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Special Issue: Disability and Family Care in Modern European History

JMEH

Journal of Modern European History
1–16


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From Institutions to Families? The Changing Allocation of Responsibility for Cognitively Disabled Children in Dutch Postwar Long-Term Care Policies

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Abstract

Who is responsible for health care? Neoliberal policies since the 1970s seem to place this responsibility increasingly on the individual, in a process that is called responsibilization. The recent literature on neoliberalism, however, has questioned the preference of free-market liberalism for individual responsibility and shows how neoliberals often made common cause with communitarian conservatives on social policies. Melinda Cooper, for instance, has argued in her book *Family Values* that free-market liberals and social conservatives in the US both identified the family as a 'wholesale alternative to the 20-century welfare state'. This article investigates whether this coalition of neoliberals and social conservatives, who agree on the importance of familial solidarity in addition to market freedom, has also played a role in the making of Dutch health care policies. By tracing how responsibility for long-term care has been allocated in the postwar Netherlands in the specific case of children with (cognitive) disabilities, the author will show how 'the family' has increasingly been embraced by policymakers as the main responsible party. This is remarkable because the Dutch postwar welfare state sought to loosen family ties in favour of individual arrangements. However, attempts by different stakeholders to deinstitutionalize Dutch health care during the 1990s unintentionally moved the state's responsibility for long-term care not so much onto individuals as onto families.

Keywords

Disability, long-term care, family, welfare state

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Who is responsible for the long-term care of disabled children? Throughout history, people have often answered this question with 'the family', and in particular with 'the mother'. In the modern era, however, this answer is no longer self-evident, as welfare states and specialized institutions have increasingly taken a role in caring for disabled children. Moreover, feminists have questioned the gendered division of care, and with it the dominant role of mothers in the care of disabled children. In the Netherlands, specialized institutions have played an important role in disability policies since the 19th century, when residential institutions began to take care of children with sensory, physical and cognitive disabilities, although families remained important too. After World War II, the Dutch welfare state started to play a more important role in disabled children's lives. This role was not always visible because care was often provided by families and institutions. However, since the 1960s and 1970s the Dutch state has become central in the regulation of long-term care.[1]

In comparison with other European countries, the Dutch welfare state was built up relatively late and quickly.[2] During the long 1960s, the Dutch created a system of welfare provisions that, as historian Denny Oude Nijhuis recently stated, 'by most standards belonged to the most equitable and solidaristic in the world'.[3] When it comes to the austerity policies that have shaped European welfare states since the 1970s, the Dutch case seems part of a more general trend, but until recently scholars tended to see Dutch austerity policies as modest compared to those of other countries, and have considered neoliberalism to be a non-Dutch, Anglo-American ideology. New research on Dutch neoliberals has contested these assumptions, however. If we understand neoliberalism as a political ideology in which the state must actively guarantee the maintenance of the free market, we can discern the influence of neoliberals in the Netherlands throughout the whole postwar period.[4] Margo Trappenburg, for instance, has reinterpreted Dutch health care policies by using Melinda Cooper's book *Family Values*, which explores the entanglement between neoliberals and social conservatives, as a heuristic device to investigate the relation between neoliberalism and social conservatism in the Dutch context. She argues that during the 1990s, 'neoliberal discourse was combined with conservative elements' by health care policymakers.[5] In line with Cooper, Trappenburg has made it clear that we have to be careful when framing neoliberal policies as placing responsibility on the individual, a process that is called responsibilization. She questions the preference of free-market liberalism for individual responsibility, and shows how Dutch neoliberals often made common cause with communitarian conservatives on social policies by making families responsible for social care – despite propagating clichés about individualized societies.

In this article, I want to contribute to the literature about the Dutch welfare state by tracing how responsibility for the long-term care of cognitively disabled children was allocated by health care

1. P. van Trigt, *Blind in een gidsland. Over de bejegening van mensen met een visuele beperking in de Nederlandse verzorgingsmaatschappij, 1920-1990*, Hilversum 2013.
2. A. de Swaan, *Zorg en staat. Welzijn, onderwijs en gezondheidszorg in Europa en de Verenigde Staten in de nieuwe tijd*, Amsterdam 2004; K. van Kersbergen, 'Religion and the Welfare State in the Netherlands', in: idem / Ph. Manow (eds.), *Religion, Class Coalitions and Welfare States*, New York 2009, 119–145.
3. D. Oude Nijhuis, 'The Puzzle of Dutch Welfare Solidarity and the Politics of Old Age Pension Reform (1945-1975)', in: *BMGN - Low Countries Historical Review* 136 (2021) 4, 58–80.
4. B. Mellink / M. Oudenampsen, *Neoliberalisme. Een Nederlandse geschiedenis*, Amsterdam 2022, 7–17.
5. M. Trappenburg, 'Hoe Elco Brinkman alsnog zijn zin kreeg: neoliberalisme, communitarisme en linkse idealen in de Nederlandse gezondheidszorg', in: *Sociologie* 15 (2019) 3, 289–307. See also M. Cooper, *Family Values. Between Neoliberalism and the New Social Conservatism*, New York 2017; L. Stokes, 'The "Market-Conforming" Family: Foreign Families, the 'Grandmother Solution' and the West German Welfare State', in: *Contemporary European History* 32 (2023) 2, 221–234.

policymakers from World War II until the early 2000s.[6] The emphasis of this paper is on responsibility for long-term, daily care which does not include (special) education, although some institutions did combine education and daily care. By addressing how this allocation was perceived and co-designed by parents of children with cognitive disabilities, I will also deliver a contribution to the field of disability history, in which parents (and parents' organizations) are increasingly being investigated as relevant actors.[7] Based on existing literature and new research on public debates, I will argue that responsibility for the long-term care of cognitively disabled children was allocated to state-subsidized institutions during the first decades after the World War. Thanks to parents' organizations, this form of care was enriched with small-scale institutions that mimicked family life. From the 1970s, parents increasingly tried to raise their disabled children at home, but due to economic crises and the existence of institutionalized care, it was hard to obtain financial support for this. If parents did not want institutionalized care, they were (financially) responsible for providing it themselves. This changed during the 1990s and 2000s, when a personal assistance budget was introduced in the Dutch long-term care system. As a result, long-term care was no longer the sole domain of institutions, as parents could use the personal assistance budget to organize care themselves. However, as we will see, providing citizens with public money proved difficult for a neoliberal government.

1. Approach and sources

This research is inspired by an argument made by disability historian Catherine Kudlick in her article 'Why We Need Another Other'.[8] Kudlick proposes adding disability to the historian's analytical toolbox alongside other, more familiar concepts such as race, gender and class. She wants disability historians not only to write the history of disabled people, but also to use disability to shed new light on other topics, following Joan Scott's attempt to transform women's history into gender history.[9] In reconstructing the changing role of the family in Dutch postwar disability policies, my primary aim is not to deliver a new chapter of the history of disabled people, but to find out how responsibility for long-term care has been allocated by policymakers, and what this teaches us about the (neoliberal) development of the Dutch welfare state. In this article, therefore, I hardly discuss the actual lives of disabled people nor do I address in detail the changing meanings of concepts such as disability, or the differences between different types of disabilities. I instead trace the general discourse about the role of families in the long-term care of cognitively disabled children, with the modest ambition of showing and explaining the (dis)continuities in this policy discourse.

My analysis is based on secondary literature and primary sources, the latter consisting in the first place of parliamentary debates from the 1970s onwards, when the family emerged as a relevant policy category. These debates are available online. I have selected those debates in which

6. This precedes a profound transformation of the Dutch welfare state during the 2010s, see A. J. Kruiter, Femmianne Bredewold, in: M. Ham (ed.), *Hoe de verzorgingsstaat verbouwd wordt: kroniek van een verandering,* Amsterdam 2016.
7. R. Rössel, *Belastete Familien? Eine Alltagsgeschichte westdeutscher Haushalte mit behinderten Kindern (1945-1990)*, Frankfurt 2022; P. Schmüser, Familiäre Rehabilitation? Eine Alltagsgeschichte ostdeutscher Haushalte mit behinderten Kindern (1945–1990), Frankfurt 2023; A. C. Carey / P. Block / R. K. Scotch (eds.), *Allies and Obstacles: Disability Activism and Parents of Children with Disabilities*, Philadelphia 2020. Parents of cognitively disabled persons are included in my article because they often continued to play a role in the care of their adult children.
8. C. J. Kudlick, 'Disability History: Why We Need Another 'Other'', in: *American Historical Review* 108 (2003) 3, 763–793.
9. J. Scott, 'Gender as a Useful Category of Historical Analysis', in: idem, *Gender and the Politics of History*, New York 1999, 28–50.

politicians dealt with the long-term care of (cognitively) disabled children and discussed the role of the family. I have also analyzed issues of *Klik*, a magazine for people involved in the long-term care of people with cognitive disabilities, which focused on changing policy. In the Dutch context, *Klik* is the main magazine for a broader public that deals with cognitively disabled people, and as such it gives a good insight into the main developments in the field. I have selected and examined the sections of the magazine that address the role and responsibility of families and parents in the long-term care of (their) disabled children. Due to my sources (in particular the magazines), the emphasis will be on families with cognitively disabled children. I have used the secondary literature to better understand these changing policies and to provide context. As I have already suggested, my emphasis on the allocation of responsibility comes with limitations. The policy debates I have studied for this article provide insight into this allocation, but say little about the agency of parents or their socio-economic position, and provide barely any information on the gender division of care work within families.[10] This brings me to my last disclaimer: this article does not offer a profound historicization of concepts of the family because my sources do not allow this. We know that the ways in which families were organized and seen in society changed during the postwar period, but these changes were hardly addressed in the consulted sources. In debates about the role and responsibility of the family, the latter has often been understood as an unchangeable unit consisting of parents and children. Where changes to the family are addressed in these debates, I have discussed them.

2. Private institutions and early parental initiatives during the 1950s and 1960s

The role of families in the long-term care of cognitively disabled children was seldom explicitly addressed by policymakers before the 1970s. Apparently the situation in the postwar decades did not merit special attention. However, this did not mean that nothing was expected from families, or that they did not play an important role. At the time, the Dutch tended to see civil society organizations and citizens (including families) as primarily responsible for long-term care. The World War and developments such as the publication of the Beveridge Report in the UK stimulated debates about the role of the state, but not about the family. Daily care for people with disabilities and/or chronic illnesses only began to be publicly funded when the government introduced state-regulated national insurance for long-term care in the late 1960s.

The lack of attention to the family in public debates is also reflected in research: historians have scarcely examined how families assumed responsibility for their (cognitively) disabled children. There is anecdotal evidence that a lot of children were raised as 'normally' as possible, without special schools or services. In an interview about her childhood in the 1950s, one woman recalled that her disability was not really an issue for her parents. She was accepted like the other children in her family, and in daily life practical solutions were found for her inability to walk. At school, for instance, she was carried by her friends from one classroom to another.[11] These types of stories help to explain why only 2.2% of schoolchildren attended special schools.[12]

We know, however, that other disabled children and their parents made use of special services, or were forced to do so. These were often organized by private or voluntary care organizations

10. See J. Crane, 'Agents of Change? Families, Welfare and Democracy in Mid-to-Late Twentieth-Century Europe', in: *Contemporary European History* 32 (2023) 2, 173–185.
11. E. Pollaert / P. van Trigt, Van internaat naar inclusie? Een leergeschiedenis van 'het gehandicapte kind' 1950-2020, Amsterdam 2020 (unpublished report).
12. *Ibid*.

operating locally or nationally, often informed by a religious worldview, and paid for by other citizens, churches and/or local governments. They generally offered not only (special) schooling, but also a permanent place for children to live. When families could not care for their disabled children, these services could be very helpful. This was particularly the case for children with cognitive disabilities, a group about whom we know a relatively large amount.[13] However, recent investigations into violence in youth care show that parents were not always free to make choices concerning their disabled child. People with authority, such as clerics and pedagogues, sometimes forced parents to hand their child over to an institution. The strong development of the social and human sciences after World War II and the increasing numbers of Dutch professionals and experts on childhood disability did not change this situation. On the contrary, these professionals did not always take parents' knowledge about their children seriously. The staff of long-term care institutions often considered themselves the real experts and expected parents to trust them.[14]

For this reason, parents, and in particular parents of children with cognitive disabilities, increasingly started to organize during the 1950s, sometimes encouraged by teachers or clerics who were not themselves parents of a disabled child.[15] They wanted to share their experiences and to have a say in their children's lives, and this would be easier if they worked together. Parents' associations were initially organized along religious lines, but were willing to cooperate, and so the Federatie van Oudervereningingen (Federation of Parents' Associations) was founded in 1964.[16] Parents organized not only to influence institutions and develop alternative forms of care, but also to improve the care given at home. Social workers played a key role in thinking with parents about how they could arrange care for their disabled children; yet there were frequent complaints within parents' organizations about this service, which parents claimed was not always helpful. In practice, however, it was difficult for parents to improve care.[17] Furthermore, parents' organizations were not only focused on improving their own members' situations, but they also wanted to prevent deplorable situations in which cognitively disabled children were hidden or locked up by their parents because of shame and stigma.[18]

One of the main achievements of the parents' movement was the introduction of so-called 'family-replacing homes' (*gezinsvervangende tehuizen*) in the 1960s. Some parents were dissatisfied with large-scale institutions and founded their own small-scale facilities, which they often ran themselves. The new homes had a shared living room and individual bedrooms, were often divided into smaller units, and were inhabited by 15–25 persons.[19] The residents were usually adults with a cognitive disability, although many institutions for disabled children also adopted the concept. Initially, these homes received funding from alternative sources such as churches and municipalities, but from the 1970s onwards they became part of the state-regulated national insurance system for long-term care. This gave an enormous boost to the initiative and to the development of a so-called 'semi-mural sector' alongside intramural institutions.[20] In this way, parents

13. H. Beltman, *Buigen of barsten, hoofdstukken uit de geschiedenis van de zorg aan mensen met een verstandelijke handicap in Nederland 1945-2000*, Groningen 2001, 63 and 71.
14. Commissie Onderzoek naar Geweld in de Jeugdzorg, *Sector- en themastudies*, Den Haag 2019; Beltman, *Buigen*, 142.
15. Beltman, *Buigen*, 155.
16. Canon Sociaal Werk, 'Oudervereningingen', https://www.canonsociaalwerk.eu/nl_han/details.php?cps=11&canon_id=281 (30 April 2023).
17. Beltman, *Buigen,* 139 and 148.
18. Ibid., 154.
19. Canon Sociaal Werk, 'Gezinsvervangende tehuizen', https://www.canonsociaalwerk.eu/nl_han/details_verwant.php?cps=1&canon_id=281&verwant=281 (30 April 2023).
20. P. van Trigt, *Blind in een gidsland*; Jacques van Gerwen, *De welvaartsstaat: volksverzekeringen, verzekeringsconcerns, financiële dienstverleners en institutionele beleggers 1945-2000*, Den Haag, Amsterdam 2000.

became active in Dutch policymaking, but their involvement was not reflected in debates about the role of families in long-term care in the 1970s, as we will see.

The introduction of family-replacing homes is hardly conceivable without the Dutch state, which became a more important player in the care of people with disabilities during the 1960s. The state encouraged parents' organizations to work together and made the development of family-replacing homes possible. Although the more prominent role of the state led to new initiatives, there were also elements of continuity in the Dutch care system. Despite new laws and forms of finance, many traditional care providers remained active, and so in practice, people with (cognitive) disabilities and their families still had to deal with the same organizations and people.[21] What we see in the first decades after the war is the development of a Dutch welfare state characterized by an entanglement between the state and societal organizations, with the latter often informed by a particular religion or worldview.[22] New initiatives and actors could be integrated into this mixed welfare economy, but in general, responsibility for the long-term care of disabled children rested with state-subsidized institutions, in which professionals played a leading role.

3. Public institutions and parental involvement during the 1970s and 1980s

Thanks to initiatives such as family-replacing homes, parents were able to have a say in their children's care. Dutch parents thus became part of an international movement of disabled people and their allies that fought for emancipation and questioned the power of professionals and institutions. From the 1960s, disabled people across the world started to claim their rights and demand societal inclusion more vocally – often as part of, or inspired by, other social movements.[23] In parallel to these local and national protests, parents of children with cognitive disabilities started to lobby for a declaration of the rights of 'mentally disabled' people. This was ultimately adopted by the United Nations in 1971, and was subsequently used by parents and self-advocates in the Netherlands.[24] At the same time, some Dutch parents did not want their children to live permanently outside institutions, and saw the family-replacing homes in particular as a good alternative to both home care and big institutions. This is why the Dutch did not pursue the deinstitutionalization policies that were more common in Scandinavia and elsewhere. Even the so-called Dennendal affair, one of the more radical Dutch experiments of the 1970s, was not an attack on institutionalization. Dennendal was a facility for people with cognitive disabilities whose director and staff changed their policies because they no longer wanted a professional regime; instead, they wanted to live 'simply together as humans', with no strong distinction between people with and without disabilities. In the end, the experiment was shut down, partly

21. Van Trigt, *Blind in een gidsland.*
22. F. Giomi / C. Keren / M. Labbé, 'Productive Entanglements. The Dynamics of Public-private Interactions in the History of Social Protection', in: idem (eds.), *Public and Private Welfare in Modern Europe Productive Entanglements*, London 2022, 1–14.
23. G. Brégain, 'The Radicalization of the Disability Rights Movements (1968-1981). An Entangled History (Argentina, Brazil, Spain)', in: S. Barsch / A. Klein / P. Verstraete (eds.), *The Imperfect Historian. Disability Histories in Europe*, Frankfurt am Main 2013, 133–153; J. Stoll, 'Disability Movements. National Policies and Transnational Perspectives – Introductory Remarks', in: *Moving the Social* 53 (2015), 5–10.
24. D. Herzog, *Unlearning Eugenics. Sexuality, Reproduction, and Disability in Post-Nazi Europe,* Wisconsin 2018, 73; P. van Trigt, 'A History of 'Legal Capacity' and the 'Family' in the United Nations' Disability Policies since the 1970s', in: J. Moses / M. Koenig (eds.), *Family, Human Rights and Internationalism* (forthcoming).

due to pressure from parents who were worried about the safety of their children and the lack of professional care.[25]

The end of the Dennendal experiment was not the end of the ideas behind it, however. Another institution, the Hafakker, also started to organize itself in small units of six to eight persons with cognitive disabilities, with the aim of living 'simply together'. These units were seen as different from the family-replacing homes, which the Hafakker considered to be 'small institutions'. Interestingly, the Hafakker's units were conceived as families – not only because the aim was to create a 'lovely and homely' atmosphere, but also because the personnel were to conduct themselves not as experts, but as parents: 'They can give love and build a relationship. Like parents, they do not need to be experts to take responsibility. Doctor Spock [referring to the bestselling book *Baby and Child Care* by US paediatrician Benjamin Spock] on their bookshelf is enough'.[26] In the early 1980s, however, the Hafakker abandoned the family metaphor because its employees did not see themselves as parents. Nonetheless, it retained an emphasis on a homely atmosphere and good relationships.[27] In addition, the Hafakker maintained positive links with the biological families of its residents. However, not all families welcomed the involvement of an advisory board, as was proposed by the Hafakker. They contributed to the individual lives of their disabled family members in different ways, varying from neglect to close involvement.[28]

The ideology behind Dennendal and the Hafakker was not representative of the institutionalized care of disabled children and cognitively disabled adults more broadly. That much is apparent from the ending of the Dennendal experiment. So how was responsibility for the long-term care of disabled children framed? During the 1970s and 1980s, there was both continuity and discontinuity with the previous decades. To start with the continuity: intra- and semi-mural institutions and professionals remained important, and parents still sought to be involved in institutionalized care, though they complained that they were not always taken seriously by professionals or by institutional boards. Care often remained focused on the disabled individual, without taking the family into account as a relevant factor.[29] As we have seen in the case of the Hafakker, some institutions paid special attention to their relationships with parents and appointed social workers to improve them.[30] At the same time, parents tried to guarantee their involvement in institutions for disabled children on a more structural level. Parents of cognitively disabled children campaigned for a legal right to intervene in services for their children, even if they were adults.[31] They did so in part because institutions were often organized as foundations with a powerful board, with no (legal) opportunities for other actors to participate.[32]

In 1975, a working group of parents' committees produced a report that advised institutions to give parents structural influence over their children's care.[33] This perspective was, however, only partly integrated into the work of another committee working on the democratization of the health care system more broadly.[34] In 1977, the government nevertheless decided that people with

25. E. Tonkens, *Zelfontplooiingsregime*, *de actualiteit van Dennendal en de jaren zestig,* Amsterdam 1999.
26. I. Mans, *Het hart van de zorg. Idealen en praktijken in de verstandelijk gehandicaptenzorg bij de Hafakker (1960-2010)*, Breda 2016, 137.
27. Ibid., 150.
28. Ibid., 155–160.
29. Beltman, *Buigen*, 158.
30. 'De inrichting moet een thuis zijn voor ouders', *Klik. Maandblad voor de zwakzinnigenzorg* 4 (1975) 8, 10–13. *Klik* was a Dutch journal for people involved in caring for cognitively disabled persons.
31. 'Ouderlijke verantwoordelijkheid eindigt nooit', *Klik* 4 (1975) 6, 3; Beltman, *Buigen*, 157.
32. 'De ondeskundigheid van goedwillende notabelen en de absolute macht van stichtingsbestuur', *Klik* 4 (1975) 8, 4–5.
33. 'De inbreng van de ouders', *Klik* 4 (1975) 11, 16–17.
34. 'Oudervereningingen en democratisering', *Klik* 5 (1976) 7, 14–15.

disabilities and their representatives had to be involved in institutional policymaking. This ruling was not always applied in practice, but during the 1980s it became much more normal for parents to be involved in institutions.[35] However, the discussion about parental involvement did not change the fact that policymakers still allocated responsibility for the long-term care of disabled children to state-subsidized institutions.

Despite the increasing emphasis on parental involvement, the continuity of institutionalized care for disabled children is striking – particularly when put into an international perspective. The Dutch preparations for and celebrations of the International Year of Disabled Persons (1981) make it clear that disability was seen mainly as an issue of institutionalized care, and not so much as a question of emancipation. Self-advocates and parents of disabled children were included in the organizing committee, but government and institutional representatives took the lead. Critical voices were only heard outside the committee: self-advocates tried to disrupt an official celebration, and activists working with people with cognitive disabilities organized their own event. In other countries, protests led to the birth or the strengthening of disability movements, while governments saw the Year as an opportunity to develop or improve disability policies. Not so in the Netherlands, where the event did not really set anything in motion and deinstitutionalization was hardly pushed by Dutch policymakers until the 1990s.[36]

4. Politicizing the family: searching for support outside institutions

As I have already indicated, the 1970s and 1980s also showed discontinuity with the previous decades. From the 1970s onwards, parents of physically or sensory-disabled children increasingly preferred to raise their children at home.[37] This was a new tendency, and was probably only possible thanks to the increased prosperity of Dutch society and the challenges to the authority of professionals that began in the 1960s, and which I have already discussed. However, the economic crises of the 1970s and 1980s put pressure on Dutch prosperity and threatened this new trend. For this reason, families of disabled children appeared on the political agenda, marking a significant change in the policy discourse about long-term care. Raising cognitively disabled children at home instead of sending them to an institution was not always easy due to the need for extra support. Politicians took up this issue in the late 1970s. In 1978, the Dutch parliament voted for the government to provide assistance and support to families with a cognitively disabled child, mainly out of concern for the financial vulnerability of such families. The issue was brought forward by three politicians from confessional, conservative-liberal and progressive political parties, and the Dutch parliament unanimously agreed on the urgent need to improve the situation.[38]

When the government (at that time a confessional and conservative-liberal coalition) finally responded to the request for assistance and support, it reframed the issue from a financial question to one of accessibility of services. According to the government, families had difficulty in finding the available assistance and support. Their search was complicated by the fact that each family had different needs and could ask for support from multiple care providers. The government therefore

35. 'Voorschriften over ouderparticipatie', *Klik* 12 (1983) 9, 8–9; 'Bestuurderspet past meeste ouders niet', *Klik* 14 (1985) 6/7, 12–13; 'Belangen van bewoners zijn nog te vaak ondergeschikt', *Klik* 15 (1986) 9, 10–12.
36. P. van Trigt, 'Gelijkheid zonder beperking: over de Algemene Wet Gelijke Behandeling (1994) en de constructie van handicap in politieke instituties', in: *BMGN: Low Countries Historical Review* 134 (2019) 1, 3–27.
37. J. Vos, *Tastend door de tijd: twee eeuwen onderwijs en zorg voor slechtziende en blinde mensen*, Amsterdam 2008.
38. Tweede Kamer der Statengeneraal (TK), 'Bijzondere commissie voor het gehandicaptenbeleid : 1ste vergadering', 26 June 1978, 756.

saw good family counselling as the solution,[39] in the assumption that having a disabled child placed special demands on the family. Some families could easily deal with this, the government argued, but more often parents had difficulty in accepting the situation and determining what was best for their child.[40] Counsellors could therefore help them find appropriate care. The government's policies at that time were developed in consultation with different stakeholders, including parents of disabled children. But did they share the government's perspective?[41]

The government's claim that families had difficulty finding assistance and support echoed a complaint made by parents of children with multiple disabilities, including cognitive disabilities, a few years earlier. Such parents claimed they had to go through a 'jungle' of institutions in order to find out what was 'wrong' with their child and what treatment was needed. Although the family was seen as the most 'natural' environment for disabled children, stakeholders did not always find it desirable for children to stay at home in such cases.[42] It was not the 'jungle' that annoyed parents most. In the course of the 1970s, stakeholders in the care of disabled children increasingly stressed the importance of practical assistance for families, which was rudimentary.[43] Parents wanted 'basic' help, as one parent put it, not professional advice.[44] This shows that parents, or at least those parents who were involved in public debates, understood family counselling slightly differently from professionals and the government. In other words, the focus on family counselling in policy discourse did not mean that policymakers were really listening to parents. Parents had to lobby to be represented at a conference about family counselling in 1977, and were successful in bringing their perspective to the fore. According to them, care for cognitively disabled children remained too closely focused on the individual child. For this reason, as one of them said, parents needed to emancipate themselves and question the ideas of experts, who claimed to know better. Parents realized that if family counselling took on a more central role, it would have huge consequences for the organization of care and would eventually lead to deinstitutionalization. And because some parents doubted professional organizations' willingness to change, they established their own services, delivered by and for parents, in different parts of the Netherlands.[45] Many of these were set up by highly educated parents who had access to adequate resources.

The potential of family counselling to change the Dutch care system was also made apparent in a booklet by the Dutch Family Council (Nederlandse Gezinsraad). According to the director of this organization, the family was key to disability policy: 'the family – broadly understood – is for the human in particular the place where he or she is accepted because of who he or she is, and not because of what he or she should do or should be capable of'. With this declaration, families laid the foundations for socialization and thus integration into society.[46] However, families often received less attention than the disabled individual.[47] Another representative of the Dutch Family Council quoted researcher Beatrice Wright who stated that it is not disability that hinders

39. 'Hulpverlening aan gezinnen met een gehandicapt kind (Eindnota Motie 19)', 1982–1983, Kamerstuk 17899, 2. One likely reason for this reframing was research on the financial dimension, which could be interpreted in different ways; see 'Thuiswonend kind kost ouders net zoveel als uit huis wonend kind', *Klik* 11 (1982) 7, 36.
40. TK, 'Geestelijk gehandicapten', 1982–1983, Kamerstuk 17900, 2, 52.
41. TK, 'Gehandicaptenbeleid; brief van minister van Volksgezondheid en Milieuhygiëne', 19-04-1982, Kamerstuk 14406, 58, 24.
42. TK, 'Inventarisatie van voorzieningen voor gehandicapten. Verslag van een openbaar gehoor', 9 September 1975, Kamerstuk 13151, 3, 11–12.
43. 'We hebben te weinig armen en die armen zijn ook nog te kort', *Klik* 6 (1977) 7, 4–7.
44. 'Geen 'deskundige', maar 'gewone' hulp gevraagd', *Klik* 7 (1987) 5, 6–7.
45. 'Zonder geëmancipeerde ouders is gezinsbegeleiding bij voorbaat kansloos', *Klik* 10 (1981) 2, 8–9.
46. C. Blankestijn, 'Ten Ingeleide', in: N. Immink, *Wil ze slagroom? Hoe wij met gehandicapten omgaan*, Nijkerk 1977, 7–8.
47. Immink, *Wil ze slagroom?*, 11.

the social adaptation of the child, but the attitude of the child towards his or her disability. He added that the child's immediate neighbourhood or family was crucial in shaping that attitude.[48]

However, the committee advising the government on family counselling in the early 1980s did not force it to make a decision about structural funding.[49] With support from a charity foundation, several experimental family counselling projects had been carried out during the late 1970s and early 1980s. But due to the reluctance of the advising committee, a national roll-out of the experimental projects was uncertain in 1982. Parents were upset: 'Shall we explain it one more time? Or is it by now clear to stakeholders, and in particular those with political responsibility, what it means to have to care 24 hours a day, seven days a week and 52 weeks a year for a child who needs your full attention? A child who is not welcome among friends or family and whom you cannot easily hand over to someone else. It can be an enormous relief in such a situation for a steady and trusted person to assist if needed, or to step in if you want to go out for a while'.[50] In the counselling experiments of the previous years, this assistance and temporary relief for parents was provided by volunteers, who were assigned to families by a paid coordinator.[51] In 1982, Minister of Health Til Gardeniers said that the government did not have the financial resources to provide family counselling, but she was willing to fund a few local initiatives. Thanks to an additional gift from the charity involved, the existing experiments were continued for one more year.[52] But neither these projects nor the parents' self-help initiatives received any structural funding.

5. Social conservative scepticism towards publicly funded informal care

Why did the government not want to fulfil the wish of families with cognitively disabled children to receive subsidized assistance at home? A few years after the political discussion about family counselling, the government had already begun to question whether family counselling would ever be adopted as a long-term policy. One policy note framed it as a possible part of the transition from intramural to extramural care and as a temporary replacement for informal or self-care. The future of family counselling would thus depend on the government's policies for informal care.[53] This points to the importance the government attached to the distinction between formal and informal care. Family counselling was evidently seen as too close to informal care, which had to be provided not by publicly funded institutions, but by citizens and their social networks. In another policy document, the government pointed to societal changes that had weakened the ties between families and other societal structures, such as churches and neighbourhoods. Interestingly, the family itself was still seen as a relevant unit in the 1980s, despite these trends. The government referred to a policy document from 1966 that described the individual as primarily responsible for 'his own health and that of his family'.[54] In this context, the government praised families for taking responsibility for themselves.[55] Here we see the emergence of the family as a

48. Ibid., 34.
49. 'Eindrapport gezinsbegeleiding stelt teleur', *Klik* 11 (1982) 4, 7–8.
50. 'Gezinsbegeleiding op de tocht', *Klik* 11 (1982) 5, 3.
51. Ibid., 4.
52. 'Kamer wil geld gezinsbegeleiding', *Klik* 11 (1982) 8, 3–4; 'Gardeniers gaat deel projecten gezinsbegeleiding betalen', *Klik* 11 (1982) 9, 32.
53. TK, 'Over de ontwikkeling van gezondheidsbeleid; feiten, beschouwingen en beleidsvoornemens (Nota 2000)', 1985-1986, Kamerstuk 19500, 2, 192–193. In this note, the government also predicted a decline in the number of disabled children in the long run.
54. TK, 'Over de ontwikkeling van gezondheidsbeleid; feiten, beschouwingen en beleidsvoornemens (Nota 2000)', 1985-1986, Kamerstuk 19500, 2, 11 and 41; TK, 'Volksgezondheidsnota 1966', 2 February 1966, Kamerstuk 8462, 1.
55. TK, 'Volksgezondheidsbeleid bij beperkte middelen 1983-1984', Kamerstuk 18108, 2, 34.

'wholesale alternative to the 20th-century welfare state', in Melanie Cooper's words. According to the Dutch government, the informal care provided by the family was not to be confused with the formal care supplied by professionals. During the 1980s, it became clear that the initial ideal of financial support for families with disabled children was not a serious option for politicians and policymakers, who saw the family as a provider of informal care for which the government was not responsible.

In line with Cooper's argument, the attitude of the Dutch government at the time could be characterized as social conservatism combined with a neoliberal search for market solutions in health care.[56] This hybrid of neoliberalism and social conservatism was not entirely new, but became more prominent due to the dominance of confessional and conservative-liberal political parties in the Dutch government and across Europe during the 1980s, after decades in which confessional parties had often formed coalitions with social democrats. However, the search for neoliberal solutions to challenges in health care was still at an early stage in the 1980s, and the government's appreciation of the informal care provided by the family was scarcely accompanied by a reduction in the formal care provided by professionals. When the financial challenges faced by families with a disabled child were discussed again in parliament in 1991, the government reframed them once more as an issue of (in)accessibility, but did not question the services themselves.[57] During the same year, the government also made a small gesture towards parents by making the coordination of home care for families with a disabled member part of paid long-term care. This was an important step for these families, but the availability of coordination and of the specific forms of care needed by families depended on local conditions.[58]

The 1970s and 1980s thus show an increasing focus on (and small movements towards) the possibility of raising a child with a cognitive disability in the family instead of within the confines of an institution, along with attempts to increase parental influence on institutionalized care. Both of these things proved hard to achieve, however. Although families became more prominent in policy discourse, the government was reluctant to develop a new support system for parents and preferred to work with existing providers of institutionalized care. Moreover, the further professionalization of institutions meant that it was not easy for parents to have a say in their children's lives. Responsibility for the care of disabled children thus fell to either institutions or families; sharing it between the two hardly seemed possible. Although the Dutch health care system was characterized by different forms of private–public relationships,[59] the private part was always some sort of collective, and could not be an individual or family. This seemed to change during the 1990s.

6. Questioning institutionalization during the 1990s

During the 1990s, the notion that people with disabilities do not belong in institutions and should live as 'normally' as possible became more popular in the Netherlands. As early as the late 1980s, parents' organizations presented a report titled 'People with Possibilities', with the aim of focusing on the capabilities of disabled people instead of their disabilities.[60] The report stressed equal citizenship for disabled people, including people with cognitive disabilities. The latter group started

56. Cooper, *Family Values*; Mellink and Oudenampsen, *Neoliberalisme*.
57. TK, 'Gehandicaptenbeleid; Brief staatssecretaris met meerjarenprogramma intersectoraal gehandicaptenbeleid 1995-1998 'De perken te buiten'', 24 May 1995, Kamerstuk 24170, 2, 43.
58. 'Hulp aan huis', *Klik* 19 (1990) 12, 16–19.
59. Giomi / Keren / Labbé, 'Productive Entanglements'.
60. Beltman, *Buigen*, 159.

their own self-advocacy organization in 1985, in line with an international trend.[61] The popularity of this emancipatory perspective coincided with attempts by the government to renew long-term care and to transfer responsibility from the government and care providers to citizens and care receivers. The emphasis on integration was new, however. With implicit nostalgia, the government wrote in 1995 that for several decades the quality and quantity of care for people with cognitive disabilities in the Netherlands had set an example for other countries. But this had changed; the Dutch now had to look to other countries, because – unlike the US, the UK, Canada and the Nordic countries – they had hardly developed any facilities that enabled people to live independently or (in the case of children) with their families. In the international context, the Dutch system was criticized for its high level of segregation.[62] However, the government was open to change because segregated care seemed to be more expensive.[63] It also concluded that the relatively large semi-mural sector in the Netherlands had hindered integration.[64]

The observation that the Netherlands were falling behind was not new. In an article about a 1985 conference held by the International League of Societies for the Mentally Handicapped in Hamburg, Dutch participant Hans van der Wielen wrote that the Dutch health care system, like other European systems, tended to set people with cognitive disabilities apart in society. This went against the normalization ideology developed in the US and Scandinavia, which held that society and people with cognitive disabilities both had to adapt in order to make a 'normal life' possible. Van der Wielen wrote that when Dutch attendees at the conference heard about the successful integration of children with cognitive disabilities into the 'normal' school system abroad, it wounded their 'national pride'. He emphasized that the Dutch were not alone in this regard, as even at the conference the disabled participants had a separate building and separate sessions.[65] The ideal of integration and normalization was, as we have already seen, not entirely new in the Dutch context, but it became more influential in the Netherlands during the 1990s. Although special education persisted, a non-linear trend towards deinstitutionalization emerged during the decade.[66] This development is hardly conceivable without the efforts made by parents of cognitive disabled children, who simply refused to accept the placement of their children in large-scale institutions without individual bedrooms.[67]

But who was seen as responsible for the care required by many cognitively disabled children? A note written by parents' organizations in 1994 mentioned the so-called personal assistance budget as an important tool for enabling the integration and societal participation of people with (cognitive) disabilities. The idea of providing parents with a budget to buy their own care had already been raised during a meeting held by an organization of parents of cognitively disabled children in 1986, but at that time such a measure was not possible in the Dutch long-term care system.[68] This changed during the 1990s – a remarkable development, given the previous reluctance of the government to financially support parents who wanted to care for their disabled children at

61. Ibid., 160; Van Trigt, 'A History of 'Legal Capacity''.
62. TK, 'Gehandicaptenbeleid; Brief staatssecretaris met meerjarenprogramma intersectoraal gehandicaptenbeleid 1995-1998 'De perken te buiten'', 24May 1995, Kamerstuk 24170, 2, 44.
63. TK, 'Toekomst AWBZ Eindrapportage van de werkgroep Organisatie romp AWBZ', 21-06-2006, Kamerstuk 30597, 1, 66.
64. TK, 'Gehandicaptenbeleid; Brief staatssecretaris met meerjarenprogramma intersectoraal gehandicaptenbeleid 1995-1998 'De perken te buiten'', 24 May 1995, Kamerstuk 24170, 2, 44.
65. 'Speciale zorg isoleert gehandicapte mensen', *Klik* 14 (1985) 11, 13–15.
66. See B. Majerus / P. Verstraete, 'Dis/ order and dis/ ability', in: J. Vandendriessche / B. Majerus (eds.), *Medical Histories of Belgium*, Manchester 2021, 283–319.
67. 'Blij met toenemende kritiek van ouders', *Klik* 24 (1995) 4, 3–6.
68. 'Geef ouders zelf het geld dat de zorg kost', Klik 15 (1986) 10, 3.

home. To understand this shift, we must take a closer look at the introduction of the personal assistance budget.

7. The personal assistance budget: towards publicly funded informal care and independent living?

The literature often regards the personal assistance budget, or cash-for-care payment, as an instrument used by policymakers to make long-term care cheaper and more consumer-directed. However, it tends to overlook the fact that – as disability studies scholars have suggested – the policy was largely developed and propagated by disabled self-advocates who were participating in a global disability rights movement.[69] This movement foregrounded the ideal of independent living, while contesting the very concept of care because of its strong association with paternalism and a lack of control on the side of the care receiver. As an alternative, self-advocates have coined the concept of 'personal assistance', which is centred around people with disabilities and their needs. Experiments with, and the ultimate implementation of, a personal assistance budget started in Sweden in the early 1980s, followed by several other European countries between the late 1980s and the early 2000s.[70] The independent living philosophy and initiatives such as the personal assistance budget were welcomed in several countries as an innovation that could meet the needs of the ageing population and reform the welfare state. Existing welfare arrangements had come in for increasing criticism because they could not meet the specific needs of individuals and were accompanied by paternalistic attitudes on the part of care professionals. The personal assistance budget was also developed as an instrument to promote deinstitutionalization by moving people with (severe) disabilities from segregated institutions back into the community.[71]

In the Netherlands, self-advocates started trying to draw the government's attention to the personal assistance budget in the 1980s. As in other countries, their efforts fell on fertile ground, because Dutch policymakers were also searching for 'market solutions' in the context of a contested welfare state.[72] The personal assistance budget seemed to offer a way to combine the emancipation of disabled people with neoliberal welfare state reform. After a few pilot studies in the early 1990s, the policy was introduced in 1996 an option for long-term care alongside existing professional care 'in kind'. [73] Although it was seen as promising for 'the emancipation of cognitively disabled people and their parents' as early as 1992, it was introduced by and for individual disabled and elderly citizens who wanted to live as independently as possible.[74] The use of the personal assistance budget by cognitively disabled people and their parents raised critical questions, however. During one of the pilot studies, it became clear that recipients were not always able to access the care they wanted due to complicated procedures, as well as doubts about the ability of parents and cognitively

69. T. Mladenov, 'What is Good Personal Assistance made of? Results of a European Survey', in: *Disability & Society*, 2019, DOI: https://www.tandfonline.com/doi/full/10.1080/09687599.2019.1621740; C. Ranci / E. Pavolini (eds.), *Reforms in Long-term Care Policies in Europe*, New York 2013; J. Lundsgaard, Consumer direction and choice in long-term care for older persons, including payments for informal care: How can it help improve care outcomes, employment and fiscal sustainability, OECD health working papers no. 20, Paris 2005.
70. B. Da Roit / B. Le Bihan, 'Cash for Long-term Care: Policy Debates, Visions, and Designs on the Move', in: *Social Policy & Administration* 53 (2019) 4, 519–536.
71. A. Rafaelic, 'Direct Payments as a Means of Long-term Care Provision and a Vehicle of Resettlement form Total Institutions', in: *Dialogue in Praxis. A Social Work International Journal* 2 (2013) 1–2, 93–109.
72. See Rössel, *Belastete Familien?*.
73. P. van Trigt, 'De invoering van het Persoonsgebonden Budget (PGB) in de gezondheidszorg in 1996 en het ontstaan van 'vrije markt bureaucratie'', in: *Tijdschrift voor sociologie* 15 (2019) 3, 271–287.
74. 'Cliënt-gebonden budget door Kamer aanvaard', *Klik* 21 (1992) 4, 7.

disabled people to make 'good choices'.[75] Professional providers of care for cognitively disabled people were resistant to the personal assistance budget, as they preferred to reform the care system through moderate 'evolution' instead of breaking with the past and introducing a brand-new policy instrument.[76] The idea even met with great anger on the part of directors of institutions, who responded by developing a variant of the personal assistance budget that was more compatible with institutionalized care.[77] The budget nevertheless gave parents the power to make more informed decisions and to set up their care themselves, as they had already done in the past.

During the 1990s and 2000s, responsibility for the care of cognitively disabled children still rested with institutions and families, but in a different way than before. First, the government forced institutions to move from intra- to extramural care. Intramural care for disabled children almost disappeared, and families were seen by the government as primarily responsible. At the same time, the government regularly stated that the burden on families was heavier than in the past because of societal changes that had weakened structures such as care provided by religious organizations. For this reason, it argued, professional care remained unavoidable. Due to the increasing focus on prevention in health care, timing was seen as key: 'The government only comes into the picture if the family and the social environment prove insufficiently capable of coping with problems, or if the health or safety of the child is at stake. However, problems must be identified in time'. In 2007, the government introduced multidisciplinary teams to monitor this.[78] Most institutes transformed themselves into providers of extramural care and thus retained an important say in the care of disabled children. Despite the new emphasis on prevention and extramural care during the 1990s, the government maintained its subsidiarity principle, as is clear from its focus on timing. The replacement of the confessional parties by the social democrats in the government coalition during the 1990s did not change this continuity.

Second, the personal assistance budget made it financially possible to care for a disabled child at home. The policy ushered in a remarkable private–public entanglement: citizens used public money to organize care in their own way, and also to pay for care that had previously been seen as informal and provided for free. It was therefore no surprise that the personal assistance budget became popular among families with (cognitively) disabled children, even though it was originally designed for individual adults. It enabled families to organize care in a way that suited them and to work with people they knew. A systematic overview of how families with disabled children spent the money is still lacking, but individual cases suggest that many families used the budget to compensate mothers for their care work. Many mothers even left their 'normal' jobs to take care of their disabled children. Parents could also hire someone to temporarily relieve them, which enabled them to spend time alone, with each other or with their other children.[79] Other parents worked together to open small-scale care facilities, comparable to the family-replacing homes in the past.[80] Although most Dutch citizens who needed long-term care still opted for care in kind by official providers, the number of personal assistance budget users grew strongly during the 2000s. Yet the policy's success was short-lived.

After the financial crisis in 2008, the personal assistance budget was viewed with increasing mistrust by the government. Cases of fraud and misuse were reported in the media and resulted in a

75. 'De zorg die je zelf mag kopen is er (nog) niet', *Klik* 22 (1993) 9, 3–6.
76. 'Voorzitter koepel inrichtingen: Cliënt-gebonden budget is nergens voor nodig', *Klik* 22 (1993) 12, 27.
77. Beltman, *Buigen*, 159.
78. TK, 'Zorg voor jeugdigen met een lichte verstandelijke handicap en/of psychi(atri)sche problemen', 10 October 2007, Kamerstuk 31245, 2, 7, 32 and 46.
79. TK, 'Bijlage bij Kamerstuk, Persoonsgebonden budget nieuwe stijl 2007', 17 June 2008, Kamerstuk 26631, 259, 14.
80. J. van der Lans, *Niet-normaal. Ontwikkelingen en dilemma's in de Nederlandse gehandicaptenzorg*, Utrecht 2019, 139–150.

system in which recipients had to justify their expenses in detail and were subjected to strict controls.[81] This mistrust came with a renewed emphasis on the responsibility of citizens for long-term care. The government, still dominated by the conservative liberals, increasingly objected to the personal assistance budget because it wanted to shift the financial responsibility for long-term care onto citizens and professional providers, as in previous decades. It once again became reluctant to pay citizens public money to buy and organize their own (partly informal) care.[82] Due to a change in the Dutch welfare state in the 2010s, responsibility for the care of disabled children has been shifted even further onto parents, who, as one parent claimed in an interview, have been made 'responsible for everything'.[83] Unlike in previous decades, securing financial support for daily care and finding an institution have both become difficult for parents. Thus we see that new, more radical neoliberal responsibilization policies have only recently been introduced into Dutch long-term care, after decades in which the responsibility for care had been borne by public institutions. These new policies were accompanied only briefly by generous support for citizens who wanted to assume responsibility themselves. Moreover, it has become clear that in the case of disabled children, responsibility was placed on the shoulders of the family, and especially the mother – effectively reinstating traditional family values in the Dutch health care system.

8. Conclusion

In this article, I have reconstructed how responsibility for the long-term care of cognitively disabled children was allocated by Dutch health care policymakers from World War II until the early 2000s, using disability as a lens to shed new light on the history of the Dutch welfare state. I have shown that until the 1990s, responsibility was mainly assigned to care providers, who were fully publicly funded from the 1970s on. Parents could also assume responsibility, but until the 1990s they hardly received any funding to raise their disabled children at home. This changed during the 1990s, when parents were given the opportunity to apply for a publicly funded personal assistance budget which they could use to organize care themselves. Since then, parents have been primarily responsible, although care providers still play an important role, and the money they receive is subject to strict controls. This development is relevant to the literature on the (Dutch) welfare state because it shows that neoliberal responsibilization policies only became dominant in long-term care after the 2010s, whereas in other sectors and countries such policies became popular as early as the 1970s. In comparison to the US (analyzed by Melinda Cooper), for instance, the family only came to be seen as a 'wholesale alternative to the 20th-century welfare state' at a relatively late stage in the context of Dutch long-term care. One of the main reasons for this is that for a long time the extensive Dutch welfare state made it possible to place the financial responsibility for long-term care on institutions rather than families.

This article also contributes to the field of disability history by making clear how the extensive Dutch welfare state has both enabled and obstructed the wishes of families with a cognitively disabled child. The state supported initiatives by parents and disabled people, such as family-replacing homes and the personal assistance budget. Compared to the UK (for example),[84] disabled people were well integrated into the Dutch welfare state. Yet at the same time, the Dutch government facilitated a health care system that was dominated by institutions and professionals and did not always

81. Van Trigt, 'Persoonsgebonden budget'.
82. Ibid.
83. Van der Lans, *Niet-normaal*, 130.
84. J. Hampton, *Disability and the Welfare State in Britain: Changes in Perception and Policy 1948-79*, Bristol 2016.

aim to enable disabled children to participate in society, and it oversaw a neoliberal restructuring of the welfare state in which people lost support that had been available in the past. This finding further complicates the tendency to see deinstitutionalization as a linear, liberatory process from the 1960s onwards. How these developments in policy discourse played out in everyday family lives remains an important question that will hopefully be addressed in future research.

Funding

The author disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This publication is part of the project Disability and Self-Governance (project number 406.20.HW.004), which forms part of the Open Competition research programme financed by the Dutch Research Council (NWO).

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