

Summary

Just like home

Residential initiatives set up by parents for their children with disabilities

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Summary and discussion

S.1 Parent initiatives in this study

People with disabilities (physical, mental, psychological and/or sensory) who need help and support often prefer to live ‘as normally as possible’: on a small scale, in a normal residential area, where they have control over their own lives as much as possible (Voss et al. 2017). In order to achieve this, parents of young adults with disabilities sometimes take the initiative to set up and manage a form of accommodation for a small group. But which parents do that and for whom, and how do they fare in the longer term? The question is relevant because initiatives taken by members of the public fit well in with the ‘participation society’, but on the other hand there is the question of who succeeds and who does not.

In this qualitative study, we explore initiatives for small-scale housing that were set up by or on the initiative of parents with the goal of creating a home where their child can ‘live independently’, as an alternative to the parental home or a care institution.¹ It usually involves a small-scale housing situation where a group of residents who need care and/or support because of a disability live close together at one or several addresses. They purchase and organise their care and support together. The residents have their own apartments or rooms plus a communal space for group activities (cooking, social contacts, supervision). The care is often purchased wholly or partially collectively with a client-linked care budget (hereinafter also a ‘personal budget’), but there are also initiatives involving care given in kind. We refer to these as ‘parent initiatives’, meaning accommodation set up and managed by parents for their own children with disabilities. The broader term ‘residential initiatives’ also includes comparable small-scale accommodation formats with an ‘earnings model’, such as the Thomashuizen or housing set up by a healthcare business.² It is not always possible to make a clear distinction between parent initiatives and other residential initiatives.³

Small-scale housing fits in well with the governmental policy that people should be able to live at home as long as possible, with support from the social and care networks. Small-scale housing fits contemporary needs better than living in an institution (Dutch Parliament 2012/2013). It is unknown how many parent initiatives there currently are, but the number is estimated to be at least several hundred. It is a relatively small proportion of the number of disabled people who use intramural care.

A study on residential initiatives has been done before, but it dates from the time before the reforms in long-term care (cvz 2006; Dijk et al. 2011; MEE et al. 2014). In this study we are attempting to create an updated picture of parent initiatives, to gain more insights into the reasons why they were set up and what is needed if they are to continue. The emphasis is on the perspective of the parents/initiators, but we have also looked at other actors such as care providers and the interaction with them. The main question of this study is: What

are the key success factors for founding and a residential initiative and keeping it going, and how can these initiatives be supported?

5.2 Goal and description of the study

This qualitative, exploratory study was carried out in three phases. In the first phase we held explorative conversations with ten experts and advisors of parent initiatives (Appendix A, which can be found with this report on www.scp.nl). These were used to map out the field of work, giving us a picture of the professional network that offers support to these initiatives.

In the second phase of the study we spoke to twenty parents/representatives from various parent initiatives from across the country, in five groups of on average four participants. The conversations took place at the accommodation in order to get a picture of how it looks, a flavour of the atmosphere and an impression of the residents. We also interviewed several parents separately, including two married couples who were involved in a parent initiative, but have since withdrawn from it. We also spoke to a manager and a group supervisor of three care providers who offer care at such accommodation. We spoke to a total of 32 people in this phase. When selecting these people, we tried to create a broad image of the range of parent initiatives in the Netherlands and of the various opinions and insights of the parents and caregivers involved. The study is not suitable for making statements about the numbers and ratios in which various effects occur.

We also wanted to include the perspectives of other actors besides parents and caregivers, so in the third and final phase we held an expert meeting with experts from various disciplines and sectors who are involved in parent initiatives, such as the care administration office, municipality, care provider, housing cooperative, interest group and parent initiatives (see Appendix A). We discussed the general preliminary outcomes with them for verification and to find out their ideas about the perceived bottlenecks and possible solutions that parent initiatives could use. We used the observations from this meeting to check the report for factual inaccuracies and to refine the discussion further.

5.3 Why set up a parent initiative: who does that and for whom?

The first research question we answer is why parents themselves set up accommodation for their disabled children: what is the added value, who are the people behind it and who are the residents?

Reasons for setting up an initiative

Wanting to keep control over what happens to their child is the primary factor for almost all parents when it comes to the reasons for setting up accommodation under their own management. Additionally, they often mention the long waiting times for the most ideal place at a care institution, or the lack of any such ideal place. They think something is missing in the existing offerings, which mainly seems to be about control of care, a homely

atmosphere and mutual involvement of care providers, residents, parents and other family. Parents think that the children can get better care at a parent initiative because they have more influence there. Some have negative experiences with care institutions and are afraid that their child will become lonely and isolated from society. The need for more control is also about insights into the costs of care: people want to see whether their child is getting the care they need and what it costs.

For residents with mental or multiple disabilities – severe ones in particular – the parent initiative is usually an alternative to a care institution or similar form of accommodation. For people with milder disabilities, such as autism or psychiatric conditions and at most a mild intellectual disability, there are often few alternatives. Many parents say that independent living with supervision would not be feasible for their children: the risk of isolation, neglect and eventual homelessness is high. For some, a regional institute for sheltered living (Dutch: *riBW*) seems to be an alternative, but parents think that such an environment is too unsettled for their children, because there are also residents with various problems (such as addictions or ‘problem behaviour’). Parents think that without parent initiatives, residents with mild disabilities would often still live with their parents.

The added value of a parent initiative

Many parents are certain that the quality of life for the residents at a parent initiative is better than it would have been at a care institution. The involvement of the family is more guaranteed, because it is inevitable at a parent initiative that is managed by the parents or other family members. They are closely involved in the care and try to give the residence a homely atmosphere. At many parent initiatives, parents or other family members are also active in the board or working groups, or in activities and maintenance. Parents also believe that more is achieved with their children than in a care institution: the residents’ independence is challenged and participation in society is more obvious. However, there is no hard data comparing quality of life or quality of care and the degree of participation between residents of parent initiatives and institutions.

Supervisors and managers at care providers do not clearly state that the quality of care is better at a parent initiative, but acknowledge that the care is different, more ‘tailored’ and personalised, and often given by a permanent team. Parents and residents often experience this as better quality. The intensive cooperation with parents does require a supervisor to have specific skills. Supervisors choose this deliberately.

Certain skills are needed for setting up an initiative

Studies into initiatives from the general public do show that people must have certain competences and resources to be able to set up an initiative. This was also confirmed by this study. The parents we spoke to from parent initiatives often had a range of useful knowledge and experience: people from the commercial sector, healthcare, the financial world, the construction industry or with legal knowledge. The driving forces behind the initiatives are often people with a higher level of education, advisers also confirm. Various respondents emphasise, however, that the parents have not exclusively had a high

level of education. The groups often consist of a mix of parents, where it is not only about knowledge, but also about skills and contacts. One person may be good with paperwork, another is good at carpentry, and the next has a large network and is a good communicator. The whole is greater than the sum of its parts.

However, those involved in parent initiatives do notice that there are few initiatives that have been set up by and for people with migrant backgrounds. Initiatives with a mix of different backgrounds are also rare. Some people thought that people from non-Western backgrounds were less interested in letting their disabled children live 'independently' at a parent initiative. There is a belief that they keep them at home more often and see care as a family duty.

Most parents are deeply involved and have a good relationship with their child, but that is not always the case according to the interviewees. Sometimes there are residents with parents (or other family) who are unable to represent the child. Sometimes the parents' board has admitted someone because the board thinks they deserve it, or because they belong to the group. The parents then (together with the curator or mentor of the resident) ensure that the interests of the residents are looked after.

Parent initiatives for various target groups

Conversations with the people behind parent initiatives showed that they often already knew each other from their children's school or day activities. They had a collective wish to keep the children together, because they form a 'good group'. They want them to 'grow old together'. Others find each other when they are looking for a residential place for their child. They come into contact at information meetings about housing or through call-ups from an interest group.

In broad lines we saw two types of parent initiatives: initiatives for children with an intellectual disability, some of whom also have physical disabilities or chronic conditions, and initiatives for young people and adults with a form of autism and normal or high intelligence, or with psychiatric disorders, such as susceptibility to psychoses. The first group need permanent and long-term care or supervision (24-hour facilities) and usually get it from the care administration office set up for the Long-Term Care Act (Wlz). The second group rely on support from municipalities under the Social Support Act 2015 (Wmo 2015). This is usually about forms of residential or other supervision and the care is often not continually present. Residents can, however, benefit from each other's company and communal activities such as cooking. The groups containing people with a mental disability or multiple disabilities are often stable, but have residents of about the same age relatively often and are usually intended for growing old together. Some initiatives for residents with mental health problems or autism are focused on residential training; some of the residents then move on to living independently.

Residents with severe behavioural or social problems are only rarely considered for a parent initiative, according to those involved. Residents have to be able to function in a group and must have a strong network (good contacts with the parents). There is less need for parent initiatives or other small-scale residential formats for people with a very great

care requirement who are entirely dependent on others (e.g. bedridden, barely able to communicate). They benefit more from the safe and protected environment in a care institution (although parents then still feel the need to have a degree of control).

Relatively large differences in level between the residents

The groups often have roughly the same kinds of care requirements at the beginning, but in practice there is a wider variation in their conditions and care requirements than in a regular institution. This is because there are more options at a care institution for mixing and matching the residents according to the type and level of care needed, and because the institution can decide which ward or department they fit best. In a parent initiative, residents are not transferred and they do not in principle have to move if the care has to be modified. The care requirements of residents in a parent initiative can diverge greatly over the course of time, because the residents often go to live there at a young age and are still developing. The residents of a parent initiative do all have some degree of independence, although there are also initiatives where severely and multiply handicapped people live. In some groups, the residents are all much the same age, particularly in groups who choose to 'grow old together', although there are also groups that deliberately choose a variety of ages because that makes it easier when bringing new residents in. Differences in age do not have to be a problem, particularly for people with intellectual disabilities.

5.4 Beneficial and inhibiting factors

The second research question is about the beneficial and inhibiting factors that play a role in setting up and managing a parent initiative. The starting point – the foundation of it all – is generally the group plus a shared vision. The other 'building blocks' are a suitable legal entity, appropriate accommodation, the right indications and care, sufficient funding and good external contacts. All these points have to be considered at an early stage, although a number of them – in particular the indications and the funding – require ongoing attention. The component that is worked out in detail first depends on the opportunities, such as a housing cooperative that is willing to work with them or a subsidy that can be used. A concrete plan increases the likelihood of cooperation from other parties, such as a housing cooperative or municipality.

Solid foundations let the group survive setbacks

The group have to be able to get along with each other: that's what makes a parent initiative work. It is important to have a strong group with a shared vision of the residential format. Many groups bring in a coach or adviser to guide them in this. The group's configuration also needs ongoing attention once the initiative has been set up, according to the advisers. In some groups the parents have difficulty keeping everyone involved. Working groups in which parents discuss a specific subject or carry out a specific task can help this. Coaching or mediation may be needed to keep the group together or to resolve conflicts between parents.

As well as the group of parents, there must be a good match in the group of residents. They do not necessarily have to have the same care requirements, but there must be a click and they must not have a negative influence on each other. You often only know whether the group of residents is a success once the parent initiative has started. Many groups change one or two of the residents early on who turn out not to fit in well after all. Some groups have a stated objective of getting the residents to move on to independent living. An empty space can sometimes be awkward to fill because not only the resident but also their parents or representatives must fit in with the initiative. Some initiatives use waiting lists and do not have much difficulty filling an empty space.

Suitable accommodation is the basis

A key success factor is finding suitable premises or a group of apartments together. These are often rented from a housing corporation, but rental from a commercial party is sometimes also used. The lessor generally wants the accommodation to be re-convertible, so that it can later be used for others again. Very occasionally, parents buy premises, but that becomes difficult if the resident wants to relocate. There are some regions where it is not very difficult to bring these building blocks together. It is possible to find an old school, care centre or newly built location that can be modified to suit the requirements. It is often difficult to find accommodation for a group in larger cities, however; housing in the social rental sector is scarce there.

The legal structure affects the involvement of parents

A legal entity has to be set up for a parent initiative. In some cases it will be a foundation, in others a cooperative or other association. In the case of a foundation, there will be a board that can take decisions in the name of the parents and residents. This is only possible in an association if all the members have been consulted. This means that a foundation is often more effective. The advantage of an association, on the other hand, is that the parents (or other representatives of the residents) remain involved, look for consensus and retain control. What can happen in a foundation is that a small number of parents in the board take on a role as the 'boss' and may then for instance deem the interests of the group subordinate to those of their own child. For that reason, some parent initiatives have chosen to have independent governance. Some parent initiatives have both a foundation (for aspects such as rental agreements and contracts with the care provider) and an association (for example for the vision or for housekeeping rules). The involvement of parents or other family members is defined in a contract in many parent initiatives. There are examples where the lack of involvement by the parents became the reason for getting a resident to leave the group.

Care that you have a say in

Appropriate indications for care and a care provider that offers care that fits the tastes of the residents and parents are important ingredients for a parent initiative to be successful. These could be indications under the Long-Term Care Act that have been determined by

the Care Needs Assessment Centre (CIZ) and implemented by the care administration office, or indications under the Social Support Act that are determined and implemented by the municipality. Where there is a personal budget, for indications under both the Long-Term Care Act and the Social Support Act, this is administered by the Social Insurance Bank (SVB). The way in which parent initiatives organise the care varies widely. In a parent initiative, the parents generally use their personal budgets to buy the basic care (such as night-time services, 24-hour availability service) collectively via the foundation, and other care depending on the individual needs. Occasionally the board of a parent initiative is the employer, or each resident hires in a care provider themselves and they only live collectively. There are also some parent initiatives that receive care in kind from a care provider. With a personal budget, parents aim to maintain full control of care. There seems to be less control with care in kind, although full transparency about their finances and the content of care can still be possible.

It is essential that parents are in full control of the care. If they do not like a supervisor, or the care provider does not do what the parents ask, the parents can generally cancel the contract and hire someone else. Various parent initiatives have switched care provider, because another provider offers more hours of care for the same amount. On some occasions, the reason given for a switch was that the care provider said that the group had to be expanded to be able to work efficiently. The parents' key priority is the residents.

Funding for the accommodation is often tight

Starting capital can be indispensable when setting up an initiative. A number of parents of parent initiatives that have been in existence for at least ten years, said that they felt encouraged by the government to set up a residential format themselves at that time. One of the reasons was the introduction of the personal budget. The government-subsidised Dutch Foundation for the Disabled Child (NSGK) also made start-up grants available. Some municipalities also offer a monetary amount if parents present a good plan. To keep the parent initiative financially feasible, the group needs to have enough financial resources for expenses, care, rental of the housing and the communal area, furnishing, any automation and its maintenance, and communal activities. Most residents have a minimum income, often a 'Wajong' benefit – i.e. under the Invalidity Insurance (Young Disabled Persons) Act – and are eligible for rent allowance and care allowance. Usually their entire income is spent on the costs of the house and living expenses and there are little to no reserves. Parents said that the budgets for care from not only the Social Support Act but also the Long-Term Care Act have been badly eroded.

The residents are dependent on their indication for the funding of the care. Receiving care is often a condition for being allowed to live at the initiative. A resident who no longer has an indication can have negative consequences for the collective budget. Residents who live in residential initiatives (including those of a care business) with a long-term care indication and a personal budget can qualify for a residential initiative benefit of about €4000 a year on top of their indication for care. They can use this sum for purchasing care and 'care

infrastructure'. This could for example be automation or fire safety and other items needed for providing care.⁴

Residents with a Wmo (Social Support Act) indication have been dependent on their municipalities since January 2015. The municipality can decide whether or not to grant a residential initiative benefit. Many municipalities link this to their personal budget policy. Some Wmo-financed parent initiatives have had financial difficulties since the transition to the Wmo 2015, especially if they no longer receive residential initiative benefits. One way of bringing in enough money to maintain the communal space is by renting it out as a meeting location or organising daytime activities that others can also participate in. Money from donations from funds, for example, is often used for the communal costs. Additionally, parents often help out by paying contributions to the association. Parents spent a lot of time looking for forms of funding.

External contacts also require investing

It is also essential for parent initiatives to maintain contact with external parties such as municipalities, corporations and care administration offices, as well as funds and the neighbourhood. It is important to keep good contacts with all of these. This sometimes yields money, and at least results in goodwill. A number of parents point out that external parties such as the municipality or the care administration office do not pay enough attention to the voluntary efforts parents. What parents are doing unpaid here is done at a care institution by managers and passed on as overheads. That is why a parent initiative is relatively cheap for the quality offered, parents believe.

In some regions, parent initiatives also maintain contact with each other, give each other advice and represent their interests at the local authorities together. Sometimes there is an adviser (occasionally facilitated by a municipality) who supports groups and brings them together, but groups sometimes arrange the contact themselves.

5.5 Threats to parent initiatives

The future sustainability of parent initiatives is key in the third research question. What threats do parent initiatives see and how do parents deal with them? The third chapter of the report reveals that changes in policy can result in financial problems for parent initiatives. Parents are also afraid that the personal budget will cease to exist. There are also issues that concern the dynamic of the parent initiative: how do you grow old together and who succeeds the parents when they are no longer there?

Cutbacks have put parent initiatives under pressure

One of the largest threats for the near future that parents mention is that the funding may become insufficient to continue the initiative. The main reason for concerns about financial problems is that less severe indications are being issued than before. These concerns are especially relevant for initiatives that fall under the Wmo. Many municipalities have already lowered the rates for personal budget care or have done away with the residential

initiative benefit that residents received under the Exceptional Medical Expenses Act (AWBZ). The indications that municipalities give are often short-term, for a year or sometimes two. That creates a lot of financial uncertainty and makes it difficult for groups to make plans for the longer term. A reassessment is often a source of stress for residents and their parents and can even lead to a crisis for a resident. This may hinder the goal of increasing self-reliance.

The rates for residents with a personal budget under the Long-Term Care Act have also been decreased. Those who already had a personal budget and were living in a residential initiative in 2012 have a budget guarantee, but there are lower rates for new indications (a criterion that mostly covers new residents). The initiatives financed by the Long-Term Care Act see the residential initiative benefit disappearing as a possible threat. There is uncertainty in the field about what it should and what it should not be used to pay for now, such as the rent for the communal area. This also creates financial worries for the parents. In addition to shrinking budgets for care and care infrastructure (including the communal areas), parents are seeing a decrease in the spending limit for the daily living expenses for their children. Many do not manage to get or keep proper paid jobs and are in danger of getting their benefits cut. Rents are going up and benefit levels are being eroded. Some parents also note that their children cannot profit from any parental gift or potential inheritance, because they would then have to pay a higher personal contribution for their care and the rent allowance would stop.

Acquiring funds or renting out the communal area is one way to supplement the financial deficits, but this is not always possible. A number of parent initiatives are wondering whether they will still exist in a few years' time.

Fear of client-linked care budgets disappearing

Another concern for the future that is almost unanimously mentioned by parents is the fear that the personal budget will disappear. For parents and residents, the personal budget means that they can keep control of the care provider. Parents are uncertain about what can and cannot be paid from the personal budget and residential initiative benefit. The Social Insurance Bank (svb), the care administration office and municipalities often do not seem to understand what a parent initiative is and what distinguishes it from a residential initiative run by a business. The collective aspect of a parent initiative does not suit the individual character of the personal budgets. The budget holders and their representatives are also suffering from reputation damage because of cases of fraud linked to personal budgets. Municipalities in particular are often reluctant to grant a personal budget. Some parent initiatives have chosen for care in kind, but this also makes them more dependent on the care administration office or the municipality, which has the contracts with the care providers. Others make the case for the option of creating a different, modified type of care budget, where they can collectively purchase care and maintain control of it.

Loss of control

Parents fear becoming more and more bound by all kinds of rules and e.g. quality requirements, bringing higher costs and forcing them to 'professionalise' further. Such requirements are insufficiently tailored to parent initiatives, they say. This gives them more work to do, which sometimes becomes too much for them. They are afraid that they will no longer be able to stay in control themselves and will be forced to receive care in kind. There is then a risk that the care provider ends up in charge of the residential format. Municipalities can also restrict parents' control over who does and does not get to live at the initiative, because they influence who gets or does not get an indication for care. Every parent initiative tries to maintain control in its own way.

Growing old together – how can you arrange that?

One problem that all parent initiatives face sooner or later is that the group gets older. In particular, groups that have chosen to grow old together face an issue when members of the group die. One resident fewer means there is a vacancy and less budget for the care. It can be difficult for a new resident to join a group that has already existed for a long time. The increasing requirement for care also worries some parents. People with Down's syndrome for instance run a greater risk of developing Alzheimer's early. Will it then remain possible for them to live in a parent initiative? Some do not yet know how they will handle these issues, but there are also groups that have chosen to relocate to a place that is more suited to the age and requirements of the residents.

Who will take on the mantle?

When the parents become too old to continue the initiative and represent the interests of their child, someone else has to do it. It is then not merely about purchasing care with a personal budget and managing the finances, but also about agreeing substantive matters with the care team and administering the initiative's organisation. A parent often has more drive than a brother or sister or other family member, or an externally appointed administrator or mentor.

There are some groups where experience is being acquired with brothers and sisters in the management. Other parent initiatives have a working group that examines these kinds of issues. Others wait to see how it progresses; they're pleased that their parent initiative has come into being after many years of effort. Some parents say that they assume that a care institution will ultimately take over.

5.6 Parent initiatives' requirements

In broad terms, we can say that what parents want from their initiatives is to retain as much control as possible over what happens to their child, but one of the potential consequences of financial problems, discontinuation of personal budgets and changes to the rules is that a parent initiative as a residential format under their own control no longer remains possible. What do parent initiatives require if they are to continue to exist?

Parents want certainty

It is important for parent initiatives to know where they stand. They would like more clarity for the longer term: how big a budget they have for care is and what requirements they must fulfil. Rapid changes in the rules and finances make it extremely difficult for parents, costing them a lot of time (and they often have a job) and creating worries. They would like to find a status quo to let them plan calmly for the longer term.

A stronger position for parent initiatives

Over recent years, the general public has been encouraged to take more responsibility itself, for instance for care. Taking the initiative yourself fits in well with this approach. It also requires members of the public to be able to continue running things so that their initiatives can be designed and maintained. This can generate tensions between the public and the government: what is allowed, how are members of the public supported and how much financial scope do members of the public get from the authorities for instance for setting up a parent initiative? There can also be tensions between initiatives and 'market parties' such as care providers and housing corporations. To what extent can parents choose how and where their children are cared for and where they live? For the authorities and the market parties, these initiatives are relatively small players. Their position with respect to the authorities and the care providers is therefore vulnerable. There are some regions where parent initiatives are bundling forces in order to reinforce their position with respect to e.g. municipalities or care administration offices.

Representation of interests

It is awkward for parents and small initiatives to represent their interests: they are volunteers who often do the administration in addition to a paid job and other activities. On top of that, every initiative seems to have its own ideas, needs and challenges. There are sector organisations that parent initiatives can turn to for representation of their interests and knowledge exchange. However, representation of their interests seems to be fragmented. There are two national associations of personal budget holders, with a proportion of the parent initiatives affiliated to each. These associations function nationwide, but are often less useful regionally because every municipality has its own contacts and its own policy. That demands support staff who know the local situation. There are some regions that have advisors who know the parties in the fields such as the municipalities, housing corporations and care providers, and who can advise and support the parent initiatives. There is currently no network with nationwide coverage of organisations in which parent initiatives can receive a proportionate degree of local support.

5.7 Discussion

Now that we have a picture of the people who set up parent initiatives, who live in them and what the success factors and threats are, we can take a moment to think about what this can mean for policy, for instance. The research basically reveals four key themes in the

discussion about parent initiatives: 1) parent initiatives as an alternative to the existing offerings, 2) the accessibility of parent initiatives, 3) how future-proof they are, and 4) sharing knowledge.

Parent initiatives as an alternative to the existing offerings

The results of this study show that parent initiatives are in addition to what care institutions have on offer. What parents and residents are looking for – as big a say as possible over the day-to-day living and about who lives where and with whom – is also enshrined in the UN treaty for the human rights of those with disabilities, which also applies in the Netherlands since 2016. In the eyes of the parents we have spoken to, it would seem that institutions do not offer that to a sufficient degree. There are no hard facts about differences in care quality and the quality of life between parent initiatives and care institutions, but this could be a topic of research that could benefit both the institutions and the parent initiatives. This would allow the opinions of residents about the care provided and their quality of life to be taken into account as much as possible.

There will always be parents who choose an institution, or a residential format provided by a care business. It is even possible that some of the parents from parent initiatives would also prefer to do that if what they are trying to find for their children was also available (to a sufficient extent) in regular care. By no means all parents are willing or capable of taking on such a severe burden of organisational matters as that involved in parent initiatives. Care institutions also see the need for people to be more in control and for the use of social networks. Using these aspects is also an objective of both the Long-Term Care Act and the Social Support Act (Dutch Parliament, 2012/2013). Demand for places in institutions is decreasing and care institutions see the need growing for small-scale living with scope for their own control. It can be difficult for existing organisations to change their culture. It demands other skills from the supervisors. Regulations can also make organisational changes difficult. You can't simply hire out a ward to clients, for instance: there are too many nitty-gritty considerations. Letting people take control in the care sector can be implemented in numerous ways. There are for instance models in which the initiative and the control remain primarily with the residents or their parents, but there are also forms in which the care institution creates and manages the residential format, and everything in between as a cooperative or co-creation with the residents and their families. Perhaps care institutions and municipalities can also 'learn' from parent initiatives, whose idiosyncratic nature means they can act as 'testbeds' for innovation in care.

The unique nature of a parent initiative is also reflected in the informal atmosphere. More things are possible and there is more spontaneity – as we saw in Section 2.4. However, parent initiatives are seeing that there is more and more that they have to cope with, forcing them to 'professionalise'. There is little discussion about the usefulness of fire safety requirements, for instance, but there are other quality requirements where parents do wonder whether it is necessary to demand that parent initiatives keep close control. A parent initiative does not want to be a care institution; the residents want to live as normally as possible. And you can do what you want inside your own home. A parent initiative

that is the employer of the carers, for example, is deemed to be a small-scale care provider and therefore has to deal with rules about medication safety and compulsion and coercion. This costs parents so much time that they hire in a ‘manager’. That creates an ‘overhead’, which is exactly what parents do not want.

Accessibility for a broad group?

Research has shown that there is a degree of selection in the type of parent and resident taking part in parent initiatives. Residents must be able to live in a group and get on with others. And at least some of the parents must have skills such as being able to network well, and possess legal knowledge and financial insights. There will always be a split between parents who do have the capacity to take action for setting up an initiative and those who do not (Scientific Council for Government Policy, 2017). Whether that is a bad thing is open to question. Some of the population will prefer it if care is arranged for them. It seems above all to be an issue if there is an echelon of people at the top who get a better quality of care more easily thanks to the skills or resources they have available. The backing for initiatives from the general public then fades (Putters 2017).

Ideally, people who are not selected for a parent initiative or do not have the capacity to settle themselves, should be just as able to choose where and with whom they live and how that care is arranged. Institutions must continue to offer something for this. People who are less capable of organising things for themselves may benefit from an umbrella organisation or a care institution that brings parents together and gets down to brass tacks with them. But if the initiative is with a care institution, there is a question of whether the parents will be in full control. A housing corporation will be perfectly happy if a group of parents knocks on the door arm in arm with a care provider; that offers more guarantees in the longer term, meaning that a housing corporation will be more ready to invest in an initiative.

Support can help parents make a parent initiative more accessible, for instance in a form of independent client support for groups of parents. Such support is only available at the moment for individual clients. In some regions parent initiative advisers (generally volunteers) work to help groups realise their plans, but other regions do not have anyone in this role. Before the reforms of long-term care, more support seemed to be available in particular through MEE, an organisation providing support for people with disabilities.

Future-proofing

The idea is that people should be able to live independently as long as possible, assisted by their social network. Parent initiatives fit in well with this, though they do see this policy resulting in threats for their own futures. The coalition agreement of the Rutte III cabinet states that municipalities will be further “encouraged to make agreements with housing corporations about sufficient and appropriate accommodation, paying particular attention to small-scale and innovative residential initiatives and the onward flow from them” (vvd et al. 2017: 16). It remains to be seen what that attention will involve in practice.

The financial problems that a large number of parent initiatives see looming up before them are the most urgent threat to their continued existence. This is particularly true for residential forms funded by the Social Support Act. For the majority of residents, discontinuing their residential format would mean either moving in with their parents or having to move to a care institution. Better understanding and insights into what a parent initiative yields in the sense of avoiding crisis admissions among e.g. mental health institution residence, participation and quality of life compared to the traditional offerings would help municipalities and their policy of also providing financial support for parent initiatives. That could be a subject for a further study.

We picked up signals from parents and advisers that some municipalities are discouraging residential initiatives funded by personal budgets because they put pressure on the budget that they could use for tendering and because parent initiatives to attract residents from other municipalities, which can be unattractive for a municipality. Many parents say that the receding support for personal budgets poses a threat to the future of their parent initiative. Many parents see these client-linked care budgets as the best way of retaining control themselves. That doesn't mean that parents themselves must have contacts with the care administration office and the Social Insurance Bank about purchasing the care. The study revealed that these contacts do not always go smoothly. Some parents had problems with the care administration office for instance about spending the residential initiative allowance, which they use for renting their communal space. The discussion that was held at the expert meeting between care administration offices, parents and the interest groups of personal budget holders made clear that there are elements of the law that are unclear, for example about what a 'pure' residential initiative is according to the authorities (see Chapter 1) and what may and may not be paid for using the residential initiative allowance (an addition applied to the personal budget).⁵ This is why it is not clear whether the rent for the communal area may be paid from that allowance or not. It is also not always clear which rules initiatives do and do not have to stick to. The individual aspect of a personal budget does not suit the collective character of a parent initiative. Alternative formats such as e.g. a collective personal budget could perhaps provide a solution for groups that want to purchase care jointly.

A problem that the care administration offices also run up against is that there are care businesses that encourage their residents to request a personal budget for a single function (e.g. supervision) so that the residential initiative allowance can be demanded and create scope for care for another function via care in kind. Essentially this means that they get the overhead costs of communal care paid double. This makes the care administration offices distrustful. That feeling is also nourished by a number of cases of fraud or poor performance that have also been publicised in the media. There are for example care businesses that do not appear to expend all personal budget income on care, or that force residents to relocate if they do not agree with the care. Parent initiatives with good intentions are suffering as a result. This is an argument why constructions with parent initiatives or residential initiatives under their own control and management should be divorced from residential initiatives run by care businesses. A specific 'policy on residential initiatives'

could perhaps create a great deal of clarity (for municipalities and care administration offices as well) regarding the forms they can take and appropriate rules for them. On the other hand, too many rules can also have an inhibitory effect and parent initiatives do need a certain amount of negotiating room.

Parent initiatives also often struggle to retain control. Parents feel that they always have to watch out that their control does not get eroded and they feel threatened by the care provider, the care administration office, the municipality, regulations and the financial position of the residents. The interest group Per Saldo is currently developing an 'own control yardstick' to make clear for parents and residents how much of a say they have (or have still retained).

Knowledge sharing and support

We do not yet know very well what happens when parents are no longer capable of managing the residential format and others take it over (brothers or sisters, other family members or a volunteer mentor). Many parent initiatives are considering this question of already acquiring experience with brothers and sisters in the management. There are also ideas about a 'care will' in which parents can state what should be done to care for their child once they are no longer there. Exchanging knowledge and experiences can help parent initiatives set their policy for this. It also happens in practice, for example at residential initiative days that are organised by various organisations and at a range of locations throughout the country.

One key condition for a parent initiative to continue to exist is that the parents must also stay on good terms with each other. That does not generally happen spontaneously. It could perhaps help if payments for support by a coach or mediator could be made from the residential initiative allowance. As regards knowledge about parent initiatives, there is a great deal of information and support available. Per Saldo and Naar-Keuze offer their members assistance nationwide and act jointly in representing the interests of parents with the Ministry of Health, Welfare and Sport (vws) and the care administration offices. Because many parent initiatives have been affected by municipal policy since the Social Support Act of 2015, representation of interests at the national level is no longer sufficient. The study did show that more parent initiatives are formed in areas where the representation of interests and advice for parent initiatives are organised locally. A clear point of advice for parent initiatives thus goes hand in hand with better accessibility for parents and their children for being able to live 'just like at home' and retain control.

Parent initiatives can also support each other. People have for instance been thinking and experimenting with exchanging board members: parents from one initiative take a seat in the board of another and help them set up the residential format or the administration. Groups who go to a municipality with their plans can perhaps also be encouraged to do this, or can help found a regional cooperative for parent initiatives.

Municipalities, care administration office staff and the Social Insurance Bank (svb) often lack knowledge about parent initiatives as a residential option. Parents need a special 'residential initiatives desk' at the svb and the care administration office where such

knowledge is available. This could help improve contacts between the parents in a parent initiative and the municipalities, care administration offices and the svb.

The parents in this study have indicated that they are prepared to invest a great deal in the initiatives, but they are unable to run them without the cooperation of municipalities, care administration offices and housing corporations. More knowledge of parent initiatives and clearer standpoints adopted by these parties would help alleviate the uncertainty that many parent initiatives live with.

Notes

- 1 There are also residential initiatives set up by and for parents (or their children) or by people with disabilities themselves. Those are not included in this exploratory study.
- 2 Thomashuizen is a Dutch franchise organisation for small-scale housing.
- 3 This is because some parent initiatives were started by parents but are now managed by a business or care institution, or are run in collaboration with them. Such initiatives have not been excluded from this study as long as the initiative came from the parents.
- 4 For care in kind, an amount for care infrastructure is already included in the fee.
- 5 The way the residential initiative allowance is spent is detailed in the list of remunerations that is drawn up by the care administration offices.