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The Personalisation of Social Care: How Can a Healthcare System Be Adapted to the Specific Characteristics of People with Multiple Impairments? The case of the care of people with "rare disabilities" in France

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Abstract

Since the 1980s, "personalisation" is at the centre of the evolution of disability policies and more generally of the Welfare state. It refers on one hand to the question of self-determination through the allocation of personalised budgets, and on the other to the adaptation of care to the specificities of a given person, through the development of "person-centred" care. In this article we study the issue of the personalisation of care from a point of view intermediate to these two dimensions, that of the transformation of social care organisations. Using the example of care provided to people with multiple impairments in France, we analyse how new social care organisations have addressed the diversity and specificity of the needs of these people. This analysis thus proposes a new way to think about the personalisation of policy responses implemented by the welfare state.

Keywords: Social care; rare disability; de-institutionalisation; personalisation; disabled people's associations

Introduction

Since the 1980s, "personalisation" is at the centre of the evolution of disability policies (Mladenov et al., 2015; Power et al., 2021) and more generally of the Welfare state (Needham, 2011; Tournadre-Plancq, 2010). It refers to the question of self-determination, enabled by personal budgets (Scourfield, 2005), as well as to the adaptation of care to the specificities of a given person, through the development of "person-centred" care (Daly and Westwood, 2018; Prandini, 2018). For disability policies, this personalisation of public interventions took place as well in the context of an important reshaping of the political models of disability, from a medical model towards a social model of disability (Barnes, 2012; Oliver, 1990). The medical model of disability defines disability as an individual issue that should be repaired through a medical intervention. It is rooted in the tradition of assistance to persons with disabilities, which relied on asylum-like facilities. This model derives from the development of rehabilitation practices in the 20th century based on the normalisation of people with disabilities. In most Western countries, this model fostered the provision of accommodation and care to people with disabilities in specialised settings.

Starting in the 1970s in anglophone countries, disabled people's movements criticised this medical model and promoted a social model of disability. They had multiple criticisms but focused notably on specialised facilities that operated as segregating total institutions (Goffman, 1961). They demanded instead to be integrated into so-called 'ordinary' society. In that regard, they supported the concept of mainstreaming (Duygun, 2020; Zola, 1982) and of community care (Morris, 2004; Power et al., 2021; Scourfield, 2005). This protest led to what was called a de-institutionalisation process (Henckes, 2018; Hudson, 1991; Pedersen and Kolstad, 2009; Tøssebro, 2016). This process took place concurrently across all European countries. In each of them, it led to the reorganisation of the support and accommodation services intended for disabled people. However, it adopted different forms in each country. In Scandinavia (Saloviita, 2002; Tøssebro, 2016; Tøssebro *et al.*, 2012) and Italy (Chapireau, 2008; D'Alessio, 2012), it led to legislation ordering traditional institutions to be closed and the emergence of small housing units. In the United Kingdom, this movement was slower (Hudson, 1991), and then took on a new form following the austerity policies implemented during the economic crisis of the 2000s. This policy accelerated the closing of certain services along with the government's tendency to relegate their organisation either to the voluntary sector, the community, or even the free market (Needham, 2014; Power and Bartlett, 2018; Roulstone, 2015). In France, this change in support for disabled people focussed on the creation of in-home assistance services, starting in the 1980s (Capuano, 2012). However, this did not lead to the closure of specialised institutions (Claveranne *et al.*, 2012). Social participation of people and inclusion in mainstream environments were also emphasised from the 2000s, with the enactment of two laws revamping French disability policy in 2002 and 2005 (Winance *et al.*, 2007)[1].

The above studies analysed the process of de-institutionalisation as a process involving the closure of large, specialised institutions. They also suggested this closure was part of a transformation of the organisation and form of care without, however, analysing this process in depth. In this article, we explore the history of care for people with multiple impairments in France from 1960 to 2014 and show that changes in these specialised institutions occurred as the concept of care gradually became the focus of their concerns. These changes included adapting care to the specific needs of disabled persons as well as organising it from a practical and policy perspective. By employing the notion of social care (Daly and Lewis, 2000; Daly, 2002), we examine the way care adapted to these people was gradually reorganised within the French care system. Daly and Lewis developed this concept as a tool to analyse change in welfare states – more specifically, to analyse the transformation of the 'social and political economy within which [care] is embedded' (2000: 284). The use of this notion leads to the interaction of two levels of analysis: the macro level of care infrastructures and the micro level of care practices. At the macro level, it's a question of understanding the way in which the provision of care is shared by the state, the marketplace, the family and the voluntary sector; and how responsibilities are defined among these actors. On the micro level, it's a question of analysing the conditions related to performing care activities. In following this approach, we will carry out a dual analysis.

First, we will examine the way activities by a parents' association have succeeded in transforming care for people with multiple impairments. Gradually, this association shifted its view on how to organise personalised care for people with multiple impairments from an approach based on impairments to one based on the very specialised and personalised care that these people need (Nilholm *et al.*, 2013). This shift resulted in the emergence of a new category, that of 'rare disabilities', that was then used by the State to organise care and to create a new care organisation, the 'national rare disability resource centres' (*centres nationaux de ressources handicaps rares*). Second, through a description of the operation of two of these centres, we will examine the way in which each of them has worked to reduce the gap between the particular needs of people with rare disabilities and the existing healthcare system. Linking the notion of social care with a geographical perspective focusing on local contexts (Power, 2009), we will also show how each of these centres aims to organise personalised and adapted care that takes into account both the uniqueness of each person as well as specificities in the territorial organisation of the healthcare system. In this way, this analysis allows us to further examine the issue of personalisation of care by placing ourselves at the level of social care organisations, which represents an intermediate position in regard to the two dimensions we mentioned above (personalisation of budget or personalisation of care practices).

Methods

This article is based on two surveys, one historical and the other ethnographic. The historical survey consisted in analysing the files of an association, the Action and Coordination Committee of Parents of Children and Adults with Multiple Disabilities (*Comité de Liaison et d'Action des Parents d'Enfants Atteints de Handicaps Associés* - CLAPEAHA). Starting in the 1960s, this association undertook political action to gain recognition of the problem of children with multiple impairments. We reviewed their archives (dated from 1965 to 2013) and established a corpus consisting of the president's reports, activity reports, the minutes of the general assembly, and letters exchanged between parents and the association. The ethnographic survey focused on two national rare disability resource centres and was carried out between March 2014 and June 2016, a period during which we spent one day per week at each of these two centres. This survey consisted of research based on documents (activity reports, presentation documents, individual files), formal and informal interviews with professionals and observations of meetings. A thematic analysis was conducted by the two authors of this article using Atlas.ti© and Quirkos©.

The remainder of the article is divided into four sections. First, we review the historical context. Second, we analyse the activities of CLAPEAHA in promoting a new way of organising personalised social care through the use of national rare disability resource centres. In the third section, we analyse the decisions made by two of these centres as a result of their specific organisational and demographic context. We then discuss the issues this history raises with regards to the dual question of personalisation of social care and de-institutionalisation. We conclude by summarising the importance of this analysis from a theoretical perspective.

Historical context: the development of institutions for disabled people in France

In France, the development of specialised institutions dedicated to caring for and educating disabled children has a long history. At the end of the 18th century, it concerned deaf or blind children (Buton, 2009), then at the end of the 19th, children with learning disabilities, and later on children with physical disabilities. These establishments offered day care and in some cases overnight board as well. They offered children medical care along with a suitable education. Most of these specialised institutions were managed by associations of parents of children with disabilities (Barral, 2007), but they were publicly funded and subject to government scrutiny. The terms 'medical-educational' (*médico-éducatif*) and later 'medical-social' (*médico-social*) were used to describe this specialised sector. The organisation and government oversight of this medical-educational sector were based on a dual rationale of categorising children and categorising institutions. This rationale was formalised in the annexes of a decree initially published in 1946. This text defined what children were to receive specialised care, and the types of institution authorised to offer such care. In doing so, it categorised children according to two criteria: the nature of the impairment (mental, motor, sensory), and the child's assessed level of 'educability': 'uneducable', 'semi-educable', and 'educable'. In a new version of the text in 1970, this terminology was replaced with the terms 'severe, medium, or slight retardation', referring to a measurement of intellectual quotient. Moreover, the text defined the type of care and facility suitable for each category of child. Regardless of their impairments, children who were considered 'uneducable' went to a hospice or a psychiatric hospital; those who were considered 'educable' went to a medical-educational institute, according to the nature of the impairment; and those who were considered 'semi-educable' could be cared for by either of these institutions, depending on whether they had multiple impairments or not. This institutional sorting, based on the impairment and level of 'educability', led to the exclusion of certain children from specialised medical-educational institutions. The children were left with their family or placed in psychiatric wards, with no educational support, either because they were still considered 'uneducable' or later 'severely retarded', or because they had a combination of impairments instead of only one of the impairments listed. From the mid-1960s, the absence of any specialised educational care for those children became unacceptable for their parents, who united to form a new association.

The actions of CLAPEAHA: from creating institutions to introducing specialised care

In 1968, the Action and Coordination Committee of Parents of Children and Adults with Multiple Disabilities (*Comité de Liaison et d'Action des Parents d'Enfants Atteints de Handicaps Associés* or CLAPEAHA) was created by the parents of a deafblind girl. Its purpose was to raise awareness around the difficulties encountered by people with multiple impairments, to reflect on potential solutions for them, and to support existing actions. To do so, CLAPEAHA conducted surveys intended to identify people with a combination of disabilities. The results of these surveys led it to emphasise the specific nature of the educational techniques that certain children with multiple impairments needed as a result of the combination of these impairments (Winance and Barral, 2013). For example, a deafblind child may not be able to communicate using oral language or common sign language; rather, they need a very specific communication technique adapted to their abilities, which may differ from one individual to another.

In parallel, CLAPEAHA sought concrete ways to organise this care adapted to these people. From the outset the committee was faced with the discrepancy between the category-based rationale of the French medical-social sector, which it initially shared, and the maladaptation of existing categories to the uniqueness of each person with multiple impairments. It wished first to create specialised institutions according to new categories that would be homogeneous because they would be based on the nature of impairments. But these categories would be applied to a population that was heterogeneous, as it was composed of people who shared only the common element of having multiple impairments, and whose care was always unique as a result of this personal combination of impairments.

A related problem was the potential discrepancy between collective care and personalised care: how could one reconcile a category-based organisation of care with the personalisation of this care? How can collective care and personalised care coexist? This dilemma between 'category-based care' and 'maximum specialisation based on individual needs' was central to CLAPEAHA's approach to the organisation of care and to the evolution of its thinking. Initially, CLAPEAHA sought to establish itself within the existing organisation of the medical-educational sector, but it eventually led to proposals for an innovative care organisation for people with multiple impairments.

Organising highly-specialised institutions as a function of combinations of impairments

During the 1960s and 1970s, CLAPEAHA adhered to the category-based rationale for organising the medical-educational sector. It sought to promote the creation of institutions dedicated to new categories of children defined according to combinations of impairments, and the need for specific educational techniques. Such institutions had to be highly specialised. However, CLAPEAHA quickly realised that this hyper-specialisation of establishments entailed two overlapping difficulties: the issue of the staff employed; and that of the geographical dispersion of the people who had similar, yet uncommon combinations of impairments.

Regarding staff, specialisation required a larger and – most importantly – a more qualified workforce than did traditional institutions. However, during the 1970s and 1980s, working with people with multiple impairments was seen as demeaning, because these people were always considered 'uneducable' and incapable of changing. Caring was seen as mere nursing, without any added value. Challenging these representations, CLAPEAHA advocated the view that working with these people was rewarding because it required sophisticated technical skills and competence to educate them. CLAPEAHA's point was that the more disabled a child was, the more qualifications and skills were required to accompany them. Lastly, the skills of the professionals caring for and educating these children were based on accrued and contrasting experience with several of these children grouped together. Hence, the specialised knowledge of these professionals was acquired through working with children having the same combinations of impairments, in the same institution.

Related to the issue of staff training was that of the geographical dispersion of people with similar combinations of impairments who could be cared for at the same institution. Children with these specific combinations were scattered across the entire country. In order to bring together enough children with similar combinations of impairments – and thus enable care-givers to become more specialised by working with the same type of impairment – these institutions needed to be able to take in persons from all over France. However, during the 1980s, several changes took place simultaneously, making it difficult to develop highly-specialised institutions catering to children from across France. The economic context was less favourable to the creation of new, specialised institutions. The administrative context changed as well. France implemented a decentralisation policy: the responsibility for institutions and specialised services was transferred to local authorities (*départements*). They were granted the authority to make decisions regarding the opening of institutions, and to oversee their operations. As a result, institutions were required to recruit the people they care for locally, and on this scale it became difficult to bring together enough children with the same combinations of impairments. This context led CLAPEAHA to modify its approach and to no longer think in terms of institutions but rather in terms of specialised care.

Creating resource centres to adapt and foster specialisation of care across France

Faced with these difficulties in creating highly specialised institutions, CLAPEAHA shifted its focus and examined a new way of compensating for the maladaptation of existing institutions for children with multiple impairments. It proposed a new way of defining the persons concerned and of designing the organisation of their care. With respect to how it defined them and classified them within a common category, it shifted its attention from combinations of impairments to the difficulty some people encountered in finding suitable care and to their geographical dispersion throughout the country. At the time, it used multiple concepts to refer to these people, including 'the excluded of the excluded', 'minority', and 'rarity'. Using such terms allowed it to emphasise what it believed to be the common ground shared by these individuals: their exclusion from existing institutions and their need for specialised and personalised care techniques.

The concept of rarity was then progressively preferred. CLAPEAHA used it in reference to the national territory to stress the small number of people concerned and their geographic dispersion. This rarity pertained also to the issue of the 'specialisation and personalisation of care'. If these people were excluded from existing care, it was because they needed specialised and personalised care that was itself rare in the medical-social sector of the time.

Reference to this twofold rarity – few people facing these problems and highly specialised techniques – allowed CLAPEAHA to highlight the main issue: the discrepancy between the specific needs of some people and the healthcare offering in the form in which it was organised in France. Above all, it allowed it to propose a new way of addressing this gap by creating, instead of highly specialised institutions, what it would call national rare disability resource centres

(*Centres Resources Nationaux Handicaps Rares*). These were designed as centres of expertise composed of professionals recognised for their specialised skills in accompanying people with multiple impairments. Their role was to provide support to local professionals accompanying people with multiple impairments but who lacked the required highly specialised knowledge. This support was envisaged in two ways: the training of local professionals, or intermittent support to specific people and their care-givers.

Starting in the 1990s, CLAPEAHA advocated for the creation of these resource centres as the solution to organising highly specialised care for people with certain combinations of impairments, scattered across the country. In 1998, three national rare disability resource centres were opened experimentally. The term 'rare disability' was itself officially defined in a 2000 decree based on three criteria: the rate of prevalence of certain combinations of impairments, a list of combinations, and the need to use specialised techniques. However, the government later revised its definition of 'rare disabilities', oscillating between a social approach (emphasising the rarity of the techniques used) and a medical approach (emphasising combinations of impairments) (Winance and Barral, 2013).

The actions of two national rare disability resource centres: Transforming care provided by the system versus making up for missing elements in the system

Three national rare disability resource centres were thus opened experimentally in 1998 and gained secure status in 2010. The CRESAM was dedicated to deafblind people, the Centre Robert Laplane to people with deafness associated with other disorders, and the Centre La Pépinière to people with blindness associated with other disorders. Our ethnographic survey dealt with the last two of these resource centres. Each centre consisted of a team of approximately ten specialised professionals. Their initial budget in 1998 was approximately 400,000 €, a figure that was afterwards indexed to inflation and increased slightly when they transitioned from experimental status to permanent status in 2010. Their tasks covered three main areas: specialised support to caregivers in accompanying people with multiple impairments[2]; training and advising local professionals; and establishing specialised knowledge on rare disabilities. However, each centre worked within its own specific demographic and organisational context. This context shaped the application of the concept of 'rare disabilities' for each centre, and led each one to make decisions organising its actions from among its assigned goals.

'Rare disabilities': a concept with different concrete applications

When the national rare disability resource centres were created, the concept of 'rare disabilities' was legally defined by three criteria: a prevalence rate, listed

TABLE 1. Prevalence of hearing impairment and visual impairment in people under the age of 20 in 1998-99 (context of the creation of the resource centres)

	Severe or total hearing impairment	Medium to severe hearing impairment	Minor to medium hearing impairment
Prevalence	19,300	10,200	181,700
Rate per 1,000	1.3	0.7	12.3
	Severe or total visual impairment	**Medium visual impairment**	**Minor visual impairment**
Prevalence	4,200	12,100	54,000
Rate per 1,000	0.2	0.7	3.6

Source: (Boumot et al., 2005: 138-141; Lelièvre et al., 2007: 23) based on the HID study 98-99 – carried out by the Observatoire régional de santé des Pays-de-Loire.

combinations of impairments, and the technical nature of the expertise necessary to accompany the people in question. This legal definition, which varied in official texts, adopted a practical form for each centre, in relation to its demographic and institutional context. We describe this dual context based on the statistical surveys available for the study period (1998-2014) regarding people with a sensory impairment: deafness or blindness. These are the two reference impairments for the two centres studied, the target population of which is made up of people for whom this primary impairment is combined with other impairments[3]. We furthermore concentrate on people under the age of 20, which make up the majority of the applications to the two resource centres studied[4].

Initially, it is of interest to look at the prevalence rate and demographics of these two populations at the time of the creation of the resource centres. Table 1 presents this data based on a national survey carried out at the time. This table conveys a relatively simple initial observation that is nonetheless very important. There were almost 5 times more young people who were deaf or hearing impaired than young people who were blind or visually impaired. Considering solely the prevalence of blindness among young people, a rate of approximately 1/10,000 is obtained, which is the prevalence rate used to define a rare disability. The prevalence was similar for young people with a severe visual impairment, the issues of which are quite different from those of blindness. For young people with hearing impairment, this rate was far higher. The two populations – people with deafness and people with blindness – were hence very different in size, which defined a foundational context that was very different regarding the definition of 'rare'.

In line with these contrasting demographics, we observe a very different geographic network of institutions and specialised services caring for people

TABLE 2. Institutions for young people with sensory impairment – Mainland France and overseas territories

		ES 1995	ES 2001	ES 2006	ES 2010
Number of institutions as of 31 December	for children with hearing impairment	98	105	87	76
	for children with visual impairment	32	33	36	30
Number of established available places as of 31 December	for children with hearing impairment	7,957	6,505	5,526	5,063
	for children with visual impairment	2,668	1,998	1,987	1,817

Sources: (Makdessi and Masson, 2010: 147; Makdessi and Mordier, 2013: 184).

TABLE 3. Distribution of children monitored by in-home special education and care services by main categories of impairment

	ES 2001	ES 2006	ES 2010
Children with language and speech impairments	450	1,349	2,411
Children with hearing impairment	3,377	4,183	4,515
Children with visual impairment	2,071	2,766	3,463

Sources: (Makdessi and Masson, 2010: 204; Makdessi and Mordier, 2013: 255).

with hearing impairment or visual impairment. Our approach to these differences is based on data on the number of institutions and specialised services existing in France for children with hearing or visual impairment. To do so, we use data from the '*Établissements sociaux-handicap*' surveys (ES in the tables) carried out regularly by the French government[5]. Table 2 contains data on the number of specialised institutions (boarders or day-users) and Table 3 contains data on the number of in-home care services.

Several findings can be derived from these two tables. First, regarding institutions, we note a general downward trend. This decrease is found for both types of impairment. It is conveyed through a decrease in the number of institutions and a decrease in the number of available places. In parallel, we note an increase in the number of children monitored and helped by in-home care and education services. This increase is significant for children with language and speech impairments but is more modest for children with hearing or visual impairment. These two trends reflect the transformation of the healthcare offering that took place at the time in relation to the general de-institutionalisation shift described in our introduction.

Second, with respect to specialised institutions (Table 2), we note that there are approximately twice as many institutions for children with a hearing impairment compared to those for children with a visual impairment. A smaller yet significant difference is also found in the number of in-home care services (Table 3). To put it simply, the healthcare and accompaniment offering was very different, depending on whether the child had a hearing or a visual impairment. For the former, an institution or specialised service likely existed in the vicinity, whereas for the latter it was much less likely. There were far fewer specialised resources providing suitable care for blind children, who were likely to be isolated or monitored by non-specialised professionals, as opposed to deaf children, who were monitored by specialists in a more timely manner.

The demographic and institutional contexts of the initial impairment – whether visual or auditory – were thus radically different in terms of the number of children and the number of specialised services and institutions. As a result, the concept of 'rare disabilities' took on a specific meaning for each type of combination. For the Centre Robert Laplane, rarity concerned people with deafness associated with other disorders or with a severe language disorder, although within a network structured around deafness. For the Centre La Pépinière, rarity concerned people with blindness associated with other disorders, for whom blindness alone was in itself often problematic, because these individuals were isolated and had no specialised assistance. Each centre was led to make decisions structuring its specific actions in order to adapt assistance to the particular characteristics of its 'rare disability'. In other words, 'adapting and specialising care' could not have the same meaning for each one of the two centres.

Organising and implementing adapted specialised care by helping people or supporting professionals

The goal of the two national resource centres was to provide the highly specialised expertise necessary for the care and education of people with rare disabilities – expertise not possessed by local professionals. Families or professionals called upon their services to help them understand a person with a rare disability and provide specialised care adapted to them. In these situations, the centres attempted to promote an approach that challenged prevailing professional practices. This approach was supported by easy-to-implement techniques. It aimed at transforming educational practices and attitudes towards people with disorders that care-givers struggled to come to grips with. Moreover, it aimed at adapting care to the characteristics of each person by passing on technical and attitudinal know-how. In practice, these actions took on specific forms for each of the two centres, depending on the demographic and institutional context presented above. Within its specific context, each of the centres identified 'emergencies' on which they focused their efforts.

At the Centre Robert Laplane, the perceived emergency was to help the teams negotiate the population change faced by specialised institutions and services. The Centre Laplane described this population change as follows: as a result of the spread of cochlear implants, the improvement in hearing aids, legislation on schooling, and parents' desire for inclusion, a large number of children with hearing impairment went to regular schools and no longer attended traditional institutions. As a result, only children for whom school integration posed a problem came to these institutions and remained in them. These were primarily children with whom communication was more difficult, and who were likely to have an associated impairment. For teams that were initially trained to care for more independent children, poor management of the population shift could have resulted in severe difficulties: behavioural problems, maladapted care, discouragement among teams. Most of the children on whose behalf families or professionals consulted the Centre Laplane were already receiving institutional care. But this care had failed because the impairments associated with deafness or the causes of language disorders had been poorly identified by local professionals.

Most applications to the resource centre were for children between the ages of 7 and 15 (55% of calls), and then for children between the ages of 4 and 6 (29%). The Centre Robert Laplane views this age distribution as indicative of an increase in the uncertainty of families and professionals, making them turn to the resource centre once regular rehabilitative methods have failed. Before turning to the centre, these children had been cared for locally by specialised institutions. Initially this care seemed appropriate, but gradually it failed due to associated impairments that had not been initially visible. Doubts regarding the relevance of the methods used therefore increased, until the resource centre was brought into the picture. The resource centre's mission, starting with an individual situation, was thus to train professionals collectively and pass on specialised knowledge and skills to them for managing cases of deaf children who had associated impairments. To train these professionals and thus transform specialised institutions or services, the resource centre sought to establish long-lasting ties with these structures. Its long-term goal was to adapt the healthcare system to the characteristics of people whose deafness is associated with another impairment.

At the other centre, the Centre La Pépinière, the perceived emergency was to support the care of very young children who were blind or visually impaired and who did not receive suitable care locally, given the limited number of specialised institutions and services scattered across the country. Without adequate stimulation, the risk of these children developing associated disorders such as 'autistic-like' behaviours or behavioural problems is very high. The distribution of instances of first contact as a function of age was very different at the Centre La Pépinière: 29 % of contacts concerned children between 0 and 3 years of age, and 22% children from 4 to 6 years of age. Hence, the majority of cases at the Centre La Pépinière were very young children. Its actions were structured differently; they were directed at the child and not at the professionals taking care of them, and needed to take place early on.

The centre's intervention consisted both in understanding how the child functioned and in proposing concrete solutions to modify the care and assistance provided to this child on a daily basis by their various caregivers. The goal in this case was not to train professionals into accompanying people with rare disabilities, but to provide them with a set of tools to help a particular child. The centre's actions were often isolated or intermittent and were summed up in a report handed out to the different caregivers, detailing at length the practical methods for accompanying the child. The aim was not to adapt care structures but rather to adapt current care practices to the needs of a given child. Specifically, the Centre La Pépinière did extensive work with professionals and parents who were not specialists in visual impairment, and who were not likely to deal with other blind children. This differed from the Centre Robert Laplane, which worked with deafness professionals at centres specialised in hearing impairment and who very likely worked with other deaf children who had associated disorders as well.

Discussion

The issue of persons with multiple impairments occupies a specific place in French disability policies, but reveals common challenges of these policies as well. Calls for personalised care for people with multiple impairments anticipated the laws of 2002 and 2005, which reshaped social care for all people with disabilities. These demands were made in the sector which appears to be most concerned by de-institutionalisation – defined as the actual closure of specialised facilities – and may prefigure a more comprehensive transformation of the social care system. Our analysis of this transformation was guided by the approach of Daly and Lewis (2000), which links the macro and micro levels within the notion of social care. At a macro level, we have shown that the rarity of the situations that were targeted created tensions from the outset in the territorial organisation of care, which in France is characterised by complex relationships between the central state, local authorities and the voluntary sector (Barral et al., 2000). This issue thus led on the one hand to the reconfiguration of these relationships, via the creation of a new type of social care organisation, the resource centres, and on the other hand to the personalisation of care practices, through the involvement of these centres at the local level.

Then at a micro level, we have shown that these resource centres promote an approach centred on the person, their interests and their needs, accompanied by expert knowledge of the possible combinations of impairments and ways to mitigate the incapacities they may produce. They do it under the constraints of a French system structured around categories of disability and care and which more often than not may have a tendency towards paternalistic[6] educative and rehabilitative strategies. But at their level the resource centres try and go beyond these constraints. The personalisation they put in place involves two dimensions: that of the evaluation of the combined impairments, which can dramatically vary from one person to another, and that of the needs and expectations of the actual person. As social care organisations, these resource centres represent an intermediate level between the national level of policy-making and the level of actual care practices. At this intermediate level, they carry out both individual action on behalf of a given person and the organisation of their care, and organisational actions directed as a specialised service or facility. While they are not agents of de-institutionalisation, they empower the persons they counsel and transform the institutions where they intervene to provide better care and take into account the actual persons they care for.

The financial support they received enabled high quality care and training, with sometimes spectacular outcomes – a dramatic improvement in the living conditions of the affected persons, as well as improvement for professional or familial care-givers. The "experiment" seemed convincing. However, these outcomes covered only a fraction of the potentially concerned group. The centres couldn't respond to all the needs, whether at a personal or an institutional level. The end of the experimental period in 2010 and the established status of the centres did not lead to a scaling up of the activities of the centres in order to cover all the needs in their field, but rather to coordinating tasks at a national level and regionalised coordination teams, as well as the opening of a fourth centre for other conditions. It all seems as if the experiment continued on in new areas without an effort to better address the already identified needs. It leaves an impression of a dilution of means, scarcely covering a fraction of a population with complex care needs, and perhaps only those with more salient problems or those who actually know about the existence of qualified resource centres.

The example of rare disabilities also shows the tensions that the French care system faces and its difficulty in transforming traditional specialised institutions. These institutions changed considerably, notably after the laws of 2002 and 2005. Over the past 15 years, there has also been a huge increase of places available in diverse in-home care services. But the two systems seem to coexist: the development of a service offer aimed at mainstreaming didn't lead to a reduction of places in specialised venues, which remain structured around impairment- and autonomy-based categories. In the narrower field of care for people with a sensory impairment it was possible to close some specialised institutions while supporting ultra-specialised care for some complex situations within the resource centres. But it appears to be an exception, and then again it is not clear that all needs are properly met. Dealing with situations that test the system to its limits, these resources centres are able to navigate the gap between services aimed at mainstreaming and specialised institutions. Their mere existence shows it may be possible to bridge seemingly overwhelming differences that shape the French care system.

Conclusion

In this article we reviewed the history of the organisation of care for people with multiple impairments in France. The main issue in this history concerned ways of organising specialised and personalised care for these people within the French social care system. A new approach to organising specialised and personalised care was progressively implemented. This new approach constitutes a compromise between a disability-based approach and an approach based on individuals' specific needs. Furthermore, it coexists with the traditional form of organisation of the specialised sector, which is centred on the type of impairment. This new form of organisation of specialised care was based on the invention of a new concept ('rare disabilities') and a new type of care structure (national rare disability resource centres). This concept had a dual utility.

First, it was a compromise between an approach based on the type of impairment and one based on specific needs. Instead of doing away with a 'medical' definition of impairments, the concept was based on a list of combinations of impairments, but which operated as a proxy, resulting in specific needs related to accompaniment. Hence, the particularity and specialisation of assistance were intrinsically tied to the distinctiveness of impairments.

Second, this concept had the capacity to encompass specific concrete realities while retaining a single theoretical definition. The concrete application of the concept varied according to the combinations of impairments dealt with, whether deafness with associated disorders or severe language disorders for the first centre studied, or blindness with associated disorders for the other centre. Consequently, the resource centres differed in the way they sought to improve the adaptation of the care system to the characteristics of individuals. One acted indirectly by seeking to transform existing institutions and services; the other acted more directly on individual situations considered problematic.

Our analysis of this history allows us to revisit the issues of the de-institutionalisation process as it has taken shape in France. The desire to be included in mainstream society is undeniably one of the concerns of this process. It has led to the transformation of traditional institutions providing accommodation and care into smaller and more outward-oriented institutions or day centres. However, a second major concern of this process is the issue of personalisation: the specialisation of care and its adaptation to the characteristics of individual people. In using the notion of social care as an analytical tool, we‘ve shown that this issue of personalisation required and led to a transformation of care organisations. To fill the gap between the specific needs of certain subjects and the care offering, a new form of social care organisation was conceived that focuses either on care for a given person or on transforming specialised institutions in order to organise person-centred care. Examining these organisations and their limits – at an intermediate level between policy and practice – could be a promising way to investigate the personalisation of social care and, more generally, recent changes in the Welfare State.

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Competing interests

The authors declare none.

Notes

1 Law No. 2002-2 of 2 January amending social and medical-social action [*Loi n° 2002-2 du 2 janvier 2002 rénovant l'action sociale et médico-sociale*] and the Law of 11 February 2005 on the equality of rights and opportunities, participation, and citizenship of disabled people [*Loi du 11 février 2005 pour l'égalité des droits et des chances, la participation et la citoyenneté des personnes handicapées*].

2 Around 150 persons with a rare disability per centre and per year.

3 In France, there is no statistical survey on people with 'rare disabilities'; simply carrying out a survey of this type poses methodological problems (INSERM, 2013).

4 According to our calculations, on the first occasion the resource centre was contacted, the age of the beneficiary was under 20 for 96% at the Centre Robert Laplane and 83% for the Centre La Pépinière. These people are at times monitored for many years, subsequently passing the age of 20.

5 The precise source and description of the survey (in French) is available here: https://drees.solidarites-sante.gouv.fr/etudes-et-statistiques/open-data/etablissements-de-sante-sociaux-et-medico-sociaux/article/l-enquete-aupres-des-etablissements-et-services-pour-enfants-et-adultes, retrieved on 1 December 2020.

6 In the sense discussed by Eva Feder Kittay (2007).

References

Barnes, C. (2012), 'Understanding the social model of disability: Past, present and future', in N. Watson, A. Roulstone and C. Thomas (eds), *Routledge handbook of disability studies*, London & New York: Routledge, 12–29.

Barral, C. (2007), 'Disabled Persons'Associations in France', *Scandinavian Journal of Disability Research*, 9 (3-4), 214–236.

Barral, C., Paterson, F., Stiker, H. J. and Chauvière, M. (eds.), (2000), *L'institution du handicap. Le rôle des associations*, Rennes: Les Presses Universitaires de Rennes.

Boumot, M.-C., Lelièvre, F. and Tallec, A. (2005), 'La population en situation de handicap visuel en France. Importance, caractéristiques, incapacités fonctionnelles et difficultés sociales. Une exploitation des enquêtes HID 1998 et 1999', Nantes : Observatoire régional de la santé des Pays de la Loire, https://drees.solidarites-sante.gouv.fr/IMG/pdf/handicapvisuel.pdf. [accessed 08.12.2021].

Buton, F. (2009), *L'administration des faveurs: l'état, les sourds et les aveugles (1789-1885)*. Rennes : Presses universitaires de Rennes.

Capuano, C. (2012), '"Aux origines des aidants familiaux". Les transformations de l'aide familiale aux personnes âgées, handicapées et malades mentales en France dans la seconde moitié du vingtième siècle', Research report for the MiRe/DREES and the CNSA.

Chapireau, F. (2008), 'Trente ans après : la révolution psychiatrique italienne en perspective', *L'Évolution Psychiatrique*, 73 (3), 517–528.

Claveranne, J.-P., Robelet, M., Piovesan, D., Cret, B., Jaubert, G. and Guilhot, N. (2012), 'La construction sociale du marché du handicap: entre concurrence associative et régulation politique (1943-2009)', Lyon: IFROSS – Université Lyon 3, https://hal.archives-ouvertes.fr/hal-00756821v2/document. [accessed 08.12.2021].

D'Alessio, S. (2012), *Inclusive education in Italy*. Rotterdam: Springer Science and Business Media.

Daly, M. (2002), 'Care as a Good for Social Policy', *Journal of Social Policy*, 31 (2), 251–270.

Daly, M. and Lewis, J. (2000), 'The concept of social care and the analysis of contemporary welfare states', *The British journal of sociology*, 51 (2), 281–298.

Daly, M. and Westwood, S. (2018), 'Asset-based approaches, older people and social care: an analysis and critique', *Ageing and Society*, 38 (6), 1087–1099.

Duygun, T. (2020), 'Policy translation in Turkish disability policy: The role and limitations of international organisations', *Global Social Policy*, 20 (3), 305–332.

Goffman, E. (1961), *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*, New York: Anchor Books.

Henckes, N. (2018), 'Les deux désinstitutionalisations. Psychiatrie, sciences sociales et modernisation après la seconde guerre mondiale', in I. Coutant and S. Wang (eds), *Santé mentale et souffrance psychique : un objet pour les sciences sociales,* Paris: CNRS Editions, 143–160.

Hudson, B. (1991), 'Deinstitutionalisation: What Went Wrong', *Disability, Handicap and Society*, 6 (1), 21–36.

INSERM. (2013), *Handicaps rares : Contextes, enjeux et perspectives,* Paris: Inserm.

Kittay, E. F. (2007), 'Beyond Autonomy and Paternalism: The Caring Transparent Self' in T. Nys, Y. Denier and T. Vandevelde (eds), *Autonomy and Paternalism. Reflections on the Theory and Practice of Health Care*, Leuven: Peeters, 23–70.

Lelièvre, F., Sander, M.-S. and Tallec, A. (2007), 'Le handicap auditif en France. Apports de l'enquête HID 1998-1999', Série Etudes n°71, Paris: DREES, https://drees.solidarites-sante.gouv.fr/sites/default/files/2020-10/dtee71.pdf. [accessed 08.12.2021].

Makdessi, Y. and Masson, L. (2010), 'Établissements et services pour enfants et adolescents handicapés. Résultats de l'enquête ES 2006 et séries chronologiques 1995 à 2006', série statistiques n°148, Paris: DREES, https://drees.solidarites-sante.gouv.fr/sites/default/files/2020-10/dt148.pdf. [accessed 08.12.2021].

Makdessi, Y. and Mordier, B. (2013), 'Établissements et services pour enfants et adolescents handicapés. Résultats de l'enquête ES 2010', collection Statistiques n°177, Paris: DREES, https://drees-site-v2.cegedim.cloud/sites/default/files/2020-10/dt177.pdf. [accessed 08.12.2021].

Mladenov, T., John, O. and Cribb, A. (2015), 'Personalisation in disability services and healthcare: A critical comparative analysis', *Critical Social Policy*, 35 (3), 307–326.

Morris, J. (2004), 'Independent living and community care: a disempowering framework', *Disability & Society*, 19 (5), 427–442.

Needham, C. (2011), 'Personalization: From Story-line to Practice', *Social Policy & Administration*, 45 (1), 54–68.

Needham, C. (2014), 'Personalization: From day centres to community hubs?', *Critical Social Policy*, 34 (1), 90–108.

Nilholm, C., Almqvist, L., Göransson, K. and Lindqvist, G. (2013), 'Is it possible to get away from disability-based classifications in education? An empirical investigation of the Swedish system', *Scandinavian Journal of Disability Research*, 15 (4), 379–391.

Oliver, M. (1990), *The Politics of Disablement: A Sociological Approach*, New York: St. Martin's press.

Pedersen, P. B. and Kolstad, A. (2009), 'De-institutionalisation and trans-institutionalisation - changing trends of inpatient care in Norwegian mental health institutions 1950-2007', *International Journal of Mental Health Systems,* 3, Article number: 28.

Power, A. (2009), 'Spatial Perspectives on Voluntarism in Learning Disability Services in Ireland', *Journal of Social Policy* 38 (2), 299–315.

Power, A. and Bartlett, R. (2018), 'Self-building safe havens in a post-service landscape: how adults with learning disabilities are reclaiming the welcoming communities agenda', *Social and Cultural Geography*, 19 (3), 336–356.

Power, A., Coverdale, A., Croydon, A., Hall, E., Kaley, A., Macpherson, H. and Nind, M. (2021), 'Personalisation policy in the lives of people with learning disabilities: a call to focus on how people build their lives relationally', *Critical Social Policy*.

Prandini, R. (2018), 'Themed section: the person-centred turn in welfare policies: bad wine in new bottles or a true social innovation?', *International Review of Sociology*, 28 (1), 1–19.

Roulstone, A. (2015), 'Personal Independence Payments, welfare reform and the shrinking disability category', *Disability and Society*, 30 (5), 673–688.

Saloviita, T. (2002), 'The closure of Nastola care home: A longitudinal study on deinstitutionalisation', *Scandinavian Journal of Disability Research*, 4 (2), 138–155.

Scourfield, P. (2005), 'Implementing the Community Care (Direct Payments) Act: Will the Supply of Personal Assistants meet the Demand and at what Price?', *Journal of Social Policy*, 34 (3), 469–488.

Tøssebro, J. (2016), 'Scandinavian disability policy: From deinstitutionalisation to non-discrimination and beyond', *ALTER-European Journal of Disability Research/Revue Européenne de Recherche sur le Handicap*, 10 (2), 111–123.

Tøssebro, J., Bonfils, I., Teittinen, A., Tideman, M., Traustadóttir, R. and Vesala, H. (2012), 'Normalization Fifty Years Beyond – Current Trends in the Nordic Countries', *Journal of Policy and Practice in Intellectual Disabilities*, 9 (2), 134–146.

Tournadre-Plancq, J. (2010), 'L'heure du choix. Personnalisation et compétition dans l'État social britannique', *Raisons politiques*, 37 (1), 147–169.

Winance, M. and Barral, C. (2013), 'From "ineducability" to "rare disabilities". Evolution and emergence of political categories involved in shaping the French medico-social sector', *ALTER - European Journal of Disability Research/Revue Européenne de Recherche sur le Handicap*, 7 (4), 244–259.

Winance, M., Ville, I. and Ravaud, J.-F. (2007), 'Disability Policies in France: changes and tensions between the category-based, universalist and personalized approaches', *Scandinavian Journal of Disability Research*, 9 (3-4), 160–181.

Zola, I.K. (1982), *Missing Pieces: A chronicle of living with a disability,* Philadelphia: Temple University Press.