

DOWN SYNDROME

Information Advice and Strategies for
Special Schools in Dorset

Welcome and Introductions

- ▣ Wendy O'Carroll
- ▣ Founder and Chief Executive of regional charity Ups and Downs Southwest – providing support, information, advice and training to parents & professionals involved with DS for 19 yrs
- ▣ Independent Parental Supporter with LA's Parent Partnership Service for ten years
- ▣ Trainer for SCOPE's FACE2FACE service
- ▣ Child Protection Governor at a school for children with moderate learning difficulties until 2012
- ▣ Local co-ordinator for National Charity 'Downs Heart Group' until 2011
- ▣ Last but definitely not least – parent of two children - Anna 27yrs old and Oliver who is 19 yrs old and has Down Syndrome



Ups and Downs Southwest



- Parent led and staffed Organisation
- Family Support Service – empathic, holistic, tailor made – a listening ear
- Home and Hospital visits
- Information and advice – by telephone, email, as well as face to face
- Help with benefit applications – DLA, ICA, PIPs Family Fund etc
- Help support information and guidance with EHCPs
- Library/resource base /keeping up to date with latest information and research
- Support for families at meetings with LA, Schools, Agencies Statutory Bodies, Tribunals etc
- Training Programmes, advice information and support for Professionals
- Specific Training and Awareness Raising for Medical Staff – Midwives Health Visitors, Doctors, Paediatricians etc

Ups and Downs Southwest

- Preschool meetings
- Family Day events
- Youth Clubs
- Activity days
- Conferences, Training Days for professionals and parents
- Website and Facebook Page
- Unique library of images And Positive Awareness Posters of children and young people who have DS



My job is extremely arduous..







Two Things to Remember!

- ▣ Confidentiality and Respect
- ▣ There is no such thing as a stupid question!

What is Down Syndrome?

- ▣ Third copy of Chromosome 21
- ▣ Additional genetic material disrupts development
- ▣ Three types: Trisomy 21, Mosaic DS, Translocation DS

Just Like You

Just Like You: Full length 13mins

<http://www.imdb.com/video/wab/vi14984985>

Shorter: 3mins

[https://www.youtube.com/watch?v=Q4p9GyW
XWcw](https://www.youtube.com/watch?v=Q4p9GyWXWcw)

Students with Down Syndrome in the classroom – points to consider

- ▣ Visual Learners
- ▣ Auditory memory affected by shorter phonological loop.
- ▣ Sight Reading
- ▣ Spiky developmental profile – most frequently noticeable in the vast difference between their level of understanding, and their speech and language production level.
- ▣ Imitate/copy those around them
- ▣ Sensory Issues and behaviours
- ▣ Overload - Have trouble processing EVERYTHING – more difficulty syphoning out/ignoring extra input.

Factors that Facilitate Learning

- ▣ • Strong visual learning skills
- ▣ • Ability and desire to learn from peers
- ▣ • Ability to learn read and use the written word
- ▣ • Learning best from pictorial, concrete and practical materials – especially in Numeracy
- ▣ • Keen communicators despite language problems
- ▣ • Structure and routine
- ▣ • Ability to use sign and gesture

Factors that Inhibit Learning

- ▣ • Delayed motor skills – Fine and Gross
- ▣ • Speech and language delay and production difficulties
- ▣ • Short Term Auditory Memory – listening, processing, storing/remembering & sequencing
- ▣ • Shorter concentration span – need motivation
- ▣ • Consolidation & retention problems
- ▣ • Generalisation, thinking & reasoning
- ▣ • Avoidance strategies
- ▣ • Auditory and visual impairment

Assess the Level

- In order to differentiate, you need to know the level of the pupil.

BSquared

English, Writing - Level 1B

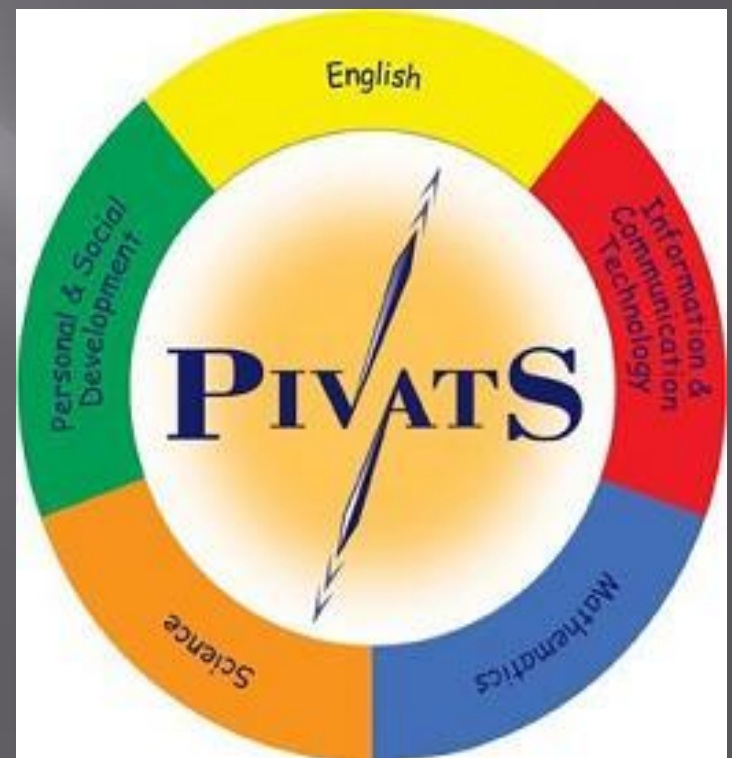
Name: Jack Sing

Home Language:

Started: 12 Mar 2005 Completed: 14 points - 34%

Creating and Shaping Texts		Text Structure and Organisation
04.06 Talk to an adult about what they wish to write ☐ Adds information when asked questions about what they want to write ☐ Answers questions about the content of their writing ☐ Makes amendments on reading own writing In group story writing suggest: ☐ - place ☐ - character	05.06 Caption related to picture content 01.06 Gives some detail in story ie colour 03.06 Share story with others 06.06 Listens to other peoples stories 11.06 Want to take writing to and from school ☐ Rereads writing using same words ☐ Use phrases to convey ideas ☐ Use phrases to convey information ☐ Identify differences between their own work and teachers transcription	<u>Writes using simple structures:</u> ☐ story ☐ lists ☐ caption ☐ messages ☐ speech bubbles ☐ reminders
Sentence Structure and Punctuation	Presentation	Word Structure and Spelling
03.06 Full stops appear randomly in writing ☐ Begins first name and surname with a capital letter	10.06 Begins letters in the correct place 10.06 Moves round letters in correct direction ☐ Finishes letters correctly ☐ Writes most lower case letters correctly ☐ Writes most upper case letters correctly 07.07 Begins on the left hand side of the page ☐ Begins the next line below the previous line ☐ Takes a pride in the appearance of their work ☐ Uses a comfortable pencil grip ☐ Writes simple text using IT	09.06 Matches upper and lower case letters 11.06 Writes initial sounds of words 07.07 Writes final sounds of words 12.06 Identifies vowel in CVC word ☐ Writes phonic based CVC words ☐ Writes some words from high frequency word list ☐ Uses classroom word lists to aid spelling ☐ Suggest a word to put in a verse using rhyming awareness ☐ Writes some CVC rhyming words ie hit, sit, fit.....

Writing Level 1B - Pupils structure some phrases and simple statements using recognisable words to communicate ideas. At least half the letters of the alphabet are correctly formed and orientated.



Teach reading
to
teach talking

Using reading to build an expressive vocabulary

- ▣ Good readers are generally good talkers: teaching reading early (2-4yrs) results in greater language gains.
- ▣ Reading:
 - Is visual: the written word stays on the page!
 - Helps the child with DS retain the *sound* of a word for longer
 - Builds the size of a child's spoken vocabulary
 - Models sentence structures and grammatical structures
 - Helps flex the working memory
- ▣ Many children with Down syndrome have a reading age which out-strips expectations.
- ▣ The target reading age for our children is around 8 years: this is a functional reading age for which most UK tabloids are written.
- ▣ With a reading age of around 8, children with DS will begin to be able to decode unfamiliar words phonetically

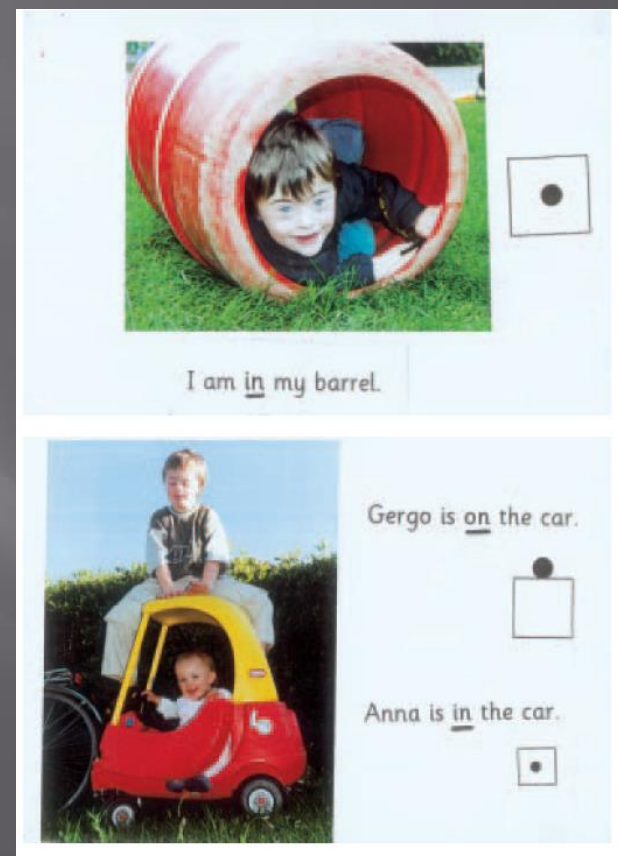




See-and-Learn



- ❑ **Matching Pictures:** start when child can understand 50 single words. Match picture to picture, building a sight recognition of 16 images in sets of 4 – nouns and verbs (baby, ball, eating, sleeping etc). Test comprehension by moving to *selecting* and finally, *naming*
- ❑ **Matching Words:** Once this can be done with accuracy, begin matching written word to written word, building an initial sight vocabulary of 16 written words in sets of 4, all of which were previously matched in picture form. Again, test comprehension by *selecting* and *naming*.
- ❑ **Build Vocabulary:** *At the same time* introduce new pictures to build new vocabulary.
- ❑ **Test:** – with matching, selecting and naming – these 16 words in two-word strings.
- ❑ **Create sentences:** Move on to teach the new vocabulary within the context of simple books.





Errorless learning

How to make writing work for children with Down syndrome...



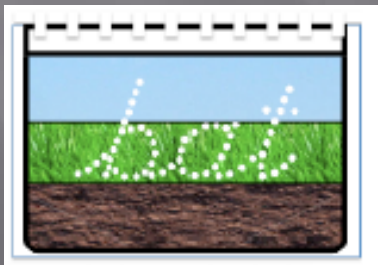
- ❑ Don't control the act of writing: hand-on-hand
- ❑ Don't always allow the supporting adult to control the act of composition by always transcribing: it creates an over-reliance on scribing
- ❑ Don't remove the peer motivator: withdrawal from class during whole class writing activities is not a positive
- ❑ Inspire; show how writing is message-making: set targets which focus exclusively on functional skills (handwriting, punctuation, capitalisation, etc)
- ❑ Let them rehearse a sentence orally (talk partners)
- ❑ Set writing tasks which motivate, entertain or sit within the child's interest and knowledge-base
- ❑ Give them an audience!

Handwriting

- ▣ Many children with DS press too softly on the paper. When you add perceptual issues to this, using a pencil becomes unhelpful. Use a black marker.
- ▣ A blank sheet of paper is less helpful to a pupil with DS – rule wide lines on the page with black marker.
- ▣ Offer squared paper to developing writers – helps consistency of letter size and spacing.
- ▣ Additional visual clues can help, such as red and green markers to indicate where to start and stop writing.
- ▣ A writing slope is helpful to many pupils with DS.

Letter Formation

- ▣ Teach upper and lower case simultaneously
- ▣ Have the child draw a letter in the air, on someone's back, on the playground in chalk, walk a letter chalked on the playground
- ▣ Tracing over letters can progress to drawing between the parallel lines of a letter
- ▣ Roll 'n' Write
- ▣ Write from the start
- ▣ Handwriting without tears
- ▣ Garden or Sky Writing from www.speechteach.co.uk

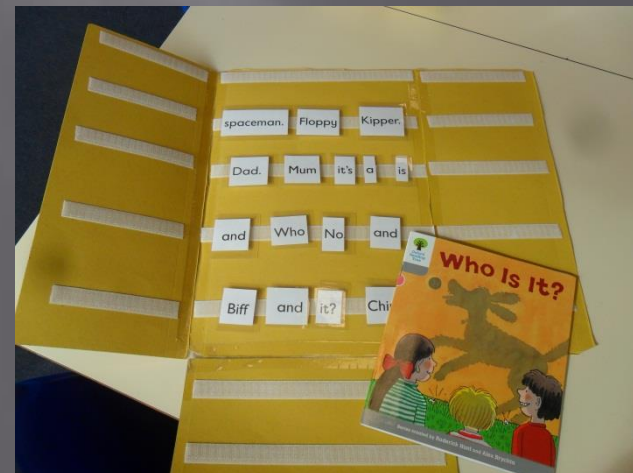
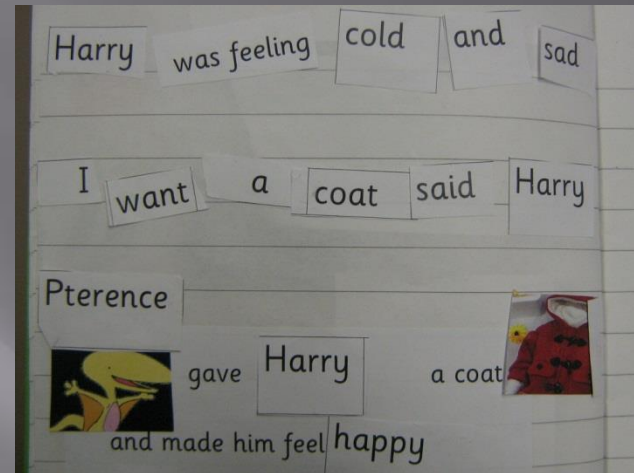


Things to bear in mind...

- ▣ Copying from the board will be very hard for lots of children with DS. Either highlight a short passage for them to copy or provide them with an individual copy on their desk.
- ▣ Alternatively, provide them with an individual copy on their desk which has been chopped up. Ask them to re-order the words and match to the original to self-check.
- ▣ Adapt language to match the child's level of receptive language
- ▣ Take account of poor focussing – many interactive whiteboards have poor contrast/high glare

Alternatives to Writing

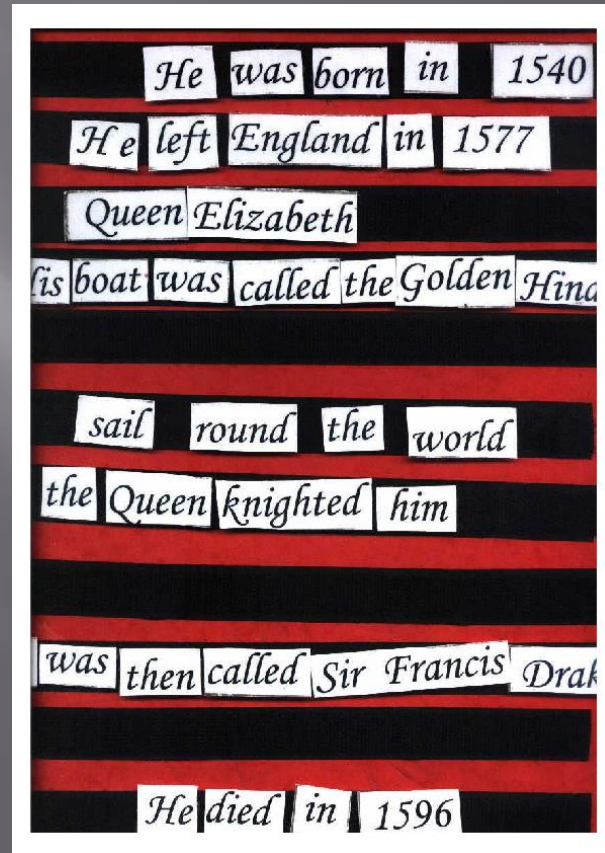
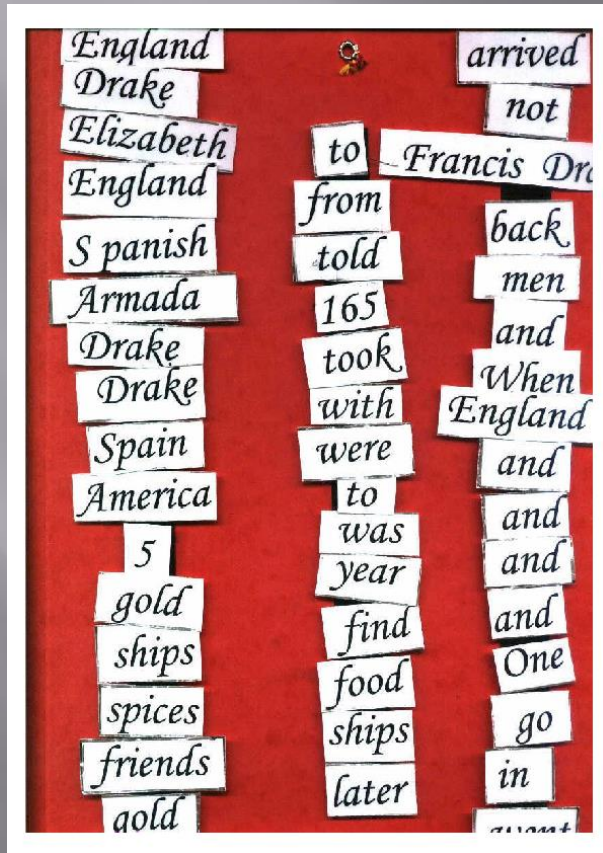
- ❑ Cloze procedure
- ❑ Multiple choice
- ❑ Matching
- ❑ Sentence builders
- ❑ Clicker
- ❑ Apps
- ❑ Writing frames
- ❑ Word maps
- ❑ Story boards



Writing Difficulties

- ▣ Break tasks down:
 - writing for legibility (hand-writing/letter formation)
 - composing a message
 - Constructing/re-ordering a coherent sentence
 - writing to demonstrate your understanding and recall
- ▣ We encourage schools to look for other ways for our children to record their knowledge, other than by writing it down.
- ▣ Keep writing as a separate objective to recording knowledge!
- ▣ Use the wider curriculum as an opportunity to work on these key aspects of writing:
 - Building banks of key, subject specific vocabulary
 - Constructing sentences to demonstrate comprehension of key vocab
 - handwriting

Writing Folders



Independent Classroom Skills

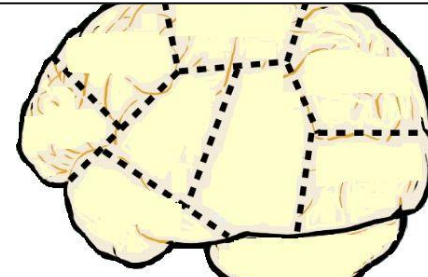
- ▣ Ensure an inclusive classroom approach – the activities the pupil with DS is set need to look largely the same as those set for everyone else
- ▣ This needn't be accurate, or even legible, if it enables the pupil to feel they are participating in a whole class activity on the same terms
- ▣ Their focussed literacy time can come elsewhere in their day
- ▣ Amelia & Earthquakes: “building shakes”; “plates snap”; “earthquakes are vibrations”; “seismic waves”

Phonological Loop

Hear the sounds in the word



Articulatory rehearsal



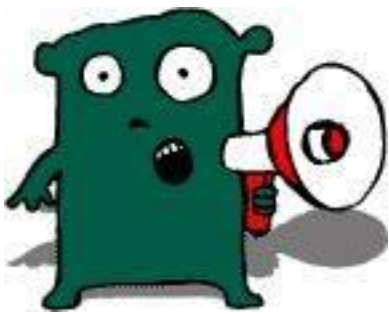
Repeat the word internally

Long term memory

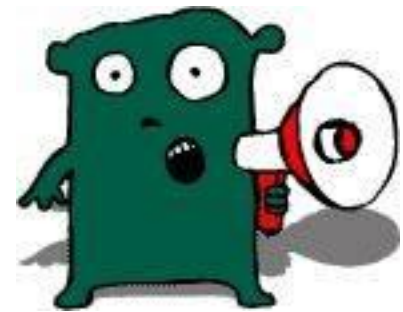
Remember the word



Speak the word



Typically Developing Child



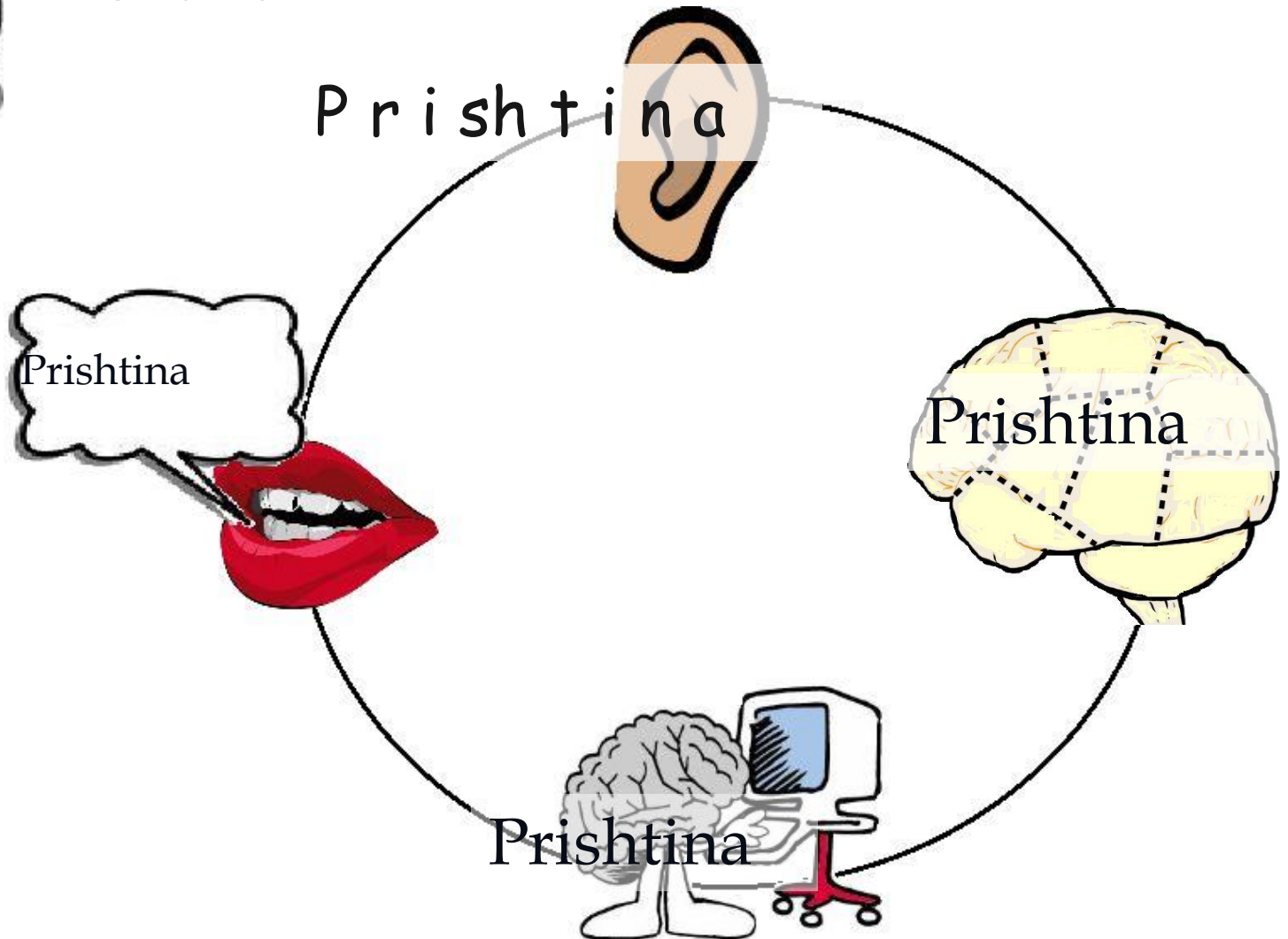
Prishtina

Prishtina

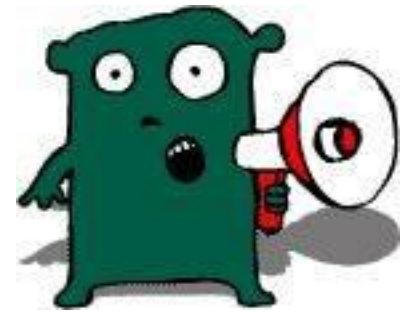
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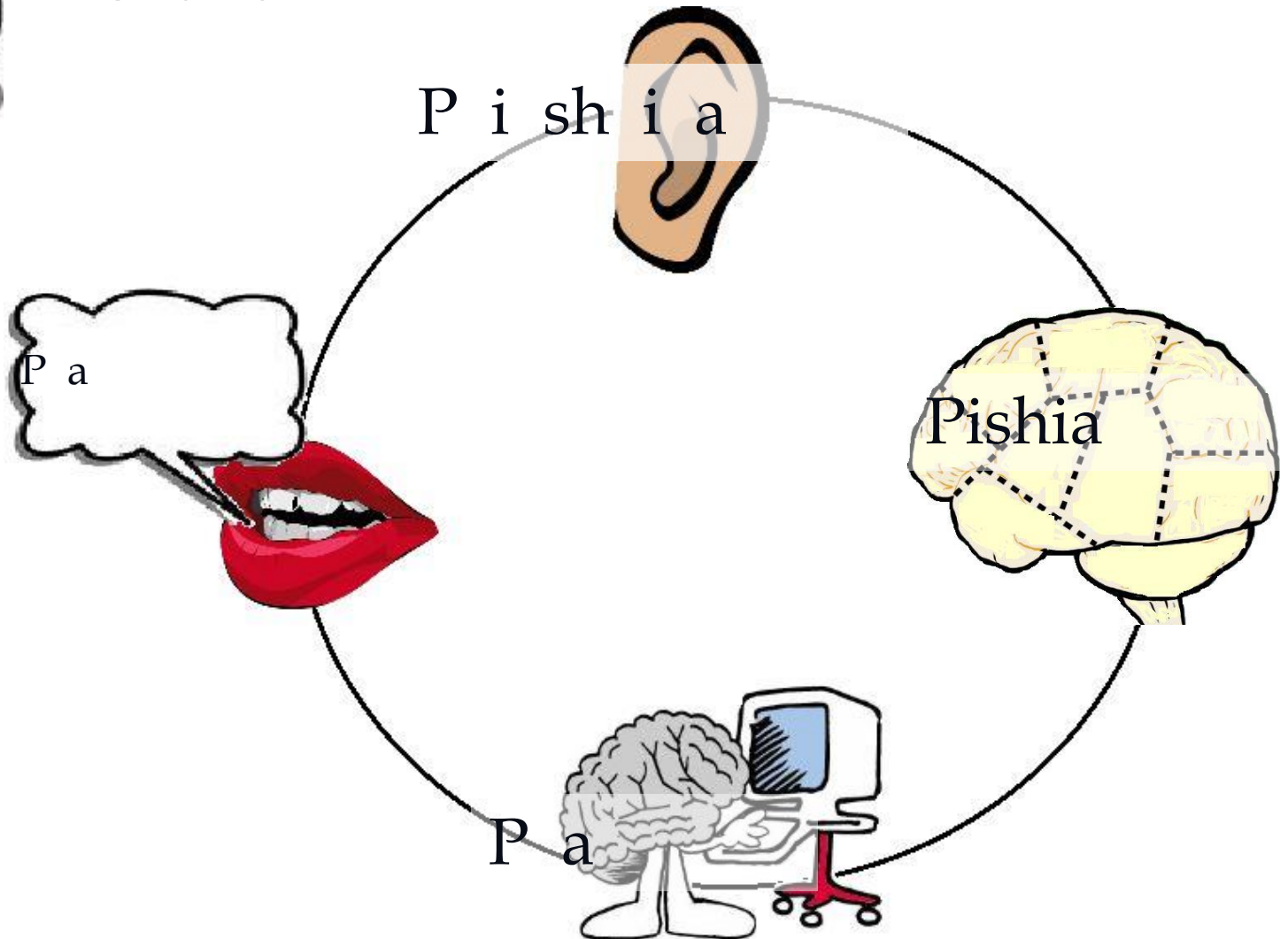
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Child with STAM



Prishtina



Language Difficulties

- ▣ *Children with DS need a spoken single word vocabulary of around 400 words for mastery of sentence structure and grammar in spoken language.*



Building on the bank of key vocabulary our children can understand is the best way to enable them to more fully access the curriculum.

*Focus on vocabulary building &
sentence construction when
differentiating the wider curriculum*



Be specific!

- ▣ Topic-specific vocab as a way in to everything!
- ▣ Start with *See & Learn* methods & build towards using the vocabulary in sentences to demonstrate comprehension
- ▣ Matching, selecting, scrambling & re-ordering sentences; cloze procedure; Clicker
- ▣ Reinforce visually with pictures, diagrams, symbols and readable text.
- ▣ Keep your focus on *picture producing* words
- ▣ Teach high frequency non-picture producing words within the context of simple phrases and sentences.

A witch can



boil rats



fry newts

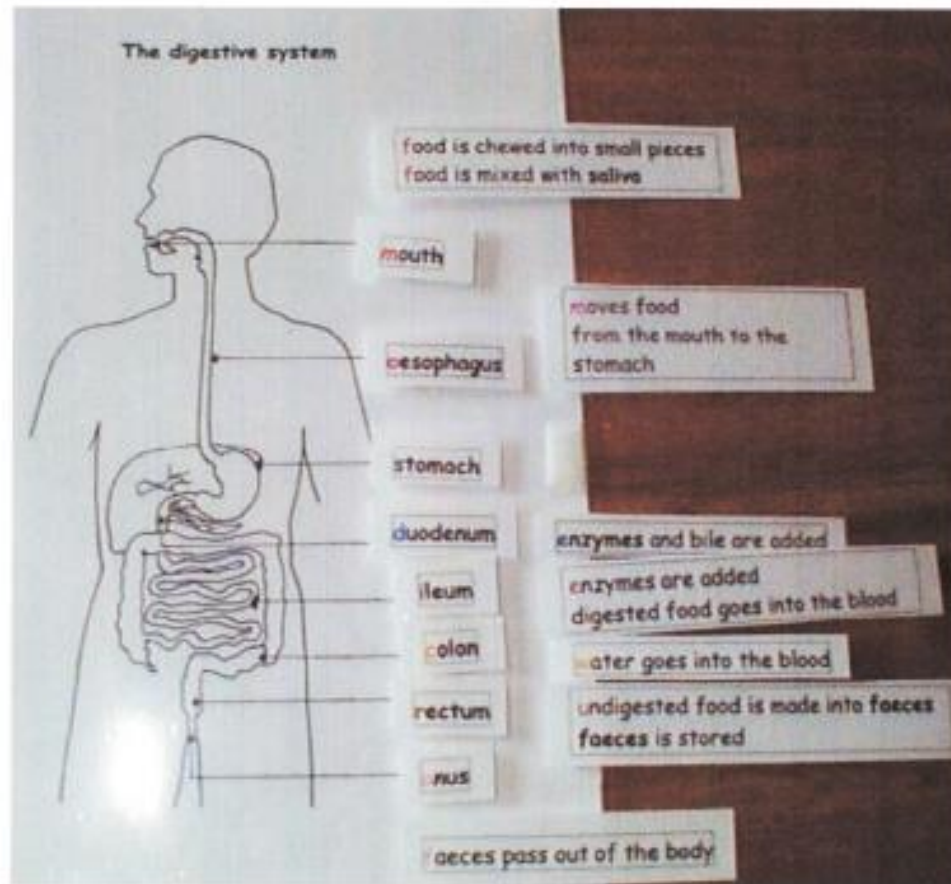
in her cauldron

fly on her broomstick

make magic spells

.





Dangerous War

By Tom Powell

Five bombs like big gun-bullets.
The explosion made a doughnut of black smoke and a puff of ash.
Crumpled grey doughnut clouds shooting over the ground.
A ball of gas eating the soldiers skin and eyes
And flames burst everywhere.
The fire buried the whole ground.
Men surrounded by death and filled with hate.
Deadly in blood.

Flames; fire;
explosion;
dangerous



Gas; eating eyes



Smoke; ash;
doughnut-shaped



Buried; death;
deadly



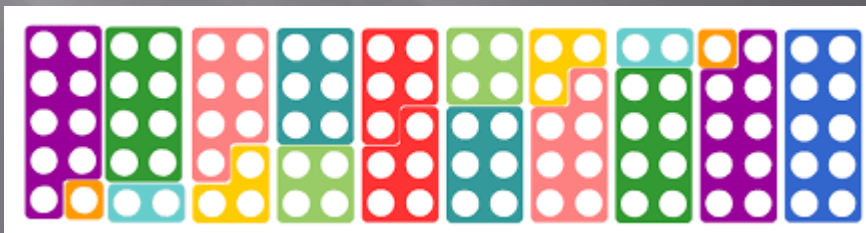
Some Common Pitfalls



- Too much writing expected.
- Too much talking.
- Overloading and multi-tasking.
- Having too low expectations.
- Worksheets that are too busy and too complicated.

Numeracy

$$四 + 五 = 九$$



Why Numicon?

- ▣ Hands-on and visual
- ▣ Motivational
- ▣ Teaches number through pattern and concept image.
- ▣ Numerals are abstract
- ▣ Numicon shapes give meaning to numerals
- ▣ Teaches calculating alongside counting
- ▣ You can see children's thinking

Cecilie Mackinnon

- ▣ Cecilie Mackinnon, Training Consultant,
Downs Ability Web: www.downsability.co.uk
Email: cecilie@downsability.co.uk

Behaviour

- ▣ Trying to Communicate?
- ▣ Or a method of accessing required Sensory Feedback

LOOKING THROUGH THE SENSORY LENS



Sensory Processing

Process of taking in information from the environment via all the sensory systems and then interpreting and organising the information so that the brain can direct the body to respond appropriately.

We ALL have sensory stuff going on!



The Buzzing Fly

- ▣ Our Central Nervous System is responsible for EVERY SINGLE human function
- ▣ You can't eat, stand, talk, see, etc etc without feedback playing an essential part in that function
- ▣ When the CNS is not functioning as it should EVERYTHING is impacted by that.
- ▣ Sensory needs override all other human objectives
- ▣ Needs HAVE to be fulfilled

Sensory needs are INNATE

- ▣ Needs HAVE to be fulfilled before anything else can be focussed on
- ▣ Sensory issues reduce ability to function
- ▣ Sensory systems need to be in a state of regulation to enable cognitive function
- ▣ Reward charts won't work if you've got a buzzing fly in your ear!
- ▣ Many of our children have a CNS which is inherently challenged – this challenged system will develop differently, become more and more disordered and will be reading the environment differently. – ALL functions are then affected by the disorder within the system!
- ▣ Amygdala overtakes the conscious mind

http://thebrain.mcgill.ca/flash/d/d_04/d_04_cr/d_04_cr_peu/d_04_cr_peu.html

Proprioception

- ▣ Proprioceptive information relates to feedback about the position and movement of the body. This information is received from receptors situated in our joints and muscles.
- ▣ It assists us in knowing where our body is in space and is important for developing adequate body and spatial awareness
- ▣ Proprioception helps our system regulate and often has a calming and orienting impact on a child who experiences Sensory Integration Dysfunction



Vestibular system

- ▣ Vestibular system refers to receptors located in our inner ears which tell us about the direction we are moving in and at what speed
- ▣ This helps us modulate our own equilibrium



Hyper and Hypo sensitivity

▣ Hypo (UNDER)



▣ HYPER (over)



The Hyposensitive Child 'The Sensory Seeker'

- ▣ Under responsive - receives information less intensely.
- ▣ May not notice being touched
- ▣ May seek lots of movement, or make loud noises
- ▣ May also not be aware of parts of their body - appearing clumsy or heavy handed.
- ▣ Require extra sensory activity to have better awareness, maintain arousal and attention.
- ▣ Behaviour often seen as biting/ mouthing, noise making, movement seeking, head butting/shaking.
- ▣ Can appear listless and passive or seek movement or makes continual noises



The Hypersensitive Child 'The Sensory Avoiding Child'

- ▣ Can be irritable, flinch from touch – avoid certain activities
- ▣ May adopt a rigid position so as not to move
- ▣ May avoid textures such as some fabrics, teddy bears - may dislike having messy hands
- ▣ Can be rigid about routine
- ▣ Can be frightened by movement



The Fluctuating Child Modulation

- ▣ Often reactive to touch or movement
- ▣ At other times does not react or register at all
- ▣ Sensitive to some things and not others
- ▣ Difficulties maintaining arousal and attention
- ▣ Seeks big movements but avoids touch



Shut Down OR Melt Down

- ▣ Some children become bombarded with sensory information
- ▣ Information comes too fast or from too many stimuli
- ▣ The child's defense can be to shut down, becoming disengaged, appearing flat and unresponsive
- ▣ Or to 'explode' and become 'out of control'

Principals of Treatment The effects of proprioception

- ▣ A calming influence on the sensory system
- ▣ Increases opportunity for organised movement
- ▣ Improved directional control of movement
- ▣ Better emotional security
- ▣ More normal muscle tone
- ▣ Improved body awareness
- ▣ Improved arousal level: providing an alert and calm state
- ▣ Improved concentration
- ▣ Help to stabilise tactile defensive behaviours

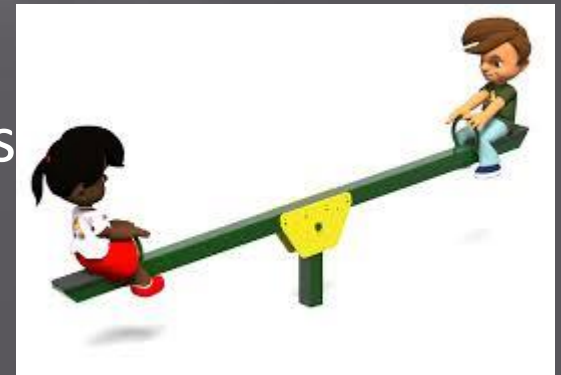
Proprioceptive Activities

- ▣ Joint compression
- ▣ Tapping
- ▣ Pulling
- ▣ Pushing
- ▣ Jumping
- ▣ Weighted blankets, pillows
- ▣ Lumbar belts (prescriptive)
- ▣ Lycra wear suits etc (prescriptive)
- ▣ Bear hug vests (prescriptive)



The effect of vestibular input

- ▣ Improved postural tone
- ▣ Can help child become calm and confident with movement activities
- ▣ Improved muscle tone
- ▣ Improved orientation and security in relation to gravity
- ▣ Coordinated movements of both sides of the body (this aids development of hand dominance)
- ▣ Ability to maintain a stable visual field
- ▣ More balanced arousal level
- ▣ Enhances interpretation of other senses
- ▣ (Can evoke nausea)



Vestibular activities

- ▣ Linear movement is calming
- ▣ Rotary movement is arousing
- ▣ Used in conjunction with proprioception
- ▣ Swinging
- ▣ Bouncing
- ▣ Dancing



Assessment



- ▣ Must be an Occupational Therapist skilled and experienced in sensory work
- ▣ In depth questionnaires
- ▣ May take several sessions
- ▣ **Nerys Hughes** Specialist Occupational Therapist
Nerys Hughes is the clinical lead for 'Whole Child Therapy' and a specialist children's occupational therapist. She has worked in a variety of settings including the NHS, national charities and independent private therapy services. Nerys uses a whole person approach to therapy and specialises in sensory integration therapy, therapeutic listening, primitive reflex integration and intensive interaction. As well as providing clinics, Nerys regularly trains other therapists and professionals nationally and internationally, and delivers talks on sensory integration and the multi-discipline approach to therapy.
Telephone : 020 3441 6810 Email : info@wholechildtherapy.com
- ▣ Whole Child Therapy, The Forum Greenwich, Trafalgar Road, Greenwich London, SE10 9EQ

The S Word

- ▣ People talk as if being “stubborn” is part and parcel of having Down syndrome;
- ▣ It isn't.
- ▣ It is the direct result of not having the language or the skills to negotiate a position.
- ▣ Our kids will keep doing something in a specific way either because of the feedback they're getting or because it is safe, it is known and it has worked in the past.
- ▣ When we introduce something new, we threaten that 'safe place'.

Stubborn? Or resistant?

- ▣ Let go of the myth of stubborn and see it as resistance:
 - to something new
 - to something that is not understood
 - to giving control over to somebody else
 - to someone they may not trust or understand
 - to something uncomfortable in the environment
 - to a situation over which they feel they have no choice
 - to something at which they feel they cannot succeed
- ▣ We need to enable our children to feel safe enough to try something new or different



Behaviour as Communication

We need to ask ourselves a number of questions,
but the main one is...

▣ *WHAT ARE THEY TRYING TO TELL US?*



What's Tricky?

- ▣ Saying accurately what they want, think and feel
- ▣ Talking about things that have happened
- ▣ Using language to learn, sort out problems and deal with emotions
- ▣ Following rules of conversation and interaction
- ▣ Having a less rich experience of language because they use less words with us
- ▣ The Phonological Loop

The Communication Environment

- ▣ Learning through listening is difficult; showing as well as telling is crucial but not always easy to do 'in the moment'
- ▣ We often step in and decide what we think they want, feel, need and this can cause frustration
- ▣ Our kids have to process the enormous amount of language we all use and its really tiring and they can use behaviour to make it STOP



The Communication Environment

- ▣ Slow the pace; the '10 second rule'.
- ▣ Provide language 'scripts' to support social interaction and the rules of social etiquette: *Can I...*
- ▣ Time with peers in school and community who are good role models for communication.
- ▣ Support visually- make the context of communication as visual for them as possible.
- ▣ Keep demands and choices separate: *Shall we go and line up now* ISN'T the same as *Line up time!*
- ▣ Ensure that people's faces match their verbal expressions: 'Am I in trouble here or not?'



Success - The Great Motivator

Opportunities for success

- ▣ While our children's language, cognitive and motor skills are still developing, their days will be filled with tricky stuff
- ▣ How can we soften the impact of this for them?
- ▣ Think about the sorts of tasks and responsibilities that make your student feel important/helpful/grown up and pepper their day with lots of opportunities for success in these little things.



- ❑ By far the biggest reward for our children is our attention!
- ❑ The key is therefore to IGNORE ALL UNWANTED BEHAVIOURS!
- ❑ Remove eye contact, turn your back, use little or no speech. If a behaviour is aggressive towards another person, give your attention to the 'victim'.
- ❑ Where a child is sitting or lying and refusing to move to where you need them to be, words probably won't work. Mirror their physicality/body language. Sit with them. Distract. Take the 'instruction' out of your voice.
- ❑ Equally important is the need to return your attention to the child the second the behaviour stops. Praise them for the first thing you can: whether its for something that is actually 'good', or simply something that isn't unwanted. "Good sitting", at a push!
- ❑ Enable your child to EARN good rewards rather than threaten their removal for unwanted behaviour.

Spare the Rod...

- ▣ In terms of behavioural management, a 'reward' is any memorable consequence of a particular behaviour:
 - Being scolded or told off
 - Having a toy removed from them
 - Making someone cry out in pain
 - Making someone have to chase you
 - Having to have a long conversation and apologise
 - Seeing someone pick up all the things you've thrown or being made to pick them up yourself
 - Losing cool rewards as punishment
 - Making someone stop what they're doing immediately and rush to your aid in concern...with a pillow...or a 999 call...

Tricky Transitions

- ▣ Like it or not, all good things come to an inevitable end sooner or later. Our kids are often highly reluctant to transition from one activity to another, especially when the new activity is far less appealing than the old.
- ▣ Pre-teach: prepare them in advance so that it doesn't come as a surprise. Some families have even employed a visual timetable at home because it is a familiar and successful strategy in school. It need only be very simple: "Now"; "Next"; "Later".
- ▣ Use photographs or props where you can. Set them up with a task which will be sufficiently appealing/ego-boosting so as to win them over.

HOW WE ARE ALL WIRED

- ▣ We are all relational, social beings.
- ▣ It's what we need to function, to be happy
- ▣ At the core of this is having relationships that are reciprocal, the necessary give n take
- ▣ Mostly it is about being needed and making a contribution
- ▣ Our brains NEED this to happen

FUNCTIONAL IDENTITY

- ▣ Jobs
- ▣ Responsibilities
- ▣ Taking care of myself but also..
- ▣ Doing this for others
- ▣ Something's not getting done if I'm not around
- ▣ Extrinsic praise is necessary but an intrinsic hit of self worth is VITAL

Part of the pack

- ▣ Its not that our kids can't understand what to do, they just don't get the practice
- ▣ Patterns of behaviour
- ▣ 'Me being the needy one is how I show up'
- ▣ A part of something bigger than themselves
- ▣ We are going to help you, but you have to play your part
- ▣ Its so dispiriting to always be the needy one...

David Pitonyak



<https://www.youtube.com/watch?v=UYDFz9i56ak>

...e...



ion

How's yours?

The Child who would never be able to talk

<https://vimeo.com/123363244>

