

6.1.1 Parental Questionnaire Focusing on the Coping Skills of Children with EB in Everyday Life

Parental questionnaire focusing on the coping skills of children with EB in everyday life

Name of child:


Date of birth:

Age:

EB type:

Date:

Key




very well well poor not at all with help

Please mark where appropriate

The line beside the Smileys gives
space for remarks or additions

SELF-CARE

Dressing and undressing

Putting on and taking off underclothes







Putting on and taking off socks/stockings







Trousers








Pullover/T-Shirt







Shirt/jacket







Which types of material are tolerated best?

Cotton ☐ silk ☐ synthetic materials ☐

Other _____

Putting on and taking off shoes**Outdoor shoes**

Does your child use:

Special shoes ☐

inserts ☐

padding ☐

Other _____

Fastenings**Buttons**

Shoelaces

Zip

Velcro

Does your child use any adaptive devices or adaptations to make using fastenings easier?

Eating and drinking**Cutting food**

Eating with a spoon or fork

Does your child use:

Special cutlery ☐

teaspoon ☐

Other _____

Drinking out of a glass or cup

Hygiene and grooming

Shower

😊😊 😊😊 😞😞 😞😞 🖐️ _____

Bath

😊😊 😊😊 😞😞 😞😞 🖐️ _____

Does your child use:

Bath board ☐

anti-slip mat ☐

Other _____

Cleaning teeth

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Does your child use:

Manual toothbrush ☐

electric toothbrush ☐

special toothbrush ☐

Other _____

Combing/brushing hair

😊😊 😊😊 😞😞 😞😞 🖐️ _____

Applying cream

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Toileting (including wiping intimate parts)

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Sleeping

Mattress/pillow/special protection

Foam mattress ☐

sprung mattress ☐

latex mattress ☐

Water bed ☐

feather pillow ☐

foam pillow ☐

Ergonomic pillow ☐

support cushion(s) ☐

sheepskin protection ☐

Other _____

Material of the bedclothes

Silk ☐

cotton ☐

Other _____

Sleeping positionBack ☐side ☐front ☐**Household activities****Opening a bottle**

Opening a tin/can

Opening packaging

Preparing a snack

Opening and closing a drawer

Putting an electric plug into a socket and taking it out

Opening and closing a water tap

Shopping**Taking items off the shelf**

Taking out coins

Carrying bags

Open the door with a key

LEISURE/HOBBIES

What hobbies does your child have?

Sport ☐music ☐drawing/painting ☐handicraft ☐Reading ☐friends ☐singing ☐

Other _____

Which kinds of sport does your child do?

Horse riding ☐cycling ☐swimming ☐ball games ☐

Other _____

What measures to you take to prevent blistering in sport?

Knee pads ☐elbow pads ☐gloves ☐gel inserts ☐

Other _____

Is your child integrated into a group of friends?



Does your child take part in any club or group activities?

Which ones? _____

What relaxation/pain reduction method(s) does your child use?

Relaxation techniques ☐breathing techniques ☐massage ☐Music ☐sound bed ☐

Other _____

Can you go on holiday with your child?



Where do you go and what kind of holiday is best?

Pony club (riding) ☐city trip ☐

Other _____

What conditions do you and your child need when on holiday?

Bathtub ☐washing machine ☐pureed food ☐air conditioning ☐

Other _____

SCHOOL

Writing with pen/pencil

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Does your child use a special pen/pencil?

Writing on a PC

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Does your child use any special adaptations?

Special mouse ☐

touch screen ☐

special keyboard ☐

Other _____

Speed of writing

😊😊 😊😊 😊😞 😞😞 _____

Is the speed adequate for:

Copying from the board ☐

dictation ☐

tests ☐

Other _____

Turning pages of a book/magazine/newspaper

😊😊 😊😊 😊😞 😞😞 _____

Using a mobile telephone

😊😊 😊😊 😊😞 😞😞 _____

Using scissors

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Does your child use special scissors?

Standard scissors ☐

child's scissors ☐

Loop/self-opening scissors ☐

table-top scissors ☐

Other _____

How does your child sit best in the classroom?

At the front ☐ at the back ☐ single place ☐ wheelchair ☐ upholstered chair ☐

Other _____

Does your child have any special device for sitting for long periods?

Padding ☐ rounded seat edge on upholstered chair ☐

Rounded edge of table ☐ rounded corners ☐

Other _____

Carrying a school bag

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Does your child use assistive devices or techniques?

One set of books at school and one at home ☐ trolley ☐

Other _____

Does your child have his/her own carer in the school?

For how many hours a day and with what conditions?

What is the best place for your child to spend the breaks in?

In the classroom ☐ in the passage/corridor ☐ in the playground ☐

Is your child integrated into class life?

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Does your child participate in gymnastics?

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Alternatives? _____

Does your child participate in handicraft lessons?

😊😊 😊😊 😞😞 😞😞 🖐️ _____

What activities are possible? _____

Is it planned for your child to stay at school beyond the minimum age?

If so with what plans?

What professional opportunities do you see for your child?

MOBILITY

Transfer

Get into bed and get up again

Turnover in bed

Sit down on a chair and get up

Sit down at the table and get up

Sit down on a sofa or armchair and get up

Pick something up from the floor

Get in and out of public transport

Locomotion

Walk

How far?

Run

How far?

Go up and down stairs

Cross the street within the time span of the green light

Tricycle

😊😊 😊😊 😞😞 😞😞 🖐️ _____

Scooter

😊😊 😊😊 😞😞 😞😞 🖐️ _____

Does your child use any special adaptations?

Safety scooter ☐ special handlebars ☐

Other _____

Balance bike

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Bicycle

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Does your child use any special adaptations?

Balancing wheels ☐ special handlebars ☐ backpedal brake ☐ gel saddle ☐

Other _____

Do you use a wheelchair?

Yes ☐ no ☐

Do you use any special adaptations?

Electric wheelchair ☐ special cushion ☐

Other _____

How does your child go to school?

Private car ☐ school bus ☐ public transport ☐ bicycle ☐ on foot ☐

Other _____

Taking your child in the car

Do you use any special adaptations?

Child safety seat ☐ padded seatbelt ☐ air conditioning ☐

Other _____