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ROYGBIV



ROYGBIV

Panic !



Fx Speech Pathology Gurus

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Speech and Language in FXS

Language is almost always affected in fragile X syndrome (FXS) and a delay in language acquisition is one of the first characteristics. They articulate poorly and have a repetitive language, using the last word or sentence they have said or have been told. They have a tendency to change subjects as they talk and to repeat what they have heard. Even if comprehension is correct, they are unable to answer questions. Sometimes this is due to the fact that they don't expect the question or because they are not paying attention. They react better to short and concise commands. Their speech is fast with a poor control of the rhythm and inappropriate pausing in words, making it difficult to understand them. Some children with severe language dysfunction will require a complementary communication system to aid them.

Speech Therapy in FXS

“In speech therapy we will improve their communicative skills, both in comprehension as in expression, minimising or eliminating negative patterns, with exercises, techniques and strategies. Work is needed on the use of alternative language if necessary and finally work on feeding problems caused by the low muscular tone and on sensorial problems such as tactile hyper/hypo stimulation or difficulties to plan their movements.”

Individuals...

“In conclusion, we must bear in mind that each child is different and so are their specific needs.”

- [Fürgang C R.](#)
- furgang@arrakis.es

Food for thought...

- Cognitive development is important to the development of language and speech. In children diagnosed with Fragile X syndrome, cognitive development complications lead to the secondary development of speech and language deficits. In addition to cognitive impairment that directly affects speech and language development, children with Fragile X syndrome also commonly experience deficits with auditory processing as well as short-term memory. When these three complications are present, speech and language therapy is almost ineffective.



The flip side...

- To show what can happen with a child when they are given the proper support services, when Josh was first assessed by the school district (December 1997), it was determined that speech delay was his greatest weakness. Upon entering school, he immediately received speech therapy. After 1 year of speech therapy, speech is now considered one of his **STRENGTHS** instead of his weaknesses.

Assessment

- If your child has been diagnosed with Fragile X syndrome, it is important to obtain speech and language testing in combination with testing to determine to what extent your child experiences short-term memory complications. Because these factors play a role in your child's ability to engage in successful speech and language therapy, they must be assessed and re-assessed during your child's growth and development.

Assessment

- Assessment should be an on-going process, not a once a year formal evaluation. Speech therapists monitor progress with language samples and "diagnostic teaching" (testing for a concept, teaching it, and testing again) throughout the year.
- Formal test scores are only necessary for funding purposes.



Speech Disorders



- Speech Disorders include:
 - Articulation and phonological disorders
 - Fluency (e.g. stuttering)
 - Voice (pitch, loudness, quality – e.g. hoarse, breathy nasal)
 - Verbal dyspraxia

Speech characteristics in FXS

- Fast and uneven rate
- Disordered rhythm
- Imprecise articulation
- Oral and verbal dyspraxia
- Increased volume
- High pitch
- Jocular litanic
- Cluttered quality (repetition of sounds, words, phrases)

Why is speech affected?

- High incidence of middle ear infections
- High arched palate, requiring more effort to form sounds
- Soft contacts instead of hard ones
- Oral hypersensitivity
- Weakness of facial muscles
- Dyspraxia
- Social anxiety?

Speech - intervention strategies

Rate, rhythm, 'cluttering'

- Model correct rate / rhythm
- Melodic intonation therapy
- Increase self monitoring
- Voice synthesizer for auditory and visual feedback

Speech - intervention strategies

Oral and verbal dyspraxia

- Music, singing, movement
- Integrate therapy with OT

Dyspraxia

- Oral dyspraxia
- Verbal dyspraxia
- motor planning difficulties
- difficult to use an accurate movement in the mouth
- Sequencing is challenging
- Work with an OT
- Mouth Madness – Catherine Orr

Oro-motor functioning

Oral motor functioning for eating and speech production

Increased, decreased or mixed sensitivity. Work with an OT. Work away from the face and move closer.

Stuffing and idiosyncratic chewing (decreased oral sensitivity, need for tactile feedback, types of foods)

Drooling (low oral tone and lip closure), encourage early motor and verbal imitation, oral exploratory play and stimulation, deep pressure input, lips, blowing, sucking to strengthen.



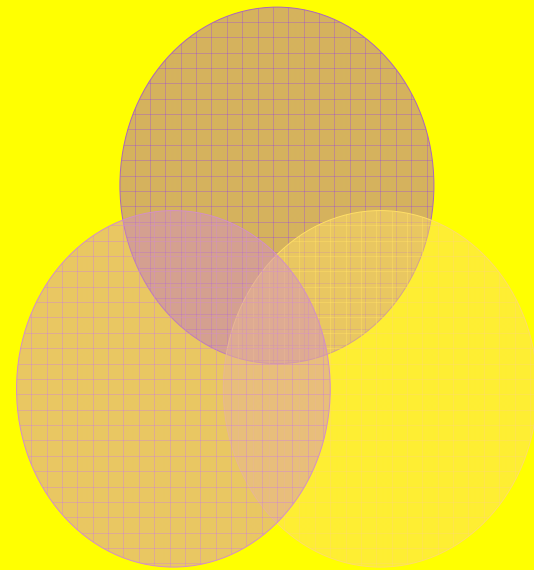
- Both foods and toys can be used in oral-motor activities in order to provide incentives. Blow toys, whistles, and straws can be used to help build up oral -motor strength and functioning. Foods can help with chewing, oral-motor strength and calming.
- Crunchy and chewy foods, such as fruit snacks, celery, bagels, and gum.
- Serves as oral stimulation and may help prevent the child's chewing on clothing, straps, or skin. Thera-tubing also helps.

Receptive and expressive language



Bloom and Lahey's Taxonomy of Language

- Form: Syntax, morphology and phonology
- Content: Semantic components (meanings)
- Use: Pragmatics (social language in different contexts)



Glossary – Language – 1

- Receptive language: This refers to a child's understanding of language. It includes the comprehension of meaning on different levels as well as understanding of language structures.
- Expressive Language: This refers to a child's use of vocabulary and sentence structures, in a meaningful manner, when expressing himself. The ability to express thoughts, ideas and feelings.

American Speech and Hearing Association
(ASHA) www.asha.org

Terminology of Communication Disorders (Nicolosi,
Harryman, Kresheck 1989)

Glossary – Language - 2

- Auditory Processing Disorders: The impaired ability to attend, discriminate, recognize or comprehend auditory information, despite normal hearing. Include difficulty with STAM (short-term auditory memory) and figure-ground discrimination.
- Phonological Awareness: The ability to reflect on and manipulate the sound components of spoken words (Snowling, 2001). Includes skills such as syllabification, rhyme identification and production, identifying beginning, middle and end sounds, manipulating sounds to form new words, reading and spelling of 'nonsense' words. Awareness of sounds in words/the ability to play with sounds.

American Speech and Hearing Association (ASHA) www.asha.org
Terminology of Communication Disorders (Nicolosi, Harryman,
Kresheck 1989)

Glossary – Language - 3

- **Pragmatics:** The social usage of language. Includes greeting, initiating conversation, keeping a conversation going, turn-taking, giving and accepting compliments, dealing with conflict situations, changing your language according to whom you are speaking to.
- **Non-verbal communication:** Involves the use of alternate and/or augmentative communication systems (AAC). E.g. PECS (Picture Exchange Communication System), Signing, Computer devices. Contact ComTec.

American Speech and Hearing Association (ASHA) www.asha.org
Terminology of Communication Disorders (Nicolosi, Harryman,
Kresheck 1989)

Language characteristics in FXS

- Relative strengths receptive & expressive vocabulary
- Syntax skills commensurate with language age
- Strong verbal and behavioural imitative skills
- Strong visual skills
- Good sense of humour

Language Characteristics

- Pragmatic - topic maintenance, tangential, impulsive
- Echolalia
- Perseveration - phrase and topic, automatic phrases
- Semantic relations - temporal, sequential, inferences
- Poor abstract reasoning
- Poor auditory memory, sequencing difficulties

Medical intervention to help Speech and Language development

- Ear infection

As ear infections are common to boys, and as such infections may cause intermittent hearing loss, an aggressive approach to preventing ear infections is important to pursue.

Grommets

Antibiotics

Hearing should be tested by an audiologist regularly, to be sure there is not a mild hearing loss.

- ADHD
- Medication may be able to help some boys to control their repetitive "self-talk", their anxiety and some of their social disorders. (See also Medication by Dr. Randi Hagerman.)

AAC

- Augmentative and alternative communication (AAC)
- From gestures and sign language, to picture cards, communication boards, and computerized interactive devices.
- Serves as a bridge to spoken language.
- AAC can accompany oral language, so that a communication partner offers the child with fragile X both the auditory input (words and sentences) and a visual cue (a picture, sign, logo, or gesture). This can strengthen the child's understanding of language.
- AAC offers the child a way to express himself. By pointing or gesturing, a non-verbal child can make his wants or needs known.

- Utilise a total communication approach
- Fade out signs as verbalisations increase
- Reinforce any attempts at speech, shape responses by modelling correct utterances



Therapy programmes

- Floortime
- Hanen
- ABA (Applied Behavioural Analysis)
- PROMPT (Oro-motor)
- MORE (Integrating the mouth with sensory and postural functions)

Attention

- Inattention
- Hyperactivity
- Impulsivity

- Rx - medical
 - OT with sensory integration and diet
 - behavioural and environment

Attention



- Utilise interest areas
- Supplement with visual input eg photos
- Minimise auditory and visual distractions
- Work in small, partitioned areas
- Use headphones to dampen sound
- Calming activities (OT)
- Work for short periods of time

Attention

Environmental accommodations - 1

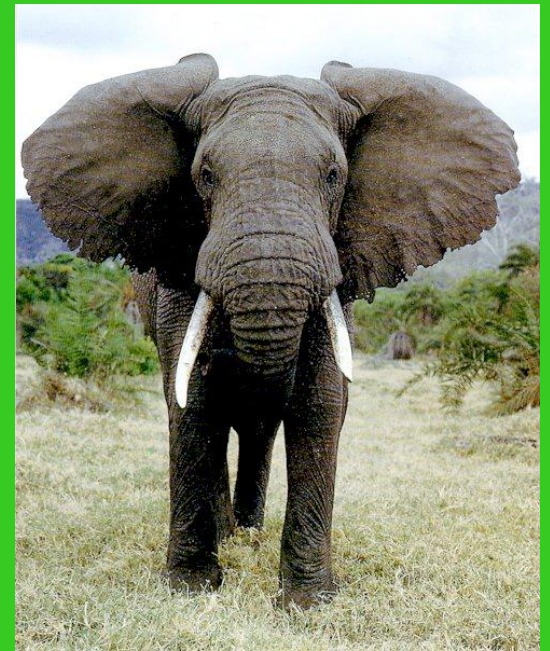
- Seat near quiet, role model / buddy
- Seat away from high traffic areas
- Use calm, quiet voice
- Use sentence completion eg 'the time is ...',
...
- Allow extra time, shorten tasks
- Allow movement, extra breaks
- Daily routines, picture schedules

Attention

Environmental accommodations - 2

- Use high interest materials
- Concrete visual aids
- Humour, drama, music, computers
- Clear concise directions, limit choices
- Private visual signal to cue on task
- Prepare transitions - verbal, song, distract
- Positive redirection eg “use your words”

Intervention



Memory

- Elicit attention prior to task
- Pair auditory information with visual cue
- Rhythm and music to cue recall
- Use short instructions intrinsic to task

Intervention

Abstract reasoning, problem solving skills

- Utilise realistic, meaningful materials of interest
- Begin at level of concrete and systematically increase level of abstraction
- Use computers / game format
- Interactive multimedia with skill levels

Intervention

Verbal perseveration

- Allow increased processing time, tangential comments
- Model desired utterances, topic maintenance
- Reduce complexity of utterances
- Monitor anxiety and adapt (calming, focus)
- Provide opportunities to practice speech acts
- Redirect verbally
- Ask to re-auditorise
- Emphasise topic with high interest materials

Movement

- May help to elicit speech
- E.G. rollercoaster, see-saw
- Integrated therapy with an occupational therapist is ideal.



Closure

Fill in the missing bits, as individuals with Fragile X manage better this way.

e.g. Mary went to the _____.

Macbeth was the king of _____. The witches predicted that _____'s sons would be the future kings. They also predicted that Macbeth would be safe until _____ came to his castle.

Benefits of using drama -1

- Combines auditory and visual input
- Provides an opportunity to teach and rehearse desirable responses/behaviours
- A variety of environments and communicative partners can be simulated
- Therapist can purposefully use undesirable responses to help individual recognise them



Benefits of using drama- 2

- Rehearsing behaviour in an unfamiliar or strange situation may help to decrease anxiety
- Working in a group environment allows individuals to learn from one another in a non-threatening environment



John's Therapy Programme

- Giving his opinion and asking others for theirs.
- Greeting appropriately and eliminating learned responses e.g. Welcome back.
- Token system for clear, slow speech.

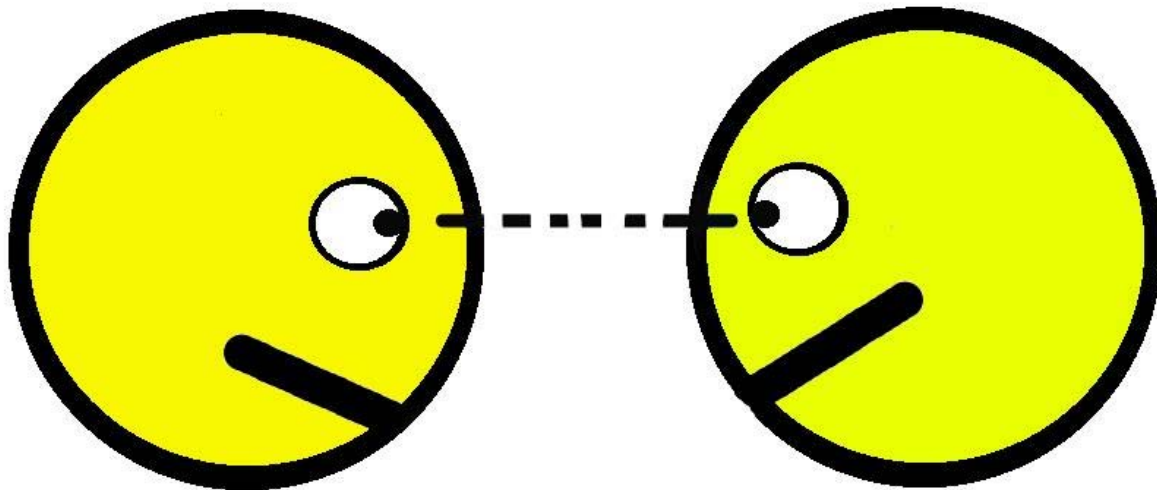
“John”

- Moderate intellectual disability
- 15 years old
- Was in a Special school, now in a mainstream secondary school on a modified curriculum
- Integration aide attends all sessions

John's therapy Programme

DON'T demand eye-contact:

Eye-Contact



- Insisting on social niceties such as ‘please’ and ‘thank you’ when receiving an item he has asked for.
- Pairing an oral task with visuals to provide John with additional information e.g. a picture to start a discussion..
- Being assertive i.e. correcting his conversational partner when an incorrect fact or detail was perceived

Sentence strips...

- Asking questions using sentence beginnings such as “Can it...?”, “Is it...?” and with regards to his paper routine, “Do you need...?” and “Can I have...?”. A sentence strip with the necessary phrase was suggested and this has helped.

Asking questions...

- Social questions – a sheet with visuals for each question was prepared. John needs to interview three peers each week.
- Asking questions. Sections of the programme “See what you’re asking” were used. Prompts should range from giving him the question word initially, to just gesturing or giving him the initial sound of the question word.

An outline of a hand was demonstrated with a questions word (e.g. who, where etc) and the topic written in the palm of the hand as a cue for asking questions about others' experiences, comments.



- Providing novel comments instead of echoing the conversational partners comment.
- Encouraging John to use his words rather than sounds and gestures
- Being able to say “I don’t know” when unsure of an answer, rather than giving an answer for the sake of it.
- Sequence stories. The emphasis has been on getting John to relay a series of events in order, rather than only one or two of the steps. Visuals of familiar procedures (e.g. pouring orange juice) as well as short stories were provided.

Safety Programme

- Safety Programme –Each card includes a picture for discussion as well as role play ideas.. Skills practised: Providing identifying information (Code game was suggested to help him learn dad's mobile number in chunks). Telling someone where you are going and when you will be back (if appropriate).
- We have role played the following scenarios with the appropriate language :
- Not opening the door for a stranger
- Not accepting a ride from a stranger
- Not accepting lollies or food from strangers

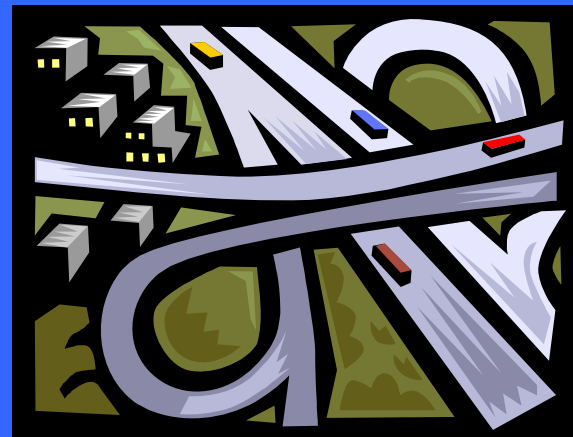
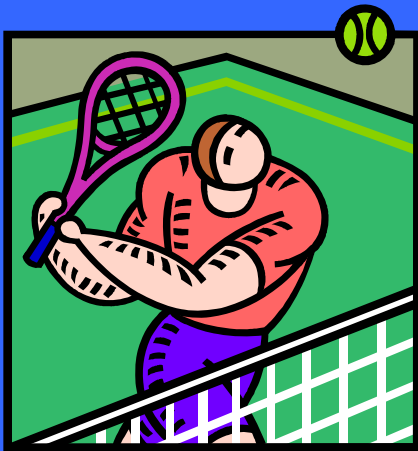
Ask and Tell

- Just asking = Interviewing
- Just telling = Giving a speech
- We need a balance of the two.

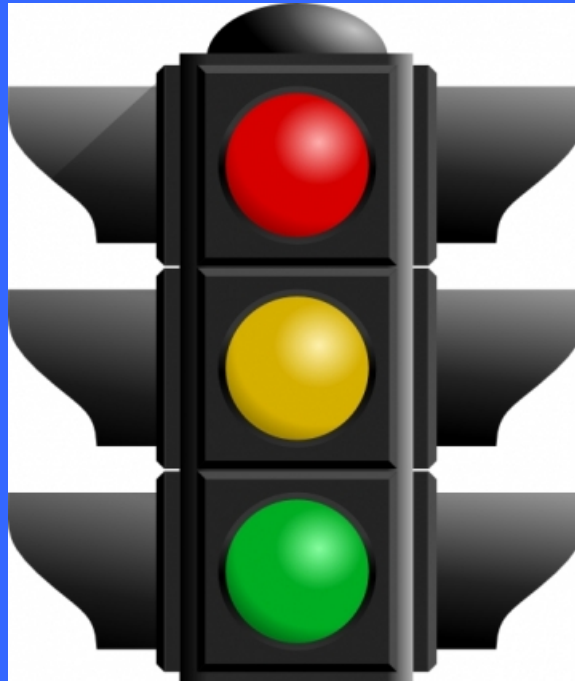
- Ideas: Coloured links
 - Ask and tell cards (question mark and speech bubble)

Staying on topic...

- Tennis match analogy
- Car on the road analogy



- Traffic light picture on diary to encourage John to only speak while standing still. Stop moving (red), think what you want to say (orange), say it (green).



Providing sufficient information

- Barrier Games e.g. hammer and nail, brushing teeth
- Analogy of a tree with branches
- Parachute



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Compliments

- Giving compliments e.g. I like your... or Well done for ... John will be prompted to give one compliment a day.
- How to receive compliments appropriately

- Emotions: Reading emotions in picture scenes. Expressing how he is feeling and including a reason e.g. I'm happy because...



Emotions

- Students may need help recognising their own, recognising others', as well as 'seeing' the effects of their behaviour on others
- Names of the different emotions and reasons as to why people may feel that way
- Use different shades of a colour e.g. irritability (light blue) vs. rage (navy blue)
- Emotions Barometer (Tony Attwood) e.g. volcano
- One setting may set off different emotions (e.g. hospital, airport)
- One situation may set off different emotions (e.g. test being postponed)

Rude vs. Polite, Public vs. Private

- Discriminating between 'rude' and 'polite' responses. We have mainly worked on deciphering a rude versus polite tone of voice, but will now move onto the choice of language i.e. the words that determine if the message is rude or polite. He is using 'thank you' consistently during sessions.

Abstract language

- Opinions and ‘guessing’ at the unknown e.g. “What do you think he’s drinking in this picture?” or “What do you think she’s reading about?” The idea is for John to risk take by giving a probable answer, but to understand that there is no absolute correct answer. We have also demonstrated that there could be several possible answers, and that each person may have a different answer, all of which may be correct.

Associations

- Using associations to assist with words that John has difficulty saying e.g. as John was struggling to pronounce the number 40, I suggested that this be broken up into a 'four' and a drawing of a cup of 'tea'.



With regards to left and right, we worked on making the letter “L” with his thumb and pointer finger of his ‘left’ hand. By the end of the session, he consistently knew which was his left hand.



Social Stories

- Social story for telling aides when he needs to go to the toilet.
- Drawing pictures as part of a “Comic Strip story’ about appropriate vs. inappropriate behaviours at a function e.g. its OK to join in the group dancing, but not when a couple are dancing together.

Social Stories – Carol Gray ‘(1994) The New Social Stories Book.

Social Stories are short stories that describe a situation in terms of relevant social cues and common responses, It provides a child with accurate and specific information regarding what occurs in a situation and why. They are written in present tense, in appropriate language and have pictures if necessary. Avoid absolutes – rather use words such as ‘sometimes’ and ‘usually’. Try and mainly use descriptive sentences and perspective sentences. Descriptive sentences tell who is involved in the situation, what people are doing, where the situation takes place and why. Perspective sentences describe the reactions and feelings of the people involved. Directive sentences tell what you want the child to do and may start with something like “I will try to...”.

Examples of social stories

1. Washing Hands

I should wash my hands when they have germs on them.

I wash my hands before I eat.

My parents are happy when I wash my hands.

2. Touching Other Girls' Things

Sometimes girls touch other girls' things

I feel sad when someone touches my things without me letting them

If I want to touch something that belongs to another girl, I need to ask first.

I should say "Please can I touch that?"

Sometimes girls may say "yes", and then I can touch their thing.

If a girl says no, I can always look with my eyes instead of touching.

I could also walk away and look at something else.

An adult could also help me if I'm having a problem.

It's OK to touch other people's things if they let us.



Guess Who?

Ideas:

- Auditory memory “Find me a man with brown hair and a brown moustache”
- Expressive language: “Pick a card and describe the person to me in enough detail so that I can identify them”
- Understanding negatives e.g. “Show me someone who hasn’t got/doesn’t have/has no glasses”
- Using complex sentences “The man (with the green hat) has a moustache.
- Asking questions: “Does your person have blonde hair?”

Social Competence

- Is knowing what to say and do and what not to
- When to say or do it and when not to
- Knowing in what manner to speak or act



Social skills – not an exact science

- No absolutes e.g. drawing attention to the student's difficulties vs. helping them to 'blend'
- One set of rules may not apply in a different setting
- What works for one student may not work for another
- So many subtleties

Kinder suggestions

- Chapter Headings from Learning Language and Loving It:
- Let the child lead – facilitating interaction with even the most withdrawn and hard-to-reach children
- Helping Children become conversational partners (turn-taking)
- Encouraging interaction in group situations – adapting activities and routines to promote interaction and conversation
- Get yourself out of the act - fostering peer interaction. Physical environments that promote interaction and how to help isolated children become more involved with their peers.
- SSCAN
- Small groups are best
- Set up an appropriate activity
- Carefully observe each child's level of participation and interaction
- Adapt your response to each child's need
- Now keep it going!
- Step in, set up and then fade out of the activity. May need to be very directive initially (e.g. "You could say..."). You may be actively involved in game/role-play initially, then making suggestions from the outside, then just observing and getting involved when necessary.

Ideas for explicit teaching:

- Comic strip stories (colours and patterns)
- Visual schedules (digital camera)
- Do/Don't lists (e.g. Friendly Kids, Friendly Classrooms)
- Role plays (with puppets first if necessary)
- Recipes e.g. 7 step to social problem solving

Ideas for explicit teaching

- How Does your Engine Run Programme
- Classroom/TV detective
- Secret sign
- Use labels
- Teach emotions

Labels

- Friendly/Unfriendly
- Helpful/hurtful
- Cool/weak/aggro
- Right way/ wrong way
- Appropriate/inappropriate
- Private/public



Social skills involved in a simple game of “Memory”

Asking others to come and play, turn taking, gaining attention, eye-contact, using a name, directing the activity, giving and receiving compliments, social niceties, entering and exiting a game appropriately, deciding who can play, appropriate versus inappropriate behavior, peer feedback e.g. “I don’t like it when you are not fair”

Self-esteem

- Chart: What am I really good at vs. not so good at
- Area of strength must be valued by peers
- Promote area of strength e.g. leader of a sport group, tutoring others with maths.
- If you can't find an area of strength – create one!
E.g. a position that others are reliant on or that requires specialized training.
- King's Throne
- Preteach an area that will be covered in class

Creating Empathy

- Exposing the students difficulties may actually assist them to be socially accepted as well as include peers to achieve goals.
- Students are experts on their own difficulties
- Simulate the difficulty e.g. physical/sensory/emotional

Conversation Emergency Kit

- If someone has told a story about something funny, frightening or embarrassing that has happened to them, you could use one of these stories below to continue the conversation. Remember, it may be a story that involved you, or it may be a story that happened to someone else. It may even be a story that someone else has told you. Make sure that your story 'links' onto the story that has been told. You could start off with one of the following 'links':
 - Listen to THIS funny/embarrassing/scary story
 - I've also had a really funny/embarrassing/scary experience
 - Write one or more examples under each heading
 - A funny story that I was involved in or heard about
 - A frightening experience that I was involved in or heard about
 - An embarrassing story that I was involved in or heard about.

Conversation skills

- Ask/tell i.e. a conversation is not a speech nor an interview
- Staying on topic - Use car analogy
- Reverse back onto the previous road
- Comments/questions must be 'linked'
- Not too little, not too much

Conflict resolution

Cool, weak ,aggro

Dobbing

Avoid telling a lie or using humour

Don't add fuel to the fire

Safe areas vs. black spots

Safety in numbers

Comic strip conversations and social stories

The End