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ABSTRACT

Families with disabled children run a greater risk of being poor, and although policies providing poor families with financial benefits should be effective in reducing poverty, the actual effectiveness is often jeopardized by the issue of non-take up (NTU). Yet, how NTU affects the impact of benefits aimed at disabled children is for the most part uncharted territory. In this article, we fill this gap using a mixed-methods approach to (i) estimate the magnitude and characteristics of NTU in the Belgian ‘supplemental child benefit’ by drawing on a large-scale administrative dataset on childhood disabilities; and (ii) explore the determinants of NTU by means of semi-structured interviews with experts. We estimate a NTU rate of at least 10%, a substantial figure given that the benefit is not income-tested. This mainly concerns children with ‘less visible disabilities’ (autism spectrum disorder and other intellectual and psychological disorders) and results from insufficient information provision about the benefit’s existence and eligibility criteria; process costs, for instance the long waiting period and complexity of the procedure; and the way the scale to assess a child’s disability is constructed.

Keywords: Non-take up, child benefits, disability, mixed-methods, targeting, means-test

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1 INTRODUCTION

Families with disabled children run a greater risk of being poor, and poor families are more likely to have disabled children. The overlap between childhood disability and child poverty has been documented extensively, across as well as within countries (e.g. Emerson & Hatton 2007). Although policies providing poor families with financial benefits should be effective in reducing poverty, the actual effectiveness is often jeopardized by the issue of non-take up (NTU), the observation that people who are legally entitled to benefits do not receive them (Hernanz et al. 2004). Yet, how NTU affects the impact of benefits aimed at disabled children is for the most part uncharted territory. In this article, we use a mixed-methods approach to (i) estimate the magnitude and characteristics of NTU; and (ii) explore the determinants of NTU, for the 'supplemental child benefit' for disabled children in Belgium.

Recent reviews demonstrate that NTU is a common problem across EU and OECD countries. In particular for means-tested benefits, NTU frequently affects more than half of the eligible population (Eurofound 2015). E.g. estimates of NTU in social assistance benefits across OECD countries range from 40% to 80% (Hernanz et al. 2004). Recent estimates for social assistance NTU for Belgium are in the same ballpark, ranging from 57% to 76% (Bouckaert & Schokkaert 2011). For benefits targeted at disabled people, estimates are scarce. For the United Kingdom, it was estimated in the 1990s that between 30% and 70% of eligible working age persons received (part of the) Disability Living Allowance (Craig & Greenslade 1998). To our knowledge, studies regarding NTU of Belgian disability benefits do not exist and never has anyone attempted to estimate the take-up of benefits targeted at disabled children. That will be our first contribution to the literature.

Policies that are aimed to reduce poverty or designed to alleviate the increased healthcare costs owing to a disability, are missing their very own purpose if they fail to reach those most in need. Yet, in order to improve the effectiveness of such benefit schemes, it is indispensable to unravel the complexities involved in explanations of NTU. In doing so, we draw on van Oorschot's (1996) dynamic model of benefit receipt as an explanatory framework to explore the determinants of NTU. We regard NTU as an (undesired) outcome of multilevel actor-behavior, located at three different levels (claimants, administration, and benefit scheme) involving three different actors (claimants, administrators, and policy makers). Moreover, NTU at the claimant level does not occur at one specific moment in the procedure, but is the product of claimants' experiences while going through three consecutive stages: threshold, trade-off, and application stage. In each of these stages, the behavior of the administrators and the design of the benefit scheme might induce NTU as well. That will be our second contribution to the literature: by means of semi-structured interviews with stakeholders we explore their role in order to get better purchase on the determinants of NTU.

2 UNDERSTANDING NON-TAKE UP: A DYNAMIC MULTILEVEL MODEL OF CLAIMING BENEFITS

More than two decades ago, Wim van Oorschot (1996) put forward a powerful critique on the majority of studies at the time that tried to explain NTU by focusing solely on the claimant level. Many economists, for instance, tended to see NTU as the result of utility-maximizing decisions of rational actors (e.g. reviews in Craig (1991) and Currie (2004)). According to such logic, potential claimants outweigh the benefits and costs associated with claiming, and act

accordingly. In a famous example, Robert Moffitt (1983) models individuals' NTU behavior as the result of welfare stigma, a social and psychological 'cost' associated with benefit claiming. Other costs identified in the literature include information costs, i.e. the lack of information or misinformation on benefits, and process costs such as queuing, filling in complex forms, and the uncertainty of the outcome (Van Mechelen & Janssens (2017) provide an overview). Benefits, then, include the level and duration of the benefit. Only if potential claimants regard the benefit level worth the trouble of going through administrative hassle, for instance, they will claim the benefit.

Although such focus on costs and benefits is helpful to shed light on individual behavior and responsibility in explaining NTU, van Oorschot (and others, see e.g. Craig (1991)) emphasized that the claiming process is not simply a matter of balancing costs and benefits at one point in time. It is rather a *dynamic* process in which claimants go through consecutive stages where costs can outweigh benefits. Van Oorschot identified three such stages.

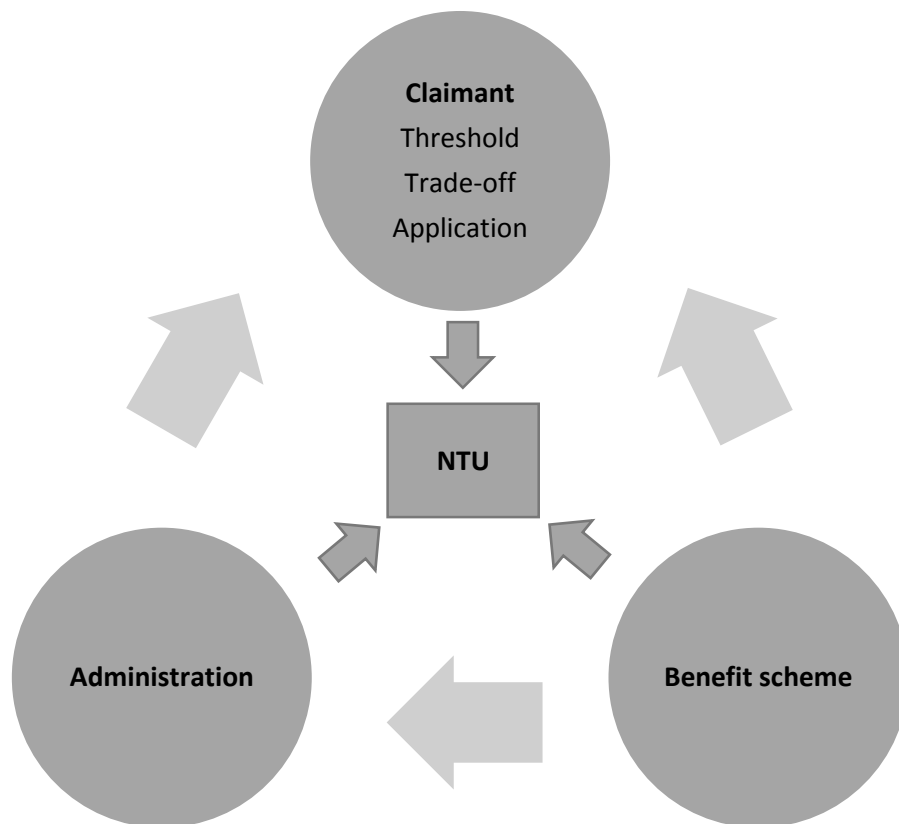
First, in the *threshold stage*, individuals need to overcome several barriers before they actually claim a benefit. Here, information costs are relevant: people need to be aware of the benefit's existence, and if they do, they have to consider themselves eligible. Second, once the first stage is crossed, they enter the *trade-off stage*. In this stage, individuals trade off 'claim inhibiting factors' and 'claim stimulating factors' (van Oorschot 1996: 16). Here, costs, especially process, social and psychological costs, and benefits come into play again. Is the benefit worthy of going through all the trouble? What will other people think? If the benefits outweigh the costs, people will claim the benefit and enter the third, *application stage*. This stage can result in receiving the benefit, or the application can be rejected. Here too, costs are relevant. If individuals are not aware of, for instance, all the information necessary for

successfully applying for a benefit, their claim can be rejected. Moreover, claimants can drop out of the process at each stage, and re-enter the process at a later time, for instance when one's personal situation has changed.

An important part of the explanatory framework is that NTU is regarded as the result of a *multilevel* process in which different actors are involved: claimant behavior is influenced by administrators and by the design of the benefit scheme. At the administrative level, influencing factors include the quality and quantity of information provision, the simplicity of the application procedure, the internal (e.g. stigmatizing communication) and external (e.g. collaboration between stakeholders) organization of the responsible agencies (Van Mechelen & Janssens 2017; van Oorschot 1996). At the benefit scheme level, factors include the degree of selectivity, the associated selection criteria, and the discretionary power built into the system (Van Mechelen & Janssens 2017). The multilevel perspective is important at each stage of the claiming process. For instance, administrators can or cannot provide sufficient information at the threshold stage. At the trade-off stage, stigma might stem from conditions associated with claiming, such as being obliged to do volunteer work or engage in mandatory training programs (Dwyer & Wright 2014). At the application stage administrators can wrongfully reject applications, or decide for or against granting a benefit depending on their discretionary power in making the final decision. Figure 1 visualizes the dynamic and multilevel nature of the benefit claiming process.

In the subsequent analyses, the explanatory framework as shown in Figure 1 will be applied to gain more insight into the NTU of the supplemental child benefit for disabled children in Belgium.

Figure 1 Theoretical framework



3 POLICIES FOR DISABLED CHILDREN IN BELGIUM: MULTIPLE RECOGNITION LEVELS

Belgium is a federacy in which competences for person-related matters are largely regionalized. As a result, the 'policy package' targeted at disabled children is fragmented. Various income supplements, social and fiscal benefits, and in-kind support measures are available at the federal and regional level. Here, we focus on the Belgian region of Flanders.

First, children with higher care needs, including disabled children, might be entitled to supplemental child benefits at the federal level. This is a top-up of the regular child benefit. To claim said supplement, children need to receive the regular child benefit first, and their disability needs to be assessed. Doctors of the *Federal Government Service for Social Security* (FGS) assess the severity of the disability and score the child on a 36-point scale for which they make use of standardized criteria. The scale consists of three complementary pillars which gauge the impact of the child's disability in terms of (i) physical and mental consequences (maximum 6 points), (ii) consequences for the child's participation in daily life (maximum 12 points), and (iii) consequences for the family (maximum 18 points). Although the scale explicitly includes non-medical criteria, the assessment is called a 'medical examination'. The higher the score a child receives on the total scale, the higher the alleged impact of the child's disability on the family's care burden and the higher the supplemental child benefit will be. The supplement ranges from €80 for the lowest scores up to more than €500 per month if the child scores at least 18 points (see Appendix 1 for an overview). Of all Belgian children under the age of 21 in 2015, 2.37% are recognized as disabled at the federal level and hence receive supplemental child benefits (Famifed 2016).

Second, if disabled children want to make use of subsidized care services (such as residential, semi-residential or ambulatory care) or apply for additional financial support to purchase devices (e.g. wheelchairs) or pay for adaptations to the home, a recognition at the regional level is needed¹. To acquire this recognition in Flanders, a multidisciplinary team of the *Flemish Agency for Persons with a Disability* (FAPD) assesses whether children are

¹ Since March 1, 2014 a distinction is made between directly and non-directly accessible care services based on the frequency of care use. Only when individuals deplete their directly accessible quantity, they need a FAPD recognition. In this paper we discuss the situation prior to this reform as the data is from 2010.

substantially and long-term limited in their social participation due to their disability. Such team consists of at least a doctor, a psychologist or pedagogue, and a social worker or social nurse. This is not a medical examination per se, but an assessment of the child's needs in relation to the care request, taking account of the child's medical, psychological and social situation. Once the recognition is obtained the child can make use of care services, depending on the availability of places, apply for support measures or financial help to purchase devices.

It should be noted that disabled children in Flanders can also be enrolled in special or inclusive education, for which yet another recognition is necessary. As a matter of fact, 4% of children in primary and secondary education are enrolled in special education, by far the highest percentage in Europe (EASIE 2017). Obviously this can be an important source of care support for (families with) disabled children as well.

In sum, at both policy levels different recognition procedures are in place, and in general they operate separately from each other. Only when children have at least 18 points on the 36-point scale for the supplemental child benefit, an accelerated application procedure at the FAPD is possible. Due to a recent state reform, the regions will gain competences for regulating child benefits from 2020 onwards (Béland & Lecours 2017). However, at the time of writing none of the Belgian regions plan to change the supplemental child benefit scheme.

In the next sections, we will exploit these different recognitions to estimate the NTU rate of the supplemental child benefit by means of administrative data.

4 METHODS AND DATA

We draw on quantitative and qualitative data to estimate NTU of the supplemental child benefit as well as to gain more insight into its determinants. For estimating NTU, we use two administrative datasets. First, microdata from the Datawarehouse Labor Market and Social Protection (DWH LM&SP) is linked with FAPD and census data. The DWH LM&SP compiles administrative data from Belgian social security agencies as well as information on personal and household characteristics (including household type and migration background) from the National Registry. We obtained a random sample of 50% of children below 21 years old with a recognized disability at the federal level living in Belgium in 2010 ($n = 25,717$), including their score on the 36-point scale. To this dataset, information on the use of care services or support at the FAPD is added. The latter includes the child's disability type as recognized at FAPD, the type of care service used, the received subsidies to purchase devices or to adapt one's house, and whether these applications were granted, refused or are still in process (waiting list). Information on parental education is added from the 2011 Census. Additionally, we obtained a randomly drawn control group of children below 21 years old without a recognized disability from the DWH LM&SP, of equal size ($n = 25,057$, after removing children having siblings with disabilities).

Since this dataset does not allow to identify disabled children that are only recognized at the Flemish level, we complement this with an administrative dataset including basic personal and household characteristics of all disabled children who are recognized by the FAPD only ($n = 8,968$). The data include the same information on the disability type as mentioned above but unfortunately do not include information on parental education or household type.

Finally, we also obtained aggregated figures on the number of all children below 21 recognized at the Flemish level, federal level, or both. The data includes neither enrollment in special or inclusive education nor information on private expenditures for unsubsidized care services or support.

In order to estimate NTU in the supplemental child benefit at the federal level, in a first step we exploit the differences between the recognitions at the two levels based on the aggregated data. In a second step, we discuss differences in personal, household and disability characteristics, drawing on the microdata.

These results are complemented by qualitative analyses to gain better understanding of the determinants of NTU. Therefore, we conducted semi-structured interviews with experts and stakeholders, working in different organizations involved in carrying out policies for disabled children at both the Flemish and federal level. A total of eight interviews with 11 persons were conducted. The interviewees were recruited in two ways, either via contacts the authors already had at the institutions or by an internet search for the responsible person within a specific organization. The initial contact was made by e-mail in which we explained the twofold purpose of the interview. First, we wanted to get a clear understanding of the specific role played by the organization. Second, the respondents were asked to identify potential NTU problems they experienced in their specific setting. All respondents received a questionnaire approximately one week in advance. The interviews took place between February and October 2017. The majority were conducted at the respondents' office and the duration varied from 70 minutes up to 170 minutes (see Table 1 for an overview). All interviews were recorded, transcribed in a verbatim way and analyzed with NVivo. We applied an initial node structure based on the theoretical framework explained in Section 2.

Subsequently, within a specific node, potential NTU determinants were identified. In what follows, we refer to the respondents by their chronological number (see first column of Table 1).

Table 1 Interviews

Number	Institution	Who	When	Duration
1	FGS	3 tenured control doctors	3 February 2017	02:43:10
2	FGS	1 social worker of the social service	2 March 2017	01:29:14
3	Children's hospital	1 social worker of the social service	9 March 2017	01:40:57
4	Health Insurance Fund	1 head of social service	30 March 2017	01:45:27
5	FAPD	2 employees of Team Policy and Organization	4 April 2017	02:36:14
6	Pupil Guidance Center	1 employee responsible for special education schools	12 May 2017	01:12:27
7	Center for Developmental Disorders	1 coordinator	16 October 2017	02:45:24
8	Special education school	1 orthopedagogue	27 October 2017	02:50:32

5 RESULTS

5.1 *NTU in the supplemental child benefit*

Policies for disabled children are located at both the federal and Flemish level and the data reveal large discrepancies between the two. The first rows of Table 2 show that of all Flemish children with a recognized disability at either level, 42% are only recognized at the federal level (and only receive supplemental child benefit), 21% are only recognized at the Flemish level (and only applied for subsidized care services or support), while only 37% are recognized at both.

It is perhaps not surprising that a substantial group of disabled children receive supplemental child benefits but do not make use of subsidized care services or support (42%). Parents may

prefer to provide home care for their disabled children, may choose to purchase care with a non-subsidized provider, or their child is at school during the day. It is surprising, however, that 21% of disabled children are only recognized at the Flemish level, forgoing supplemental child benefits. Why would parents forgo (sometimes substantial) cash support that is tailored to their child's disability, if that same disability is recognized at the Flemish level anyway?

One possible reason is that these children did apply but were rightfully rejected at the application stage, at least according to the standardized criteria. Official FGS statistics for 2010 indeed show that 14.16% of valid applications are rejected because the child is awarded too few points to be recognized (personal communication FGS 2018). Another possible reason is that parents started the application but dropped out on the way. This applies to 2.18% of the applications where the parents did not show up on the medical examination, chose to revoke their claim or did not send the necessary medical reports (personal communication FGS 2018). Whereas the former percentage can indicate an indirect form of NTU (we will discuss the role of the benefit scheme level in §5.3.3), the latter is NTU in its purest form: parents do not take-up the benefit because they struggle with the application process. Correcting the initial figure of 21% for these rejections and drop-outs results in an adjusted lower-bound NTU estimation of 10%, assuming that all children rejected at the federal level are recognized at the Flemish level (see Table 2 for calculations and assumptions). Relaxing that condition results in an upper-bound estimation of 19%. So, at least one out of ten children with a recognized disability in Flanders do not receive supplemental child benefit because they did not apply or dropped out during the process. Since NTU of the regular child benefit in Belgium is estimated to be extremely low (between 0.25 and 0.49%, Famifed 2017), and given that the supplemental child benefit is not subjected to any other income- or means-test besides the recognition of the disability at the federal level, this is a rather substantial

NTU rate. It is telling that all of the respondents of the semi-structured interviews were surprised by its magnitude. Moreover, it is likely to be an underestimation since only children with *formally* recognized disabilities are included. Some children have not (yet) undergone medical examination, or families have not yet accepted the disability as being an issue, while other children are enrolled in special education without a formal recognition of their disability although they could qualify.

Table 2 Raw and adjusted NTU estimations

Steps	Federal only	Federal + Flemish	Flemish only	Total
0. Initial mismatch				
Recognitions	17,279 (a)	15,070 (b)	8,781 (c)	41,130 (d)
%	42% (a) / (d)	37% (b) / (d)	21% (c) / (d)	100%
1. Estimate federal level applications				
FGS (+ FAPD)				
Recognitions	32,349 (a) + (b) = (e)		8,781 (c)	41,130 (d)
Applications (+14.16%)	37,685 (f)			
Refused	5,336 (f) – (e) = (g)			
2. Assume refused are recognized at Flemish level				
(i) all: (c) – (g)			3,445	
NTU % of (d)			8%	
(ii) initial overlap only (37%): (c) – 0.37*(g)			6,826	
NTU % of (d)			17%	
3. Increase with dropout rate (+2.18%)				
(i) NTU % of (d)			10%	
(ii) NTU % of (d)			19%	

Source: compiled by the authors based on personal communication with FGS (2018)

5.2 Characteristics of disabled children

Let us now turn to the characteristics of children with recognized disabilities. Table 3 shows results for disabled children, subdivided by recognition level, as well as for the control group

of children without any recognized disabilities. Given the combination of two datasets (see §4), not all information is available for all groups.

In line with previous research, the results show that (i) the youngest children (0-5) are underrepresented among the disabled child population (Blackburn et al. 2010); (ii) more boys than girls are disabled (Emerson & Hatton 2007); (iii) the prevalence of single parenthood is higher among disabled than among non-disabled children (Clarke & McKay 2008); (iv) parents of disabled children are more often low (or medium) skilled compared to their non-disabled counterparts (Sebrechts & Breda 2012); and (v) they live more frequently in households with other disabled household members (Blackburn et al. 2010).

The scores on the 36-point scale suggest that those with more severe disabilities are more likely to combine cash and care, indicating that disabled children posing less of a care burden are less likely to apply for care support or services at the Flemish level. Finally, the share of disabled children with both parents born outside the EU27 is lower among those who are recognized at the Flemish level only whereas it is higher among those who are recognized at the federal level only, compared to their non-disabled counterparts. This suggests that parents with a migration background are more likely to apply for cash benefits and less likely to apply for care services or support. Although there is some evidence that non-EU migrants in Belgium are more likely to provide home care for their children (Kil et al. 2017), at this point it remains an open question how the underrepresentation of disabled children from an migrant background at the Flemish level can be explained.

Table 3 Personal, family and disability characteristics of Flemish children, 2010

	Federal only	Federal + Flemish	Flemish only	Non-disabled children
Personal characteristics				
<i>Age</i>				
0-5	17%	18%	13%	29%
6-11	39%	39%	30%	27%
12-17	37%	37%	43%	28%
18-20	7%	7%	14%	16%
<i>Gender</i>				
Boys	62%	67%	70%	51%
Girls	38%	33%	30%	49%
Family characteristics				
<i>Country of birth parents</i>				
Belgium	83%	90%	90%	86%
EU27	4%	2%	3%	4%
Non-EU27	14%	8%	6%	10%
<i>Parental education (highest level)</i>				
Low-skilled	23%	21%	No info	15%
Medium-skilled	45%	42%	No info	36%
High-skilled	32%	37%	No info	49%
<i>Household type</i>				
Couples with children	80%	78%	No info	84%
Single parents	19%	21%	No info	15%
Other	1%	1%	No info	1%
<i>Other disabled household members</i>				
Yes, at least one	17%	19%	No info	2%
Disability characteristics				
<i>Severity of disability (points)</i>				
1-5	0%	0%	No info	/
6-10	63%	51%	No info	/
11-15	23%	27%	No info	/
16-20	9%	12%	No info	/
20+	5%	10%	No info	/
<i>Single disability: type</i>				
Autism spectrum disorder (ASD)	No info	17%	29%	/
Severe behavioral disorder (SBD)	No info	2%	9%	/
Minor intellectual disability (MID)	No info	5%	8%	/
Other intellectual disability	No info	10%	8%	/
Other psychological disorder	No info	1%	7%	/
Sensory disability	No info	4%	3%	/
Physical disability	No info	5%	2%	/
Suspected retardation	No info	0.4%	0.5%	/
<i>Multiple disabilities: types</i>				
2 or more: ASD, SBD, MID	No info	5%	3%	/
ASD, SBD and/or MID with other disabilities	No info	29%	21%	/
2 or more other disabilities	No info	21%	9%	/

Source: own calculations based on DWH LM&SP (2010), FAPD (2010) and Census (2011). Note: country of birth: at least one parent born in Belgium/EU27 or two parents born outside EU27.

If we shift our focus to the 'NTU-group' of interest, i.e. disabled children recognized at the Flemish level only, and compare them to disabled children that are recognized at both levels, one observation clearly stands out. There is an overrepresentation amongst the NTU-group of autism spectrum disorder, intellectual and psychological disorders. ASD is the most common disability amongst all disabled children, but the share is much larger in the group not receiving supplemental child benefits. Put differently, roughly one third of children in the NTU-group have ASD, while another third consists of children with other intellectual or psychological disorders. Three of the respondents (5, 6, 7) stated that this was no surprise to them. Respondent 7 raised that *"these are actually the children for whom we do not actively inform the parents that they might be eligible"*, and according to respondent 5 *"there has always been criticism of the FGS that disabilities such as autism that are not sufficiently visible ... are not sufficiently recognized"*.

5.3 Determinants of NTU

In order to receive the supplemental child benefit, parents of disabled children have to go through nine different steps (Figure 2). At each step, NTU can occur. To get a better grasp of its underlying determinants, we interpret the findings from the semi-structured interviews drawing on van Oorschot's explanatory framework of NTU as a dynamic, multilevel process. We focus on the level of the administration and benefit scheme throughout the three, consecutive stages of benefit claiming.

Figure 2 Supplemental child benefit application procedure, 2010

1. Request to start the procedure at the child benefit fund
2. FGS sends acknowledgement of receipt to parents
3. FGS sends two questionnaires to parents: part A on psychosocial and family information and part B on medical information
4. Parents fill in part A and go to child's doctor with part B
5. Parents send part A + B to FGS within six weeks from step 3
6. FGS control doctors conduct a medical examination
7. FGS notifies parents and child benefit fund about the decision
8. Child benefit fund communicates the amount to be received to parents
9. The child benefit fund pays supplemental child benefit

Source: compiled by the authors

5.3.1 *Threshold stage*

The first stage can only be crossed if potential claimants know about the benefit's existence and consider themselves eligible. The majority of stakeholders raised concerns that parents are often unaware that their children might be eligible for the supplemental child benefit. Throughout the interviews, multiple channels through which parents can be notified about the existence were identified, including interest groups, the parents' social network, social services of hospitals or health insurance funds, special education schools, pupil guidance centers, diagnostic centers, rehabilitation centers, doctors (both general practitioners (GPs) and specialists), the Flemish Agency for Child and Family Welfare, and the internet. However, there is much diversity in the way they actually inform parents about the benefit. For instance,

four respondents (3, 6, 7, 8) provide parents with information regarding the supplemental child benefit only when they believe children will be actually eligible, based on their own experience and knowledge of the benefit criteria. Respondent 8 indicates that the school for special education provides information sheets to parents upon registration, but only to children with ASD, intellectual or physical disabilities and not when the child has 'minor' intellectual disabilities or severe learning difficulties. Moreover, this happens on the school's own initiative, there is no legal obligation to do so and some schools do not provide any information at all (1, 6, 8). Respondent 7 admits that the doctors in the Center for Developmental Disorders only provide information to parents of children with 'visible' physical disabilities. Both respondents argue that they do not want to falsely raise parents' expectations about receiving supplemental benefits. However, they indicated that if parents have questions about the benefit their organization provides them with detailed information including a warning that they might be ineligible. Even if children are being treated in a rehabilitation center, their parents are not always informed that they could also apply for supplemental child benefits. Caregivers in these centers are often focused on providing good care while losing sight of the bigger picture (5). More generally, in none of the surveyed organizations, basic information about the supplemental child benefit is commonly available (e.g. no flyers in waiting rooms).

Differences in the way parents are informed also exist among GPs and specialists. Many disabled children are followed-up by their GP, for instance, but there is no guarantee that the doctor is fully aware of the benefit and its eligibility criteria. Although it is the duty of social workers of the FGS to inform their partners and frontline organizations, they admit that it is very difficult to disseminate information to the almost 9,000 GPs working in Flanders (2). In addition, two respondents (2, 7) highlight that some doctors are reluctant to provide

information because it entails more work for them without getting any remuneration. Doctors have to fill in part B (see Appendix 2) of a medical information questionnaire, and this is necessary before the assessment by the FGS doctors can take place.

An important issue in the threshold stage is whether parents consider their child as eligible for the benefit. Some respondents (1, 3, 4) raise concerns about the name of the benefit. Although it is called the ‘supplemental child benefit for children with a disability or disorder’ (*Toeslag voor kinderen met een handicap of aandoening*), long-term or seriously ill children (e.g. young cancer patients) can also be entitled. In fact, a more accurate name would be something like the ‘supplemental child benefit for children with higher care needs’. The 36-point scale combines a medical with a social view. The medical view is reflected in the first pillar wherein a disability percentage is assigned to children; the social view is generally reflected in the second and third pillar in which the impact on self-reliance and the family’s care burden is gauged. It is the combination of points on the three pillars taken together that determines eligibility. This is not always clear for parents, however. Respondents indicate that parents sometimes believe that their child is ineligible because it does not have a disability, only to realize they do qualify after they have been informed that the assessment is not purely medical (2, 3, 4, 8).

5.3.2 *Trade-off stage*

Once potential claimants have crossed the threshold stage, they enter the trade-off stage in which they weigh perceived benefits against perceived costs. The perceived benefits include both the level and duration of the benefit. However, both elements are not predefined when parents consider to apply for the supplemental child benefit. The amount varies from €80 up

to more than €500 per month while the duration of the benefit can go from six months up to the moment the child reaches the age of 21. When the benefit expires, children need to be re-examined to extend the benefit. Usually the granted duration is adjusted to the typical school transition ages, meaning that children are re-examined at the ages of three, six, and twelve years, but the youngest children often have to come back for reassessment every two years (1). Sometimes benefits are granted immediately up to the age of 21 without any additional examination, for instance in the case of diabetes type 1 (1).

Two respondents (6, 8) understand that there should be some kind of follow-up, but wonder why this should be so frequent. *“A moderate intellectual disability or ASD is not gone after two years, why do they already have to show the same things? The way in which ASD is expressed does not have the same impact at every stage of your life, but every two years is very fast.”* (6). Other respondents state that frequent reassessment is necessary precisely because it is not purely a medical examination but also about the consequences for the family. And these consequences can change (2, 3). In any case, for parents it is unclear from the beginning for how long the benefit will be granted and how generous it will be.

Regarding the perceived costs, both process costs and social and psychological costs are relevant. One clear administrative obstruction parents run into when applying for the benefit is a waiting period. The FGS website documents the average waiting period, steps 1 to 7 in Figure 2, varying from one to three months depending on the region where you live. This is however a gross underestimation of the actual waiting period (1, 3, 4). If everything goes smoothly, the *minimum time* needed is about three months but usually it takes six to eight months (1, 3). This often leads to frustration amongst parents, particularly among those facing financial difficulties while having to cope with medical expenses (3, 4).

Parents themselves sometimes contribute to the long waiting period: applications can be incomplete, or parents do not show up for the medical examination (in 2.18% of the applications, see §5.1). This is related to the complexity of the procedure. Parents have to gather medical records, meet specific deadlines, and be able to physically go to the assessment by the FGS doctors (6, 7). Apparently it is a common complaint amongst parents that they feel pushed from pillar to post during the application procedure (3, 6, 8). Yet, not all respondents buy into the argument that the procedure is complex: *“The administration is not too bad. You have the request, the questionnaire, the medical part and then it is actually waiting for the doctor’s examination and waiting for the decision.”* (4).

Moreover, five of the respondents indicate that parents can get help to reduce these process cost (2, 3, 4, 7, 8). This includes information provision, assistance with filling in the questionnaire (Part A), and preparing parents for the assessment (e.g. advice on where to put emphasis on). Still, it is mentioned multiple times during the interviews that the administrative language and terminology used in the communication of the FGS is not comprehensible for all parents and regularly needs clarification (2, 3, 4).

Social and psychological cost such as stigma might prevent parents from applying as well. Some parents are still grappling with the fact that their child is disabled. Having to go through the whole procedure can be traumatizing in such cases (2, 4, 7). Moreover, even if parents have accepted the disability, the fact that they have to go through ‘another examination’ can be frustrating: *“so many examinations have already happened, I already have so many reports from specialists, is that not enough?”* (4).

5.3.3 Application stage

In the final stage, claimants start the application which can subsequently be approved or declined. It also happens that parents drop out at this stage (see above). We focus on problems that could arise in two steps: filing the questionnaires, and the assessment by the FGS doctors (steps 4 and 6 in Figure 2).

Parents have to complete a questionnaire concerning psychosocial and family information (part A, see Appendix 2), and it is important that they respond to the questions in an elaborate way as this has repercussions for the number of points their child will be granted on pillars 2 and 3:

For example, if you look at toilet, there is no question on whether a child is continent or incontinent, it says 'independence in washing and hygiene'. ... As a parent you should in fact say 'my child of seven years old is actually incontinent and she is wearing diapers', but if you do not get that question explicitly and you have not thought about it, then that is certainly not written down by the control doctor, while it leads to a quotation and points. (Interview 3)

Besides, parents have to find a doctor willing to fill in the medical questionnaire (part B, see Appendix 2). Respondents 1 and 2 underline the importance of adding medical and school performance reports to the application to better assess how the disability impacts on the child's life. Since these reports are not always centralized, for instance with the GP, parents

have to gather these reports themselves. This can be burdensome for more vulnerable parents who are less able to navigate administrative systems or for parents who do not go see a GP in the first place.

After filing the questionnaires, the child has to be examined by a FGS doctor. For that, parents receive an invitation to go to FGS offices at a proposed date. These offices are located in Belgian/Flemish central cities. Home visits are rarely an option and consequently parents may encounter logistic problems in organizing this trip. Moreover, if the proposed date does not suit their agenda, parents have to contact the FGS and motivate why they want to change. In total they get two chances (1, 4). Some children, however, do not have to come to the medical examination as they are automatically granted points. In 2010, this accounted for 20% of all applications, though this mainly concerns renewal applications and priority cases (1). First applications and particularly those of young children have to be examined in person.

Control doctors typically approach the child first during the medical examination and they ask questions directly to them to verify the information provided in the questionnaires. If they are finished with talking to the child, they already have a clear idea about the number of points they are going to grant (1). Only when parents ask, they can also have a moment alone with the control doctor to complete and clarify what their child said during the examination. Preparation by parents is key, which may create an imbalance between stronger and more vulnerable families (3, 4, 8). Furthermore, the examination lasts approximately 20 to 30 minutes, which might be too short to capture all of the child's developmental delays and behavioral problems (5, 8). Finally, respondents indicate that some parents report an unpleasant experience with the control doctor: he or she did not make enough time, was unfriendly, or did not seem to know much about their child's disability (3, 4).

The perception lives that the control doctors seem to more easily recognize a physical or visual disability than a less visible impairment such as ASD (5, 6), and that is what we find in the microdata as well (see §5.2). This is presumably partly the result of how the 36-point scale is constructed. Despite integrating a medical and social perspective, the emphasis is put on the former. Pillar 1 assigns a percentage to the child's disability. The scoring relies on a list of pediatric disorders as well as on the official Belgian scale to determine the degree of disability². However, the latter is outdated and not adjusted to the specificities of childhood disability nor to intellectual disorders as it was developed right after the Second World War to capture the reduction in earnings capacity of war victims. The list of pediatric disorders does comprise intellectual and psychological disorders, and ADHD, but to assign a disability score for these disabilities much emphasis is put on IQ test results while other aspects such as social adaptability are lacking. Control doctors state these tests are not sanctifying, for instance when the child has to take medication like Ritalin in case of ADHD or when a child is from a different cultural background (1). For children with ASD and a normal intelligence, then, it is almost necessary to explicitly specify (preferably in an additional medical report or school performance report) the limitations they experience due to the ASD (6). In sum, *“for ASD or ADHD, assigning a percentage to the disability is really difficult, it is guesswork”* (1).

An additional problem for these ‘less visible disabilities’ is that much weight is attached to the score on pillar 1 in calculating the benefit amount. If the child scores six to eight points in total but less than four points on pillar 1 (hence less than 66% disability percentage), the benefit amount will be four times less than when at least four points would have been awarded (see Appendix 1). Many of the respondents would prefer for the percentage to be dropped from

² For the full decree (in Dutch or French), see http://www.ejustice.just.fgov.be/cgi_loi/change_lg.pl?language=nl&la=N&cn=2006020831&table_name=wet

the classification system or at least to receive less weight in defining the benefit amount (1, 2, 5). Pillars 2 and 3 try to capture the consequences to the child's participation in daily life and to the family, in essence a social perspective on disability. Yet, here too, medical criteria are used to assess this. For example, two out of three subscales of pillar 3 look at the type and frequency of treatment and medical supervision needed for the child, inside or outside their home.

6 DISCUSSION AND CONCLUSION

In this paper we examine the extent and determinants of NTU of the supplemental child benefit for disabled children in Belgium. We exploit differences in disability recognitions at the federal and Flemish policy level, drawing on a unique and large-scale administrative dataset. We find that at least 10% of children with a recognized disability in Flanders do not receive supplemental child benefits at the federal level because they did not apply or dropped out during the process. This is a rather substantial rate, given that the NTU estimate in the regular child benefits is extremely low and that the benefit is not means-tested, only subjected to a disability recognition at the federal level. We find that the disability type is of major importance to understand this NTU rate: two thirds of children missing out on the supplemental child benefit have ASD or other intellectual or psychological disorders.

To better understand the underlying determinants of NTU, we conduct semi-structured interviews with experts and interpret the findings drawing on van Oorschot's (1996) dynamic multilevel framework of claiming benefits. The results point out the role of costs and benefits

at each stage of the application process. First, NTU results from insufficient information provision about the benefit by frontline organizations and doctors. More generally, it is confusing and difficult for parents since different kinds of support measures are located at different policy levels, all applying their own recognition and application procedures. Second, parents face process costs: they have to gather medical reports, meet specific deadlines and be able to physically go to the assessment by the FGS doctors. There is a minimum waiting period of three months. On top of that, neither the benefit level nor the duration are predefined when parents consider to apply and are hard to estimate beforehand.

Finally, NTU is probably partly the result of how the benefit scale is constructed. Despite integrating a medical and social perspective, the emphasis is still put on the former. Assigning a disability percentage to the less visible disabilities like ASD, ADHD and other intellectual or psychological disorders is not straightforward. Yet the disability percentage has important repercussions for the amount awarded. Even the parts of the scale meant to gauge the child's self-reliance and the family's care burden still strongly reflect a medical perspective.

Our analysis hints at three policy implications. First, more effort needs to be put into providing frontline organization, doctors and parents with correct information about the benefit's existence and eligibility criteria. Although automatic benefit entitlement is difficult if not impossible to implement, given its reliance on an assessment of the child's disability, we believe there is much to gain in terms of proactive information provision: when a child is enrolled in special education, hospitalized for a long time, recognized at the Flemish level, or examined by a GP, information on the supplemental child benefit should be provided by default. Related to that, simply removing the word 'disability' out of the benefit's name and

changing it to something like 'higher care needs' might circumvent the stigma associated with disability and might be more telling for parents.

Second, a revision of the benefit scale seems warranted. The benefit criteria still puts much emphasis on the medical perspective of the child's disability which is detrimental for children with less 'visible' disabilities. A validation nor reliability study has never been done before. A study using a vignettes set-up could be a next step to pinpoint the role of how the benefit criteria treat these less visible disabilities and whether, and if so how, they are assessed differently by different FGS doctors.

Finally, our results point to the need for coherence in the disability policy package. The recent transfer of competences for child benefits from the federal to the Flemish level to be concluded in 2020 provides a unique opportunity to align the recognition procedures for both cash and in-kind support to disabled children.

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APPENDIX 1 SUPPLEMENTAL CHILD BENEFIT: PILLARS, SUBSCALES, POINTS AND BENEFIT AMOUNTS, 2018

Pillar	Subscale	Points
1. Degree of incapacity	0-24%	0
	25-49%	1
	50-65%	2
	66-79%	4
	80-100%	6
<i>Total P1</i>		<i>max 6</i>
2. Activity and participation	Learning, education and social integration	max 3
	Communication	max 3
	Mobility and movement	max 3
	Self-care	max 3
<i>Total P2</i>		<i>max 12</i>
3. Family burden: highest score doubled	Follow-up of the treatment at home	max 3
	Leaving the home for medical supervision and treatment	max 3
	Adaptations to way of living	max 3
<i>Total P3</i>		<i>max 18</i>

Source: personal communication with FGS (2018)

Total points	Points on P1	Benefit amount €/month
< 6	≥ 4	80.75
6-8	< 4	107.55
6-8	≥ 4	414.28
9-11	< 4	250.97
9-11	≥ 4	414.28
12-14	n/a	414.28
15-17	n/a	471.07
18-20	n/a	504.71
> 20	n/a	538.36

Source: Famifed (2018)

**APPENDIX 2 PSYCHOSOCIAL AND FAMILY INFORMATION (A) AND
MEDICAL INFORMATION (B)**

tel.: 0800 98 799
(elke werkdag van 8.30 u tot 13.00 u)
fax: 02 509 81 85
e-mail: via het contactformulier
op www.handicap.fgov.be



7112

NAAM : ~~XXXXXXXXXX~~

VOORNAAM : ~~XXXXXXXXXX~~

DOSSIER : ~~XXXXXXXXXX~~

N/REF :
0018/JBE

0018

Bijkomende kinderbijslag

IN TE VULLEN EN TE VOEGEN BIJ DEEL B.

VOOR DE OUDERS

INLICHTINGENFORMULIER

DEEL A : PSYCHOSOCIALE EN FAMILIALE GEGEVENS

(inlichtingen verstrekt door de ouders)

Indien er een ernstig gevaar bestaat voor de gezondheid van uw kind is, onder bepaalde strikte voorwaarden, een bijzondere behandeling van uw aanvraag mogelijk (zie Deel B van het formulier in te vullen door uw arts).

Deze bijzondere procedure voorziet in een vaststelling van de handicap door de medische dienst van de FOD Sociale Zekerheid, op basis van medische verslagen zonder medisch onderzoek van uw kind.

Indien aan de medische voorwaarden is voldaan, ziet u dan enig bezwaar tegen deze bijzondere procedure van uw aanvraag? (*aankruisen wat van toepassing is*) :

- Neen, ik verzet mij niet tegen deze bijzondere procedure.
- Ja, ik verzet mij tegen deze bijzondere procedure en vraag een medisch onderzoek door de medische dienst van de FOD Sociale Zekerheid.

Naam en voornaam van het kind : Mijnheer ~~XXXXXXXXXX~~

Rijksregisternummer van het kind : ~~XXXXXXXXXX~~

Benaming en adres van uw kinderbijslaginstelling :

(facultatief) Refertenummer op het formulier "aanvraag tot medische vaststelling" van uw kinderbijslaginstelling :

Wie heeft het inlichtingenformulier ingevuld?

Naam, voornaam :

Hoedanigheid (ouder, familie, leerkracht, maatschappelijk werker, behandelende arts) :

Tel.nr. :

GSM nr. :

E-mail adres :

Datum :

Handtekening :



Met het oog op een vlotte behandeling van uw aanvraag, wordt u uitgenodigd om deze vragenlijst in te vullen en mee te sturen met uw aanvraag.
Deze vragenlijst helpt om de toestand van uw kind volledig te evalueren.

U mag deze zelf invullen of laten invullen door een derde (arts, sociaal assistent, ...)

Neem even de tijd om deze vragenlijst in te vullen. Vul alleen in wat voor het kind van toepassing is. Gebruik gerust uw eigen bewoordingen of uitleg, maar tracht zo nauwkeurig mogelijk te zijn.

Over onderwijs en gedrag van het kind thuis

Volgt het kind bijzonder of aangepast onderwijs?

Zo ja, vanaf wanneer? Maand/Jaar:

Welk type onderwijs? en waar?

Verblijft het in een instelling? Zo ja welke?

En sinds wanneer?

Wordt het regelmatig of langdurig opgenomen in een ziekenhuis?

Wanneer de laatste maal? en hoelang?

Volgt het kind thuisonderwijs?

Welke zware en/of langdurige behandeling heeft het kind?

Welke begeleiding of stimulering wordt er thuis gegeven door de ouders (vb. bij psychomotorische achterstand, gedrags- of zintuiglijke stoornissen)?

Is het gedrag van het kind thuis storend?

Welke moeilijkheden heeft het kind op school om met vriendjes om te gaan?

Andere nuttige gegevens :

Communicatie

Welke moeilijkheden heeft het kind bij het spreken?

In welke mate is het zicht of het gehoor gestoord?

Welke moeilijkheden heeft het kind om iets te begrijpen, te lezen of te schrijven?

Andere nuttige gegevens :

Over mobiliteit en verplaatsing

Welke moeilijkheden heeft het kind om zich te verplaatsen?

Gebruikt het kind krukken, beugels of prothesen of welke andere hulpmiddelen?

Welke moeilijkheden zijn er bij het fietsen, spel- en sportactiviteiten?

Andere nuttige gegevens :

Over opvolging van de behandeling (gedurende tenminste 6 maanden) thuis.

Krijgt het kind geneesmiddelen? Welke en hoeveel maal per dag (inclusief aërosol)?

Kine thuis, lidmaatprothese of beugel, korsetten of gipsen?

Huidverzorging, drukkledij of zalven: welke en hoeveel maal per dag?

Oogprothese, gehoorapparaat of cochleair implant?

Gastrostomie, anale dilataties, stomie, maagsonde, lavementen, urinaire sondage, enz ...

Sinds wanneer wordt de behandeling thuis gegeven?

Volgt het kind een dieet? Welk dieet?

Andere nuttige gegevens :

Over verplaatsing voor onderzoek of behandeling

Het gaat niet over verplaatsingen naar school of in schoolverband.

Welke oefeningen (vb. logopedie, kinesitherapie, ergotherapie) of begeleiding (vb. psychologisch) volgt het kind?

.....
.....

Waar gebeurt dit?

Wie zorgt er voor de verplaatsing?

Hoe vaak gebeurt dit per week of per maand?.....

Sinds wanneer?

Andere nuttige gegevens :

Over voeding, wassen, kleden en de aanpassing van de manier van leven

Welke moeilijkheden zijn er bij het eten?

.....

Welke aandacht of maatregelen zijn er nodig bij wassen of hygiëne?

.....

.....

Waarom bestaat de noodzaak tot thuisblijven van één van de ouders voor verzorging van het kind?

.....

Zo ja: halftijds of volledig?.....

En vanaf wanneer?

Waarom kunt U niet terecht voor gewone kinderopvang (kribbe, onthaalouder)?.....

.....

Welke inspanningen van de ouders of moeilijkheden zijn er voor jeugdbeweging, sportactiviteiten of vakantieverblijf?

.....

Andere nuttige gegevens :

.....



FOD SOCIALE ZEKERHEID

Directie-generaal
Personen met een handicap

tel.: 0800 98 799

(elke werkdag van 8.30 u tot 13.00 u)

fax: 02 509 81 85

e-mail: via het contactformulier
op www.handicap.fgov.be



7122

Brussel, 14/01/2016

NAAM : ██████████

VOORNAAM : ██████████

DOSSIER : ██████████

N/REF :
0018/JBE

0018

Bijkomende kinderbijslag

INLICHTINGENFORMULIER
DEEL B : MEDISCHE GEGEVENS

Medisch geheim

IN TE VULLEN DOOR EEN GENEESHEER

Strikte voorwaarden voor bijzondere procedure voor evaluatie zonder medisch onderzoek
(K.B. van 27 april 2007)

Aankruisen wat van toepassing is :

- Gereserveerde prognose op korte termijn (volgens het K.B. van 27 april 2007)
- Zware behandeling met gevolgen voor de immuniteit
- Belangrijke chirurgische ingreep in de loop van de 6 maanden na de geboorte of een ongeval
- Hospitalisering of posttraumatische revalidatie in een instelling gedurende minstens 6 maanden
- Het kind geniet palliatieve verzorging

De eerste voorwaarde moet voldaan zijn en één van de vier volgende.
Deze procedure kan niet meermaals na elkaar worden toegepast.

IDENTITEIT VAN HET KIND :

Naam en voornaam : Mijnheer ██████████

Rijksregisternummer : ██████████

Geslacht : M Geboortedatum : ██████████

VERBLIJFPLAATS VAN HET KIND :

Instelling :

Straat : Nummer : Bus :



Postcode : Plaats :

Telefoon / GSM-nummer :

E-mail :

ALGEMENE INLICHTINGEN OVER HET GEZIN :

	Leeftijd	Gezondheidstoestand	Beroep en/of studie
Vader	_____	_____
Moeder	_____	_____
Broers/zusters van het kind	_____	_____	_____

IDENTITEIT VAN DE GENEESHEER DIE DIT DOCUMENT HEEFT INGEVULD :

Naam : _____ **Voornaam :** _____

Adres :

Telefoon / GSM-nummer : _____

Fax : _____ **E-mail :** _____

RIZIV-nummer : _____

Antecedenten :

Medische antecedenten :

Datum	Diagnose	Behandelingen
.....	_____	Periode van tot (Maand / Jaar)
_____	_____	Periode van tot (Maand / Jaar)
_____	_____	Periode van tot (Maand / Jaar)

Chirurgische antecedenten :

Datum	Diagnose	Ingrepen
_____	_____	_____
.....	_____	_____
_____	_____	_____

Schoolbezoek :

Gewoon onderwijs :

Buitengewoon onderwijs :

Plaats : Type : OV : van tot of sinds

Plaats : Type : OV : van tot of sinds

IQ-test:

Type test : Datum : IQ tot.: VIQ : PIQ :

Type test : Datum : IQ tot.: VIQ : PIQ :

Type test : Datum : IQ tot.: VIQ : PIQ :

Instellingen (MPI / revalidatiecentrum / psychiatrie, ...) :

Plaats : van tot Of sedert :

Opnameverslag / evolutieverslag :
.....
.....
.....

Gedrag (beschrijving) :
.....
.....
.....
.....
.....

Huidige aandoeningen :

Diagnose	Datum van de 1e symptomen	Datum diagnose	Begindatum van de behandeling
.....
.....
.....

Type van de huidige behandeling :

<u>Geneesmiddelen (benaming)</u>	Posologie	Begindatum (Maand / Jaar)
.....
.....
.....

<u>Operaties</u>	Type	Datum
.....
.....
.....

<u>Ziekenhuisopnames</u>	Periode van	tot	(Maand / Jaar)

<u>Revalidatie :</u>	Begindatum	Frequentie (per week of maand)	Plaats
Logopedie
Kinesithérapie
Ergotherapie
Psychotherapie
Thuisbegeleiding

Behandeling (specifiëren) : intermitterend of continu?

Specifieke veiligheidsmaatregelen en/of preventieve maatregelen (thuis, school, vervoer) :

GELIEVE TE VERMELDEN WELK GESPECIALISEERD VERSLAG BIJ DIT FORMULIER WORDT GEVOEGD :

	Een recent verslag van een psychomotorische ontwikkelingstest
	Een CLB-verslag
	Een evolutieverslag van de kinderpsychiater / psychiater
	Een evolutieverslag van de oogarts met visus na correctie en met gezichtsveldbepaling
	Een evolutieverslag van de hemato-oncoloog
	Een evolutieverslag van de kindercardioloog
	Een evolutieverslag van de nefroloog met vermelding van de nierfunctie (creatinineclearance)
	Een evolutieverslag van de longspecialist + uitslagen longfunctietesten
	Een evolutieverslag van de kinderarts
	Een evolutieverslag van de neuroloog
	Een evolutieverslag van de uroloog
	Een evolutieverslag van de orthopedist
	Een evolutieverslag van de reumatoloog
	Een evolutieverslag van de endocrinoloog
	Een verslag van de prestaties op school (o.a. een stageverslag – gedrag op school)
	Een overzicht van de gevolgde revalidatie (logo – kine – ergo – resultaten multidisciplinair onderzoek)
	Andere : ...

DATUM EN HANDTEKENING :

STEMPEL VAN DE GENEESHEER :