### 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

<table>
<thead>
<tr>
<th>Name of child:</th>
<th>Date of birth:</th>
<th>Age:</th>
<th>EB type:</th>
<th>Date:</th>
</tr>
</thead>
</table>

**Key**

- ☺☺☺☺    very well
- ☼☼    well
- ☼    poor
- ☼    not at all
- ☼    with help

*Please mark where appropriate*

---

**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: __________________________

---

*The line beside the Smiley gives space for remarks or additions*
### Putting on and taking off shoes

**Outdoor shoes**

<table>
<thead>
<tr>
<th>JJ</th>
<th>JK</th>
<th>KL</th>
<th>LL</th>
<th>☐</th>
</tr>
</thead>
</table>

*Does your child use:*

- Special shoes  
- Inserts  
- Padding

*Other*  

### Fastenings

**Buttons**

<table>
<thead>
<tr>
<th>JJ</th>
<th>JK</th>
<th>KL</th>
<th>LL</th>
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</thead>
</table>

**Shoelaces**

<table>
<thead>
<tr>
<th>JJ</th>
<th>JK</th>
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</table>

**Zip**

<table>
<thead>
<tr>
<th>JJ</th>
<th>JK</th>
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</table>

**Velcro**

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<tr>
<th>JJ</th>
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<th>KL</th>
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</thead>
</table>

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

### Eating and drinking

**Cutting food**

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<th>JJ</th>
<th>JK</th>
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</table>

**Eating with a spoon or fork**

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<tr>
<th>JJ</th>
<th>JK</th>
<th>KL</th>
<th>LL</th>
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</thead>
</table>

*Does your child use:*

- Special cutlery  
- Teaspoon

*Other*  

**Drinking out of a glass or cup**

<table>
<thead>
<tr>
<th>JJ</th>
<th>JK</th>
<th>KL</th>
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</thead>
</table>
### Hygiene and grooming

#### Shower

| JJ | JK | KL | LL | ☐ ☐ ☐ ☐ ☐ ☐ ☐ |

#### Bath

| JJ | JK | KL | LL | ☐ ☐ ☐ ☐ ☐ ☐ ☐ |

**Does your child use:**
- Bath board □
- anti-slip mat □
- Other  

#### Cleaning teeth

| JJ | JK | KL | LL | ☐ ☐ ☐ ☐ ☐ ☐ ☐ |

**Does your child use:**
- Manual toothbrush □
- electric toothbrush □
- special toothbrush □
- Other  

#### Combing/brushing hair

| JJ | JK | KL | LL | ☐ ☐ ☐ ☐ ☐ ☐ ☐ |

#### Applying cream

| JJ | JK | KL | LL | ☐ ☐ ☐ ☐ ☐ ☐ ☐ |

#### Toileting (including wiping intimate parts)

| JJ | JK | KL | LL | ☐ ☐ ☐ ☐ ☐ ☐ ☐ |

### 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  

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**Chapter 6 • Independence in Everyday Life and Provision of Assistive Devices**

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Sleeping position
Back □ 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?

Which ones?

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**

| ☻☻ | ☻☻ | ☻☻ | ☻☻ |

*Does your child use a special pen/pencil?*

**Writing on a PC**

| ☻☻ | ☻☻ | ☻☻ | ☻☻ |

*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**

| ☻☻ | ☻☻ | ☻☻ | ☻☻ | ☻☻ |

*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

### 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?

### Does your child participate in gymnastics?
*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**

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**Turnover in bed**

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**Sit down on a chair and get up**

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**Sit down at the table and get up**

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**Sit down on a sofa or armchair and get up**

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**Pick something up from the floor**

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**Get in and out of public transport**

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### Locomotion

**Walk**

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**How far?**


**Run**

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**How far?**


**Go up and down stairs**

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**Cross the street within the time span of the green light**

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</thead>
<tbody>
<tr>
<td>Device</td>
<td>Special Adaptations</td>
<td></td>
<td></td>
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<tr>
<td>--------------</td>
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<tr>
<td>Tricycle</td>
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<tr>
<td>Scooter</td>
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<tr>
<td>Balance bike</td>
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<tr>
<td>Bicycle</td>
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<tr>
<td>Wheelchair</td>
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<td></td>
</tr>
<tr>
<td>School</td>
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</tr>
<tr>
<td>Car</td>
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</tbody>
</table>

**Tricycle**

- Safety scooter [ ]
- Special handlebars [ ]
- Other [ ]

**Scooter**

- Safety scooter [ ]
- Special handlebars [ ]
- Other [ ]

**Balance bike**

- Balancing wheels [ ]
- Special handlebars [ ]
- Backpedal brake [ ]
- Gel saddle [ ]
- Other [ ]

**Bicycle**

- Balancing wheels [ ]
- Special handlebars [ ]
- Backpedal brake [ ]
- Gel saddle [ ]
- Other [ ]

**Wheelchair**

- Electric wheelchair [ ]
- Special cushion [ ]
- Other [ ]

**School**

- Private car [ ]
- School bus [ ]
- Public transport [ ]
- Bicycle [ ]
- On foot [ ]
- Other [ ]

**Car**

- Child safety seat [ ]
- Padded seatbelt [ ]
- Air conditioning [ ]
- Other [ ]