



Questionnaire Shwachman Diamond Syndrome

July 21, 2021

Why this form

Rare Care World's website brings together information about rare conditions such as Schwachman Diamond Syndrome (SDS) to provide people with a rare condition worldwide, their families and others the same information. For this purpose, the ICF coding established by the WHO (World Health Organisation) is used.

We intend to ensure that people with a rare condition in the Netherlands, and in principle in any country developing a personal health record, can fill out a form within their own PGO (personal health environment) about a number of activities with which they have problems in accordance with the ICF coding. The form you are reading now is an example, in this case for people with SDS.

Explanation of the questions

The form is built the same way as using the ICF as is done through the website of the WHO, but is rewritten for someone with SDS in the Netherlands, who can fill out a form him/herself, with or without help from others. Moreover there is extra explanation at each activity.

The different activities have been numbered as used in the ICF. People with a condition other than SDS may have the same problems. The aim is to develop similar forms for them with the same numbering and description. In order to make it clear that the person concerned will fill out the form himself, the sentence about this will return in each item.

Do you have questions about the form? Please contact Rare Care World at info@rarecare.world

More about the ICF::

- More information about the International Classification of Functioning, Disability and Health can be found at
 - <https://www.rarecare.world>
 - <https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health>
- The Dutch summary can be found at <https://www.rivm.nl/media/WHO-FIC/ICFwebuitgave.pdf>
- The Dutch text has been simplified for both the website and the form. However, the full text is always included on the website under the heading 'Omschrijving door de WHO' ('Description by the WHO')

Activities and Participation		SDS						
<p>The purpose of this questionnaire is to get a clearer picture of the problems you experience in carrying out activities. You are asked to give yourself a rating for each component.</p> <p>. At the first question it says 'with help' or 'with tool'. Please fill in if you can do this in daily life with help or tool.</p> <p>. At the second questions you are asked if you can do it without that help or tool</p>								
Severity of the problem		No difficulty	Mild difficulty	Moderate difficulty	Severe difficulty	Complete difficulty	Not specified	Not applicable
d210	Undertaking a single task	0	1	2	3	4	8	9
	With help or tool							
	Without help or tool							
<p>Explanation: Carrying out simple or complex and coordinated actions related to the mental and physical components of a single task, such as initiating a task, organizing time, space and materials for a task, pacing task performance, and carrying out, completing, and sustaining a task</p> <p><i>Think of:</i> <i>insight, overview, perseverance, performance anxiety, concentration.</i></p>								
<p>Please describe your problem here:</p>								
<p>This questionnaire has been filled in by the person involved, with or without help from family, caregiver or healthcare provider.</p>								
d240	Handling stress and other psychological demands	0	1	2	3	4	8	9
	With help or tool							
	Without help or tool							
<p>Explanation: Carrying out simple or complex and coordinated actions to manage and control the psychological demands required to carry out tasks demanding significant responsibilities and involving stress, distraction or crises, such as driving a vehicle during heavy traffic or taking care of many children.</p> <p><i>Think of:</i> <i>Concentration, taking responsibility, dealing with stress, dealing with crisis situations, action-response, sometimes aggressive behaviour due to impotence, fear, irritation.</i></p>								
<p>Please describe your problem here:</p>								
<p>This questionnaire has been filled in by the person involved, with or without help of family, caregiver or healthcare provider.</p>								

d310	Communication with - receiving - spoken messages	0	1	2	3	4	8	9
	With help or tool							
	Without help or tool							
	<p>Explanation: Comprehending literal and implied meanings of messages in spoken language, such as understanding that a statement asserts a fact or is an idiomatic expression.</p> <p><i>Think of:</i> <i>Difficulty with concentration, holding attention, (minimal) general and language development, fear of failure</i></p>							
	Please describe your problem here:							
	This questionnaire has been filled in by the person involved, with or without help from family, caregiver or healthcare provider.							
d4751	Driving motorized vehicles	0	1	2	3	4	8	9
	With help or tool							
	Without help or tool							
	<p>Explanation: Driving a vehicle with a motor, such as an automobile, motorcycle, motorboat, or aircraft may be difficult.</p> <p><i>Think of:</i> <i>Coordination problems (too many actions eye-hand and eye-foot coordination), concentration, processing too much information, performance anxiety. Passing driving examination (theory and practice) costs extra effort, time and money.</i></p>							
	Please describe your problem here:							
	This questionnaire has been filled in by the person involved, with or without help from family, caregiver or healthcare provider.							
d570	Looking after one's health	0	1	2	3	4	8	9
	With help or tool							
	Without help or tool							
	<p>Explanation: Ensuring physical comfort, health and physical and mental well-being, such as by maintaining a balanced diet, and an appropriate level of physical activity, keeping warm or cool, avoiding harms to health, following safe sex practices, including using condoms, getting immunizations and regular physical examinations.</p> <p><i>Think of:</i> <i>Taking good care of yourself (medicine use, mental and physical health), making independent decisions, being dependent on others, cold, infections, fatigueness, endurance, etc.</i></p>							

Please describe your problem here:								
This questionnaire has been filled in by the person involved, with or without help of family, caregiver or healthcare provider.								
d610	Acquiring a place to live	0	1	2	3	4	8	9
	With help or tool							
	Without help or tool							
<p>Explanation: Buying, renting, furnishing and arranging a room, house, apartment or other dwelling.</p> <p><i>Think of:</i> <i>Living independently, assisted living, accessibility, affordable, help in furnishing your home, help in administration and finances, etc. In case of bying: mortgage, insurance, etc.</i></p>								
This questionnaire has been filled in by the person involved, with or without help from family, caregiver or healthcare provider.								
Please describe your problem here:								
d640	Doing housework	0	1	2	3	4	8	9
	With help or tool							
	Without help or tool							
<p>Explanation: There may be problems with taking care of the household and cleaning the house.</p> <p><i>Think of:</i> <i>Provide food and drinks, washing and ironing, changing bedding, cleaning toilet and bathroom, window cleaning, vacuum cleaning, storing shoppings, removing garbage, fatigueness, etc.</i></p>								
Please describe your problem here:								
This questionnaire has been filled in by the person involved, with or without help from family, caregiver or healthcare provider.								
d710	Basic interpersonal interactions	0	1	2	3	4	8	9
	With help or tool							
	Without help or tool							
<p>Explanation: Interacting with people in a contextually and socially appropriate manner, such as by showing consideration and esteem when appropriate, or responding to the feelings of others.</p> <p><i>Think of:</i> <i>Problems to express yourself, getting no understanding, sometimes becoming aggressive through impotence, turned inward.</i></p>								

	Please describe your problem here:							
	This questionnaire has been filled in by the person involved, with or without help from family, caregiver or healthcare provider.							
d720	Complex interpersonal interactions	0	1	2	3	4	8	9
	With help or tool							
	Without help or tool							
	<p>Explanation: Maintaining and managing interactions with other people, in a contextually and socially appropriate manner, such as by regulating emotions and impulses, controlling verbal and physical aggression, acting independently in social interactions and acting in accordance with social rules and conventions.</p> <p><i>Think of:</i> <i>Entering into relationships, ending relationships, having a grip on one's own behaviour in company, behaving according to social rules in company, keeping social distance, dealing with emotions.</i></p>							
	Please describe your problem here:							
	This questionnaire has been filled in by the person involved, with or without help from family, caregiver or healthcare provider.							
d 820	School education	0	1	2	3	4	8	9
	With help or tool							
	Without help or tool							
	<p>Explanation: Gaining administration school, education, engaging in all school-related responsibilities and privileges, and learning the course material, subjects and other curriculum requirements in primary and secondary school education, including attending school regularly, working cooperatively with other students, taking directions from teachers, organizing, studying and completing assignments tasks and projects, and advancing the other stages of education.</p> <p><i>Think of:</i> <i>School choice, learning problems, concentration problems, fatigueness, being sick more often, needing more support and explanation, performance anxiety, cooperation with others (classmates, teachers), in further education: get stuck between shore and ship, absence for medical reasons, etc.</i></p>							
	Please describe your problem here:							
	This questionnaire has been filled in by the person involved, with or without help from family, caregiver or healthcare provider.							
d 850	Remunerative employment	0	1	2	3	4	8	9
	With help or tool							
	Without help or tool							

Explanation: Engaging in all aspects of work, as an occupation, trade, profession or other forms of employment, for payment, as an employee, full or part-time, or self-employed, such as seeking employment and getting a job, doing the required tasks of the job, attending work on time as required, supervising other workers or being supervised, and performing required tasks alone or in groups

Think of:

Being rejected due to limitations. Difficulty finding and keeping suitable work, independently or with the help of an authority (UWV (= Dutch Employee Insurance Agency), municipality, job coach), disability working hours and fatigue (part-time or full-time), fewer possibilities, guidance needed, in case of referral UWV: application for assessment of work capacity, incapacitated for work (Wajong = Young Persons Disability Benefits Act).

Please describe your problem here:

This questionnaire has been filled in by the person involved, with or without help from family, caregiver or healthcare provider.

d920	Recreation and leisure	0	1	2	3	4	8	9
	With help or tool							
	Without help or tool							

Explanation: Engaging in any form of play, recreational or leisure activity, such as informal or organized play and sports, programmes of physical fitness, relaxation, amusement or diversion, going to art galleries, museums, cinemas or theatres; engaging in crafts or hobbies, reading for enjoyment, playing musical instruments; sightseeings, tourism and travelling for pleasure.

Engaging in informal or casual gatherings with others, such as visiting friends or relatives or meeting informally in public places is hard for some people with a rare condition. Because they look different or are not able to speak, listen, see, travel or engage with others.

Think of:

Sports, visiting musea or cinema, hobbies, playing music instruments and travelling. Fysical access. Introverted, loneliness, difficulty establishing contacts, behaviour in company according to social rules, feeling excluded, inability to measure against others, performance anxiety, etc.

Please describe your problem here:

This questionnaire has been filled in by the person involved, with or without help from family, caregiver or healthcare provider.