

Report on development of Children with disabilities' and Parents' Wellbeing and Inclusion Checklist tool 2022 - Phase 1

Disability Inclusive Development TO27/SMILE (a locally driven sustainable, scalable model of disability-inclusive education in Jema'a LGA, Kaduna State, Nigeria)



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Inclusive Futures

Promoting disability inclusion

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Background

This report describes a piece of participatory research undertaken in 2022 as part of the UK-aid funded Disability Inclusive Development project (as part of Task Order 27). This is the first phase of the work, which will continue in 2023. We aimed to develop a tool to measure how children with disabilities (and their parents) perceive their inclusion in school and society, as well as their wellbeing. The tool was developed in a way which was informed by what children themselves see as important. It was also designed to show changes in experiences and perceptions overtime through repeated use of the tool over a one-year period. The process of planning, designing and testing the tool was undertaken by researchers from the Institute of Development Studies (Mary Wickenden and Stephen Thompson) in collaboration with local consultants (Oluwatosin Adekeye and Noela Gwani), and with input from members of the Task Order 27 Steering Committee (Ndubuisi Sylvester Iroham and Risikat Toyin Muhammed).

1. Introduction

Several global frameworks have been developed to ensure children with disabilities have access to education and are included in its processes. For example, Article 28 of the United Nations (UN) Convention on the Rights of the Child details how every child has the right to an education (UN 1989). In 1994, the Salamanca Statement called for education for all, and urged for education services to be inclusive of all children (UNESCO 1994). This right was reaffirmed specifically with regards to children with disability by Article 24 of the UN Convention on the Rights of Persons with Disabilities (CRPD) (UN 2006). Additionally Sustainable Development Goal 4 aims to deliver inclusive and equitable quality education and promote lifelong learning opportunities for all. Target 4.5 details how by 2030, equal access to all levels of education and vocational training will be provided for persons with disabilities among other marginalised people (United Nations 2015). UNESCO (United Nations Educational, Scientific and Cultural Organization) (2020) were joined by the World Food Programme (WFP), UNICEF (United Nations International Children's Emergency Fund), and World Health Organisation (WHO) in calling for recognition of the importance of investing in the wellbeing of children (including those with disabilities) to improve learning.

These high-level commitments and statements have provided goals to work towards, however, at the local level, there has been very little investigation into what inclusion might mean for children with disabilities, and how being included may impact on their wellbeing. While clearly ensuring a person's wellbeing is generally seen as something positive, there is no universal definition of what wellbeing actually is. The term is used interchangeably in the research literature with 'quality of life', 'happiness' and sometimes 'welfare'. In its broadest sense, wellbeing may be understood to include objective measures of circumstance, subjective measures based on individual experience, and the broader environment they inhabit (White 2013). Other ways of understanding wellbeing include considering economic indicators, alongside the subjective and objective measures, recognising that wellbeing involves decisions relating to what is desired relative to resources and constraints. Essentially, wellbeing can be understood as being about the lives of people and the social contexts they inhabit (Camfield, Crivello and Woodhead 2009).

UNESCO describe an inclusive approach to education as one where:

each individual's needs are taken into account and that all learners participate and achieve together. It acknowledges that all children can learn and that every child has unique characteristics, interests, abilities and learning needs. Special focus is placed on learners who may be at risk of marginalization, exclusion or underachievement.

(UNESCO 2022, para 2)

The CRPD calls for persons with disabilities to be involved in decision-making processes concerning issues relating to them (UN 2006). Despite this limited research has examined how children with disabilities perceive social inclusion (Koller, Pouesard and Rummens 2018). To address this gap, the aim of this work was to focus on how

children with disabilities (and their parents) perceive wellbeing and inclusion, as part of a project that is developing inclusive schools in Kaduna state in Nigeria. This research sets out to develop a tool to explore the children's experience of inclusive school and home settings, using a participatory approach.

Some tools that broadly measure wellbeing in children have been developed, but none fit exactly the purpose we had identified. For example, KIDSCREEN questionnaire – which is a cross-cultural measure of health-related quality-of-life assessment for children and adolescents in Europe (Ravens-Sieberer *et al.* 2005). Although not developed specifically for use with children with disabilities, it was relevant to the current work as it was developed as a self-report measure applicable for healthy and chronically ill children and adolescents. KIDSCREEN has been evaluated for reliability and validity in an African context (South Africa). The evaluation found the tool did offer sound measurement if minor adaptations are included and the context is considered when the data is analysed (Taliep and Florence 2012). However the KIDSCREEN's focus on health-related quality of life is slightly different from our aim, which was to work with the children and parents to generate items for the tool that they see as important in relation to school and home. Another tool, the Participation Scale, which was designed by Van Brakel *et al.* (2006) to measure social participation for use in rehabilitation, stigma reduction and social integration programmes, provided some useful learnings with regards to self-reporting style tools to measure participation in society, although this was not designed for children.

A comprehensive review of the literature that focused on measuring wellbeing found that the following concerns exist about the measurement of children and young people's wellbeing:

- There is no consensus on the key domains or their weighting.
- There is a disproportionate focus on the negative aspects of children's wellbeing (i.e. an assumption that children with disabilities might have worse experiences and lower wellbeing than others).
- Indicators often assess the absence of a particular factor (e.g. ill health), assuming that with its absence comes wellbeing.
- Most measures are objective. Subjective wellbeing (i.e. the children's own perspective) is under-developed.
- Existing wellbeing tools lack clear definition and are often conceptually confused.
- Little is known about the wellbeing of particular subgroups of children (including children with disabilities).
- Age differences are largely ignored.
- Children and young people are not given the opportunity to participate in defining what wellbeing means to them.

Another relevant tool

A participatory approach was selected so that the tool being developed would reflect the children and parents' worldviews more closely than the normative approaches that are sometimes used, recognising the cultural, social, and subjective dimensions of human experience (Camfield, Crivello and Woodhead 2009). A participatory process was developed to enable children to have a say in what wellbeing means to them and define the questions that should be asked accordingly. It is important that the autonomy of the children is recognised and respected, and it was assumed that children with disabilities can if given the chance self-report their wellbeing. Our approach was to ensure that the

tool was not framed around the absence of a particular factor. As such the focus would not be on impairments and health conditions as individual characteristics, but might include these in relation to other factors, such as access to resources, structural factors, and personal characteristics (Mitra 2018). Based on what the children (and their parents) regarded as important, the scale was designed to assess experience of schooling, but also experiences of home and community life.

It was decided that a Likert scale would be used as the main response mode, allowing the child to tell us how they feel about various aspects of their life at school and at home, choosing from 5 points on a scale from very bad to very good (White and Sabarwal 2014). The 5 points were represented by emoticon faces. In addition, a qualitative aspect was included, to ensure that the children had the opportunity to express their feelings and reflect on their experiences subjectively and to clarify their choice on the 5-point scale. A mixed method approach, involving quantitative measures as well as qualitative discussion, reflection and case studies allows wellbeing to be assessed in a more encompassing and holistic way (White 2013).

2. Overview of the process



3. Details of the process

3.1 Pre-planning and preparation

Recruitment

Two local consultants were recruited based on expertise in participatory research and/or working with children with disabilities and two Nigerian steering committee members (experts on disability and special education). We aimed for gender balance and had a man and a woman in each of the IDS team, consultants and steering committee members.

Team briefing and training

Team briefing and training sessions were conducted online. The training covered both theoretical and practical aspects, including:

- **Concept of children's wellbeing and inclusion**
Background to Quality of Life/wellbeing concepts, what assessments/tests/tools there are already, disabilities and rights (UNCRC 1989 and UNCRPD 2007), critical examination of children with disabilities research, what children's participation research is.
- **Safeguarding/ethics**
Critical issues in undertaking ethical research involving children with disabilities were discussed (informed by Thompson, Wickenden and Cannon 2020). Various standard ethics considerations were covered (including the right to participate voluntarily, confidentiality, informed consent/assent, do no harm, respect and dignity, non-judgemental and honesty), as well as why these are particularly important in disability focused projects. Guidance on disability-inclusive child safeguarding was discussed (drawing on Able Child Africa 2021) including risks of physical abuse, neglect, emotional abuse, exploitation and sexual abuse, and also the safeguarding code of conduct – upholding a safe and respectful environment, the 'two adult rule', use of non-violent methods to manage behaviour, respect for dignity when taking photos, filming or writing reports. We also considered and discussed the safeguarding advice from Sightsavers.
- **Participatory methods**
Inclusive methods were discussed with a view to engaging the children and parents on wellbeing and inclusion in the school and in the community. The activities discussed had practical, visual and physical elements, not just talking, while keeping it simple, including emphasis on everyone participating, visual methods e.g. drawing pictures (maps), games (ball), singing, social reinforcement (praise). The parents' session included focus group discussions where parents were encouraged to express what they felt would make their child feel included, actions needed to improve child inclusion, what would make

a perfect school for their child, resources available to support their child and what would make their child feel comfortable. Inclusive/accessible design was discussed – the training explored the use of several participatory methods for engaging children and their parents to facilitate inclusion. This included ice breakers, songs, graffiti walls, dream cloud, visual timetable, mapping as discussed below.

Preparation for workshops with children and parents

Following the training all materials such as participants information sheets, consents, assent were prepared and translated to Hausa, the primary language of the participants. Other workshop materials such as recorders, notebooks, biros, and pencils, cardboard and refreshments were procured. Purposive sampling to recruit children from the two schools selected was done in collaboration with the school head teacher to ensure representation by age, gender and type of disability.

Liaison with schools

With support from Sightsavers local teams, the schools were selected (these are schools that are part of the larger inclusive education project SMILE), letters of introduction written to the state ministry of education, local Government Education Authority through the secretary and then the school head teachers. The cooperation was very good at all levels.

3.2 Phase 1 - Workshops to generate ideas for checklist from children and parents

Three-day workshops were held for the children in each of two SMILE schools in Jema'a. Participatory methods such as ball in a circle name game and singing songs were used as icebreakers to energize and help the children relax and feel confident to express their opinions. A graffiti wall of post it notes with different colours was used to help the children who could write talk about what they liked about the school while those who couldn't write were shown several pictures from a picture book to help them communicate. The dream cloud was also used to help the children draw their hopes for the future. As these activities were taking place, a visual timetable where all the activities of the day were written out and children ticked the activities as they progressed, this also helped to engage the children and structure the sessions. The facilitator drawing a map helped the children to describe their experience and challenges/barriers in getting to school. A community map was then used to indicate the position of structures they liked/disliked including their experience in the community. Expression cards with short open statements were used by the children to express their views, needs and wants. Through these activities a picture was built up of what the important aspects and priorities were for the children.

The parents' workshop had two Focus Group Discussions. The first one was to generate ideas for wellbeing and inclusion at the school and the community. A second Focus Group Discussion considered what a school that considers the wellbeing of children would look like? How would that school be an inclusive school? After the discussions, parents developed questions that could be asked of other parents, and they also role-played asking other parents what an inclusive school and community would look like. We wanted to find out what they thought were the most important aspects. They then had a presentation made by the children on thoughts about wellbeing and inclusion. This was a presentation on activities carried out the last three days of their workshop.

Analysis of outputs from workshops

To analyse the outputs from both the children and parents' workshops, quotes from the children and parents were collated and used in discussion, a joint online session of the team critically analysed the main messages about school, home/community and life in general. Key themes were identified from the data, these being overlapping but slightly different for children and parents.

Design of draft checklist and evaluation of workshop process

Based on the evolving themes, draft checklists were developed arriving at a list of statements/questions which would use a spectrum of faces (5-point scale from very bad to very good) as possible responses. A 10-item checklist was developed for both parents and children (different but related questions). An assessors' instruction sheet was developed, which included an example of how to introduce the faces scale and practice it before starting the questionnaire. The checklist questions were translated into Hausa.

3.3 Phase 2 - Piloting the checklist in 2 schools with children and parents

The developed tool was piloted in the same two schools earlier used for the participatory workshops and as a relationship had already been established with them. However, children who had earlier participated in the workshops were not recruited for this phase of the work.

4. Results

4.1 Phase 1

Two schools were selected in Jema'a local government area - Model Primary School Takau and Waziri Aliyu Primary School, Kafanchan. After receiving approval, the workshops were held in June 2022.

Table 4.1 Details of children and parents who participated in the workshops

Model Primary School, Takau				
Number of Children	Ages of children	Gender of children	Children impairment types	Number of Parents
7	5 - 9	3 boys, 4 girls	Physically impaired, speech impaired, behaviour impaired, hearing impaired, visual impaired, communication impaired	7
Waziri Aliyu Primary School, Kafanchan				
Number of Children	Ages of children	Gender of children	Children impairment types	Number of Parents
8	8 - 11	5 boys, 3 girls	Behaviour impaired, hearing impaired, physically impaired	8

4.1.1 Description of activities in workshops

The three-day workshop with children were held on normal school days and a classroom was assigned for that purpose.

Introductions/registration

The purpose of the workshop was described to all. There was space to discuss and they could ask for clarification if necessary. All the participants who were available decided to participate - none of them declined. Parents/guardians of participating children with disabilities signed consent/assent for their children and themselves to participate.

The activities during the children's workshops were deliberately designed to be very participatory and possible for all children to join in, even if they had not been in school very long or had not yet developed 'academic' skills such as reading and writing. There was an intentional effort made to make the workshops unlike 'normal' school activities, even though they were being held in a familiar school setting – a classroom. The usual rules (e.g. not talking in class etc) did not apply as we wanted to create an atmosphere where the children could express their views more openly than is perhaps

usual in school. The activities were designed to give the participants multiple opportunities to express their feelings and share their experiences (even if they were critical of the school or society), as their confidence increased over the 3 days.

Introductory activities and icebreakers

There were lots of ice breakers and energizers to allow the children to feel relaxed. They included:

- Ball game – the facilitators threw a ball to the participants and asked them a question (e.g. their name or favourite food). This got them excited and released any tension or nervousness they may have had in an unfamiliar situation.
- Songs – the children sang songs/rhymes that they were familiar with
- Guessing game - the children made sounds and gestures of different animals and others guessed the animal.
- Fancy business cards – the children were asked to give a fancy name that they would like to be called by and asked to say what they want to become in the future.
- Group ground rules - ground rules were suggested by the children, (e.g. listen to each other etc) which were written on a flip chart and pasted on the wall.

Visual Timetable

This was designed to help the children understand planned activities for the day. All the activities were written on the flipchart table with accompanying pictures. At the end of each activity a child volunteered to mark that the activity was finished. This helped the children with cognitive or behaviour difficulties to know what was happening and what would happen next.

Likes and Dislikes

Using post it notes, children talked about their likes and dislikes about school. These were then collected and grouped together.

Different faces rating

This activity was done using a grid with different faces that expressed different emotions (from very sad to very happy). The aim was to understand things that are most important to the child and also to see if a faces rating scale would work well.

There were statements written on a grid, such as:

- How I am treated by my teachers
- How I am treated by my classmates
- How people assist me on my way to school
- How I am treated by my parents
- How I am treated by my friends in the community.

Dream cloud

Dream bubbles were drawn on cardboard and children were asked to mention what they would like to become in future and why. They also mentioned what they would like to do for their community.

Road to school

The facilitators sketched a map of the community on a cardboard, and the children mentioned aspects and structures that were found on their journey to school. Some of the children also drew on the cardboard.

Mind map

Speech bubbles were drawn on a flipchart. The children here talked about some things that make them angry or sad at home and at school.

Community mapping

Using cardboard, markers and coloured paper the facilitator drew a map of the community while the children mentioned structures/features in their community and then discussed those they liked or disliked. This was designed to provide opportunities for discussion/elaboration – e.g. why don't you like that place?

Express yourself cards

Statements were written on cards for wants, needs, my rights.

Questions to ask other children

The children generated possible questions that they could ask other children with disability about their wellbeing and inclusion in school and at home. The children practiced asking each other the questions.

Dice game

A big dice box was made with different questions, such as 'who could help me more at school?'; 'what makes you feel included?'; 'who could help me more at home?'; and 'what would make my life better?' The facilitator rolls the dice and asks questions as they come up.

4.1.2 Parents' workshop

Registration and introduction

All parents/guardians attended. The purpose of the workshop was described to them, and they responded to say that all was understood especially reading from the information sheet. They mentioned that the children have told them about what they have done on the previous days of the workshop.

Energizers

There were several energizers used at the workshop with the parents. Some include allowing the parents to mention their favourite food, and several games. The aim was to get the parents relaxed and willing to talk.

Focus Group Discussion

Parents freely discussed what makes an inclusive school.

Introduction to the tool- the kind of questions to ask other parents

Parents brainstormed together questions they could ask other parents. Within themselves they practiced asking each other, to see how the questions worked and which were most important.

Tool template - different faces scale

The parents were introduced to the different faces scale on which they were able to differentiate the emotions (e.g. from very bad to very good). They practiced using the template with some statements.

Wrap up activity – children and parents together

During the last session of the parents' workshop the children were invited to join the parents to talk about what they had done to close the workshop. The children were excited to show their parents what had happened during their three-day workshop while the parents appeared really impressed with the output of their children. The writing and drawings from the various activities were placed on the wall of the room while facilitators and children showcased and talked through what they had done.

Phase 1 reflections on the process from consultants and steering committee members

The reflections from phase 1 indicate that in general the process went well. All children could participate and were excited to do so. The importance of building up trust between facilitators and participants was noted. At first the children were shy, but in time, the children got to know the facilitators, and this made the process easier. There were some challenges around sign language, with one child understanding a different version to that which the interpreter was using. The youngest participants (who were only 5) became tired and sleepy during the exercises and found it harder to contribute. No gender imbalance was observed, with both boys and girls getting involved. The school setting was not fully accessible. In particular it was noted that there was a lack of ramps. Access to classrooms and toilet facilities were found to be limited.

The team worked well together and drew on the different strengths of the two consultants and two steering committee members. The children and parents seemed happy to be involved. The consultant reported,

[They were] excited that people wanted to hear from them, cared about them.
[They were] particularly excited that we wanted to hear what they thought – not imposing ideas on them – especially the parents.

There were some challenges with the exercises. The children in particular tended to repeat each other. Also, when the children were asked about what they liked about /disliked it was noted that the presence of teachers may be restrictive. There were also some distractions from other children not involved in the process.

The participatory approaches were well received by the team and presented a novel way of approaching research.

This was unusual research - in Africa! We were actually collecting data – it was fun, but we were collecting data. It was a different way of doing things.

There were some concerning hints about exclusion in the community, and worryingly experiences of bullying and beating. None of this was reported by any of the participants directly, but it was suggested that this type of behaviour was common in society in general. As a result of the risks, many parents of children with disabilities tend to be very protective of their children (perhaps over-protective), which can potentially further isolate them from society.

Data from workshops was analysed and draft checklists developed

Using the material generated in the workshops, a draft checklist was designed by the team. The aim of the checklists is to find out how a child or a parent feels about their school and home and community environments, and whether they/their child feel included and supported well. The questions on the checklist were based on things that children and parents had mentioned in the workshops. The main aim was to identify things that could be improved in the children's school and home environment so that they feel fully included and valued and have the support they need and good relationships with both adults and other children.

The main themes identified were rather similar across the two schools and there were also some parallels between the children's and parents' ideas. For example, the problem of inaccessibility of buildings and the compounds, bullying (by other children and by adults), teachers not having the right skills, feeling left out, the importance of friendships. All of these aspects were then included as items in the checklist.

4.2 Phase 2

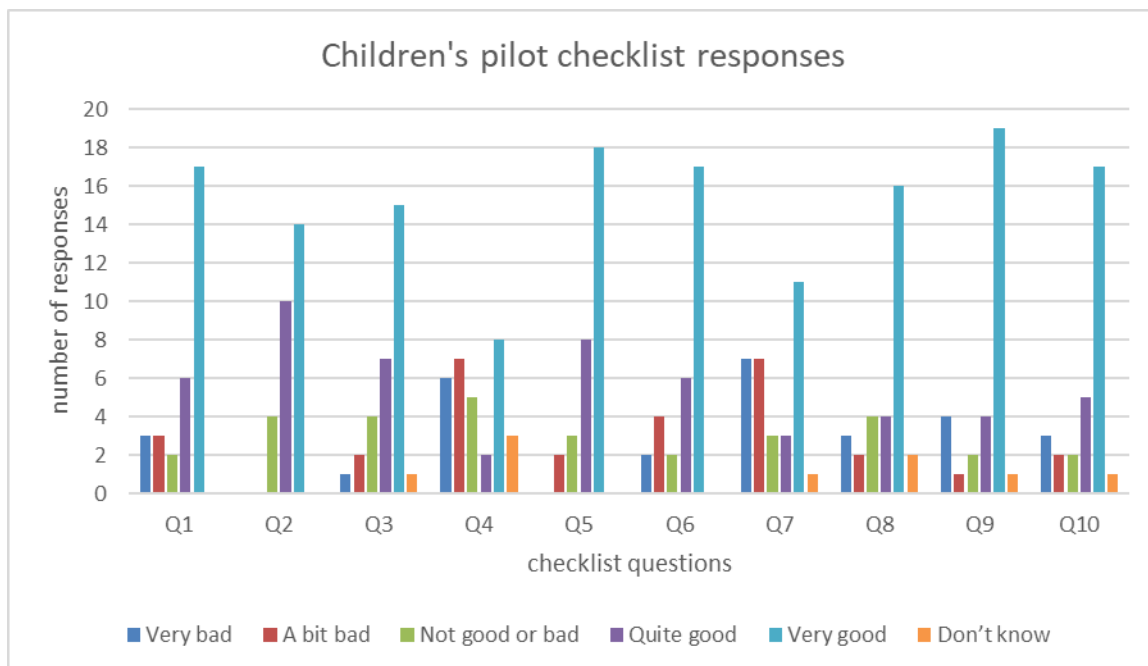
The draft checklists were piloted in the same two schools, but with different children with disabilities who had not been part of the design workshops. It ran in August 2022 over two days in each school. Below are the number of children and parents who participated in the checklist pilot phase. These were all the children identified as having a disability in the schools and their parents.

Table 4.2 Details of children and parents who completed the draft checklist

Model Primary School, Takau				
Number of Children	Ages of children	Gender of children	Children Impairment types – as described by teachers	Number of Parents
13	8 - 15	9 boys, 4 girls	Intellectual impairment, hearing impairment, speech impairment, sickle cell, visual impairment, learning impairment	13
Waziri Aliyu Primary School, Kafanchan				
Number of Children	Ages of children	Gender of children	Children Impairment types as described by teachers	Number of Parents
19	5 - 17	12 boys, 7 girls	Visual impairment, albinism, intellectual impairment, physical impairment, learning impairment, hearing impairment	19

Below is a summary of the range of responses to the 10 questions on each checklist.

Figure 4.1 Responses from children - spread of responses from very bad to very good for each question



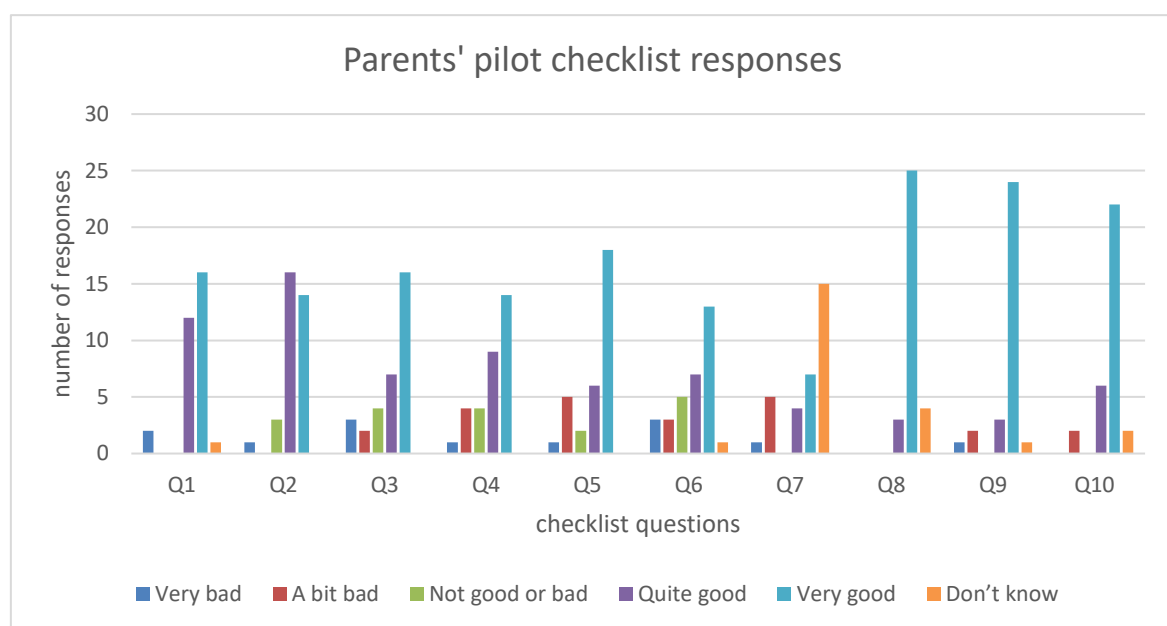
Key to questions. 1. Journey to school 2. Classroom 3. Playground/compound 4. Toilets 5. Help from others 6. Teachers' treatment 7. Bullying 8. Treatment by other children 9. Treatment by others 10. Feeling included

For the vast majority of the questions the children gave positive answers (i.e. quite good or very good) and relatively few very bad or a bit bad answers were given. The

worst rated areas were about the toilets and bullying where 13 and 14 children said that this was very bad or bad respectively. In contrast other questions about relationships with others (no. 5, 6, 8 and 9) seem very positive.

There may be several reasons for these mainly positive ratings: the children could be genuinely happy with their experiences and not have any reason to give negative ratings, it could be that they are not confident or used to being negative or critical about things, particularly when going to school may be a new experience. They may not feel able to rate badly or feel pressure from school or parents not to. A third possibility is that the questions are not sensitive enough and so the responses are close to ceiling (i.e. most of the responses were at the highest level), fourthly the response options may not suit the children, or they may not understand them.

Figure 4.2 Responses from parents - spread of responses from very bad to very good for each question



Key to questions 1. Teachers' skills 2. Teachers' attitudes 3. Child's relationship with others 4. Attitude of other parents 5. Community attitudes to child 6. Physical environment at school 7. Toilets 8. Child's inclusion in school 9. School is adapted to child's needs 10. Child safety at school

Similarly to the children, the parents' responses were mainly in the positive side of the spectrum, with questions 8, 9 and 10 which are rather generic questions about the general inclusive ethos of the school being the most positive.

The lowest ratings were about the physical environment and possibly about the toilets, although many parents said they had never seen the toilets in the school for

themselves (hence a high number of don't knows). Attitudes of other parents towards their child was also rated with rather a spread of views rather than being overwhelmingly positive. There was some confusion about the difference between teachers' skills and attitudes and this question will be reworded alongside some other adjustments to wording and order of the questions.

An instruction sheet (see annexe) for the 'testers' reminded them to do a practice use of the 5 faces with a 'definitely positive', a 'definitely negative' and an 'ambiguous' example. An evaluation of how well the questions worked was carried out during the piloting process and it was clear that although most questions worked well and were understandable, some needed further explanation, repetition or rewording in order to be fully responded to. An assessment summary feedback table on each question is provided in the annexe. Some children needed repeated clear direction and reminders about looking at the scale of 5 faces and deciding which one applied each time. The testers felt that as they used the checklists, they became more practiced at how to phrase questions to make them clear. The best way to translate an English phrase into Hausa gradually emerged.

4.2.1 Phase 2 reflections on the whole process of development of the checklist from consultants and steering committee members

A reflective process with the team was undertaken to gain insight into how the consultants and steering committee members felt the work had gone. There was a general sense from the consultants that the experience was positive for the team and the children and parents.

Prior to the activities, the team had some doubts around the capacity that the children would have to communicate and participate. These doubts were addressed and reduced once the practical work began. The participatory approach involved thinking about things in a different way. This challenged the consultants but allowed them to look at things in a different way, as one of them explained:

It changed my primary mindset about children with disabilities – it is not about what YOU think they need but about how THEY want to engage with society.

The participatory methods used (including different games and activities) facilitated rich engagement with participants, building trust, while working towards talking about different aspects from which the questions were generated. The consultants liked the adaptive nature of the methods – when things were stalling or not going as expected, changes could be made. This flexible approach was found to suit working with children with disabilities particularly well. They also liked how participatory the workshops could be, with the children themselves having the opportunity to suggest energisers or ways of undertaking activities.

Due to the ongoing security situation in Kaduna state much of the preparation and training of the team had to be done online. One of the consultants reflected that this experience had changed how he viewed undertaking this type of work virtually:

A week ago I was planning training for another project someone said we can't do it virtually – I said we can do it!

However, the online nature of the planning process was also cited as a difficulty. To date, the IDS team have not met the consultants or steering committee members in person. Unstable internet connectivity often made this even more challenging, and at times very frustrating. The online format made it very hard for the Nigerian team to 'check in' with the IDS team while the interventions were being undertaken.

The resourcing for this work was relatively lean with the team on the ground consisting of two consultants and two steering committee members. This meant that the team members had to shuffle a lot of tasks. When one of the consultants became ill, it placed a lot of responsibility on the shoulders of the other consultant, as they reflected:

We had only a few hands – we needed more people to arrange things – communicate, organise etc. we had a lot to do. It was stressful when [one of the team] was ill.

This situation was not ideal, but thanks to the hard work and commitment of the team, they coped and did a good job.

In terms of reflecting on working with children with disabilities, the consultants found that it became clear that participatory methods could be used to engage with the children and assist them to communicate and share their experiences. Such approaches are important to promote agency and freedom of expression.

If engaged, they can tell us what they want. Not what we want them to say, but what they want.

It made the consultants think about how the methods could be used in other situations, perhaps with other marginalised groups, such as people who are homeless. They also reflected how researchers working in this field require certain characteristics (such as patience and communication skills) in order to successfully engage with participants. The researchers need to have a positive and disability inclusive mindset from the start.

All [the children] are talented in some way – it is about bringing it out in some way.

This can require some flexibility. If a child doesn't seem to respond to verbal engagement, try another medium such as giving them a pencil and paper. Flexibility and adaptivity is key, thinking carefully about the needs and desires of the child.

Some ambiguities about translation emerged and needed more attention. Careful consideration regarding translation is needed. It is important that the locally accepted words are used, to avoid any confusion. A more suitable translation was sometimes arrived at over time, taking on board feedback from participants and partners. In addition, it was felt that clearer explanation was needed prior to undertaking the exercise. As part of the introduction, it needs to be emphasized that it is not a test and there are no right or wrong answers. Further example questions could be used during introduction (with assured answers) (e.g. You have a mango tree which has a good

harvest, how does this make you feel?). This would ensure that all participants understand the exercise and what to expect.

It was felt that in general the use of the Likert scale with smiley faces as emotional cues didn't work well with all children. The scale could be refined to address this by using 'simpler' smiley faces (avoiding mobile phone emojis) and potentially introducing corresponding colours (red for very bad, moving to orange for not good or bad, and then green for very good). These colours may help some children as an extra cue. However, for others with perceptual difficulties they may confuse – so it may be useful to have both coloured and black and white versions available.

In terms of the engagement with parents, the consultants reported that this was a positive experience. The parents felt happy to talk and were pleased with being given the opportunity, as one of the consultants explained,

[Being involved] gave them hope – that society and the government might look into discrimination and find ways to make their children part of society.

However, it wasn't always straight forward working with the parents. There were some language barriers reported, as well as some potential cultural barriers. In particular, the women who were Muslim did not contribute much. In addition, some of the parents were very protective of their children, due to previous negative experiences. A balance had to be struck so that very protective parents did not compromise the child's participation, and safeguarding was ensured. Also, some of the questions were found to need refining for the parents – for example the question about the toilet facilities was not received well by most parents as they had no awareness of the school facilities. It emerged that parents do not usually visit the different areas of the school premises.

Some dilemmas were noted: in terms of reflecting on inclusion and wellbeing, the consultants noted that these terms can be understood variably in different contexts (e.g. urban vs rural) and reflect different expectations and varying knowledge of what might be possible:

Some people think that just going to school is enough and do not have a developed awareness of what a more inclusive approach would look like. It is not always clear what might be needed to ensure meaningful inclusion – is being in school enough? but they end up sitting on the floor with no furniture, is that progress?

Some are unaware of other options/possibilities, particularly if a situation or way of being is common and accepted.

There were also some reflections relating to the potential challenge of raising expectations of improvements which may not happen soon, which is morally difficult. Change may be slow. Quality of education for all children has to be the goal, but if education is inclusive but of poor quality this is a dilemma.

Going to a school that is not that great versus not going at all may be a decision that has to be made.

5. Analysis and discussion

5.1 How the checklists questions and process worked

Here we present our reflections on the success of the checklists as a new tool for hearing the views of children with disabilities and their parents, about their inclusion and wellbeing.

Because the checklists were based on the ideas generated by the children and adults in the design workshops, the questions broadly worked well and seemed to be of interest to the participants. However, there were some aspects which seemed in need of refining/clarifying/further specification, including: 1) the instructions sheet for the assessors, 2) some of the questions themselves (wording etc), and also 3) the means of responding (the faces scale). In a team workshop we reflected on the process overall and asked ourselves questions such as:

- Are the instructions sufficiently clear - would a new assessor know what to do?
 - Which questions in the checklist work well/don't work well/ need changing?
 - Do we need to remove or add any questions? Do the questions overlap or leave out anything important? Are the questions sensitive enough to be able to show change over time?
 - Any changes to the overall process? (e.g., the response scale/the format of the recording sheet, the inclusivity/accessibility of the process for all impairment groups)
1. The instructions for assessors: it was felt that the introductory words and the use of some practice examples worked well, although the idea of an extra example to practice using the scale was discussed (e.g. If you had a mango tree that had a lot of fruit on it, how would you feel?).
 2. In relation to specific questions there were a number of examples of the exact wording (in Hausa) needing more careful thought. The researchers found that after a few pilots with different children, they arrived at a form of words which worked best. These better translations and suggested phrasings need to be on the checklist form to avoid unnecessary misunderstandings, and to preserve some aspect of uniformity across participants (so that responses can be compared). The simplest type of wording should be used and it should be emphasised that it is fine to repeat or rephrase a question to aid understanding.
 3. The means of responding (use of 5 faces Likert scale from very bad to very good) was discussed at length. It generally worked well with the parents, and the children - once they had understood the task, although some needed reminders and extra explanations. Sometimes the assessors needed to check and verify by asking the child a qualitative follow up question to be sure that their choice of face reflected what they seem to be feeling (e.g. so, tell me more

about it? Tell why you think that?) These responses should be recorded as part of the data.

5.2 Overarching issues

Generally, both the children and the parents seemed comfortable in the checklist situation. This was probably because it had been established as a friendly, relaxed environment, and was a familiar space in their school. An element of excitement about a new activity and for some being interested in the questions and enjoyment at being asked something about their lives may have helped. Additionally, the task was fairly short (30-40 minutes for children, 20 mins for parents) and the activity was non-stressful as they were able to succeed at it.

5.3 Aspects which were potentially problematic – some reflections from our discussions

The idea of asking people (especially children) to rate their present situation is potentially problematic because they may have little idea about what better (or worse) would look like. There may be a tendency to say things are alright (even though someone else looking from the outside might be able to see things are really good or really bad about the situation (e.g. if you have never seen a really clean, accessible toilet you might think a dirty toilet that was difficult to get into was 'normal' and not know what improvements to suggest).

There will be some children who will find the task of doing the checklist too difficult. We need to try to think how to reduce the number of children in this category by considering additional accessible adaptations. Children with communication difficulties (particularly difficulties with understanding), cognitive difficulties, multiple impairments may struggle with understanding the questions and choosing an answer. We are considering developing a visual version of the checklist so that the child can look at a picture of each question (in the form of a picture booklet). This might be possible but will depend on resources being available.

The age of the child is also important to consider. We have decided not to recommend using the checklist with under 6 year-olds (some 5 year-olds were included in the pilot but struggled to respond). For older children (e.g. 11-18 years) a different set of questions, or some additional ones, or more response options may be good to introduce. We are considering having 2 versions - for younger and older children/young people. Of course, the varying developmental levels of children with disabilities in particular is an added complication in addition to any chronological age cut off.

Additionally, we need to consider what should be done about needs identified in the individual checklists. For example, if a child reports that they are scared to go to school because of bullying in the playground then there needs to be a mechanism to report this back to the school. Sometimes such information may be confidential, sensitive and/or have a safeguarding aspect so needs handling carefully. Any guidance about the use of the checklists by various organisations and agencies needs

to include a prompt for consideration of actions that need to be taken in the light of the checklist findings.

In contrast children and parents may give useful generic ideas and recommendations to make school or the community more inclusive and these may be expressed by several individuals. This should also be treated as significant and there needs to be a route for this to be acknowledged and reported (if not immediately acted upon).

6. Future plans – the next phase

The next phase of this work is to incorporate changes to the tool based on the learnings from the pilot and subsequent process of reflections. The creation of a visual version of the checklist so that participants can look at a picture of each question would be desirable from both an accessibility and a functionality perspective, but this may be dependent on resources available. Ideally pictures for a visual version would be produced by a Nigerian artist to ensure the images are culturally appropriate and locally relevant.

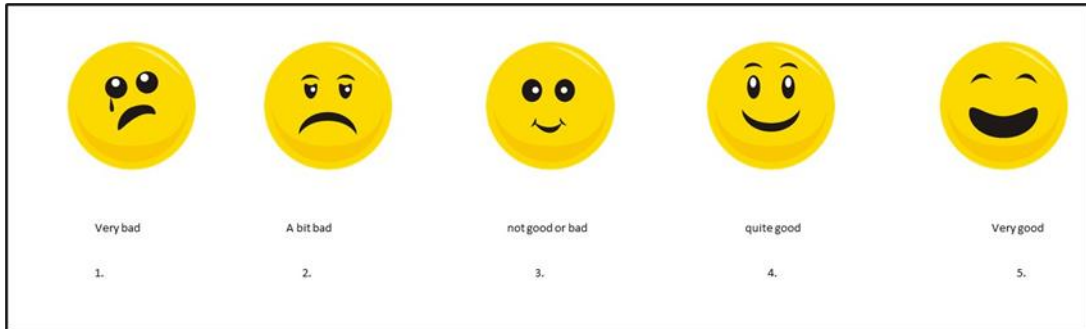
We plan for the tool to be used again in Jema'a in June 2023. This will provide the opportunity to assess changes over time in those schools, but also to further validate the tool and test any changes (including the visual version). This needs to happen prior to the end of the current task order, which finishes in September 2023.

Further validation of the tool could be provided by testing it in other contexts. The Disability Inclusive Development programme currently has education task orders running in Kenya, Tanzania and Bangladesh, which may provide opportunities to undertake further testing of the tool. However, questions remain regarding how this would be funded and resourced.

To share the learnings from this work, we will write a journal article between July and September 2023, which will focus mainly on the process of developing the tool. We aim to submit the article to a suitable peer-reviewed journal that focusses on childhood research (such as *Childhood* or *Children & Society*) or on inclusion (such as *International Journal of Inclusive Education*).

Annexe 1

Faces scale (original version) N.B. To be revised



Annexe 2

Draft checklists

N.B. The checklists are in process of revision – DO NOT use in this format!

Inclusion and wellbeing checklist – Children

Make sure you do the practice questions first to get the child used to the faces.

Name of school.....Child no. Date.....

Team member.....

Faces rating scale > Questions	 1.	 2.	 3.	 4.	 5.	? Don't know	Notes
1. How is your journey to school?							
2. What do you think of your classroom environment?							
3. What do you think of the playground/outside environment/compound?							
4. How are the toilets in your school?							
5. What do you think about the help you get from others at school?							
6. Teachers' treatment of you/how do your teachers treat you?							
7. How much do you feel bullied at school?							
8. How do you feel about the way you get on with other kids at school?							
9. What about how you are treated by others at home (children & adults)?							
10. Do you feel you are included in school like other kids?							
Anything else you want to say about your life at							

school/home/your community/village?	
What did you think of this checklist? (e.g. did I ask you about the right things? Did I leave out anything important?)	






Inclusion and wellbeing checklist – Parents

N.B. The checklists are in process of revision – DO NOT use in this format!

N.B. Make sure you do the practice questions first to get the parent used to the faces.

Name of school..... Parent no. Date.....

Team member.....

Faces rating scale >						? Don't know	Notes
Questions	1.	2.	3.	4.	5.		
1. What do you think of teachers' skills							
2. What do you think of teachers' attitudes to your child?							
3. How is your child's relationship with other children?							
4. How is the attitude of other parents to you and your child?							
5. What are community attitudes and support like for you and your child?							
6. What do you think about the physical environment of school							
7. What about the toilets in the school?							
8. Inclusion in school. Is your child welcome and included?							
9. Is the school adapted to your child's needs?							
10. Do you feel your child is safe in school?							
Anything else you want to say about your child at school/at home/in the community?							

What did you think of
this checklist?

(e.g. did I ask you about
the right things? Did I
leave out anything
important?)

Annexe 3

Draft instructions for checklist administration – being revised

SMILE Inclusion and Wellbeing Checklist for Children with disabilities and their parents

Instructions for using the tool (*N.B. suggested actual words to use are in italics*)

Introduction

The checklist is designed to find out how a child with disabilities or their parent feels about their school, home, and community environments, whether they/their child feel included and supported well, and whether they feel they have a good life overall. The questions are based on things that children and parents told us during the workshops that were run in Jema'a. The aim is to identify things that could be improved in the children's school and home environment so that they feel fully included and valued and have the support they need as well as good relationships with both adults and other children.

The checklist and what paperwork you need.

There are two different checklists, one for children and one for parents.

Both checklists have a table with 12 statements/questions for the child or parent respond to. You will need one paper form for each child and adult that you do the checklist with. Make sure you have plenty of copies.

Write the child or parents number on the top, not their name. Keep a list of names and numbers separately.

You will also have a 'faces scale' sheet printed out separately – for the child or adult to look at and point to.

Signed consent from the parents

You need to explain briefly to the parents about the checklist and give them the info to read if they want to. Use the word **checklist** (it is not a test of any sort!) If they are happy for their child to do the checklist, make sure you have a signed consent from them before doing the checklist with the child. Also ask them if they are happy to do the parents' checklist themselves. We are interested in their views not just the children's.

If either the parent or the child doesn't want to do the checklist, that is okay – do not try to force them or insist. They can refuse if they want to! When parents sign the consent form, make sure you keep it safely.

Getting ready

Make sure you have all the paperwork ready, and a quiet and private place to do the checklist with comfortable chairs and table for you both to sit at. If possible, make sure that other people are not in the room. Have a friendly chat before you start. Do not be very stern and strict! Explain that:

The checklist is designed to find out what you (child or parent) feel about things at school and also at home and in the community. There are no right or wrong answers. It's about how you personally feel. Try to give an honest answer.

What you say may be useful to help make things better in the future. So do say if something is not very good at the moment or you have an idea about how to make things better.

Introduce the faces scale and practice with it

Show them the faces scale

This is a special chart we're going to use in a minute.

See - there are different faces, a very sad one, a little bit sad, one in the middle that is not happy or sad, one that is a bit happy and one that is very happy. (you can skip the next bit with parents!)

Can you point to the one that is very happy? Okay great. Can you show me the one that is a bit sad? (and so on till they have pointed at each).

So, if I ask you how you feel about something, you could point to one of the faces. Shall we try?

So if I said – how do you feel about having a big plate of food? Which one would you choose?

How about if a mango tree near your house had lots of fruit on it? How would you feel about that?

Or if I said – how do you feel when you see someone crying? Which one would you choose. Okay great.

What if I ask you how you feel about playing outside your house? Which one would you choose? Great – why is that?

(good to ask them to follow up with why – because we'll do that in the real checklist).

Doing the checklist itself

So now we are going to think about some different questions to do with you at school and also at home.

There are 12 questions. So, each time you have to point to a face to show how you feel. Okay let's start.

Put the faces chart on the table near them near enough for them to touch it

Ask them question 1. And show that you are putting a tick on the face they indicate on your form.

Then go to question 2. Etc. Try not to rush. Give them time to think. Repeat the question if necessary. You can explain it a bit too – e.g., what do you feel about your

classroom environment? – is it easy for you to get in the class and move around, are the chairs suitable for you?

Once they have chosen a face – ask them to tell you a bit about why they chose that one. Write in the notes column.

When you have finished no. 6 – you can say –

this is great – look we are halfway through. 6 more to go! Are you okay to continue?

At the end

Ask if there is anything else they want to tell you about their school or home or community or life in general. Write anything they say in the box.

Ask them what they thought about the checklist? Was it easy to do? Did they understand it? Did they like the questions? Can they think of any other questions that we should ask people?

Thank them for joining in!

Give them a sticker to wear on their shirt (or a sweet) for joining in.

Finally – while you are using the checklist, note down any questions that you think don't work well or need a rethink re phrasing (also make a note of Hausa words which work well), or any other aspects that should be kept or could be improved. This is still only a draft – so we can refine it later and before using it in other places or publishing it! Your feedback is really important.

Annexe 4

Researchers' collated feedback on individual questions (Children)

Question	Team feedback	Suggestions for changes
1. How is your journey to school?	Question one was okay, they answered and understood clearly.	
2. What do you think of your classroom environment?	The wording for question two maybe changed to 'How comfortable are you in the classroom?'. This was the way some of the children understood the question.	Adapt the wording. Is the classroom suitable and comfortable for you? Can you move around, are the floor, the seats and desks okay for you?
3. What do you think of the playground/outside environment/Compound?	No problems with question 3	
4. How are the toilets in your school?	No problems with question 4	Maybe make this more specific? Can you get in and of the toilet okay and is it clean enough?
5. What do you think about the help you get from others at school?	We may want to be specific here as to 'help from who'. Suggest changing question to 'what do you think about the help you get from teachers and pupils at school?' Re-word this to read - what do you think about the help you get from teachers and pupils at school?	Make into 2 questions - one about help from adults in school and one about help from other children in school
New no 6		Extra question as above – help from other children in school
7. Teachers' treatment of you/How do your teachers treat you?	Suggest changing 'Teacher's treatment' to 'teachers support'	Change wording or possibly delete as covered by 5?

	Re-word this to read – How do your teachers support you	
7/8. How much do you feel bullied at school?	<p>The word ‘bully’ in question 7 may not be changed if in English language, but when translated to Hausa, can be changed into ‘mockery’</p> <p>The word ‘bully’ should be described in terms of specific behaviour</p>	Maybe swop 7 and 8 around. So that 7 is the broader question about how you get on with /interact with other children at school and then 8 is about bullying etc
8/9. How do you feel about the way you get on with other kids at school?	<p>Suggest changing question 8 to ‘How do you feel about the way you interact with other children at school?’</p> <p>Re-word this to read - How do you feel about the way you relate with other children at school?</p>	So, 8 would be about bullying – but reworded – e.g. about teasing, mocking, hurting you?
9/10. What about how you are treated by others at home (children & adults)	Question 9 okay	Maybe split this one too? I.e. how do children at home/in your village treat you and next one about adults in the village
11		Add in one on – how adults at home/in the village treat you
10/12. Do you feel you are included in school like other kids?	<p>Suggest changing question 10 to ‘Do you feel your child is included in school activities like other kids?’ this comment relates to parents.</p> <p>Re-word this to read - Do you feel your child is included in different school activities (singing, reading, playing) with other kids?</p>	<p>Keep child question the same?</p> <p>Or do you feel you can join with and do everything that other kids do in school? Are you treated the same as others</p>
11/13. Anything else you want to say about your life at		Add in – is there anything that you like or

school/home/your community/village?		don't like that you want to tell me about?
12/14. What did you think of this checklist? Does it ask about the right things?		

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