

Picture my Participation

Administration Manual

Imms, C., Granlund, M., Bornman, J. & Elliott, C.

2014

The original authors acknowledge the efforts of an international team of contributors to data collection and testing of the instrument including:

Karina Huus, Patrik Avidsson (Sweden), Alecia Samuels, Shakila Dada (South Africa), AiWen Huang, Cynthia Liao, Lin-Ju Kang (Taiwan), Claire Willis (Australia), Veerle Garrels (Norway).

Research Version April 2018

Picture my Participation

Picture my Participation is an instrument designed to assess the participation attendance and participation involvement of children. Participation in this instrument is defined as involvement in a life situation that has two essential elements: attendance and involvement. In *Picture my Participation*, attendance is operationalised as how often a child takes part in activities across a range of life situations (measured from always to never). Involvement is operationalised as the extent to which a child shows interest or is attentive to and engaged in an activity, which might be understood by a child as trying hard or doing a lot in the activity (measured from very to not involved).

Picture my Participation is still under development. At this stage, the way the scoring is designed, the instrument measures the positive aspect of participation (rather than participation restrictions).

Picture my Participation is primarily designed to be administered as a picture-supported interview with children and aims to elicit the voice and perspective of children about their participation. It is also possible to administer the instrument with parents or caregivers who know the child well across a variety of life situations.

Picture my Participation can be administered for a variety of reasons, in both research and clinical settings. Depending on the purpose of assessment, you may choose to administer all, or only some of the sections (for example, you may not wish to measure environmental barriers or facilitators).

If implementing *Picture my Participation* with children diagnosed with an intellectual disability, the interview should be done in the same manner suggested in the manual and if being administered on repeated occasions, preferably it should be done in the same setting on each occasion (e.g., if the first interview was done in school the second interview also needs to be done in school).

If implementing the instrument with children requiring communication support, the interview should be done in the same manner suggested in the manual using the child's usual methods of communication, including using any augmentative communication aids.

Primary caregivers with sufficient literacy skills can complete the instrument independently, using the survey format. It is also possible to administer the instrument with parents using the interview procedure in the same manner as the children. Collection of biographical information about the child and completion of the Ten Question Questionnaire (TQQ), if desired, only needs to be done on the first occasion of assessment.

If repeated measures are being taken (in a study or in practice) it is recommended that wherever possible, the same administrator should complete the instrument with the same children and/or same primary caregiver

Administration of the instrument

Who is Picture my Participation for?

Picture my Participation has been developed for children aged 5 to 21 years who have a disability. Disability is an umbrella term, referring to impairments (a problem in body function or structure), activity limitations (a difficulty encountered by an individual in executing a task or action), and participation restrictions (a problem experienced by an individual in involvement in life situations). It is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives (WHO, 2015).

Where should Picture my Participation be administered?

Picture my Participation should be administered in an environment where the child and family are comfortable and is culturally appropriate.

What equipment is needed?

Parent:

- Consent letter
- *Picture my Participation* Response Score Sheet: Caregiver (Appendix 1)

Children:

- Assent Letter for children
- Talking Mat (Piece of carpet/ cardboard to display the *Picture* cards on)
- Copy of each image* for each activity; for the attendance and involvement ideas
- *Picture my Participation* Response Score Sheet: Child (Appendix 2)
- Pen or pencil for recording

* Images included in this manual are selected from *Picture Exchange Communication* images (freely available online). The images can be adapted to be culturally appropriate to the setting in which the instrument is administered. We will be building an image bank to support this adaptation.

* Images should be printed colour and individually laminated for durability.

How long will it take to do Picture my Participation?

The interview with the scoring takes approximately 30 minutes to administer depending upon the child's ability to follow the ideas and respond. Those requiring communication support may need more time. Prior to administration of the interview, the setting up of the equipment takes approximately 2 minutes and packing up requires about 2 minutes.

Who should administer Picture my Participation?

The interviewers can be from any background. The instrument has been designed so that 'expert training' is not required for its use, but rather interviewers who are new to *Picture my Participation* should complete a self-directed eLearning tutorial. This tutorial provides an understanding of the International Classification of Functioning, Disability and Health (ICF), the rights of children, and the construct of participation: these concepts are central to *Picture My Participation*.

It is essential that the interviewers complete the tutorial, read the manual completely and become familiar with the requirements of each sub-section of the instrument prior to administration.

What are the items and instructions for the interview?

Step 1: Introduction of *Picture my Participation* to child and family

"We want to hear your story about who you are and what you do. Your story is important to us because we want to understand about your involvement with your home, school and community. We are interested in how often you do activities, how involved you are in the activities and what things make it easier or more difficult to participate. There are no right or wrong answers just sharing of ideas. We understand that this is your business and we will make sure your story does not become part of the 'grapevine'".

The following components are for the primary caregiver to complete (see Appendix 1):

- Consent letter (differs between countries)
- Picture my Participation Response Score Sheet: Caregiver (Appendix 1)

The following components are for the interview with the child (see Appendix 2):

- Assent letter (differs between countries)
- Picture my Participation Response Score Sheet: Child (Appendix 2)

Step 2: Caregivers complete the consent letters and if applicable the Caregiver Picture my Participation

The Response Score Sheet: Caregiver is found in Appendix 1

Step 3: Interviewer administration of *Picture my Participation* attendance and involvement scales

The **Response Score Sheet: Child** is found in Appendix 2.

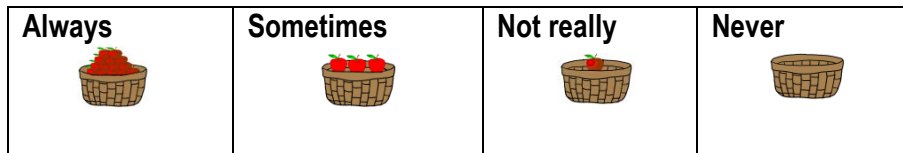
- Assent from the child
- Complete Demographic Information (Appendix 2: Section A)

Frequency of attendance and involvement dimensions

- a. Place the frequency template in front of the child and explain the levels of frequency using clear plain and appropriate language.

For example "These pictures show different amount of apples in a basket. The basket full of apples (point to the picture) means always, this basket with fewer apples means sometimes (point to the picture), the basket with one apple means (point to the picture) not really and the empty basket (point to the picture) means never".

Attendance template



- b. Explain to the child that you are going to show them some pictures (picture cards are the pictures in Appendix 2: Section C) of children attending various activities and that you would like to know if they also attend these activities.

- c. Then ask the child the trial items. (Appendix 2: Section B)

Example "Do you eat ice cream?". Give the picture to the child. "Could you put the ice cream picture under the basket that matches for you."

- d. Explain to the child that you are going to show them some pictures (picture cards are the pictures in Appendix 2: Section C) of children attending various activities and that you would like to know if they also participate in these activities.
- e. Through a process of talking with the child about their usual daily lives and sharing ideas and conversation, ask the child to sort each of the picture cards on the attendance template on the Talking Mats
- f. Record the child's participation profile on the Picture my Participation Response Score Sheet (Appendix 2 Section C)
- g. Then you can ask the child if there is anything else they do you haven't asked about that they would like to add

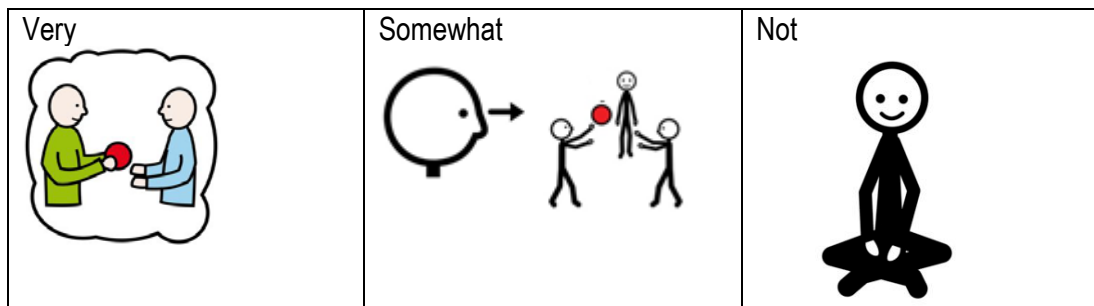
Attendance scoring table

Score	Level	Definition
	Always	The child attends all of the time
3	Sometimes	The child attends some of the time
2	Not really	The child occasionally/rarely attends
1	Never	The child does not attend

- h. Place the involvement template in front of the child and explain the levels of involvement using clear plain and appropriate language.

For example “These pictures show different levels of involvement. In this picture (point to picture) these children are very involved – they are really trying hard, and doing a lot in the activity of playing ball. In this picture (point to picture) this child is only somewhat involved – he/she is watching what others are doing more than doing the activity her/himself. In this picture (point to picture) this child is not involved. He is just waiting for something else to happen or do.

Involvement Template



Example: Alex, you say that you always attend meal preparation with or for the family. When this happens how involved are you – are you doing a lot of things, so are you very involved (point to picture) or are you somewhat involved (point to picture) or are you not involved (point to picture).

- i. Through a process of talking with the child about their usual daily lives and sharing ideas and conversation, ask the child to sort each of the picture cards on the level of involvement template on the Talking Mat.
- j. It is not necessary to ask about involvement for any picture that the child has indicated they **never** attend or is not available. Involvement is assumed to be **NOT** in each of these instances.
- k. Record the child’s participation profile on the Picture my Participation Response Score Sheet (Appendix 2 Section C).

Involvement Scoring Table

Score	Level	Definition
3	Very	These children are very involved – they are really trying hard, and doing a lot of the game
2	Somewhat	This child is only somewhat involved – he/she is watching what others are doing more than doing the activity herself
1	Not	This child is not involved. He is just waiting for something else to happen or do.

Step 4: Prioritisation

In development of *Picture my Participation* we have determined that selection of three priority items will provide us with key information about important participation activities across countries, and provide evidence about the validity of the tool in relation to inclusion of an appropriate range of activities. In practice, these priority items can form the basis of participation goal setting for therapy, education or parent planning.

It may be reasonable in clinical practice to only ask about involvement within the three priority items/activities.

- a. Ask the child “Of all of the activities that we have talked about, what are the **3** activities that are the most important to you?”

Example: They might be important because you have to do them really often, they might be important because you really love to do them, they might be important because you really want to be able to do them – there are lots of reasons why an activity might be important to you.

- b. Talk with the child about the **3** most important activities and select the picture cards for those activities and place them on the Talking Mat.
- c. Record the child’s participation profile on the Picture my Participation Response Score Sheet (Appendix 2 Section D)

Step 5: Barriers and Facilitators




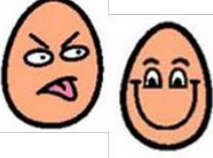

The purpose of this section is to identify the key barriers and facilitators of the priority activities. This information will assist in identifying common barriers across settings, and informing planning and intervention to support participation goals associated with priority activities.

- a. Place the Barriers and Facilitators Template in front of the child and explain the barriers and facilitators using clear plain and appropriate language.

For example “These pictures show what helps you (point to picture) and what makes things difficult for you to do the activity (point to picture). Ask the child about the first activity identified in the above

step (prioritisation). Explain to the child that you are interested in knowing what makes it easier (point to the easy picture) or makes it harder to do (point to the difficult picture).

Barriers and Facilitators Template

Products and technology	Natural environment and human-made changes to the environment	Support and relationships	Attitudes	Services, systems and policies
				

- b. Example Thinking about [activity 1], are there things that make this hard to do? Can you tell me about them? Are there things that make it easier/help you to do this activity? Can you tell me about them?
- c. Repeat process for priority activity 2 & 3
- d. Transcribe what the child says on to the **Picture my Participation Response Sheet: Child**
- e. Score and Code the Childs responses on to the **Picture my Participation Response Sheet: Child**

Barriers and Facilitators Scoring table

Childs most important activities (List here)	Easier / Harder	Please write in the child's own words what's make it easier or harder to do the activity	Interviewer assigned code				
			Product technology /	Natural human environment /	Support relationship /	Attitudes	Service systems policies /
1	What makes it <u>easier</u> to do?						
	What makes it <u>harder</u> to do?						
2	What makes it <u>easier</u> to do?						
	What makes it <u>harder</u> to do?						

3	What makes it <u>easier</u> to do?						
	What makes it <u>harder</u> to do?						

Note: the interviewer selects the category of the facilitator or barrier, not the child or parent.

Definition of codes for barriers and facilitators:

Code	Definition of code	Example
Products and technology	This relates to products, instruments, equipment or technology adapted or specially designed for improving the functioning of persons with disability.	I use my mobile phone to set a reminder to take my medication
Natural environment and human-made changes to the environment	This relates to animate and inanimate elements of the physical or natural environment and components of that environment that have been modified by people.	I cannot use my wheelchair when we go hiking
Support and relationships	This relates to people or animals that provide practical, physical or emotional support, nurturing, protecting and assisting as well as relationships to other persons in all aspects of daily living, but excludes the attitudes of the person(s) who are providing the support.	I enjoy shopping on my own but and I can go by myself with my guide dog.
Attitudes	This relates to the attitudes that are observable through consequences of customs, practices, ideologies, values, norms, factual beliefs and religious beliefs, and relates to those attitudes of the person(s) external to the person with disability, not of the persons with disability themselves.	I love pets but my mom won't allow me to keep a dog.
Services, systems and policies	Services relate to structured programmes, public, private or voluntary services established at local, community, regional, national or international level in order to meet the needs of persons with disabilities. Systems and policies respectively relate to administrative control and monitoring mechanism and rules, regulations and standards established at the different levels mentioned above, in various sectors of society.	I would like to go to the neighborhood school but the school do not allow me to attend there.

Step 6: Scoring and Interpretation

Picture my Participation is currently undergoing validation. This work will help us determine the most effective method of combining scores within and potentially across scales. At present, each item for each construct is scored separately.

1. Attendance:

Never = 1;

Not really = 2;

Sometimes = 3;

Always = 4.

If the activity is not available, Attendance score = 1 (Never)

2. Involvement:

Not = 1;

Somewhat = 2;

Very = 3

If the activity is not attended, then involvement score = 1 (Not)

3. Prioritisation: text data coded against first, second and third priority

4. Barriers: categorical data coded against the first, second and third priority

Appendix 1

Picture my Participation Response Score Sheet

Caregiver

Picture my Participation

Response Score Sheet

Caregiver

Imms, C., Granlund, M., Bornman, J. & Elliott, C.

2014

The original authors acknowledge the efforts of an international team of contributors to data collection and testing of the instrument including:

Karina Huus, Patrik Avidsson (Sweden), Alecia Samuels, Shakila Dada (South Africa), AiWen Huang, Cynthia Liao, Lin-Ju Kang (Taiwan), Claire Willis (Australia), Veerle Garrels (Norway).

Section A: Demographic Information.

These questions are about your child and about you, the person filling in the survey.

Please fill out all of the questions below by making an **X** in the appropriate box or writing the answer in the space provided.

What is today's date? year / month / day

Participant study number:

.....

Questions about your child

1. Date of birth of child: year / month / day

2. What is the gender of your child? Male Female

3. What month and year did your child begin attending the current school? year / month

4. The following table has questions about your child's abilities.

Please mark either the 'Yes' or 'No' column with an **X** in relation to your child.

	Ten question questionnaire	Yes	No
1	Compared with other children, does or did your child have any serious delay in sitting, standing, or walking		
2	Compared with other children, does your child have difficulty seeing, either in the daytime or at night		
3	Does your child appear to have difficulty hearing? (Uses hearing aid, hears with difficulty, completely deaf?)		
4	When you tell your child to do something, does he/she seem to understand what you are saying		
5	Does your child have difficulty in walking or moving his/her arms or does he/she have weakness and/or stiffness in the arms or legs?		
6	Does your child sometimes have fits, become rigid, or lose consciousness		
7	Does your child learn to do things like other children his/her age?		
8	Does your child speak at all (can he/she make him or herself understood in words; can say any recognizable words)?		
9	Is the child's speech in any way different from normal (not clear enough to be understood by people other than his/her immediate family)?		
10	Compared with other children of the same age, does your child appear in any way mentally slow?		

Questions about you, the child's parent or primary care giver

5. Date of birth of person completing this form: *year / month / day*

6. What is your relationship with the child?

Father Mother Grandmother Other (please specify).....

6. What is your current work status?

Employed full time Employed part time Unemployed

7. Do you receive a disability grant or government funding for your child?

Yes No

8. What is the highest educational qualification that you completed?

Grade 10 or less Grade 12 Diploma Degree Post graduate degree

9. How many people are living in your house (including you)?

Adults Children

10. Are you receiving a social grant?

Yes No

11. In your opinion, does your child have a learning difficulty/

Yes No

If yes, what is the severity of your child's learning difficulty?

Mild Moderate Severe

Section B: Participation in Home and Community Activities

The following questions ask about your child's attendance and involvement in home and community activities. The different home and community activities are listed below:

We are interested in the how often your child takes part in the listed activities, and in how involved your child is when he or she does take part.

The levels of *attendance* are described below:

Level	Definition of attendance
Always	The child attends all of the time
Sometimes	The child attends some of the time
Not really	The child occasionally/rarely attends
Never	The child does not attend

The levels of *involvement* are described below:

Level	Definition of Involvement
Very involved	Generally, the child is involved throughout the activity. He/ she shows a lot of initiative and/or interest in and attention to what he/ she and others are doing during the activity.
Somewhat involved	The child is involved in the activity some of the time. He/ she shows some initiative and/or interest in and attention to what he/she and others are doing during the activity.
Minimally involved	Child is involved in a small part of the activity. He/she only shows a little initiative and/or interest in and attention to what he/she and others are doing during the activity.

For each activity place an **X** in one of the boxes indicating the *level of attendance* of your child in the appropriate column.

For each activity your child attends, also place an **X** in the involvement section to indicate the *level of involvement* they usually show when attending this activity.

Home and Community Activities	Attendance				Involvement		
	Always	Some-times	Not really	Never	Very	Some-what	Minimal
1. Daily routines at home for personal care (dressing, choosing clothing, hair care, brushing teeth)							
2. Family mealtime (with usual family members)							
3. Looking after his/her own health (medication)							
4. Gathering daily necessities for the family (water, food, picking vegetables, fuel)							
5. Meal preparation with or for the family							
6. Cleaning up at home (clothing, house-hold objects, laundry, rubbish, yard work)							
7. Taking care of other family members							
8. Taking care of animals (pet, or domestic livestock)							
9. Interact with the family (family time)							
10. Family/community celebrations (birthdays, weddings, holiday gatherings)							
11. Getting together with other children in the community (playing with others)							
12. Organised leisure activities (sports, clubs, music, art, dance)							
13. Quiet leisure (listening to music, reading)							
14. Religious and spiritual gatherings and activities							
15. Shopping and errands (market)							
16. Taking part in social activities in the community (parties, play group, parades)							
17. Visit to health center (e.g. Doctor, dentist, other health care service)							
18. Formal learning at school							
19. Overnight visits and trips							
20. Paid and unpaid employment							
21. Does your child participate in any other activities? Please list:							
TOTAL (for office use only)							

Section C: Prioritisation

Of all of the activities listed above, what are the **3** activities that you think are the most important to your child? Please fill in these **3** chosen activities starting with the most important one.

Most important activities
1.
2.
3.

Section D: Barriers and Facilitators

We are now interested in what things help your child and what things make it harder for your child to participate in these activities. Please fill in the same 3 most important activities identified above into the table below. You will then need to think about what makes it easier or harder for your child to participate in the activity.

Please write the reasons in your own words.

Childs most important activities (List here)	Easier/Harder	Please write in your own words what's make it easier or harder for your child to do the activity
1	What make it <u>easier</u> to do?	
	What make it <u>harder</u> to do?	
2	What make it <u>easier</u> to do?	
	What make it <u>harder</u> to do?	
3	What make it <u>easier</u> to do?	
	What make it <u>harder</u> to do?	

This is the end of the questions.

Thank you for taking the time to tell us about your child's participation.

Appendix 2

Picture my Participation Response Score Sheet

CHILD

Picture my Participation

Response Score Sheet

CHILD

Imms, C., Granlund, M., Bornman, J. & Elliott, C.

2014

The original authors acknowledge the efforts of an international team of contributors to data collection and testing of the instrument including:

Karina Huus, Patrik Avidsson (Sweden), Alecia Samuels, Shakila Dada (South Africa), AiWen Huang, Cynthia Liao, Lin-Ju Kang (Taiwan), Claire Willis (Australia), Veerle Garrels (Norway).

Section A: Demographics (Interviewer to complete)

What is today's date? *year / month / day*

Participant study number:

Administrator name:

Profession:.....

Where the interview was conducted:
(e.g., School playground, at home, at a library, at the soccer field)

Country:.....

City:

Child's Gender:





Male Female

Child's date of birth: *year / month / day*

Section B: Participation in Home and Community Activities








TRIAL ITEMS







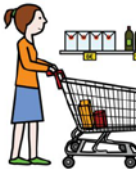


The trial items are to help the child understand the process of choosing symbols or pictures to describe their responses. The trial items relate to the *attendance* part of the assessment

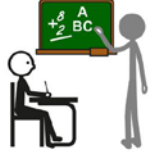


Always =  Sometimes =  Not really =  Never = 

PCS Symbol	Questions	Always 	Sometimes 	Not really 	Never 
	Do you eat ice cream?				
	Do you watch TV?				
	Do you play with real snakes at home?				

RECORD ATTENDANCE AND INVOLVMENT IN EACH OF THE ACTIVITIES

Home Community Activities		Attendance				Involvement		
		Always	Some-times	Not really	Never	Very	Some-what	Minimal
1. Personal care Daily routines at home for personal care (dressing, choosing clothing, hair care, brushing teeth)								
		Notes:						
2. Family mealtime With usual family members								
		Notes:						
3. My own health Looking after his/her own health (medication)								
		Notes:						
4. Gathering supplies Gathering daily necessities for the family (water, food, picking vegetables, fuel)								
		Notes:						
5. Meal preparation Meal preparation with or for the family								
		Notes:						
6. Cleaning at home Cleaning up at home (clothing, house-hold objects, laundry, rubbish, yard work)								
		Notes:						
7. Caring for family Taking care of other family members								
		Notes:						
8. Caring for animals/pets Taking care of animals (pet, or domestic livestock)								
		Notes:						

Home Community Activities		Attendance				Involvement		
		Always	Some-times	Not really	Never	Very	Some-what	Minimal
9. Family time Interact with the family								
		Notes:						
10. Celebrations Family/community celebrations (birthdays, weddings, holiday gatherings)								
		Notes:						
11. Playing with others Getting together with other children in the community								
		Notes:						
12. Organised leisure Organised leisure activities (sports, clubs, music, art, dance)								
		Notes:						
13. Quiet leisure Quiet leisure (listening to music, reading)								
		Notes:						
14. Spiritual activities Religious and spiritual gatherings and activities								
		Notes:						
15. Shopping Shopping and errands (market) Shopping								
		Notes:						
16. Social activities Taking part in social activities in the community (parties, play group, parades)								
		Notes:						
17. Health centre Visit to health center (e.g. Doctor, dentist, other health care service)								
		Notes:						

Home Community Activities		Attendance				Involvement		
		Always	Sometimes	Not really	Never	Very	Somewhat	Minimal
18. School Formal learning at school								
		Notes:						
19. Trips and Visits Overnight visits and trips								
		Notes:						
20. Employment Paid and unpaid employment								
		Notes:						
Other (a)								
		Notes:						
Other (b)								
		Notes:						
TOTAL (for office use only)								

Note: Pictures are from Picture Exchange Communication

Sections C: Prioritisation

Of all of the activities listed above, what are the **3** activities that are the most important to the child?

Please fill in the 3 most important activities identified into the table in Section D. You will then need to talk with the child about what makes it easier or harder for him or her to participate in the activity.




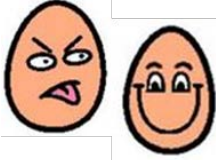

Sections D: Barriers and Facilitators

We are now interested in what things help the child and what things make it harder for the child to participate in these three activities.

- a. Place the Barriers and Facilitators Template in front of the child and explain the barriers and facilitators using clear plain and appropriate language.

For example “These pictures show what helps you (point to picture) and what makes things difficult for you to do the activity (point to picture). Ask the child about the first activity identified in the above step (prioritisation). Explain to the child that you are interested in knowing what makes it easier or makes it harder to do.

Barriers and Facilitators Template

Products and technology	Natural environment and human-made changes to the environment	Support and relationships	Attitudes	Services, systems and policies
				

- b. *Example Thinking about [activity 1], are there things that make this hard to do? Can you tell me about them? Are there things that make it easier/help you to do this activity? Can you tell me about them?*
- c. Repeat process for priority activity 2 & 3
- d. Transcribe what the child says on to the Table below. After the interview is finished with the child, assign a code to the child’s descriptions.

Please write the reasons in the child's own words. Assign a code after the interview is completed by referring to definitions in the manual.

Childs most important activities (List here)	Easier/Harder	Please write in the child's own words what's make it easier or harder to do the activity	Interviewer assigned code				
			Product technology /	Natural human environment /	Support relationships /	Attitudes	Service systems policies /
1	What makes it <u>easier</u> to do?						
	What makes it <u>harder</u> to do?						
2	What makes it <u>easier</u> to do?						
	What makes it <u>harder</u> to do?						
3	What makes it <u>easier</u> to do?						
	What makes it <u>harder</u> to do?						