

Assessment framework intensive child care

The medical assessment for determining potential intensive care involves examining two elements - namely 'personal care' and 'supervision' - which are both divided into five functions. 'personal care' relates to 'personal hygiene', 'toilet training', 'eating and drinking', 'mobility' and 'medical care'. 'supervision' relates to 'behaviour', 'communication', 'being home alone', 'guidance outdoors' and 'keeping busy'. For each function, it will be examined whether the care in question is intensive. If this is the case, 1 point will be awarded.

What will constitute positive medical advice?

The arrangement is intended for children from 3 to 17 years old. In principle, the total score will determine the outcome of the medical advice. The advice will be positive if:

- 5 functions have been awarded a point for children from 3 to 5 years old;
- 4 functions have been awarded a point for children from 6 to 9 years old;
- 3 functions have been awarded a point for children from 10 to 17 years old.

PERSONAL CARE

FUNCTION 1 Personal hygiene	<ul style="list-style-type: none"> • Washing and showering • Drying • Washing hair • Dressing and undressing • Brushing teeth
	Situation
Score 1	<ul style="list-style-type: none"> • Complete care is needed. Cooperation or assistance by child is not possible or only to a very limited extent. <p style="text-align: center;">Or</p> <ul style="list-style-type: none"> • Able to perform a few actions him/herself but not without someone else being present at all times. In addition: <ul style="list-style-type: none"> ○ instructions are needed for (almost) all actions and ○ specific physical assistance (complete control) is needed for some of the actions.
No score	<ul style="list-style-type: none"> • Can do most physical things autonomously, but a lot of supervision and possibly assistance is needed for some of the actions; or • Can do (almost) everything physical autonomously, but frequent explanations, encouragement and checks are needed without someone needing to be close by at all times. • Can do (almost) everything autonomously, but certain checks are needed afterwards as well as minor assistance to finish off. • Does not need any assistance whatsoever.
<p>Areas of attention for the assessment: '(Almost) everything' can be defined as four of the above mentioned actions. Please note: children without an illness or disorder can also earn a point in this area.</p>	

FUNCTION 2: Toilet training	
	Situation
Score 1	<ul style="list-style-type: none"> • Cannot go to the toilet during the day or at night. <p style="text-align: center;">Or</p> <ul style="list-style-type: none"> • Needs a lot of assistance when going to the toilet, namely someone must be present at all times and/or must offer assistance with some of the actions.
No score	<ul style="list-style-type: none"> • Goes to the toilet during the day but not at night. Sleeps (possibly uninterrupted) without nappy needing to be changed. • Toilet trained in principle, but minor accidents are encountered on a regular basis (at least 1x per week) • Toilet trained but needs hygiene-related assistance after defecating. • Hygiene-related assistance and/or checks are needed during menstruation. • Toilet trained but encouragement and checks are needed, reminders at particular times; possibly the occasional accident; • Toilet trained and can go to the toilet autonomously.
<p>Areas of attention for the assessment: Please note: children without an illness or disorder can also earn a point in this area.</p>	

FUNCTION 3: Eating and drinking

	Situation
Score 1	<ul style="list-style-type: none">• Catheter-based nutrition (possibly in addition to regular food).Or• Needs help when eating food, due to an illness or disorder.Or• Has a persistent (longer than one year) and/or therapy-resistant eating disorder that has been confirmed by a paediatrician/psychiatrist.Or• Permanent supervision is needed due to risk of aspiration (choking).Or• Need for continuous encouragement during the meal due to<ul style="list-style-type: none">○ a medically essential alternative feeding pattern or diet (for example, high-calorie intake for cystic fibrosis or ketogenic diet for epilepsy).○ psychiatric conditions and/or (confirmed) behavioural issues.
No score	<ul style="list-style-type: none">• Able to eat and drink autonomously, but needs occasional encouragement when doing so.• Able to eat and drink autonomously, but needs special cutlery or crockery.• Able to eat and drink autonomously but preparation must be done by others due to an illness/condition.
Areas of attention for the assessment: Total Parenteral Nutrition (TPN) also scores.	

FUNCTION 4 Mobility	This relates to severely limited ability to walk due to motor- or energy-related limitations.
	Situation
Score 1	<ul style="list-style-type: none"> • Unable to walk; moves around by crawling/sliding. <p style="text-align: center;">Or</p> <ul style="list-style-type: none"> • Needs wheelchair and requires help for transfers and/or movement. <p style="text-align: center;">Or</p> <ul style="list-style-type: none"> • Only able to walk with continuous assistance and support from a companion. <p style="text-align: center;">Or</p> <ul style="list-style-type: none"> • Due to severe energy-related limitations, a wheelchair that is pushed by a companion is always needed when outdoors.
No score	<ul style="list-style-type: none"> • Travels using a wheelchair, but is able to travel autonomously indoors and outdoors, and needs no help during transfers. • Able to move around autonomously indoors (by walking or walking with assistance) and to a limited extent outdoors, but needs a wheelchair for longer distances, whereas average children of the same age do not require a stroller/pushchair. • Able to autonomously walk (climb the stairs). A wheelchair is not used more than occasionally for excursions.
<p>Areas of attention for the assessment: This relates to <i>motor-related limitations</i> when walking and climbing the stairs. Young children that are transported in a pushchair or similar means of transport due to other reasons, do not earn a point. Also not if behavioural problems or sensory limitations are involved.</p> <p>In this case, we base ourselves on the available resources. Sentro Aksezo/Public Health does not get involved in discussions about which (more suitable) resources should possibly be issued in specific situations. The assessment takes place based on the current situation. Should the medical assessment reveal a desire to adjust the aids, the usual application route will then be followed. Once the final regulation is in place, it may make sense to reapply if it appears that the score changes.</p>	

FUNCTION 5: Medical care

	Situation
Score 1	<ul style="list-style-type: none">• Long-term (longer than a year) <i>specialised intensive</i> medical nursing in a home setting. This relates to the following situations:<ul style="list-style-type: none">○ Children with severe somatic issues or a physical disability who, due to this problem, require care or nursing where permanent supervision is needed. This relates to uninterrupted supervision and active observation during the whole day when it comes to physical functions, whereby the parents/care providers must actively check the child's vital bodily functions. For example, this involves actively checking respiration, swallowing, decreases in consciousness, internal or subcutaneous bleeding, blood pressure and body temperature. If there are abnormalities, immediate action is needed to avoid imminent danger. In this case, the danger relates to an acute drop in oxygen levels due to, for example, respiratory failure, an obstructed airway, a severe epileptic episode or shock. Examples of timely intervention involve administering (extra) oxygen, suction, administration of medication, and reanimation.○ This can also relate to children with milder complex issues or a physical disability, where one or more specific nursing actions are needed and where close care is needed at all times. Although nearby care must be available during the whole day for these children, permanent active observation is not needed. It thus involves availability of care, where a more passive form of supervision is needed. However, the care is actually needed at planned as well as unplanned moments. As far as the specific nursing actions are concerned, they are actions like administering oxygen, connecting and disconnecting respiratory equipment, administering intravenous medication or parental nutrition, exchanging canulae and opening and rinsing catheters, etc. <p>Or</p> <ul style="list-style-type: none">• Need for <i>time-consuming preparation</i> of individual diet, which has been prescribed by a doctor.

<p>No score</p>	<ul style="list-style-type: none"> • Long-term medical care/treatment in a home setting. • Able to catheterise/perform colonic irrigation autonomously, but needs certain guidance, for example, preparations, tidying away materials, instructions/inspection of necessary actions, etc. • Supervision of Ventriculoperitoneal drain (brain drain) • Need to prepare individual diet, which is not time-consuming. • Paramedic treatment plus daily exercises by the parents in a home setting • Checks or encouragement during intake chronic and daily medication • Needs daily long-term/chronic skin care by someone else • Must be guided during regular hospital visits, at least 1x per month • Short-term medicine use or medical treatments • Temporary paramedical treatment
<p>Areas of attention for the assessment:</p> <p>The diet does not involve ready-made products. Preparation must be <i>time-consuming</i>, as possibly needed on several occasions when preparing non-ready-made nutrition via catheter and total parenteral nutrition (TPN).</p> <ul style="list-style-type: none"> - Most children with TPN use an ‘all-in-one’ system, delivered ready-made by, for example, the pharmacy at the hospital. They do not earn a point in this case. - However, children whose food must be consumed separately (carbohydrates, fats and proteins separately) or prepared separately will earn a point (ca. 10% of clients with TPN, oncoline). - Catheter-based nutrition that is supplied in ready-made form (in liquid form or as a powder that must be diluted) will not earn a point (irrespective of whether it is 1x per 24 hours or every meal). - Only things that have been objectified and take more time for medical reasons will be classed as ‘time-consuming’. - Non-regular treatments or medicines are also not awarded a point. The same applies to vitamin preparations, or other things that are not used based on a medical prescription. - Incidental periods with medication, for example, in case of asthma exacerbation, are also not awarded a point. 	
<p>Comments</p> <ul style="list-style-type: none"> - Please note: In some cases, earning a point for this item is sufficient to qualify for the arrangement. This is the case for very intensive medical care: for children where permanent supervision is needed (1st bullet under ‘score 1’: ‘severe complex somatic issues’); another criterion is that it is expected to last for longer than a year. In case of doubt concerning permanent supervision: present to the medical advisor. 	

SUPERVISING THE CHILD (SUPERVISION)

FUNCTION 6: Behaviour:	Under this item a point is only awarded for behavioural pathology that comes with an explanatory diagnosis by a suitably qualified specialist.
	Situation
Score 1	<ul style="list-style-type: none"> • There must be permanent supervision for behavioural problems and escalations that occur, or are at risk of occurring, throughout the day. <ul style="list-style-type: none"> ○ For PSY: a (child) psychiatric diagnosis at behavioural pathological level has been made by a suitably qualified professional. ○ For VG: objectified by a suitably qualified expert, such as an AVG or behavioural specialist.
No score	<ul style="list-style-type: none"> • A (child) psychiatric diagnosis at behavioural pathological level has been made by a suitably qualified professional; but there is no permanent supervision • There are structural and severe behavioural problems, but there is no permanent supervision. • No or an insufficiently documented behavioural pathology by a suitable expert. • Only reactive behavioural problems or pubescent reactions.
Areas of attention for the assessment: This only relates to permanent supervision. Mild ADHD and mild autism should not be awarded a point.	

FUNCTION 7 Communication	This relates to (1) the technical ability to speak and (2) how <i>basic</i> communication takes place. Thus not to writing, reading or learning disorders or interpretation problems.
	Situation
Score 1	<ul style="list-style-type: none"> • Inability to speak. <p style="text-align: center;">Or</p> <ul style="list-style-type: none"> • Speech cannot be understood by anyone or only by close carers/parents; only uses gestures to show that s/he wants something. <p style="text-align: center;">Or</p> <ul style="list-style-type: none"> • Only communicates with gestures and individual words. <p style="text-align: center;">Or</p> <ul style="list-style-type: none"> • Due to a severe autism-related condition, (almost) never reacts to instructions and questions, or only with gestures or (supporting) gestures and individual words. More or less no communication is possible.
No score	<ul style="list-style-type: none"> • Personally initiates contact with others. • Also heard and understood by third parties. • Can sufficiently participate in regular education.
<p>Areas of attention for the assessment:</p> <ul style="list-style-type: none"> - This relates to speech and language disorders. - ADHD and ODD do not earn a point for communication unless there is a demonstrable additional diagnosis to explain them. - If the reaction of the child is inadequate, but can be attributed to behavioural pathological problems, this will earn a point for the other components. 	

FUNCTION 8: Being home alone	
	Situation
Score 1	<ul style="list-style-type: none"> Cannot be alone at home for longer than 30 minutes due to an illness or disorder.
No score	<ul style="list-style-type: none"> Can be alone at home for longer than 30 minutes, during the day and/or in the evening Can be at home alone during the day, but not in the evening and at night.
<p>Areas of attention for the assessment: This relates to what the child is capable of and not what it is not (yet) allowed. The 'not being capable' must be plausible or have been objectified.</p>	

FUNCTION 9: Guidance outdoors	
	Situation
Score 1	<p>Due to an illness or disorder, can:</p> <ul style="list-style-type: none"> not go outdoors alone Or only play in own 'fenced' garden Or only play outside because this is permitted by the residential environment and social situation, and supervision from inside the house is possible or the child is directly (and continuously) visible.
No score	<ul style="list-style-type: none"> Can only play outside in the immediate residential environment or at the agreed place, with checks/supervision at certain moments. Cannot be involved in traffic (lack of road safety) outside own residential environment unless there is guidance. Can only travel one or two learned routes alone by bus or bike. Plays outside with the agreement that s/he must return home at a particular time Only visits friends and family. Is able to go shopping alone (possibly with instructions). Goes to school/sports club alone.
<p>Areas of attention for the assessment: This relates to what the child is capable of and not what it is not (yet) allowed. The 'not being capable' must be plausible or have been objectified.</p>	

FUNCTION 10 Keeping busy, helping hand

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	Situation
Score 1	<p>Due to an illness or disease:</p> <ul style="list-style-type: none"> • there is need to offer a comprehensive and complete day structure with continuous individual attention and activation. <p style="text-align: center;">Or</p> <ul style="list-style-type: none"> • the child cannot keep him/herself amused or busy alone. <p style="text-align: center;">Or</p> <ul style="list-style-type: none"> • all activities must be organised and guided indoors. <p style="text-align: center;">Or</p> <ul style="list-style-type: none"> • the lifestyle of the family has been fully adjusted and strongly limited due to a severe chronic illness (for example, leukaemia, terminal renal insufficiency, late-stage Duchenne, cystic fibrosis).
No score	<ul style="list-style-type: none"> • Need for a fixed structure and day programme due to behavioural issues or other child psychiatric disorders. • Slight change in lifestyle due to severe chronic illness, reliance on wheelchair and/or severe sensory disability. • Need for extra structure or explanation/preparation/guidance due to (mild) mental disability. • Occasionally needs attention in relation to processing illness/disability, perception, explanation about tasks, preparation for new situations and reassurance, but can also amuse him/herself or concentrate on something for a certain amount of time. • Can amuse him/herself or play in own bedroom for a certain amount of time. • Able to amuse him/herself alone, possibly with guidance at times. • Can spend a lot of time alone or focus on something in own bedroom or the living room.