Rijksdienst Caribisch Nederland
RCN-Unit Sociale Zaken en Werkgelegenheid

Assessment Framework Intensive Care (in connection with DKIZ)

Some background information regarding the double child benefit for children with an intensive care need (DKIZ).
The RCN Social Affairs and Employment Unit (RCN SZW Unit) implements the Child Benefit Provision Act BES and determines whether parents qualify for double child benefit for children living at home with an intensive care need. The purpose of the double child benefit is to provide the parents of severely disabled children living at home who require significant additional effort from their parents with a contribution towards the costs and a token of appreciation. Previously, the Temporary Allowance Scheme Children with Intensive Care BES existed.

The Child Benefit Provision Implementation Decree BES provides that intensive care exists where the case concerns a child that is so severely restricted in the daily functioning as a result of an illness or disorder of a physical, intellectual, sensory or mental nature that the care and supervision by the parents is aggravated to a serious extent compared with healthy children (Section 1a(1) of the Child Benefit Provision Implementation Decree BES). In order to determine whether a child requires intensive care, the RCN SZW Unit obtains an opinion based on medical data from the adviser (Section 5a(2) of the Child Benefit Provision Act BES). Further rules regarding the manner in which the adviser establishes whether there is question of intensive care as referred to in Section 5a of the Child Benefit Provision Act BES are laid down in the Child Benefit Provision Regulations BES.

Parents / carers submit an application for double child benefit to the Sentro Akseso (Bonaire), the Prevention Clinic (St. Eustatius) or Public Health (Saba). The RCN SZW Unit then asks the adviser for an opinion in order to determine whether intensive care is indeed involved. If the adviser issues a positive opinion (and several other conditions are met), double child benefit is granted by the RCN SZW Unit.

A specific assessment framework has been developed for establishing the intensive care need.

Assessment framework
Step 1 in the assessment is establishing whether there is question of an illness or disorder as referred to in the Child Benefit Provision Regulations BES. It is necessary for the illness or disorder to be substantiated with objective medical information from a relevant expert. If there is no illness or disorder that has been medically objectified, a negative opinion follows immediately. If there is an illness or disorder, step 2 follows.

Step 2 in the assessment is examining the care need on two elements, namely 'care' and 'supervision', each with five underlying functions. 'Care' concerns 'personal hygiene', 'continence', 'eating and drinking', 'mobility', and 'medical care'. 'Supervision' concerns 'behaviour', 'communication', 'being home alone', 'accompaniment outside the home' and 'occupying'. For each function it is determined whether or not an intensive care need exists. If this is the case, a score of 1 point is obtained (Section 2c of the Child Benefit Provision Regulations BES).

When is there a positive opinion on the basis of this framework?
The scheme is intended for children aged 3 up to and including 17 (Section 5a(1) of the Child Benefit Provision Act BES).
The total score in principle determines the outcome of the opinion. The opinion is positive if:

- 5 functions receive a score for children aged 3 up to and including 5;
- 4 functions receive a score for children aged 6 up to and including 9;
- 3 functions receive a score for children aged 10 up to and including 17.

Relevant points for attention when scoring

- The assessment framework is a tool for determining whether there is question of an intensive care need.
- In some cases a single score on the function 'medical care' suffices to qualify for double child benefit. See the point for attention with the relevant item for this.
- A single score on the function 'behaviour' is sufficient to qualify for double child benefit.
- The examples in the description of 'no score' are intended as a tool for arguments that parents may put forward. The examples are not exhaustive. A score can be obtained if a child meets the description under 'score 1'.

CARE

Function 1 Personal hygiene	
	Situation
Score 1	• Full assistance is needed. Cooperation or assistance by the child is not possible or only to a limited extent. Or • Can physically perform a number of actions independently, but not without permanent supervision and direction from another person. In addition, with (virtually) all actions instructions and/or assistance are needed.
No score	• Can physically perform the actions largely independently, but with some of the actions a great deal of supervision and possibly assistance is necessary. • Can physically perform (almost) all the actions independently, but frequent explanation, encouragement and checking are needed, without it being necessary for someone to be permanently nearby. • Can physically perform (almost) all the actions independently, but some checking afterwards is needed and possibly some assistance with finishing. • Does not need assistance with anything.
Points for attention in the assessment: Note: a child without an illness or disorder can also obtain a score here.	

Function 2 Continence	
	Situation
Score 1	• Is not continent during the day and at night. Or • Needs a great deal of assistance with going to the toilet, namely someone must be continuously present and/or provide assistance with some of the actions.
No score	• Is continent during the day, but not at night. Sleeps (through or otherwise) without a change of night-time nappy. • Is in principle continent, but accidents occur regularly (at least once a week). • Is continent, but needs assistance with hygiene after defecation. • Assistance and/or checking is needed with regard to hygiene during menstruation. • Is continent, but stimulation and checking are needed in the sense of reminders at certain times, possibly a sporadic accident. • Is continent and can go to the toilet entirely independently.
Points for attention in the assessment: Note: a child without an illness or disorder can also obtain a score here.	

Function 3 Eating and drinking	
	Situation
Score 1	• Receives tube feeding (whether or not in addition to ordinary food). Or • Must be assisted with consuming the meal because of an illness or disorder. Or • Has an eating disorder established by a paediatrician / psychiatrist that is durably present (longer than a year) and/or therapy-resistant. Or • Permanent supervision is needed because of a risk of aspiration. Or • There is a need for supervision and observation with regard to eating and drinking sufficiently healthily over the twenty-four-hour period. This concerns, for example: o a medically necessary deviant dietary pattern or diet (for example high-calorie intake with cystic fibrosis or a ketogenic diet with epilepsy) or actions relating to diabetes; o encouraging or restraining the child in connection with psychiatric conditions and/or (objectified) behavioural problems.
No score	• Can eat and drink independently, but needs encouragement or restraint from time to time in doing so. • Can eat and drink independently, but needs adapted cutlery or crockery in doing so. • Can eat and drink independently, but as a result of an illness or condition the preparation must be done by others.
Points for attention in the assessment: Total Parenteral Nutrition (TPN) also receives a score here.	

Function 4 Mobility	
This concerns severely limited walking function as a result of motor or energetic limitations.	
	Situation
Score 1	• Cannot walk, moves about by crawling or shuffling. Or • Is wheelchair-dependent and needs assistance with transfers and/or moving about. Or • Can only walk with continuous assistance and support from a carer. Or

	• Outside the home a wheelchair pushed by a carer is always needed because of severe energetic limitations.
No score	• Moves about by wheelchair, but can move about independently inside and outside the home and can also transfer independently. • Can move about independently in the home (walking or walking with an aid) and outside the home to a limited extent, but needs a wheelchair for longer distances where the average peer no longer needs a pushchair / buggy. • Is able to walk and climb stairs independently. At most a wheelchair is used incidentally for an outing.
Points for attention in the assessment: This concerns *motor limitations* with walking and climbing stairs. Young children who are still transported (in a buggy or a comparable means of transport) for other reasons do not receive a score. Nor do they if it concerns behavioural problems or sensory limitations. In this regard we take as our starting point the aids that are present (the adviser does not enter into discussion about which (more adequate) aids should possibly be provided in a specific situation).	

Function 5 Medical care	
	Situation

Score 1	• Long-term (longer than a year) *intensive* medical *specialist* nursing in the home situation. This concerns the following two situations.
	  ○ Children with heavily complex somatic problems or a physical disability that, as a result of these problems, have a need for care or nursing and where permanent supervision is necessary. This concerns uninterrupted supervision and active observation throughout the entire day with regard to physical functions, whereby the parents / care providers must actively monitor the child's vital bodily functions. This concerns, for example, active monitoring of breathing, swallowing, a decrease in consciousness, internal or subcutaneous bleeding, blood pressure and body temperature. In the event of abnormalities, intervention must take place immediately because otherwise danger arises. This danger concerns in particular acute oxygen desaturation caused by, for example, respiratory arrest or an obstruction of breathing, the occurrence of a severe epileptic seizure or a shock. Examples of timely intervention are the administration of (extra) oxygen, suctioning, the administration of medication and resuscitation.
	  ○ It may also concern children with lighter complex problems or a physical disability, where one or more specific nursing actions are needed and where care is needed continuously nearby. With these children the care must indeed be available nearby throughout the entire day, but permanent active observation is not needed in this regard. It therefore concerns a form of availability of care that consists for a large part of more passive supervision. The care is, however, needed at both planned and unplanned care moments. The specific nursing actions concern actions such as the administration of oxygen, connecting and disconnecting ventilation equipment, administration of intravenous medication or parenteral nutrition, changing cannulas and keeping catheters open and flushing them through and the like.

	Or • Necessity of *time-consuming preparation* of individual dietary nutrition prescribed by a physician.
No score	• Long-term medical care / treatment in the home situation. • Can catheterise / perform colonic irrigation independently, but does need some assistance, for example laying out, tidying away materials, instruction / checking of the necessary actions. • Supervision of a Ventriculo Peritoneal drain (brain drain). • Necessity of preparation of individual dietary nutrition that is not very time-consuming. • Paramedical treatment plus daily exercises by the parents in the home situation. • Checking of intake and/or encouragement with intake with chronic, daily use of medicines. • Daily long-term / chronic skin care by another person needed. • Must be accompanied on regular hospital visits at least once a month. • Short-term use of medicines or medical actions. • Temporary paramedical treatment.

Points for attention in the assessment:
Only that which is objectified and medically necessary and takes more time is classified as 'time-consuming'. With the diet it does not concern ready-made products. The preparation must be *time-consuming* such as with the preparation of non-ready-made tube feeding and total parenteral nutrition (TPN).

- Most children with TPN use an 'all-in-one' system, delivered ready-made by, for example, the hospital pharmacy. They do not obtain a score here.
- Children with whom the nutrients must run in separately (carbohydrates, fats and proteins separately) or be prepared separately (approx. 10% of clients with TPN, oncoline) do obtain a score here.
- Tube feeding that is delivered in ready-made form (in liquid form or as a powder that has to be diluted) does **not** receive a score (regardless of whether it is once per 24 hours or per meal).
- Non-regular treatments or medicines do **not** receive a score either. The same applies to vitamin preparations, or anything else, that are not used on medical prescription.
- Incidental periods with medication, for example with an exacerbation of asthma, likewise do **not** obtain a score.

Remarks

- Please note: In some cases a score on this item suffices to arrive at a positive opinion for double child benefit on the basis of the scheme. That is the case with very intensive medical care: this then concerns children with whom permanent supervision is needed (1st bullet under 'score 1': 'heavily complex somatic problems'); an additional criterion is that the prognosis is that this will be at issue for more than a year. In the event of doubt about permanent supervision, present the matter to the medical adviser.

SUPERVISION

Function 6 Behaviour	
Under this item only behavioural pathology for which there is an explanatory diagnosis from a relevant expert obtains a score.	
	Situation

Score 1	• There must be permanent supervision in connection with behavioural problems and escalations occurring or threatening throughout the entire day. There is *active signalling and, where necessary, acting with the child. The behavioural problems call for regulation of the behaviour because the child cannot do this itself.*
	  ○ With PSY: a child psychiatric diagnosis in the area of behavioural pathology has been made by a relevant expert.
	  ○ With ID: objectified by a relevant expert such as an ID physician or behavioural specialist.

No score	• A child psychiatric diagnosis in the area of behavioural pathology has been established by a relevant expert, but there is no permanent supervision • There are structural and serious behavioural problems, but there is no permanent supervision. • Exclusively reactive behavioural problems or adolescent reactions.
Points for attention in the assessment: This concerns only permanent supervision.	

Function 7 Communication	
This concerns (1) the technical ability to speak and (2) the course of the communication. This does not concern writing, reading or learning disorders.	
	Situation
Score 1	• Inability to speak. Or • Speech cannot be understood by anyone or only by close carers / parents; only makes clear by gestures that they want something from someone. Or • Communicates only with isolated gestures and isolated words. Or • As a result of a condition (virtually) never responds to instructions and questions or only with gestures or (supporting) gestures and isolated words. Virtually no communication is possible. Or • Does not understand the other person at all or virtually not as a result of a condition.

No score	• Makes contact independently with third parties and is heard and understood by them. • Communication by means of sign language.

Function 8 Being home alone	
	Situation
Score 1	• Cannot be home alone for more than 30 minutes as a result of an illness or disorder.
No score	• Can be home alone for more than 30 minutes, during the day and/or in the evening. • Can be home alone exclusively during the day, but not in the evening and at night.
Points for attention in the assessment: This concerns what the child is capable of and not what it is not (yet) allowed to do. The 'not being capable' must be plausible or objectified.	

Function 9 Accompaniment outside the home	
	Situation
Score 1	As a result of an illness or disorder can: • not go outside alone or • only play in the own 'enclosed' garden or • only (play) outside because the living environment and social situation lend themselves to it and supervision from the house is possible or in direct (and continuous) view.
No score	• Can only play outside in the immediate living environment or at an agreed place, with checking / looking at certain moments. • Cannot take part in traffic outside the own living environment without accompaniment (not safe in traffic). • Can only cover one or two learnt routes independently by bus or by bicycle. • Plays outside with the agreement to come home at a certain time. • Goes to friends or family alone. • Can do an errand independently (possibly with instruction). • Goes to school or a club independently.
Points for attention in the assessment: This concerns what the child is capable of and not what it is not (yet) allowed to do. The 'not being capable' must be plausible or objectified. The necessary supervision can also take place remotely via, for example, a tracker / GPS.	

Function 10 Occupying, assistance	
	Situation
Score 1	As a result of an illness or disorder: • there is a necessity to offer a full, complete daily structure with continuous individual attention and activation or • the child cannot entertain or occupy itself alone at all or • all activities inside the home must be organised and supervised or • there is full adaptation and strong restriction of the lifestyle.
No score	• Necessity of a fixed structure and daily programme in connection with behavioural problems or other child psychiatric disorders. • Some adaptation of lifestyle as a result of serious chronic illness, wheelchair dependence and/or serious sensory disability. • Necessity of additional structure or explanation / preparation / accompaniment as a result of (mild) intellectual disability. • Needs attention from time to time with regard to processing the illness / disability, inner world, explanation about tasks, preparation for new situations, reassurance, but can also entertain itself alone for some time or occupy itself with something in a concentrated way. • Can entertain itself alone for some time or play in its own room. • Can entertain itself well alone, possibly with accompaniment at moments. • Can occupy itself with something for a considerable time alone in its own room or the living room.