

# Messages



Participation  
in Education  
Project

# Messages from primary school age children with little or no verbal communication



We hardly ever communicate with people our own age. We might like to spend more time with our peers without adults being around all the time

We prefer it if you use easy words and don't ask us to make lots of choices at one time

If we can walk, we often make choices by getting up and walking away from an activity - please let us do this - we might come back to it when we're ready!

We like making decisions and choices  
- you can see this in our faces and it makes a big difference to us

We like to have lots of time to make a choice  
- please don't rush us!

If we are wheelchair users, we sometimes make choices by closing our eyes, making a noise or pushing things away

We don't always want to choose who works with us. (As long as they know us well or are prepared to 'tune into' us, we don't mind)

We like watching other children do things



We sometimes need someone independent to 'speak up' for us

We need role models to encourage us to work hard and inspire us to use different ways of communicating

Please talk to us directly

We have a contribution to make to lots of things, including school councils

If we are wheelchair users, we sometimes like to choose when we can get out of our chair to have a change of position

We spend quite a lot of time waiting for things to happen



Just because we don't speak very much, it doesn't mean that we don't have a sense of humour!

# Messages from parents and carers



Our children tend to use their communication aids, signs and symbols more in school than they do at home. We tend to use more guesswork, eye-pointing and physical leading as most things that they want are accessible to them and we understand them.

Our children have some meaningful friendships, both in and out of school, but they need more role models and support with developing skills in this area. They like to do the same sorts of things that most children like doing.

Frustration at not being understood is a difficulty for most of our children and some of us worry that this will be an increasing difficulty as they get older and have more complex things that they want to convey.

In the community, some of our children will communicate with other people once they are familiar to them, but some don't communicate at all with unfamiliar people.

There are some difficulties about taking communication aids out and about due to issues around insurance and the bulkiness of the devices.

About half of us are quite happy with the effectiveness of our children's methods of communicating but some of us feel that they can't communicate effectively without the tools for them to do this being readily available and there are difficulties with this, including technical difficulties with communication aids.

Most of us are really happy with the partnership that we have with our child's school and we feel that our opinions are well listened to. This is much easier for those of us who take and collect our children from school and we value the informal contact that we have.

We have daily contact with our children's school through diaries or recorded messages. This is generally very helpful, although the quality of the information varies with different teachers and according to how much you are willing to ask.

We think the schools are doing a really good job, but we would like to see some improvements in the amount of training about communication to make it accessible for fathers and sufficiently advanced for those of us who have been on all the basic courses.

A few of us have concerns about our children making changes between teachers. It doesn't always work out well and this can significantly affect our child's ability to communicate and be confident.

Some of our children have the same teacher or teaching assistant for too long and this makes change difficult.

We don't necessarily want our children to be present for all of their review meetings, but we really would like them to contribute in whatever way is appropriate to them.

We have mixed views about our children being able to be involved in target-setting. Some of us think that we would like the children to be more involved as it could increase motivation, but others feel that they would not be able to do this meaningfully. Some of our children are already involved in their targets in that they are aware of them, but none of our children have actively chosen these targets.

Several of us would like our children to be involved in a school council but some of think this would not be appropriate until our children are older.

We have some suggestions about improving the situation regarding the involvement of our children at school: we would like to see a Voice Output Communication Aid users group, more use of computers, more choices generally, more motivation around their targets, more information about what is going to happen in the near future at school, including classroom topics so that we can understand what our children are trying to tell us about, more Speech and Language Therapy and more funding for Voice Output Communication Aids and technical support.

Most of us don't have any professionals coming to the house to talk things over with us and some of us would really appreciate it.

# Messages from teachers

We would like more training, preferably county-wide and including Teaching Assistants.

The training that is available doesn't meet the needs of children with speech difficulties and we have to adapt everything.

We would like more ideas about teaching children with little or no speech, especially things like how to teach them to read.

We already involve these children in choices in lots of ways, but we feel we could be doing more and we need ideas about how to do it.



Giving children choices empowers them and motivates them to do more.

Including the children in making and voting on class rules helps them to have fun and keep to those rules.

We start out by interpreting all behaviour as communicative.

If they use communication aids, it's time-consuming but we know it's their voice, so we do it.

It's very hard to include children in choices when the understanding isn't there and sometimes you can only present them with the ideas, they don't have the means to express them themselves.

We get great satisfaction from very small steps with these children.

You have to find a child's motivation, because it's hard work for them to communicate and they have to want to.

We should give the children the choice to correct their behaviour. Some children need more choice and space to do this, especially those on the autistic spectrum.

At the moment, primary school age children with little or no speech are not very involved in whole school decision-making like school councils, but we're working towards it and have sometimes successfully achieved it.

There's a balance to be struck between offering new experiences and helping the children to feel secure.

We sometimes involve children with little or no speech in meetings, but we're only starting to do this and need to find different ways of making it meaningful for the children.

We need a range of ways to involve children in meetings and make it a positive experience. They are all so different so we need lots of ideas.

We struggle with involving children with little or no speech in setting targets and planning, but we think it is possible and a positive thing.

We can't let them choose anything they want, but we can give them 'choices within choices' and help them by giving them information in an accessible way that is appropriate to their own needs.

We need time, training and resources to work more effectively with these children!

Total Communication training is really worthwhile for all the staff and children.

We need the whole school to be working together on communication, this is especially important when children are moving class.

People that know the children well don't treat them differently from other children, but people who are unfamiliar with them or uncomfortable might do.

We would like to know more about what's happening in other schools with children with little or no verbal communication so we could share ideas.

# Messages from Teaching Assistants, Learning Support Workers and Teaching auxiliaries



The great thing about being a key worker is that you pick up on tiny, little details about a child – which may otherwise be missed.

It's important to pass on all the information you have learned about a child to the next key worker when the child moves class. It's often little tips that count. There can be a huge amount of information in files, so it's important that face-to-face meetings are held.

We often seem to be in a rush to get on to the next thing. Many children need a long time to respond and make choices – sometimes it feels as though they have to fit in with our timetable instead of us fitting in with them.

There are key times during the day, such as lunchtime, when more staff are urgently needed to listen to and interact with children. Sometimes children are desperate to go outside, but there's no-one to take them, staff are just too busy.

Children need to have communication books with the choices that *they* could make within class – for example when reading a story or during an art or cookery lesson – with choices that are specific to them rather than just general preferences.

Children might have been allocated wonderful communication aids, but if the right mount isn't available, they're useless.

Children need space and calm to communicate effectively. If too many children are crowded into the classroom with all their equipment and computers and with different people coming and going, it can lead to distraction and unsettled behaviour.

It's often small things that act as barriers, such as flat batteries in communication aids.

With some children you can't ask, 'What's bothering you?'. If you sit down and talk to them calmly, you can often find out what the problem is.



Some teachers take their children into the Annual Review meetings. Although the children may not know many of the professionals, after they have shown their work they come back to the classroom and we can tell that they are really proud of themselves – it gives them a huge boost in self-esteem.

# Messages from Speech and Language Therapists



We increasingly look to Teaching Assistants to carry out language programmes, and it's really important that we train Teaching Assistants for this empowering role so that they develop expertise in promoting children's communication.

It is vital that children have access to their communication aids throughout the day. These are often bundled away in their bags at lunchtime, ready to go home, so they're not available for children to access in the afternoons.

Some children move from different chairs – they might be in their powered wheelchair one minute, in a manual wheelchair another, and later in supportive seating. If arrangements are not made for the communication aid mounting system to move with the child, this can create a huge barrier.

Having a consistent, small set of symbols that the child can access all the time can work really well – like sentence starters, questions, question words, and very well-used, familiar words. It is also important to change the core vocabulary for key events such as mealtimes, or a visit to a park or zoo.

We would like to see more children within the school having their communication books with the choices that they would make within class, maybe when reading a story or during an art or cookery lesson. Children need to be offered choices that are tailor-made to match their needs, rather than just a general choice.

We need to make communication systems more tailor-made. For example, many children seem to have better visual strategies, particularly those with autistic spectrum disorders and some children with Down's Syndrome. So it's important to know about children's strengths to help support them make choices and participate.

It's not just putting the relevant number of symbols in a book or onto a communication aid that's important, what also matters is taking time to ensure that the child fully understands those symbols and can use them functionally.

Choice-making on issues that are of direct concern to children plays a vital role in introducing a communication system. If they give you a symbol for a biscuit and they get one, then wow! They're off! They've got to see the power of pointing to a symbol, or pressing a symbol for a voice output.

We've designed a room at school that gives disabled children a high degree of independence. Using their communication aid or a special device, children will be able to operate doors electronically, pull down the blinds, open and shut the windows, phone up mum, or watch TV or DVDs.

We often start with objects of reference which stand for a certain activity – a fork can show that it is lunchtime, or a whistle can represent playtime. Then we may graduate to using symbols.

Support staff need training in the basic management of communication aids, so that there is less pressure on speech and language therapists' time – changing batteries and carrying out simple repairs.

More training opportunities to keep up-to-date with new developments would be very welcome.



We have set up a total communication project in our local authority. It's excellent – all the teachers have been trained and most of the Teaching Assistants. We are aiming to educate people in shops, in the library, within mainstream schools, the police and church groups – reaching out to the wider community.



# Messages from Head Teachers and Deputy Head Teachers



Key workers play a vital role – they become very knowledgeable about the child, develop a special relationship and work really closely with the child's family.

Asking children for their views about situations they have not directly experienced may be particularly hard for them, for example the possibility of moving into respite care.

Children need to fully understand what their targets and IEPs are. These need to be presented and recorded in visual, child-friendly ways, and children need to be reminded regularly about these, for example at the beginning of lessons.

Working closely with parents and listening to what they say provides a wealth of opportunities to find out about children's out-of-school lives, what they like doing, and the sort of communication strategies they use at home.

We found that when teachers filled out a sheet with the child before their annual review which focuses on their successes, their aspirations and what help they need, this can really motivate children to get involved.

We like to involve the child in their review meeting. For example, the child might bring in a piece of work – normally something that they've talked about with their teacher and chosen, something that they would like to show to the annual review – and we talk about it.

We have communication passports for all children with limited verbal communication which indicate to anyone they meet what the children like, what they don't like, and how to find out whether or not they like something.

The school council is really interesting because it's going to give the children a view – a valued one that will give them some real influence. There will be elections within their class, and we are planning that members of the school council will have a section on the school website.



The children wanted to talk about their school dinners. So we took them to visit some other schools to see how their lunches were organised. They came back and they said they wanted to make some changes and have choice, and we said okay.

We have aimed to create a total communication ethos throughout the school – not only with the teachers but also with the support staff and mealtime supervisors. It's all about how we make children important in their own decision making, and it starts when children are very young.

The children have been actively encouraged to be part of things going on at a strategic level within the authority. So there is a definite move from the local authority to actually listen to children.

# Messages from other professionals – including school nurse and communication co-ordinators

We need to change the emphasis so that it becomes our responsibility to facilitate children's communication – it's not up to them to learn to communicate with us, we have to learn to understand their communication.

Continuity between classes is essential. If children move from a class with a teacher who has been very enthusiastic about offering a range of different strategies such as switch-use and objects of reference, these must not just get thrown in a drawer when they move up.

We need funding to buy more communication aids. You can build up your own resources such as switches, photographs and objects of reference. But when it gets more technical like developing communication resources for the medical room so that children can talk to the doctors or the dentist or the optician you start talking big money. So there's a financial barrier.

We sometimes need more time and space. Some classrooms are very crowded and they can get very busy. Some of the children have speech problems, some of them have comprehension problems, others can be loud and may need a lot of attention, and sometimes you need to offer the child time to understand what you're saying and time to think about it and that often doesn't happen in very busy, noisy classrooms.

Forward planning helps when involving children in certain choices. It can take a lot of planning beforehand to help them understand what they are being asked to do and to feel sufficiently confident to express ideas and put these into some sort of visual form – symbols, colours, textures and things like that.

# Summary of Key Messages

Children can be included in all aspects of decision-making at some level, given the right support and the motivation.

An increase in whole school and whole Local Authority approaches to communication is needed to ensure continuity.

More training and support with communication is needed, for professionals, for families and Teaching Assistants in particular as they play a vital role.

There needs to be better sharing of good practice, both within and between schools.

Children with little or no speech are increasingly successfully involved with their reviews, school councils and target setting.

The funding and insurance of communication aids is an issue that needs to be addressed.

The messages in this booklet are from interviews and observation sessions conducted as part of the Participation in Education research project and from consultation with the Listening Partnership, a group of young disabled people in Bristol.

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