

Shyness? Reluctance to Speak? ASD? Or Selective Mutism?

People who can speak...
but don't

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Elective mutism DSM 3-R (1987)

"Persistent refusal to speak in one or more major social situations"

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Selective mutism DSM 4 (1994)

"Consistent failure to speak in specific social situations where speaking is expected, despite speaking in other situations"

- has persisted for at least one month, not including first month in a new setting
- not due to unfamiliarity or discomfort with the spoken language required
- cannot be better accounted for by a communication disorder (e.g. stuttering, social communication disorder)

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DSM 5, May 2013

Anxiety Disorders

- Separation Anxiety Disorder
- Selective Mutism
- Specific Phobia
- Social Anxiety Disorder (Social Phobia)
- Panic Disorder
- Agoraphobia
- Generalized Anxiety Disorder
- Substance/Medication-Induced Anxiety Disorder

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People who have selective mutism...

- WANT to speak but are unable to
- Become afraid of the act of speaking and people hearing their voices
- Become increasingly wary of any form of communication or situation which could lead to an expectation to speak
- Learn to avoid distress by avoiding the situations which might trigger their fear
- Become increasingly 'invisible' (because they avoid drawing attention to themselves). This in turn affects their self-esteem.

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Diagnostic features that are unique to selective mutism (SM)

- A sudden visible 'freeze' (increased body-tension and fixed facial expression) when the child becomes aware of a person outside their comfort zone - suddenly stops talking or starts to whisper as someone approaches.
- Cannot repeat a favourite verbal activity with a different person that they know well.
- **Total** lack of vocalisation with some people (not even to laugh or cry).
- Individuals report they want to talk but their voice gets stuck in their throat.

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Do people outgrow SM?

- No-one outgrows it – they may work through it with the right support
- No guarantee you'll work through it
- The longer it goes untreated, the greater the risk of additional mental health issues
- My caseload...

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SM affects approximately...

1 in 140 primary school children
(more in pre-school settings)
1 in 550 teenagers
1 in 2400 adults

These figures are almost certainly underestimates

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What can we do?

As with any phobia we are aiming to....

- Nip it in the bud
- Understand the fear
- Talk openly about it
- Help the person to face the fear, one tiny step at a time, at their own pace (no pressure)
- Support participation rather than avoidance

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Effective intervention involves...

- Education for all
 - SM must be understood and not maintained through pressure or avoidance or person will not be able to participate and/or engage.
- A small-steps approach
 - Informal techniques on a 24/7 basis
 - More formal small-steps programmes
- Emotional support
 - Develop general confidence and resilience
 - Peer support

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Education for all

What to say to people who have SM

- Don't ask children why they don't talk, *tell* them "Talking to new people can feel scary to begin with – so scary your words get stuck and don't come out. It's OK, you don't need to talk to play these games."
- Reassure them "You'll be able to talk to me when you're ready, but until then you can just talk to Mummy or your friends."
- "It won't always be like this – it will get easier."
- "You're not the only one who finds it hard to talk sometimes."

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What to say to people who have SM

- “Don’t worry, I’m not going to pick you to answer any questions unless you want me to.”
- “Talking is difficult at the moment but there are lots of other ways to join in & have fun. It’s OK to laugh & it’s OK to sing if you want to join in.”
- “Grandma knows you can talk to me so it’s OK to talk when she’s here. She’s not going to ask you any questions.”
- It’s OK, there’s no need to talk at the moment. All I’m interested in is....(getting these cakes in the oven/ making sure you know where everything is / making sure you enjoy your time here). You’ll talk when you’re ready, there’s no rush.”

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Be ready to deal with unhelpful comments from peers

Respond to comments and questions casually to show there’s nothing to be concerned about, e.g.

- “Jai *can* talk. He talks beautifully at home, don’t you Jai? When he’s ready, Jai will talk here too.”
- “Not everyone can talk straightaway in new places. They join in by listening and thinking hard and they start talking when it feels right.”
- Jessie’s not being unfriendly, she just hasn’t got used to talking here yet. If you play with her and do all the talking, she’ll talk to you when she’s ready.”

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My friend Daniel doesn't talk



Sharon Longo



Books for children who have SM

Speechmark Publications
(3-8 yrs)

“every child with selective mutism should have a friend like Ryan”

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Can I tell you about Selective Mutism?

A guide for friends, family and professionals



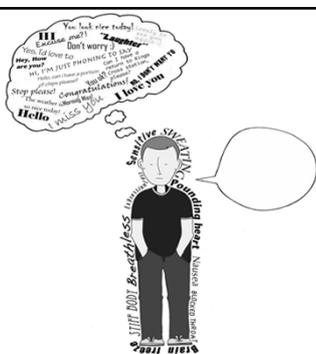
MAGGIE JOHNSON and ALISON WINTGENS

Illustrated by Robyn Galloway

Jessica Kingsley Publishers
(Suitable for children aged 5 and above, and a quick informative read for adults)

Hannah tells her family, friends, relatives and teachers how they can help

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When the words won't come out

A booklet about selective mutism for teenagers and adults

Booklet available in:

The Selective Mutism Resource Manual (2nd edition) by Maggie Johnson and Alison Wintgens

Or download it at:

Finding our Voices
www.findingourvoices.co.uk

iSpeak
www.ispeak.org.uk

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The Selective Mutism Resource Manual

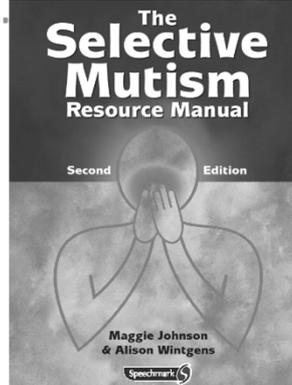


A Speechmark Practical Sourcebook

Maggie Johnson & Alison Wintgens

Includes a 244 page **online resource** of photocopiable materials.

Use code **FLR40** at www.routledge.com for a 20% discount.



Maggie Johnson & Alison Wintgens



Online information and support

- NHS Choices: Selective Mutism



- Selective Mutism Information & Research Association (SMIRA)
www.selectivemutism.org.uk and Facebook Group
- SM SpaceCafe Facebook Group

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Education: Key pieces of advice

- Master the art of avoiding direct Qs using commentary-style talk with rhetorical Qs and natural pauses while you focus on shared activity. People who have SM relax far more easily when you show you have a sense of humour and can do all the talking!
- SMILE. Worry and concern can look like exasperation/sadness/disapproval.
- Let the person talk comfortably to their family or friends in your presence as a first step towards talking to you.

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“The One Show” November 2016

A small-steps approach

Small-steps progressions

- The stages of one-to-one interaction
 - talking to one person at a time precedes generalisation to other people, group-work and being overheard in public places
- Communication risk
 - gradually move from low to high risk activities

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The stages of one-to-one interaction

Stage

- 1 – **Frozen** or absent
- 2 – **Participation**
- 3 – **Communication without talking** (points, nods, writes etc.)
- 4 – **Talking through others** (communicates indirectly via parent, friend or voice recording)
- 5 – **Voice** (uses voice to read, count or to make a sound, e.g. hums, laughs, ‘uh-uh’)
- 6 – **Single word** response
- 7 – **Phrase/sentence** response/structured initiation
- 8 – **Connected** sentences

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Communication Risk

LOW → HIGH

- rote language
- quick, e.g. factual single word
- no risk of saying wrong thing (e.g. reading)
- elicited/structured
- talking in unison
- one to one
- unsure if answer is acceptable
- alternatives/reasons
- opinions/ideas
- initiated/unplanned
- conversation (no end in sight)
- audience

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Graded question sequence (page 1 of 'Informal techniques' handout)

- Facilitate speech by gradually working through the graded question sequence *at the individual's pace*. Do this initially on a one-to-one basis or in the presence of family/friends that the person who has SM already talks to.
- As person responds (e.g. joins in an activity) move up to the next level of questioning.
- If no response, keep talking & pull back a level. When responding well, try again to move on.
- Parents use the same sequence of questions when helping children to talk to them in front of other people.

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Do I answer if someone asks my child a question?

(page 2 of 'Informal techniques' handout)

- Parents enable their children to answer questions rather than stepping in to answer for them.
- Parents can *repeat* what their child says but do not answer for them – ever!
- Simple 4-step procedure: WAIT
Repeat or Rephrase
WAIT
Move on
- Warn doctor, optician etc. in advance that child may need to answer questions by pointing to an option or by telling their parent the answer.

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Other small-steps techniques

- Sliding-in technique (informal or formal)
- Lone-Talking
- Voicemail / Telephone programmes
- Shaping
- Reading route

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Emotional support

A short film made by members of SMTalkingCircles, a Canterbury-based peer-support group

info@smtalkingcircles.org.uk

'Acceptance'

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Further Reading and References

- American Psychiatric Association (2013) *Diagnostic and Statistical Manual of Mental Disorders*, 5th edn DSM-5 American Psychiatric Publishing, Washington, DC.
- **Selective Mutism in Our Own Words** (2015) by Carl Sutton and Cheryl Forrester, Jessica Kingsley Publishers. www.jkp.com (Adults' perspectives)
- **Persona Medusa: An Embodied Tale of Anxiety** (2015) by D.J. Sharry, CreateSpace Independent Publishing Platform. (This survival story is an adult's personal account of facing and making peace with SM – get on Amazon.)
- **Can I Tell You About Selective Mutism?** (2012) by Maggie Johnson & Alison Wintgens, Jessica Kingsley Publishers. www.jkp.com £8.99
- **The Selective Mutism Resource Manual**, 2nd edn (2016) Johnson M & Wintgens A, Routledge, London & New York.

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SELECTIVE MUTISM IS A PHOBIA

Selective mutism (SM) is a phobia of talking to certain people. A person who has SM will not even want those people to hear their voice in case they are then expected to talk to them. As with all phobias....

1. Phobias can be overcome

No-one chooses to have a phobia. The fear reaction is automatic and the natural thing to do is to avoid whatever triggers it. But if approached slowly, it's possible to take back control and stop the feelings of panic.

2. Phobias are common and nothing to be ashamed of

It helps when people talk openly and non-judgementally and we know what we're dealing with – it's not 'just the way we are'. It's just a phobia.

3. Applying pressure makes phobias worse

Phobic individuals can't be rushed, and any use of force, disapproval, unrealistic targets or bribery will simply raise anxiety levels even higher.

4. Facing fears is the key to success

The most successful way to overcome a phobia is to understand how it arose and what maintains it, and then gradually face the fear *at your own pace*. In the case of SM, this can only work if other people accept you as you are and allow you to progress at whatever rate is comfortable for *you*.

5. Avoidance is not an option

The longer you put off facing your fear, the stronger it becomes and the better avoidance feels. So it's important to find ways to make difficult situations more manageable rather than avoiding them altogether.

6. It takes courage to overcome a phobia

Even though there's no danger, phobias trick us into believing that escape is the only safe option. Never underestimate the determination and courage that goes into each tiny step in the opposite direction!

Maggie Johnson, FRCSLT (2018)

Maintaining factors

Children with selectively mutism (SM) can only speak freely to a small number of people. They experience feelings of panic and extreme anxiety when they're expected to talk to anyone else – this has nothing to do with the person they're trying to talk to, it's an automatic reaction that developed in the past at a time when they found talking difficult. Without realising it, friends, family and staff may *strengthen* this fear of talking by

- i) putting pressure on the child to speak (often in quite subtle ways)
- ii) allowing the child to opt out of social situations altogether.

We need to take all pressure *off*, and then support the child to gradually face their fears in small manageable steps at their own pace.

Possible home factors that maintain silence / delay improvement

- child frequently hears 'he/she won't talk'
- the child's anxiety about talking is not openly acknowledged
- child is pressed to talk when clearly uncomfortable
- child gets no acknowledgement of their efforts; only disapproval/disappointment
- mutism causes family members great anxiety/embarrassment which is conveyed to the child and puts on pressure (e.g. frequent questioning about progress; voicing concerns; giving encouragement (rather than helpful strategies); asking child why they behave as they do and when they are going to change)
- child is set unrealistic targets or offered a reward to talk
- little expectation or need to speak/communicate
- parent/sibling always takes lead to spare embarrassment/anxiety/disappointment
- silence is modelled as a reaction to strangers or to express anger
- there are few opportunities to mix or observe social interaction outside the family
- intense warnings about speaking to strangers/taking risks
- child is allowed to miss any activity that causes anxiety, rather than modifying the activity as necessary and helping child to understand and manage their anxiety
- child gets cuddles when opting out (to comfort) rather than for participating (high 5!)

Possible school factors that maintain silence / delay improvement

- the pupil's anxiety about talking is not openly acknowledged
- pupil senses disapproval from peers/adults for not talking
- pupil feels under pressure to speak (e.g. invited to contribute and put on the spot; dreads that might be chosen to answer a question/read aloud)
- adult looks at pupil while waiting for an answer or insists on eye-contact
- rewards are in place for what pupil *might* do, rather than what pupil actually does
- pupil feels unrealistic expectation to speak eg. 'Are you ready to talk to me today?' 'I can't help you if you don't tell me'; unrealistic targets are set with no strategies
- always a large audience/possibility of someone overhearing/ little opportunity for one to one with an adult or working with friends that the pupil talks to at home
- pupil is expected to initiate requests for help/toilet or report illness/bullying etc. when unable to do so
- teasing/demands to talk from peers or over-protection, e.g. 'he/she can't talk'
- lack of social relationships/ isolation/ ignored by peers and/or teachers
- breakdown of trust (e.g. teacher given video/tape without pupil's consent; mixed messages/expectations from different staff members)
- no need to change – alternative forms of communication are used as a replacement for talking, rather than a stepping-stone *towards* talking
- attention is drawn to the fact that the pupil has spoken, rather than continuing a normal conversation

The stages of one to one interaction

Stage 1: The child does not communicate nor participate

e.g. *passively accepts help [e.g. stands while coat is buttoned] but makes no attempt to seek assistance; retreats to bedroom when visitors arrive*

Stage 2: The child participates but limited communication

e.g. *complies with requests which are perceived as non-threatening or non-invasive (may deal out cards, pass an object or draw a picture, but be unable to copy gestures or point to objects on request); joins in group activities 'singing' (mouthing) or moving in unison*

Stage 3: The child communicates without talking

e.g. *responds by nodding/shaking head; points to indicate answer or make a choice; writes a message; provides an action or gesture to complete a sentence or convey a message*

TALKING BRIDGE: The child talks to an existing conversational partner (CP) within earshot of a 'new' person

e.g. *talks to mother in same room as teacher, either quietly or at normal volume; talks to parents or siblings at home in front of visitors*

Stage 4: The child talks to a 'new' person *through* their CP

e.g. *answers teacher's question by telling parent or friend the answer; participates in turn-taking games with parent and teaching assistant or therapist (even when answering the new person, child tends to look at parent)*

Stage 5: The child uses voice with a 'new person'

e.g. *laughs audibly; joins in sound-effects for story; reads aloud (not true communication – easier for confident readers than actual conversation); says 'Mmm' for 'yes'*

Stage 6: The child uses single words with a 'new' person

e.g. *participates in single-word turn-taking games; responds to questions/prompts without parent present, giving minimum of information*

Stage 7: The child uses sentences with a 'new' person

e.g. *uses sentences in structured activities without parent present; answers questions with a phrase/sentence; little initiation unless part of a structured activity*

<p>At this stage it is important to slide parent out if they are present, if only for a short time initially (if parent is still present it counts as Stage 4). Generalisation: Can now introduce another child or adult, or carry out the same activities in a different location)</p>

Stage 8: The child converses with the 'new' person

e.g. *has an adult-led, two-way conversation, provided no one else is perceived to be listening; volunteers spontaneous comments but questions and true initiation (e.g. asking for help) may be limited.*

Source: The Selective Mutism Resource Manual (2016), Maggie Johnson & Alison Wintgens, Speechmark Publishing Ltd.

Informal ways to work through the stages of one-to-one interaction*

1. Graded questioning, at individual's pace

Introducing questions to someone with selective mutism

*move on only as
person
participates
and responds*

Chatty comments with rhetorical questions that need no answer (e.g. 'This is fun, isn't it!' 'I wonder what this is?')

Show me/Which one? requests that can be answered by pointing

Yes/No questions that can be answered by nodding or shaking head

X or Y? questions that can be answered with one word

Simple questions that can be answered with one word

Factual questions that can be answered with a phrase

Leave open-ended and personal questions until later (e.g. 'How's school going?' 'What do you think?')

*pull back if
person freezes*

N.B. Comments always outweigh questions!

2. Talking through parent or a friend

- Use parents or friends as 'go-betweens'
- Provide space to talk together, e.g. 'Why don't you two go into the book corner to discuss your plan' (*keep your distance and/or pretend to be occupied*)
- Ask questions via the friend/parent, e.g. 'Could you ask Pria where she put her lunchbox?' 'I expect you've got a favourite teacher – Mum, do you know who Joe's favourite is?' (*prime parents to redirect the Q rather than answer!*)
- Ask child to communicate via friend/parent, e.g. 'Tell Ben whose table you want to be on and we'll get it sorted',
- Move away or turn away initially, so that the conversation is private
- Gradually get closer until child talks to parent/friend in your presence
- It won't be long before they answer you without waiting for parent/friend to repeat the Q

3. Talking to parents in front of other people

- No more whispering in parent's ear – parent moves to where child can talk to them *face to face* and soon the distance from other people will decrease
- Help parents to stop answering for their child and show them how to *support* their child to answer for themselves (see next page).

An advice sheet for parents of children with selective mutism (SM)

Do I answer if someone asks my child a question?

The short answer is No!

It's natural to step in when you see your child freeze. But if a child gets used to someone answering for them, they will adopt the role of silent partner whenever that person is around. One day they *will* answer and it's so important to have everything in place for that moment when they are ready to speak out.

A few Golden Rules:

Do not answer for your child. If you adopt the routine that follows, your child will learn that it's not so bad to be asked a question; everyone seems relaxed about it, whether they answer or not. They'll be far less wary of social situations in general.

Do not put your child under pressure to answer. Calmly convey that it's fine if they answer and fine if they don't. You know they're trying hard and doing their best.

Do not apologise for your child. They'll feel they've done something wrong. If appropriate, you can always explain later that your child wasn't being rude, or share how it makes you feel that others don't see your child as they really are.

But now the long answer...

Follow this routine whenever someone asks your child a question and you'll be surprised how much easier it gets and how quickly your child succeeds in answering. *It's not usually necessary to tell younger children what you're doing or why*, but if they ask or you want to prepare an older child, see 'Why does this work?' below.

1. **WAIT** for a full 5 seconds (slowly count to 5).
If your child nods or shakes their head for Yes/No, that's fine. Add a comment to move the conversation on, e.g. 'Yes, we came last week, didn't we?' But with other sorts of questions your child will probably find it easier to answer if you don't look at them - fiddle with something if it helps!
2. If no response, make it a private conversation between you and your child:
 - gently **repeat** the question or
 - turn it into a **choice** 'X or Y?' or
 - **rephrase** it so that your child only needs to say Yes or No or nod or shake their head.
3. **WAIT** for a full 5 seconds.
If your child answers or gestures, smile and add a comment to move things on. Keep any acknowledgement of this great achievement for a private moment - your child doesn't want attention drawn to their talking in public.
4. If no response, **MOVE THE CONVERSATION ON** without answering, e.g.
 - say to your child 'We'll have a think about that, won't we?' or 'Tell me later'
 - ask the other person a question to divert attention from your child
 - change the subject
 - say your goodbyes

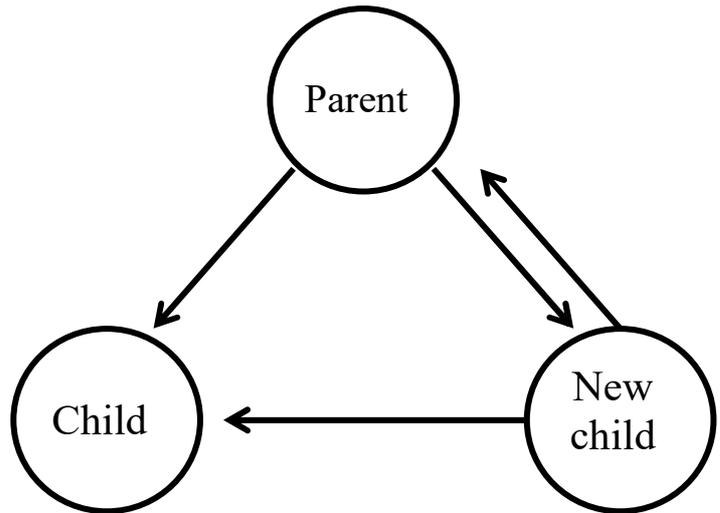
Why does this work? Your child will learn, *without any pressure*, that:

- questions are for the person who's been asked – no-one else will answer
- you know they will get good at answering if they keep trying
- *it's not a big deal* if they don't manage it, no-one minds, it's still a good day!

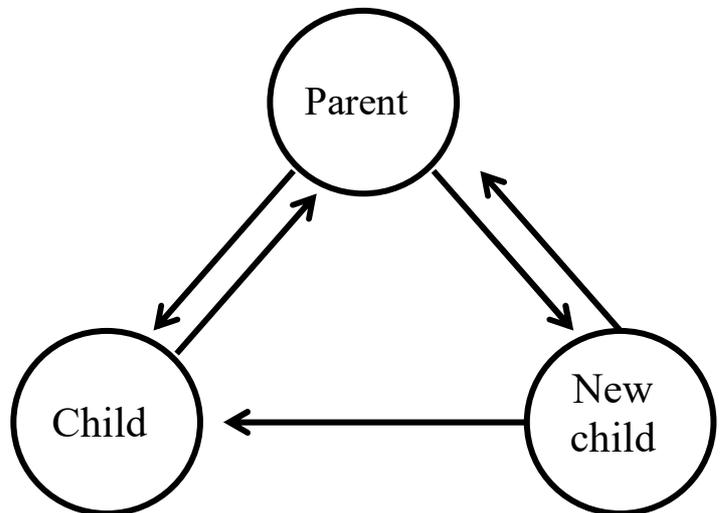
WAIT \Rightarrow **REPEAT/REPHRASE** \Rightarrow **WAIT** \Rightarrow **MOVE ON**

4. The Triangle Tactic

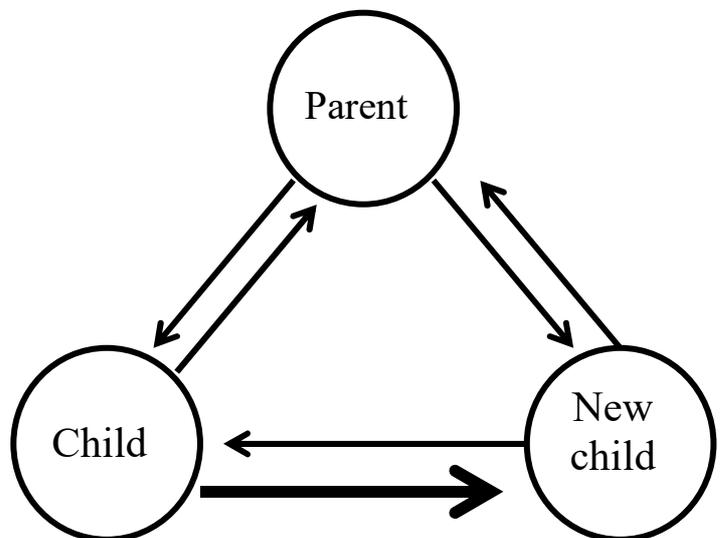
- a) Parent talks to children individually, redirecting new child's comments or questions as needed by asking Yes/No questions that their child can answer with gesture. As their child warms up, parent asks them 'X or Y?' questions and waits 5 seconds to encourage one word answers.



- b) Child starts to talk to parent. Parent passes bits of each interaction on to the other child to keep both involved in the same conversation. As child answers with single words more easily, parent asks them more general questions.



- c) Child talks more to parent and starts to make more general comments. Parent continues to redirect new child's questions but waits a full 5 seconds before doing so. Parent also introduces a 5 second pause before responding to new child's comments, creating more opportunities for their child to cut out the middle man and talk to new child directly.



5. Reading Route

This is an excellent starting point for children and young people who are competent readers and are able to read aloud when on their own with a keyworker. As such it represents the quickest route to establishing speech, but should never be adopted if it causes distress or 'shut-down'. An advantage of this method is that it does not require a parent or other talking partner's presence. Reading aloud is usually less daunting than other verbal activities as the child does not have to worry about saying the wrong thing or being expected to enter the unpredictable and personal world of conversation. Success is dependent on the child knowing that their difficulties are understood, and trusting that by reading aloud they will not suddenly be expected to speak any more than they feel comfortable. It also helps to sit beside rather than opposite the child, following the text so the child does not feel scrutinised as they read. Young children may approach this route via reading groups, where children read the same text in unison and join in as best they can, following the text with their finger and saying whichever words they can manage. Older children and teenagers may be able to read aloud following a period of rapport-building and explanation of their difficulties: introduce it by saying that you understand that certain things like being asked unexpected questions can be very difficult, but that reading aloud is usually easier because they won't need to find their own words to express themselves.

Activities can be moved towards true communication in a few sessions as follows, starting with a familiar paragraph or piece of work that the child has looked at in advance:

- a) child reads a short passage.

If voice is steady and audible rather than whispered or strained, it is possible to go straight to d). Otherwise use b) and c) for smaller steps to improve voice through repetition and gradual relaxation.

- b) keyworker and child take it in turns to read alternate sentences from a short passage or familiar poem.

- c) (emphasis moving from reading to more interactive turn-taking):

Keyworker and child read different characters' lines from a set number of pages or for a set number of minutes (local amateur dramatic companies will have comedy and pantomime scripts you can borrow and TV scripts are available to download. See also 'I Say!' in STASS catalogue.

or Child reads out numbers, the days of the week and months of the year and then says them alternately with the keyworker, aiming for steady pace, rhythm and voice (may be quiet but should not be strained).

- d) reading games and activities involving turn-taking, questions and answers. e.g. the keyworker asks questions that can be answered by reading out from the text; the child reads out crossword clues for the keyworker to solve.
- e) activities involving turn-taking, questions and answers without reading

6. Telephone Route

- voice messages →voicemail →answering Qs via phone →talking face to face