior overprotective, and when is it justified and necessary coaching? This query becomes even more complex considering the symbiotic bond that is typical of all parent-child relationships. A potential answer to the question involves revising the concept of independence. Our evidence supports Oliver's argument that:

> *...independence suggests that the individual needs no assistance whatever from anyone else and this fits nicely with the current political rhetoric which stresses competitive individualism. In reality, of course, no one in a modern industrial society is completely independent: we live in a state of mutual interdependence. The dependence of disabled people therefore, is not a feature which marks them out as different in kind from the rest of the population but different in degree.*
> (1990, p. 84)

Independence can also be defined as an infinitely variable self-concept, unique to the individual, which concerns control and choice rather than any (objective) absolute measure of competence (Oliver, 1990). Staff-parent and staff-resident relations can both be considered in the light of interdependence. As White et al. (2010) noted, however, this can require strengthening specific forms of support for disabled people, such as self-advocacy training and advocacy services.

From the specific perspective of the parent-child relationship, it can be argued that dependence/independence is a false dichotomy (Canarby, 1998). "Letting go of their child," as one mother phrased it during a gathering with members of other parent initiatives, cannot and should not be the goal, as guidance and help are non-static phenomena (Goodley, 1997). There will be moments when more support is required. Parents tell about relapses, when a tenant's care requirements had to be reconsidered until they felt better. These can occur suddenly and are hard to predict; thus, while care needs are fluid, care provision should always be underpinned by respect for personal autonomy.

There is a higher level of trust and communication between parents and staff in these initiatives than in traditional institutions, providing a stronger foundation for fostering interdependence. One initiative has directly addressed the problem of "letting go" through lectures for parents. Caregivers are ideally placed to help residents and parents manage the dynamics of interdependence, through parent education, self-advocacy training, and mediating control issues as they arise.

Reinterpreting independence embodies a critique of the Enlightenment concept of human rationality as an established opposite to emotion. Feminist theory proposes an alternative ethics of care, "which assumes relationships that are bound by mutual interdependence, and its practice involves the values of attentiveness, responsiveness, competence, and responsibility, negotiation and mutual recognition" (Parton, 2003: p. 11). Here, the moral agent is embedded in a concrete relationship with others, acquiring moral identity through interactive patterns of behavior, perceptions and interpretations.

Considering parents as moral agents, our research evidence indicates that requiring neutrality is unrealistic. Undoubtedly, the decisions parents make on behalf of the well-being of their (adult) child are greatly influenced by their love for them. The feminist ethics of care accommodates the significant role emotions play in resolving care issues.

The concept of interdependence is not only applicable on an individual level or within a collective residence, but translates to community integration and the construction of enabling environments (White, et al. op cit.). Goodley (2005) argues that social change and resilience can reside in the space between structure and individuality. It is not something that can be attributed to an individual alone, but is a product of the context in which it can emerge. Parent-initiated supported living schemes were seen to support personalisation in some ways, but not in others: understanding and addressing the tensions and context behind these decisions can help to support individual self-determination and direction over time, whilst acknowledging the reality of interdependence.

The consideration of people with disabilities' role as self-advocates also requires a deeper understanding of the limitations their impairments can create. Our data indicates that greatest dependence on staff or parents is experienced when dealing with financial or other bureaucratic affairs. Residents also pointed out that access to events or gatherings for people with intellectual or developmental disabilities may be restricted through language barriers, and noisiness or crowdedness. R. stated that his housemates with intellectual disabilities of a higher degree preferred not to come to an event

organised specifically for local disabled people, because they assumed the information presented would be not adapted to their capacities. Some parents also indicated that the family member with a disability suffers from noisiness or crowdedness when outside the home.

For supported-living projects, developing and nurturing spaces where personal development and efficacy can grow is crucial. This process must include addressing systemic, access and individual barriers.

CONCLUSION

The first part of this research focused on the ability of parent-initiated supported-living schemes to foster enhanced participation, choice and self-advocacy for people with intellectual or developmental disabilities. Findings are consistent with existing research on community-based living, which argues that small-scale housing schemes are usually more enabling environments than classic institutions.

Parent-initiated supported-living residences adhere to most of the UNCRPD guidelines, and provide evidence supporting ratification of the convention in the Netherlands. Restrictive characteristics in their structure and organisation exist, but are partially attributed to limited budgets available to clients, and constraints imposed by social housing corporations.

Evaluating the relationships between residents and their parents revealed some parent attitudes that potentially undermined residents' right to self-advocacy and impacted positive identity formation.

The second part of the paper queried how findings could be translated for use in the process of inclusive community building and belonging, including new conceptualisations of independence. Interweaving feminist theory on the ethics of care with arguments brought forward in the field of disability studies suggests valorising interdependence as a goal. This concept acknowledges that independence/dependence is not reflected in whether a person requires assistance, but by their level of control and choice (Oliver, 1990: p. 27): in other words, the extent to which support and care are personalised and self-directed.

Applying the concept of interdependence on a community level would mean that developing self-determination and self-advocacy skills is not enough to bring about social inclusion for people with intellectual or developmental disabilities. Instead, integration demands a cooperative effort involving the community, the individual, and the eradication of barriers.

The study's limitations were inherent in its methodology. Though preparations were made, communication was still an obstacle in several interviews due to participants' restricted verbal skills. For future research, stricter adherence to Hall's guidelines (2013), and potentially making use of images and photos, could facilitate

communication. The ability to interview residents without parental mediation before or during the interview could also have impacted both sample size and results.

Future research should also consider sustainability of parent-initiated supported living residences across the lifespan. Limitations were observed in their ability to accommodate significant lifespan changes, such as adult relationship formation and aging. Moreover, the question of who will take over the role of parents in running parent-initiated projects once they are too old to participate remains unresolved in most organisations.

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