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The cost of normalization: the thalidomide affected and the welfare state

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ABSTRACT

This article analyses how economic support and social benefits for thalidomide-affected children were negotiated and organized by both public and private actors in 1960s Sweden. Accounts from various archives are used to analyse how two different but coexisting understandings of disability – as a medical *and* a social problem – both influenced and underpinned not only the rehabilitation of The Swedish programme arranged for the affected children, but also the associated economic support. Contributing to a more nuanced understanding of the formation welfare solutions in the 1960s and to the intersecting research fields of the history of medicine and disability history, this article also advances our knowledge of the concept of ‘normalization’ and fosters insights into how the Swedish thalidomide scandal contributed to increased economic support for both the thalidomide affected and other groups of disabled children.

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Introduction

In the early 1960s, media worldwide reported that the medical compound thalidomide (in Sweden sold under prescription as Neurosedyn), praised for its mild sedative and anti-nausea effects, had been causing severe physical malformations in fetuses when taken by pregnant women during certain periods of gestation. The severity and complexity of the damage caused by the drug challenged the medical communities and social security systems wherever the medicine was sold. At the time, Sweden, in which approximately 100 affected infants survived to their birth, was a society in which the dominant political ideology stated that individual welfare was a collective responsibility. The social security system was organized by the state, funded by progressive taxes, and operationalized within the counties and municipalities. According to the dominant way of explaining the Swedish welfare state, this was done with a minimum of private-sector involvement.¹

In the 1960s, Swedish general health insurance covered subsidized hospital care, local health centres, and institutions for the ‘total’ care of the severely disabled. The guiding principles of social benefits, introduced after WWII and fully established by the early 1960s, implicated that they should be universal. This was to lessen the stigma, experienced by prior generations, of individual means-tested poor relief. However, the universal solutions did not cover the special needs of all individuals, i.e. individuals with

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disabilities, meaning that certain groups of disabled people became marginalized within the system.² Historian Alf Sjöblom has argued that this general understanding of the Swedish welfare state overlooks the complex interactions between various actors involved in the processes of developing welfare solutions, leading to a failure to recognize the private actors. He emphasized the need to consider both public and private welfare initiatives when studying the formation of the welfare state with its social security systems, rather than reproducing the image of 'the neat and unified building of a single system'.³ The present article contributes to a more nuanced view of the formation of Swedish welfare solutions of the 1960s by focusing on how the needs of thalidomide-affected children were met through a combination of public and private economic support. It also deepens our understanding of how the requirements of these specific welfare solutions were tied to the existing social and medical rehabilitation paradigm for these children.

By presenting an account of how the rehabilitation of thalidomide-affected children was organized, and of how the economic needs brought about by this rehabilitation were met, this article analyses how the universalist principles of the welfare state and the specific needs of a vulnerable group were negotiated at the time by actors such as the state Medical Board, politicians, the pharmaceutical company licenced to sell thalidomide in Sweden (Astra), the National Insurance Administration (Riksförsäkringsverket), and the Society of the Neurosedyn Affected (Föreningen för de Neurosedynskadade, a patient organization founded by parents of the affected in 1962, hereafter abbreviated as 'the Neurosedyn Society'). In doing so, it sheds light on a piece of welfare policy in the making. This article is written in the belief, supported by disability historians, that the social category of disability is a useful analytical lens when studying the development of modern states, as it reveals social hierarchies and social ordering, and illuminates how understandings of normality and individual autonomy have been negotiated.⁴ The case of the thalidomide affected in Sweden is no exception.

This article contributes to two overlapping and intersecting areas of research: the history of medicine and disability history. Within the history of medicine, the thalidomide scandal has been investigated from various perspectives. The scandal resulted in stricter protocols for pharmaceutical testing and regulation, and in registers of malformations in the newborn.⁵ In many countries, Sweden included, it led to new or enhanced abortion clauses.⁶ Regarding the Swedish case, psychologist Karin Paulsson, who was active in the rehabilitation of thalidomide-affected children in Sweden, channelled some of the criticism to which the rehabilitation programme has been subjected in her 1995 dissertation about the individual effects of the rehabilitation programme on thirteen of the most severely affected children.⁷ Within disability history, the concept of 'normalization' has been thoroughly investigated in relation to individuals with intellectual disabilities⁸; however, the concept and its meanings for physically disabled individuals and groups remain understudied.⁹

'Normalization' became a keyword in thalidomide rehabilitation, but it has been claimed that the intense focus of the Medical Board on identifying all the affected children and on classifying their injuries in detail contributed not only to their enrolment in the rehabilitation programme with its various components, but also to reproducing an ideal of the 'standard body' to which the thalidomide affected were compared. Viewed in retrospect, the rehabilitation efforts seem, at least initially, to have unintentionally

reproduced the dichotomy between the thalidomide affected and non-disabled children, instead of helping it dissolve.¹⁰

The study is based on a wide range of materials, partly classified, from some of the main actors – the Medical Board, Astra, institutions involved in the rehabilitation programme (e.g. Eugeniahemmet, a combined school and care institution for disabled children), and the Neurosodyn Society – as well as on parliamentary reports, journal articles, and press clippings.¹¹

The analysis is theoretically inspired by the concept of co-production as used within science and technology studies. The notion of co-production emphasizes that the production of knowledge (scientific, technological, and political) cannot be separated from the culture in which this knowledge is shaped, so knowledge production is deeply interconnected with social norms, conventions, and ideologies. Knowledge production, in turn, helps shape, alter, and modify policies, norms, conventions, etc. By using the concept of co-production, one can link what has traditionally been divided into ‘micro’ and ‘macro’ perspectives in the social sciences.¹² In this study, the concept is used to understand how solutions to the problems of economic support systems for the thalidomide affected were co-produced with the ideals of normalization and the rehabilitation programme. At the time, the discussion of each factor had to be calculated in light of the other factors when negotiating the care and rehabilitation of the affected children, as well as how the rehabilitation costs were to be covered.

The thalidomide scandal in Sweden

By being born with various injuries caused by thalidomide, the affected children became part of an international medical scandal of hitherto unparalleled proportions. Thalidomide had been praised for its low toxicity and was prescribed as a mild sedative, including to alleviate morning sickness in expectant mothers. However, when taken during specific periods of gestation, it caused the injury or even death of foetuses. Born with a wide range of injuries, such as shortened or missing limbs, damaged internal organs, and sight or hearing loss, the affected infants became the focus of intense political, social, and medical attention.¹³

Swedish public debate following the births of the thalidomide affected raised questions about the state and its medical responsibility for the situation through various regulatory bodies. Other topics discussed were how the public should have been informed, what kind of future awaited the affected, how they were to live, and how they were to be cared for, as will be outlined below. The last two topics, i.e. how to care for the children and what kind of future awaited them, related to an emerging change in attitudes concerning the disabled. At the time of the thalidomide scandal, severely disabled children were regularly placed in institutions to be cared for and educated by specialized staff. However, in the 1950s, such ‘total institutions’ had started to be criticized, with the need for greater individual patient autonomy and social conditions that more closely resembled those outside the institutions being emphasized.¹⁴

The guiding principle of the rehabilitation programme, organized by the state Medical Board in 1962 to address the needs of the thalidomide affected, was ‘normalization’.¹⁵ The concept of normalization, discussed in detail below, included the understanding that the children should ideally be able to grow up in their own families, with lives that resembled

other children's lives as much as possible.¹⁶ There was an understanding that the most severely affected children would need to spend a considerable amount of their time in institutions. However, the main thrust would be to provide opportunities for these children to grow up in their own birth families or in foster care.¹⁷ This indicates an emerging shift from the previous institutionalization model, even though the existing care systems in place for severely disabled children had not yet shifted (illustrated by the fact that parents incurred no cost to place a disabled child in a state institution¹⁸). The case of the thalidomide affected in Sweden thus helped enhance this shift from one model to another.

A recurring opinion in the media and among medical professionals told that the way forward to decrease the effects of the malformations, in addition to care in home-like environments, was to use various technological aids, such as artificial limbs. A strong belief in the possibilities afforded by new technology became an important underpinning of the construction of the rehabilitation programme in 1962.¹⁹

Both these aspects of the normalization concept – living at home and the use of technological aids – actualized discussions of the financial costs involved. This initial reaction to the thalidomide scandal, with its moral arguments about social obligations towards the children, hopes for and demands of a rehabilitation programme aided by technology, as well as the ideal of normalization and care in the home, is important to keep in mind, as it guided the actions taken to devise economic solutions for the situation. Before turning to the economic aspects, the normalization concept as well as the rehabilitation programme will be introduced in more detail.

Normalization

When it comes to the Swedish situation, the concept of 'normalization' has mainly been studied within disability history as a process starting in the late 1960s, and mainly in relation to the intellectually disabled.²⁰ In this research, normalization has been described as a process whereby the disabled could achieve greater autonomy in their personal lives through the adjustment of their living conditions to more closely resemble those of the non-disabled. This process included the gradual abandonment of life-long institutionalization by building group homes with specialized staff available, creating opportunities for the disabled to form social relations outside the institution, and organizing occupational activities during the daytime.²¹ In this research, normalization is often understood as a consequence of the gradual shift from a medical understanding to a social understanding of disability.

The more limited research on normalization in relation to the physically disabled has stated that occupational training was an important underpinning of the early 20th-century care ideology in Sweden, as a means for disabled individuals to become more self-sufficient and less dependent on poor relief. It was not until the postwar period, however, with its increased demand for workers, that the physically disabled became economically attractive as part of the Swedish workforce. The term 'normalization' was first mentioned in relation to the physically disabled in a 1946 state investigation of 'people with partial work ability'.²²

Starting in the early 1900s, support for the physically disabled in Sweden was based on various arrangements. For the blind and deaf, there was early state engagement, resulting

in state-funded educational facilities as well as occupational training.²³ For the mobility impaired, the care institutions were funded by private charities, and starting in the 1920s, incorporated the increasing influence of orthopaedic aids. Trust in what have been called 'total institutions', where all the needs of the disabled were to be provided, lasted into the 1950s, when a process of institutional modernization started. This process eventually resulted in the closing of total institutions for the physically disabled, with the last such institution closing in the early 1970s, according to disability researcher Rafael Lindqvist.²⁴

For the thalidomide affected, the guiding principle of normalization in relation to the rehabilitation programme soon came to include the understanding that they should be raised within a family. In a journal article for professional social workers written by a central rehabilitation programme actor, the national counsellor Inga-Maj Juhlin emphasized the need for thalidomide-affected children to have a 'normal upbringing in a family', in order to become 'anchored'. A family was preferred to an institution, she argued, because an institution could never provide stable 'attachment objects', as staff members would change jobs or move between wards. To meet their need for attachment, the children needed a sense of belonging to 'a smaller group of people'. While stating this, Juhlin was also aware of the complications of this approach. Some children had such severe injuries that institutional care was needed, sometimes for extended periods, and some families were unable to care for their children at home since their needs were so extensive. Juhlin noted the importance of providing economic support to the families to enable them to cope with the financial consequences of engaging in the full support of their child, at least periodically.²⁵

There were also other factors that might have impacted the situation. According to Juhlin, some families might have been hesitant to care for affected children in their homes due to anticipated negative social reactions or emotional estrangement due to the child's early hospitalization. She claimed this to be an effect of the detailed media coverage of the Belgian trial of a mother, who with the support of her family, had conducted what was defined as a 'mercy killing' of her severely thalidomide-affected infant.²⁶ The Swedish discussion included descriptions of the affected child as 'hopelessly deformed', 'stunted', and 'deprived of all opportunities for development'.²⁷ According to Juhlin, such personal ideas of the discussants on what constituted a valuable life, had spilled over to the debate on the Swedish thalidomide affected children in an unlucky way. Another factor that had impacted the situation in a negative way, according to Juhlin, was the misguided consideration from some doctors who had encouraged mothers to cut ties to their affected children. Such recommendations had been short-sighted, and damaging to both mother and child, in Juhlin's opinion. However, in cases where an upbringing within the birth family was impossible, foster families should be the alternative, she stated.²⁸

For the thalidomide affected, the principle of normalization not only contained the ideal of an upbringing within a family, with living conditions resembling those of other children. In their case, normalization also apparently included both the obligation and the right to have their physical bodies adjusted and rehabilitated to resemble standard images of a 'normal body'.²⁹ This part of the normalization ideal was tied to the established medical understanding of disability at the time, which indicated that the disabled individual should be 'normalized' and adjusted to society, and not the reverse.³⁰ According to interviews that psychologist Karin Paulsson performed with thalidomide-affected Swedish children as adults, there was a strong focus on making their bodies 'look

more normal' and on increasing their mobility with the help of prosthetic limbs. The statements from the affected are strongly supported by Paulsson's own work within the original rehabilitation programme.³¹ The ideals of normalization were not constructed apart from the rehabilitation programme, but, as we shall see, co-constructed with it.

The rehabilitation programme

Following the initial reports of injured infants being born in Germany and Sweden, the Swedish Medical Board started to assess the situation.³² A paediatrician, Jan Winberg, was hired to investigate the number of children born with anomalies, and to carefully and in detail classify their injuries with the support of information gathered from maternity clinics and hospital wards. In completing his investigation, he found that around 130 affected infants had survived to their birth. Winberg estimated that around 40 of them would need full or nearly full institutional care.³³

Following Winberg's investigation, the Medical Board made plans to organize both the immediate care and future rehabilitation of the children. To this end, a work group was formed, guided by the Medical Board, comprising four occupational teams responsible for different parts of the rehabilitation, i.e. paediatric, orthopaedic, child psychiatry, and rehabilitation teams. The paediatric team comprised a paediatrician, occupational therapist, counsellor, ward nurse, physical therapist, and other ward staff. The orthopaedic team comprised an orthopaedist, physical therapists, and an orthopaedic technician. The set-up of the rehabilitation team resembled that of the orthopaedic team: it hosted an orthopaedic technician and physical therapists, but also engaged a technician, an occupational therapist, a ward nurse, and a counsellor. The rehabilitation team also collaborated with the paediatrician and an orthopaedist. The psychiatric team comprised a child psychiatrist, a psychologist, a paediatrician, a counsellor, a physical therapist, an occupational therapist, a ward nurse, and other ward staff. Several of the involved medical professionals worked at Karolinska Hospital, which became an important collaborator.³⁴

Joint conferences were held regularly to coordinate the efforts of the teams and to plan for the anticipated needs that lay ahead.³⁵

The importance of centralized care for the most affected was stressed early on, to concentrate the needed expertise around them. It was decided that the Eugenia Home, an institution for severely disabled children located in Stockholm, would be the best place to care for the most affected children when they were being fitted with new prosthetics or otherwise needed specialized rehabilitation efforts. There, they would be rehabilitated with other disabled children, some of them with similar injuries. To coordinate the various rehabilitation needs, a national counsellor, Inga-Maj Juhlin, was hired. She was to serve as a link between the affected families and the various groups of the rehabilitation team. Another important role of hers was to counsel the families on how to apply for financial aid to cover the various rehabilitation costs.³⁶ The needs of children who were less severely injured could arguably be addressed at Sweden's various regional institutions serving children with cerebral palsy, where specialists in paediatrics, orthopaedics, logopedy, and audiology were already in place.³⁷

During periods when thalidomide-affected children stayed at the Eugenia Home, their daily life was organized according to a carefully monitored schedule that, as well as daily exercise, outdoor activities, play therapy in groups, meals, and naps, also included

individual medical treatment, fitting new prosthetics when needed, individual physical therapy, individual play therapy, as well as audiological and speech training when applicable. Children with hearing impairments received both individual and group training daily, while children with speech impairments had individual training programmes. The psychological development of each child was monitored by the staff, in addition to the assessment of every child performed during their stay, by a child psychiatrist.³⁸ As the Eugenia Home was the centralized national care unit accepting admissions from all over Sweden, this meant that some of the children were staying far from home for extended periods. When they were to be discharged from the Eugenia Home, their parents or caretakers were regularly invited to stay for a few days, to take part in the children's training programme and learn about their new prosthetics as well as the various technical aids.³⁹

The costs of normalization

For many parents, the costs of taking leave to spend time at the Eugenia Home were prohibitive, not to mention all the other costs involved in caring for the affected child at home. Caring for the affected children at home, for starters, required that one parent stay at home with the child, or perhaps that someone be hired to do so. It also required that the home should be suitable for the child's needs, which meant that adaptations had to be made. Each child also required an individualized set of technical aids, which needed age-appropriate adjustment, and prosthetic limbs or other prosthetics often needed regular replacement. Most prosthetics were state subsidized, according to regulations in place before the thalidomide scandal.⁴⁰ Although most prosthetics were free of charge for the parents, refilling the carbon dioxide cartridges, used as a power source in some of them, was not. The cartridges could only be refilled at one place in the country, i.e. the Royal Institute of Technology in Stockholm. As well as such costs, frequent journeys were needed to attend medical check-ups and various training sessions, some of which were subsidized by the national insurance office, and some not. Sometimes the journeys could not be made on public transportation, due to the lack of accessible vehicles or lack of public transportation in the countryside, both of which required specially arranged travelling. Some medical treatments were free of charge, others were not. In stark comparison to these costs, it was free of charge for the parents to have a child placed in a state medical institution, as previously mentioned. If the child was cared for at an orphanage, however, the child welfare authorities could require the parents to pay a yearly fee for its care. The parents also had to pay a fee to keep their child in foster care.⁴¹

All these circumstances created a complex, economically challenging, and unequal situation for the thalidomide-affected children and their families and caretakers. When representatives of the national work groups regularly gathered in meetings in Stockholm, organized by the Medical Board, the chair, Bengt Örne, of the Neurosedyn Society was also present. The protocol from the meeting of 5 September 1963, illustrates some of the economic challenges that the parents of the affected faced, and that they wanted the problems solved. Örne raised the issue of the unequally distributed costs involved in caring for the children. The Neurosedyn Society wanted, he stated, all additional costs for the care and rehabilitation of the thalidomide affected to be covered by public funds: care

and rehabilitation should not impose any financial hardship on the parents of a thalidomide-affected child.⁴²

The thalidomide-affected children constituted the first generation of severely physically disabled in the Swedish welfare society to grow up in family homes, in accordance with the emerging principle of normalization. Under the previous 'total institution' paradigm this had not been the case. An existing, well-established structure of total institutions was in place; the structure of the new ideal of normalization was not as well established. The connection between the new normalization paradigm and the medical understanding of disability emphasized the need for ambitious rehabilitation activities. The new ideal led not only to ambitious rehabilitation activities, but also to substantial costs for individual families. The article will now turn to various efforts to solve the economic problems of the families involved in the rehabilitation programme. The various actors – parents, politicians, the Medical Board, the pharmaceutical company, and members of the rehabilitation staff – all helped ease the costs, in what was a mix of private and public solutions.

Actors at work

The parents

The Neurosedyn Society was started in 1962 by parents of thalidomide-affected infants. The initial aim of the Society was to increase the amount of public information about the thalidomide scandal.⁴³ By late 1962 and early 1963, the Society launched an awareness campaign in collaboration with the politicians Ruth Hamrin-Thorell and Arne Persson, according to a commemorative online publication of the Society.⁴⁴ In parliament, Hamrin-Thorell raised another issue in relation to the costs of caring for the thalidomide-affected children, i.e. that specialized training was needed for the parents to be able to properly care for their children at home. This training of course cost both time and money. Hamrin-Thorell also noted that in some Swedish counties, parents who stayed at home with a disabled child were economically compensated, whereas other counties offered no such compensation, increasing the problem of inequality. Hamrin-Thorell's raising of the issue in parliament led to a parliamentary enquiry about what was being done for the thalidomide-affected children. This prompted the minister of Home Affairs to require the Medical Board to respond to parliament, detailing all the actions taken in the care and rehabilitation of the thalidomide affected as well as the new pharmaceutical regulations enacted.⁴⁵

The response was presented in parliament on 4 December 1962. After this presentation, Hamrin-Thorell stressed two specific circumstances that, in her opinion, especially justified increased support to the thalidomide affected. The first circumstance was that public authorities had permitted the use of a medical compound that turned out to be fatal for the children. According to the parents of the affected, she claimed, it was a common view that society had in this way caused these harmful effects on the children; according to this claim, it was only reasonable for public authorities to take special responsibility. The second circumstance justifying special societal support for these children was that the families were aware of the cause of the injuries: the medical compound that the mother had been taking. This, according to Hamrin-Thorell, made their tragedy even greater than that faced by other parents of disabled children. To help

the parents cope with feelings of guilt, a special counsellor would be needed, Hamrin-Thorell argued. She then turned to an argument for economic support to the families and recalled the home-care situation of one family she had met. The child's external injuries from thalidomide were marginal, but the internal damage was far greater, as the child had no inner ear. Apart from deafness, this affected the child's sense of balance. The medical evaluation of the situation stressed the importance of several hours of daily training to realize the slim potential to develop some hearing capacity as well as to exercise the sense of balance. Hamrin-Thorell emphasized the difficulty, for the mother, of upholding such an exercise routine with the child for all the years it would be needed, and hiring someone to assist with the training was likely to be costly. To ease such care burdens, Hamrin-Thorell suggested a solution similar to that already in use for adult invalids who, due to lack of work income, were not entitled to an ordinary pension. Instead of an ordinary pension, they were granted an invalid pension of SEK 2000 yearly. A similar solution could be provided for the thalidomide-affected children, she suggested, to help the families care for the children at home and to equalize the uneven economic support from the county councils.⁴⁶

The national counsellor and the county councils

The uneven distribution of economic compensation from the counties to the affected families had been noted by parents in the Neurosedyn Society at an early stage. After the national counsellor Juhlin was informed of this, at the end of 1962 she wrote to all the Swedish county councils to inquire whether and how much they would compensate parents who took care of their thalidomide-affected children at home.⁴⁷ The letter from Juhlin to the Swedish counties stated that her questions were based on inquiries from several parents of thalidomide-affected children about the possibility of receiving economic support to care for their children. It included questions about whether their county offered economic compensation for childcare for thalidomide-affected children and, if so, how severe the child's injuries had to be to render the parents eligible.⁴⁸

The answers varied considerably. Blekinge County in southern Sweden stated that they had not assigned funds to support the home care of thalidomide-affected children. Göteborg and Bohus counties in western Sweden answered that they had delegated the matter to be decided on in each municipality in the counties, and that Juhlin would have to contact the counties' social welfare boards to get the information. The reply from Kopparberg County in central Sweden, however, indicated that a change had occurred. The letter from Kopparberg County was dated January 1963 and stated that due to a recommendation from the Board of the National Federation of County Councils in Sweden on 28 December 1962, Kopparberg County had decided to provide the same sort of economic compensation to parents caring for thalidomide-affected children at home as they would to parents caring for intellectually disabled children at home.⁴⁹

The recommendation from the Board of the National Federation of County Councils in Sweden, according to Kopparberg County, stated that it was 'appropriate that county council compensation for the care of the concerned children be provided', with a suggestion that the same provision that regulated compensation for the home care of people with long-term illness should guide the compensation paid to caregivers of the thalidomide affected. Additional replies to Juhlin's inquiry dated after the December 28

recommendation indicate that several county councils were following the new recommendation, even though no uniform set of regulations applied, as some county councils compensated for medical needs, while others conducted economic means testing before any compensation was made.⁵⁰

Discussion of a permanent solution regarding economic compensation for home care for the thalidomide affected continued even after the new recommendation had been issued, and a permanent solution in the form of a general care allowance for disabled children was suggested by the Swedish socio-political committee of 1963.⁵¹ The socio-political committee was assigned the task of collecting and compiling statistical information to illuminate the effects of certain socio-political actions, and of coordinating research activities in the socio-political field.⁵² A permanent solution was urgent, the committee emphasized, in order for society to promote home care, as there was a risk that home care might otherwise be hindered by economic considerations.⁵³

The pharmaceutical company

Before any permanent public solution was in place, however, another possibility of economic support, in the form of a fund, was launched by the pharmaceutical company Astra, which had been licenced to sell thalidomide in Sweden before it was withdrawn in December 1961. The Astra Fund, together with the Astra Neurosedyn-affected Children's Foundation, was established with a donation of SEK 1 million in 1963.⁵⁴ The purpose of the Fund, according to its statutes, was to 'facilitate the care, upbringing, or education' of thalidomide-affected children and youth, and 'the care of thalidomide-affected adults in need'. The Fund could also be used for 'research in areas of importance to the thalidomide affected'.⁵⁵

For such purposes, the Neurosedyn Society applied for and was granted SEK 5000 to facilitate 'contact' between parents of thalidomide-affected children, 'preferably travel and accommodation costs', according to the accompanying letter from the Fund. The Society was to distribute the money to parents wanting to meet with other parents of the affected. After the meeting, a list of costs would be sent to the Fund. A rather swift decision procedure is indicated by the dates: the application from the Neurosedyn Society was dated October 28 and the letter granting the funds was dated December 3.⁵⁶ Thus, the need for parental education, identified in parliament by the MP Ruth Hamrin-Thorell, could at least partially be addressed with money from the private sector. Annual reports from the Neurosedyn Society include several accounts of gatherings of parents and families with educational content, organized with the help of Fund money.⁵⁷

Even though Fund money was being used to facilitate Neurosedyn Society activities, the Society argued that Astra should take greater responsibility. The Society argued that the donation was not enough compensation for the damage that thalidomide had caused their children to suffer. Therefore, the Neurosedyn Society hired a lawyer and in 1965 filed charges against Astra. After several years in court, Astra and the Neurosedyn Society eventually reached a settlement according to which annual index-linked compensation would be paid to each affected child included in the settlement for their lifetime.⁵⁸

From 1963 onwards, although not all families were satisfied with the Astra Fund, it became standard procedure for the national counsellor, Juhlin, who was a co-opted member of the Fund's Board, to provide information to parents on how to apply for

money from the Fund to cover individual costs not covered by national or health insurance, in addition to information on how to apply for county council or municipal funding. On one such occasion, Juhlin was in contact with a family living in a coastal region. Due to the distance from Stockholm, they had not been in touch with the Eugenia Home; instead, their child was being treated at a regional hospital. Juhlin had been in touch with the family in 1964 to inform them of the possibility of applying for money from the Astra Fund. In 1968, she contacted them again, and was then informed that the child had undergone surgery at a private clinic. The parents had paid out of their own pocket for the surgery, which was conducted to increase the movement function in one of the limbs. Juhlin encouraged the family to apply for Astra funding to compensate for the costs of the surgery.⁵⁹

Another family initially informed Juhlin that they did not need any support from the Fund, other than perhaps for a 'bike with support wheels'. Later, however, the family applied for Fund money to cover the costs of broadloom carpet and a drying cabinet. Some years later, they had managed to acquire the house they had previously rented, and applied again, now for a financial contribution to adapt the kitchen to the needs of the child.⁶⁰

Another case clearly illustrates the complex challenges of home care facing a low-income family. The family had several children, and the mother stayed at home to care for the affected child. The mother had serious health issues of her own that complicated lifting the child. The father struggled with employment in various low-paid jobs. At times the family had difficulties finding housing and had to live with relatives. To cover the costs of travelling to the hospital, the family had to borrow money, and then had difficulties managing the repayments. The file on this case relates how Fund money was granted to pay for a driver's licence for the mother; this considerably alleviated the transportation problem, the mother later reported. Due to the family's problems, the mother hesitated to contact local 'authorities', as she was afraid that the child would be taken into custody. Juhlin informed the mother of the possibility of applying for Fund money not only to cover expenses in relation to the extra costs of doctor's appointments and physical therapy, but also for household appliances that would lighten the workload and give her more time to care for the child. Such appliances could be a dishwasher, washing machine, or a food processor Juhlin explained. In a letter to a social worker in the municipality where the family lived, Juhlin also explained that the family could apply to cover the costs of recreational activities. She clearly stated to the social worker that the Astra Fund could only be used to facilitate such things that the local municipality, county, or general health insurance did not cover.⁶¹

The medical board

Although the Astra Fund was not designed to cover the costs of social support or treatments already covered by general health insurance, the Director General of the Medical Board, Arthur Engel, had ideas of increasing the scope of the private fund when negotiations with the National Insurance Administration (Riksförsäkringsverket) were not as successful as hoped. In a written account, Engel reported that the Medical Board had consulted with the National Insurance Administration about the possibility of the thalidomide affected receiving compensation for home care from general health

insurance. However, the National Insurance Administration could not, at the time of these negotiations, approve of special support for the thalidomide affected, as that would mean that a certain group was receiving benefits that other groups were denied, according to prevailing legislation.⁶² This would counter the universalist principle of the social benefits.

Engel then suggested that the Astra Fund should adopt a 'more active stance' to 'meet demands for compensation' in situations in which public funds could not yet be granted, especially considering the long procedural time it took for new legislation to come into force. When public authorities could not immediately compensate for individual costs, the Astra Fund could be more active, he suggested. The Medical Board, Engel argued, supported the idea that state money could be added to the Astra Fund to cover costs not currently covered by the various social insurance agencies in the country. Such costs could include doctors' visits, hotel costs, physical therapy, etc. If the state provided money, all the requested compensation could then be provided by the Fund. Moreover, Engel reasoned, as the government would need figures for the estimated amount needed, the Astra Fund could provide information about what they already covered, to guide the governmental calculations.⁶³ Distributing public funds via a private fund in order to help thalidomide-affected children was a solution used in another European country, the United Kingdom. According to historian Jameel Hampton, a UK public donation of GBP 3 million to a private fund was arranged to avoid having a specific public scheme targeting the thalidomide affected. A special benefit for thalidomide victims within the National Health Service could have prompted similar demands from much larger groups of disabled British citizens, which the government wished to avoid.⁶⁴ The donation to the British thalidomide fund attracted a fair amount of media attention, and might have been brought to Engel's attention.⁶⁵ Whether Engel's 1963 suggestion was considered by parliament or the Astra Fund is unknown.

The government

In 1964, however, a government bill was passed that proposed a specific care allowance for disabled children, which largely followed Hamrin-Thorell's suggestion, but increased it to apply to all children with severe disability instead of only the thalidomide affected.⁶⁶ Behind the proposition stood the socio-political committee.⁶⁷ Active within the committee was the physician and Social Democratic MP Elisabet Sjövall, known for strong engagement in feminist and reproductive issues.⁶⁸ It is reasonable to surmise that her active role in the committee influenced the proposition.

The care allowance was organized via the national pension fund and was defined as an 'invalid benefit'. This benefit was to be provided to any child in long-term need of extensive supervision and care due to physical handicap, disease, or intellectual disability, without being means tested. The benefit amounted to SEK 2400 per year and was index linked. The new allowance entered into force on 1 July 1964.⁶⁹ At the same time, state funding was legally granted for 'certain technical aids, intended to facilitate everyday life'.⁷⁰ With this benefit, all severely disabled children in Sweden could benefit from a universalist solution to a problem that to that point had been solved with a bricolage of solutions.

Before the proposition was passed in parliament, it was sent out to a round of consultations with various stakeholders, of which the Medical Board was one. In their

consultation comment, the Medical Board emphasized the importance of the childcare allowance, because it would encourage the families of disabled children to care for their children on their own. They also stressed the importance of family relations for the emotional development of the child.⁷¹

Conclusions

As this study suggests, the process of developing a social support system that included the thalidomide affected was not 'neat and unified' – to quote Sjöblom. Instead, it was a complex process in which both tax-funded and private initiatives were used to address the economic needs of the affected and their families. From this account of welfare policy 'in the making', it is evident that several actors were involved in providing solutions for the children. The influence of the children's spokespersons, i.e. their parents, cannot be underestimated. They gathered early on to form the Neurosedyn Society and promote increased information dissemination, and later strove for the social inclusion of their children. They recruited politicians to their cause and provided information to the rehabilitation programme and the Medical Board. They demanded the economic possibility of caring for their children at home, and equal economic rights in raising their children. Politicians, in turn, acted on their behalf in parliament and, through information, parliamentary questions, and bills, emphasized the urgency of meeting the economic needs for rehabilitation and normalization. The Medical Board provided information to the county councils, facilitated support through negotiations with the National Insurance Administration, and, when that did not work out as suggested, the General Director considered other solutions, such as providing public funding through the private Astra Fund. On another level, the national counsellor, by means of her questions to all the county councils, influenced the national recommendation issued at the end of 1962.

Astra, the pharmaceutical company, assisted by launching the Astra Fund. In the years that followed, the Fund helped cover the many expenses not covered by the general health insurance or through other public arrangements, even after the new legislation on the childcare allowance came into force. Thus, a mix of public and private solutions continued to coexist, even after a universalist welfare solution was in place.

It is also notable that, as this legislation was put into action, it covered not only the thalidomide-affected children, but all severely disabled children in need of extensive, long-term care and supervision. In that way, the situation of the thalidomide affected, and the actions of all involved, also came to benefit other groups of disabled children that had previously been marginalized within the system.

The social support system, incorporating both public and private solutions, was intimately tied to the ideal of normalization. The underlying assumption, that to be able to live meaningful lives outside institutions, the physical bodies of the thalidomide affected had to be adjusted to resemble 'normal bodies', clearly influenced the construction of the rehabilitation programme. Its many activities, in turn, generated new costs that had to be covered by, as it turned out, both public and private actors within the welfare state.

Apart from contributing to our knowledge of the Swedish welfare system in the 1960s, the present findings also contribute to both disability history and the history of medicine. The findings illustrate the benefits of studying welfare states through the lens of disability.

In the emergence of the new paradigm of normalization, which included aspects of a social understanding of disability, the underlying medical understanding of disability was still present and very much active, influencing actors at all levels, from families to policy makers. Thus, both the social and medical understandings of disability were co-produced and merged into the rehabilitation programme as well as to the economic solutions. In this way, the thalidomide scandal and its consequences illustrate aspects of the social ordering of 1960s Swedish welfare society. As we have seen, although the thalidomide affected were welcomed into the welfare state, their admission into spheres other than hospitals and institutions for the disabled was conditioned by certain requirements that included striving towards physical normality.

Notes

1. Lundberg and Åmark, "Social Rights," 157.
2. Lindqvist, "Swedish Disability Policies," 217–21, and "Swedish Disability Policy," 400.
3. Sjöblom, "The Business of Welfare," 619. For a discussion of the various influences of private and public welfare solutions internationally, see, for example, Nullmeier and Kaufmann, "Post-War Welfare State Development"; Hacker, *The Divided Welfare State*; and Kaufmann, *Variations of the Welfare State*.
4. Kudlick, "Why We Need Another 'Other'," 766.
5. Quirk, "The Impact of Thalidomide"; Ceccoli, "Divergent Paths"; Moro and Invernizzi, "The Thalidomide Tragedy"; Daemmrich, "A Tale of Two Experts"; and Lee, "Unruly Bodies, Unruly Statistics."
6. Chisholm, "The Curious Case"; Klausen and Park, "Are We Going"; Parker, "From Immorality to Public Health"; Lennerhed, "Sherri Finkbine"; and Löwy, *Imperfect Pregnancies*, chapter 3.
7. Paulsson, 'Dom säger'.
8. Ericsson, *From institutional life*.
9. See, however Chisholm, *Life After the Scandal*; Sewell, "If One Member"; and Roskies, *Abnormality and Normality*.
10. Björkman, "Thalidomide in the Welfare State."
11. The archive of the National Counsellor contains material that indicates that information (including press clippings) from abroad was gathered, or obtained, mainly about research on the classification of malformations, medical treatment, lawsuits concerning pharmaceutical companies, and the social situation of the affected children. However, regarding the arrangement of welfare solutions internationally, the material is scant.
12. Jasanoff, *States of Knowledge*, 274–5.
13. d'Avignon, Hellgren, and Juhlin, "Thalidomidskadade barn," 2786.
14. Tydén, *Från politik till praktik*; Grunewald, *Från idiot till medborgare*; and Björkman, *Vård för samhällets bästa*.
15. Juhlin, "Neurosedynbarnens problem," 1–2; and Paulsson, *Dom säger*.
16. Juhlin, "Neurosedynbarnens problem."
17. Juhlin, *Rikskuratorn*, 99–105.
18. NA, F2:1, 'Synpunkter framförda på Medicinalstyrelsens sammanträde 5. september 1963', notes by Inga-Maj Juhlin.
19. See note 7 above.
20. Hugemark and Roman, "Diversity and Divisions"; Tøssebro, "Introduction"; and Söder, "Swedish Social Disability Research."
21. Holme, "Disability, Identity and Ageing," 37; and Grunewald, *Från idiot till medborgare*, 30–31.
22. SOU 1946:24, *Förslag*; see also Ericsson, *From Institutional Life*; and Lindqvist, "Swedish Disability Policies," 218–20.
23. Förhammar, *Staffan Från tärande till närande*.

24. Lindqvist, "Swedish Disability Policies," 217–19.
25. Juhlin, "Neurosedynbarnens problem."
26. Ibid. See also Lennerhed, "Kvinnan, aborten och teratologin," 152–54.
27. Lagercrantz, "Kvinnan i Liège."
28. Juhlin, "Neurosedynbarnens problem". See also Juhlin's later discussion on the complexities of the issue of foster care in Juhlin, *Rikskuratorn*, 99–105.
29. Björkman, "Thalidomide in the Welfare State"; and Paulsson, Karin *Dom säger*.
30. Haegele and Hodge, "Disability Discourse."
31. See note 7 above.
32. For a more detailed account of the events of the formation and early attempts of the rehabilitation program, see Björkman, "Thalidomide in the Welfare State."
33. National Archive (hereafter NA), F2:1, "VPM angående vården av neurosedynskadade barn," November 17, 1962, 1.
34. NA, F2:1, Medical Board Protocol, January 30, 1963, 'Överläggningar ang den fortsatta vården av de neurosedynskadade barnen'.
35. Ibid.
36. NA, F2:1, Work material, parliamentary question, "Vården av de neurosedynskadade barnen," 5.
37. See note 33 above.
38. NA, F2:1, Work material, parliamentary question, "Vården av de neurosedynskadade barnen," 2–3.
39. NA, F2:1, PM from the Medical Board in reply to complaint to the Parliamentary Ombudsman, "Medicinalstyrelsens yttrande över JO-anmälan av neurosedynfrågan, remiss," February 10, 1964, 21.
40. Ibid.
41. NA, F2:1, 'Synpunkter framförda på Medicinalstyrelsens sammanträde 5. september 1963,' notes by Inga-Maj Juhlin, 1.
42. Ibid.
43. *Vad var det som hände?* 9, 11.
44. Ibid., 10.
45. NA, F2:1, Society for the Neurosedyn Affected, Cirkulär A43, 'Interpellation i Riksdagens andra kammare av fru Ruth Hamrin-Thorell den 16. oktober 1962'; The Swedish counties (24 at the time) were (and are) autonomous regions with responsibility for healthcare, public transport, and regional development.
46. *Riksdagens protokoll, Första kammaren nr 34, 1962, 30. november–5. desember. Debatter m.m.*, 5–10.
47. NA, F2:2, Folder 'Uppsatser om N-barn', Gunler m.fl., Specialarbete 66–67.
48. NA, F2:1, Folder 'Förfrågningar om landstingens bidragsgivning till N-skadade barn nov 1962'.
49. Ibid., letters from: Blekinge County Council, December 10, 1962; Göteborg and Bohus county councils, December 3, 1962; and Kopparberg County Council, January 4, 1963.
50. Ibid., see replies from: Kalmar County, January 21, 1963; Kristianstad County, January 18, 1963; and Luleå County, 29 and 30 January, 1963; Folder 'Uppsatser om N-barn', Gunler m.fl., Specialarbete 66–67.
51. See note 47 above.
52. SOU 1964:59, *Ett socialpolitiskt utredningsinstitut. Förslag av socialpolitiska kommittén*.
53. See note 47 above.
54. NA, F2:5, Folder 'Handlingar rörande neurosedynfrågan 1966–1972'; *Förslag av Handikapputredningen: Vård och undervisning av barn med talidomiskador*, Stockholm, July, 1966, 7.
55. NA, F4c:1, Föreningen för de neurosedynskadade 1963–1972, letter from the Astra Fund to the Neurosedyn Society, January 14, 1964.
56. NA, F4c:1, Föreningen för de neurosedynskadade 1963–1972. Letter from Å Steineck, December, 1963, to the Neurosedyn Society.
57. Ibid. F4c:1, Folder 'FfdN 1963–1972'. Skrivelser, stadgar.

58. Nilsson and Sjöström, *Pillret som väckte världen*, 206–12.
59. NA, F1A:1, Personal dossier.
60. Ibid.
61. Ibid.
62. NA, F2:1, PM by Engel, Arthur, 'Synpunkter på nuv resurser för vård och behandling av neurosedynskadade barn och för eventuellt föreliggande planer att utvidga dessa resurser'. The PM is not dated, but contains information about a meeting September 27, 1963, which indicates the PM is written after that.
63. Ibid., 2–3.
64. SOU 1964:59, *Ett socialpolitiskt utredningsinstitut*, 4.
65. Hampton, *Disability and the Welfare State in Britain*, 167. Later, in Germany, a legal settlement with the Grünentahl pharmaceutical company responsible for thalidomide provided money for a fund benefitting German thalidomide victims. This fund was later supported by federal economic contributions; see Chisholm, *Life after the Scandal*, 102–23.
66. NA, F2:1, PM from the Medical Board in reply to complaint to the Parliamentary Ombudsman, "Medicinalstyrelsens yttrande över JO-anmälan av neurosedynfrågan, remiss," February 10, 1964.
67. See note 47 above.
68. SOU 1964:59, *Ett socialpolitiskt utredningsinstitut*, s. 4; and Lennerhed, "En besvärlig människa."
69. Kungl. Maj:ts proposition nr 94, 1964," 1–2.
70. See note 66 above.
71. See note 47 above.

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References

Archive sources

Riksarkivet (Swedish National Archive). "Medicinalstyrelsens arkiv, Rikskuratorn för neurosedynfrågan."

Printed sources and literature

Agerberg, Miki. "Allt började med Neurosedynkatastrofen." *Läkartidningen* 108, no. 48 (2011): 2474–2476.

Björkman, Jenny. "Vård för samhällets bästa: Tvångsvård av sjuka och missbrukare i Sverige 1850–1970." PhD diss., Carlsson, Stockholm, 2001.

- Björkman, Maria. "Thalidomide in the Welfare State: Rehabilitation and Contested Normality." In *Medicine at the Borders of Life. Fetal Research and the Emergence of Ethical Controversy in Sweden*, edited by Solveig Jülich. forthcoming.
- Ceccoli, Stephen. "Divergent Paths to Drug Regulation in the United States and in the United Kingdom." *Journal of Policy History* 12 (2002): 135–169. doi:10.1353/jph.2002.0008.
- Chisholm, Christine. "The Curious Case of Thalidomide and the Absent Eugenic Clause in Canada's Amended Abortion Law." *Canadian Bulletin of Medical History* 33 (2016): 493–516. doi:10.3138/cbmh.33.2.162-26062015.
- Chisholm, Christine. *Life After the Scandal: Thalidomide, Family, and Rehabilitation in Modern Canada, 1958–1990*. PhD diss., Carleton University, 2019.
- Daemmrich, Arthur. "A Tale of Two Experts: Thalidomide and Political Engagement in the United States and West Germany." *Social History of Medicine* 15 (2002): 137–158. doi:10.1093/shm/15.1.137.
- D'Avignon, Marcel, Karin Hellgren, and Inga-Maj Juhlin. "Thalidomidskadade barn, erfarenheter från Eugeniahemmet." *Läkartidningen* 61 (1964): 2786–2792.
- Ericsson, Kent. *From Institutional Life to Community Participation. Ideas and Realities Concerning Support to Persons with Intellectual Disability*. Ph.D Diss, Uppsala Studies in Education 99, Uppsala University Library, Uppsala, 2002.
- Förhammar, Staffan. *Från tärande till närande: funktionshinder, utbildning och socialpolitik i Sverige*. Lund: Studentlitteratur, 2007.
- Grunewald, Karl. *Från idiot till medborgare: De utvecklingsstördas historia*. Stockholm: Gothia, 2008.
- Hacker, Jacob S. *The Divided Welfare State: The Battle Over Public and Private Social Benefits in the United States*. NY: Cambridge University Press, 2002.
- Haeghele, Justin Anthony, and Samuel Hodge. "Disability Discourse: Overview and Critiques of the Medical and Social Models." *Quest* 68, no. 2 (2016): 193–206. doi:10.1080/00336297.2016.1143849.
- Hampton, Jameel. *Disability and the Welfare State in Britain. Changes in Perception and Policy 1948–1979*. Bristol: Policy Press, 2016.
- "Hjälp åt fosterskadade." *Dagens Nyheter*, October 29, 1962.
- Holme, Lotta. "Disability, Identity and Ageing." In *Ageing with Disability: A Lifecourse Perspective*, edited by Eva Jeppsson Grassman and Anna Whitaker, 35–53. Bristol: Bristol University Press, 2013.
- Hugemark, Agneta, and Christine Roman. "Diversity and Divisions in the Swedish Disability Movement: Disability, Gender, and Social Justice." *Scandinavian Journal of Disability Research* 9, no. 1 (2007): 26–45. doi:10.1080/15017410600979553.
- Jasanoff, Sheila, ed. *States of Knowledge: The Co-production of Science and Social Order*. New York: Routledge, 2004.
- Juhlin, Inga-Maj. "Neurosedynbarnens problem – främst föräldrarnas problem." *Socionomen* 8 (1963): 1–2.
- Juhlin, Inga-Maj. *Rikskuratorn: Omhändertagandet av de neurosedynskadade barnen 1962–1970*. Stockholm: Carlsson, 2012.
- Kaufmann, Franz-Xaver. *Variations of the Welfare State. Great Britain, Sweden, France and Germany Between Capitalism and Socialism*. Dordrecht: Springer, 2013.
- Klausen, Susanne, and Julie Park. "'Are We Going to Stand by and Let These Children Come into the World?': The Impact of the 'Thalidomide Disaster' in South Africa, 1960–1977." *Journal of South Africa Studies* 41 (2015): 735–752. doi:10.1080/03057070.2015.1047181.
- Kudlick, Catherine J. "Why We Need Another 'Other'." *The American Historical Review* 108, no. 3 (2003): 763–793. doi:10.1086/529597.
- "Kungl. Maj:ts proposition nr 94 år 1964." Assessed December 30, 2021. https://www.riksdagen.se/sv/dokument-lagar/dokument/proposition/kungl-majts-proposition-nr-94-ar-1964_EP3094
- Lagercrantz, Olof. "Kvinnan i Liège." *Dagens Nyheter*, 19621109
- Lee, Francis. "Unruly Bodies, Unruly Statistics: Thalidomide and the Birth of Swedish Reproduction Epidemiology in the Early 1960s." In *Medicine at the Borders of Life. Fetal Research and the Emergence of Ethical Controversy in Sweden*, edited by Solveig Jülich. forthcoming.

- Lennerhed, Lena. "En besvärlig människa: Om Elisabet Sjövall, sexualiteten och kvinnligheten." *Tidskrift för genusvetenskap* 34, no. 4 (2013): 117–135. doi:10.55870/tgv.v34i4.3349.
- Lennerhed, Lena. "Kvinnan, aborten och teratologin." *Lychnos: årsbok för idé- och lärdoms historia* (2015): 141–163.
- Lennerhed, Lena. "Sherri Finkbine Flew to Sweden: Abortion and Disability in the Early 1960s." In *Abortion Across Borders: Transnational Travel and Access to Abortion Services*, edited by Christabel Sethna and Gayle Davis, 25–45. Baltimore: Johns Hopkins University Press, 2019.
- Lindqvist, Rafael. "Swedish Disability Policies: Ideas, Values and Practices in a Historical Perspective" In *The Routledge History of Disability*, edited by Roy Hanes, Ivan Brown, and Nancy E. Hansen, 216–230. London: Routledge, 2018.
- Lindqvist, Rafael. "Swedish Disability Policy: From Universal Welfare to Civil Rights." *European Journal of Social Security* 2, no. 4 (2020): 399–418. doi:10.1023/A:1011532222021.
- Lundberg, Urban, and Klas Åmark. "Social Rights and Social Security: The Swedish Welfare State, 1900–2000." *Scandinavian Journal of History* 26, no. 3 (2001): 157–176. doi:10.1080/034687501750303837.
- Löwy, Ilana. *Imperfect Pregnancies: A History of Birth Defects and Prenatal Diagnosis*. Baltimore: Johns Hopkins University Press, 2017.
- Moro, Adriana, and Noela Invernizzi. "The Thalidomide Tragedy: The Struggle for Victims' Rights and Improved Pharmaceutical Regulation." *História, Ciências, Saúde-Manguinhos* 24 (2017): 1–19. doi:10.1590/s0104-59702017000300004.
- "Neurosedynets offer." *Svenska Dagbladet*, December, 4, 1962.
- Nilsson, Robert, and Henning Sjöström. *Pillret som väckte världen*. Stockholm: Sjöström & Sjöström, 1972.
- Nullmeier, Frank, and Franz-Xaver Kaufmann. "Post-War Welfare State Development." In *The Oxford Handbook of the Welfare State*, edited by Francis G. Castles, Herbert Obinger, Christopher Pierson, Stephan Leibfried, and Jane Lewis, 81–104. Oxford: Oxford University Press, 2009.
- Parker, Clare. "From Immorality to Public Health: Thalidomide and the Debate for Legal Abortion in Australia." *Social History of Medicine* 24 (2012): 863–880. doi:10.1093/shm/hks036.
- Paulsson, Karin. "Dom säger att jag ser mer normal ut med benproteser": Om samhällskrav kontra barns behov. PhD diss., Stockholm University, Stockholm, 1995.
- Quirke, Viviane. "The Impact of Thalidomide on the British Pharmaceutical Industry: The Case of Imperial Chemical Industries." In *Ways of Regulating: Therapeutic Agents Between Plants, Shops and Consulting Rooms*, edited by Jean-Paul Gaudillière and Volker Hess, 137–152. Berlin: Max Planck Institute, 2008.
- Riksdagens protokoll, Första kammaren nr 34, 1962, 30. november–5. december. Debatter m.m. Accessed December 30, 2021. https://www.riksdagen.se/sv/dokument-lagar/dokument/protokoll/30-november-5-december_en9d34
- Roskies, Ethel. *Abnormality and Normality: The Mothering of Thalidomide Children*. Ithaca: Cornell University Press, 1972.
- Sewell, Claire. "If One Member of the Family is Disabled, the Family as a Whole is Disabled': Thalidomide Children and the Emergence of the Family Carer in Britain, C. 1957–1978." *Family & Community History* 18 (2015): 37–52. doi:10.1179/1463118015Z.00000000038.
- Sjöblom, Alf. "The Business of Welfare." *Scandinavian Journal of History* 44, no. 5 (2019): 617–639. doi:10.1080/03468755.2018.1562966.
- SOU 1946:24. *Förslag till effektiviserad kurators- och arbetsförmedlingsverksamhet för partiellt arbetsföra m.m.*
- SOU 1964:59. *Ett socialpolitiskt utredningsinstitut. Förslag av socialpolitiska kommittén.*
- Söder, Märten. "Swedish Social Disability Research: A Short Version of a Long Story." *Scandinavian Journal of Disability Research* 15, no. 1 (2013): 90–107. doi:10.1080/15017419.2013.781961.
- Tydén, Mattias. *Från politik till praktik: De svenska steriliseringslagarna 1935–1975.* PhD diss., Stockholm University, Stockholm, 2002.
- Tøssebro, Jan. "Introduction to the Special Issue: Understanding Disability." *Scandinavian Journal of Disability Research* 6, no. 1 (2004): 3–7. doi:10.1080/15017410409512635.
- Vad var det som hände? Föreningen för de Neurosedynskadade.* Accessed December 30, 2021. <https://docplayer.se/115266742-Neurosedyn-vad-var-det-som-hande.html>