TREATING FEARS AND PHOBIAS *BEHANDLINGS FÖR RÄDSLA OCH FOBIER* IN YOUNG CHILDREN WITH WILLIAMS SYNDROME

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ENGLISH AND SWEDISH

- Jag har lägga in en del svensk översättning inom min Powerpoint. Jag använde en kombination av
- Google översätt +
- Vad jag minns av Dansk (från 50 + år sedan) +
- Optimism!
- Jag hoppas det är användbart och inte irriterande

TREATMENT FOR PHOBIAS *BEHAVIORAL PLAY THERAPY* (BPT) OR "*REPLAYS*" *KOGNITIVE -BETEENDE -LEK TERAPI* (LEVINE, CHEDD AND KLEIN-TASMAN)

A child oriented individualized play based variation of components of CBT

En barnorienterad individualiserad spelbaserad variation av komponenter i CBT

MATERIAL FROM MY BOOKS/CHAPTERS INCLUDED

RELATED RESEARCH

- Bonnie Klein-Tasman, Ph.D. UW-Milwaukee,
- WSA funded ongoing research grant on my approach to treating anxiety. We are collaborating in this work.

OVERVIEW

- Anxiety in children with WS
- Treatment
- Questions and Discussion
- ***Snälla fråga frågor helst***

FREKVENT FEARS AND PHOBIAS IN CHILDREN WITH WILLIAMS SYNDROME

- Fears are common that are related to
  - ***att vara rädd för…***
- Sound related ***ljud / to be startled***
- Medical procedures ***medicinska förfaranden***
- Some kinds of movements ***vissa rörelser***
- Some Tactile stimuli (e.g. hats; mittens; hairbrushing)
- Sometimes others' intense emotion (e.g. anger or in a movie; sad music) ***starka känslor hos andra***

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MY EXPANDED PHOBIA DEFINITION
MIN UTVIDGADE DEFINITION AV FOBI

- Any consistent intense maladaptive response far beyond what the issue would seem to warrant
- ***Något konsekvent intensivt maladaptivt svar är mycket intensivare än vad som förväntas***
  - Often we don't know is it fear and/or is it 'strong dislike' and/or sensory ***Vi vet inte säkert om problemet är ogillar eller sensorisk eller ångest***
    - (e.g. putting shoes or mittens on; escalator)
    - Maybe it doesn't matter, anxiety or sensory or dislike, as long as the same treatment approach works
    - ***Det spelar kanske ingen roll så länge som samma teknik för att hjälper till är framgångsrik***

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SCARED OF ANGRY PARTS IN MOVIES
RÄDSLA FÖR ILSKA I FILMER
KUNDE INTE TITTA PÅ VIDEOS MED FAMILJEN

- First we watched part of a scene he was afraid of with no sound, a few still frames at a time.
- ***Först såg vi en scen han var rädd för utan ljud, stillbilder***
- Then I let the video run and he was upset
- ***Då visade jag videon bara en liten bit men han var upprörd***
- So I right away turned it away from him
- ***Så jag omedelbart vände bort den från honom***

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ANXIETY IS THE MOST COMMON PRESENTING PROBLEM FOR ALL CHILDREN IN PSYCHOTHERAPY

- 12-20% of children seen in MH settings present with extreme anxiety

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ANXIETY IS COMMON IN CHILDREN WITH MANY DIFFERENT DEVELOPMENTAL DIFFERENCES

- Complicated to measure
- About 60%-90% of children with Williams syndrome have specific phobias (e.g., Woodruff-Borden et al., 2010)
- 44% of children on the autism spectrum w/ specific phobias, most had multiple phobias (e.g., Leyfer et al., 2006)
- 56-79% of children with Fragile-X syndrome have anxiety dx (e.g. Garber et al 2008)

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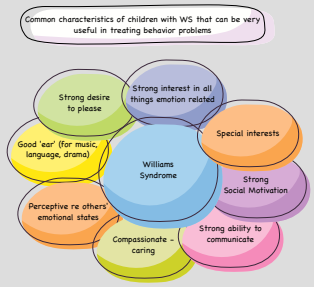

USEFUL ADAPTIVE FEAR & ANXIETY VS. INTERFERING MALADAPTIVE PHOBIA

- Some fear is very adaptive to help us avoid danger
- 'Fearless' people are at risk
  - E.g. Challenges of *lack* of social anxiety

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FEAR BECOMES MALADAPTIVE WHEN… RÄDSLA ÄR PROBLEMATISK NÄR…

- It is way out of proportion with the trigger event
- It causes intense distress in the person, interfering with their functioning
  - (e.g. upset every day before school *in case there might be a fire drill;* etc)
- It causes the child and family to avoid situations that would otherwise be fun and productive
  - (e.g. birthday parties; doctor visits; shows or concerts)

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COMMON MANIFESTATIONS OF ANXIETY IN KIDS WITH WS

- Intense distress, crying, screaming, falling to the ground or clinging to the adult, in response to the trigger
- Repeated asking of same or similar question related to topic of anxiety ***frågar samma fråga om och om igen***
- Repeated need for reassurances
- Worry, distress or avoidance around doing something that would seem 'OK-enough' otherwise
  - "anticipatory anxiety
  - Fight, flight or freeze, before, during the event

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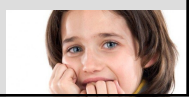
PHYSICAL MANIFESTATIONS

- Heart racing, sweating, crying,
- rocking, skin picking, nail biting
- Face reddening
- Fight, Flight, Freeze



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ANXIETY MYTHS

Felaktiga falsk övertygelser

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MYTH: ON-AGAIN OFF-AGAIN PHOBIC RESPONSES ARE BEHAVIORAL OR VOLITIONAL

- When the child is *sometimes* but *not always* afraid of something, people may think child is 'behaving badly' when they are afraid
- ***När barnet är ibland OK men ibland rädd för samma sak, folk kanske tror att barnet bara uppför sig dåligt***

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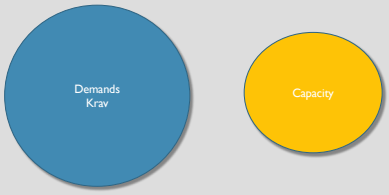
WHEN THE DEMANDS EXCEED THE CHILD'S CAPACITY -> ANXIETY



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OM BARNET REDAN ÄR OROLIGT, SAMMA HÄNDELSE KAN ORSAKA MYCKET RÄDSLA, JÄMFÖRT MED OM BARNET ÄR I ETT LUGNT, LYCKLIGT TILLSTÅND

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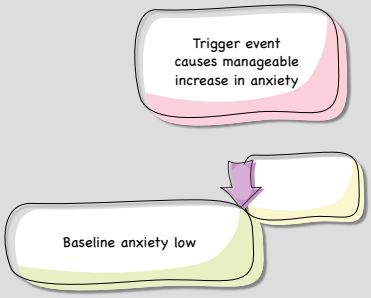

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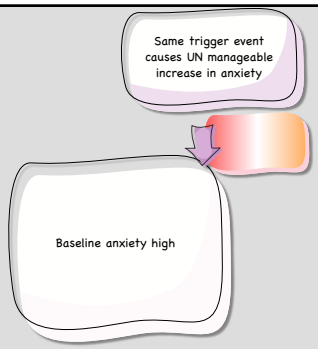

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MYTH: REASSURANCE HELPS

- Telling a child a phobia trigger is "no big deal", reassuring them they will be OK will generally not help them cope
- If reassurance resolve the anxiety it probably wasn't too intense to begin with!
- Reassurance begets need for *more* reassurance
- ***Ibland kan berolighet hjälpa men för mer intensiv rädsla, den vuxna som ger trygghet skapar behov av mer trygghet utan att minska rädslan***

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MYTH: GRADUAL EXPOSURE MEANS INCREASING AMOUNTS OF EXPOSURE OF THE WHOLE EXPERIENCE

- Scared of the cafeteria, treatment designed be to have the child spend 1,2,3,10 minutes in the cafeteria may still be starting at a too stressful level
  - Unbundling is key
  - ***Det är viktigt att separera komponenter av rädslan to treat each component enklare***

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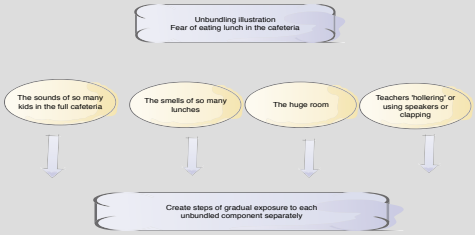
PREVIEW OF *UNBUNDLING* *SEPARERA KOMPONENTER AV RÄDSLAN*



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MYTH: BECAUSE A TRIGGER ACTUALLY CAUSES DISCOMFORT THE ANXIETY AROUND IT CAN'T BE TREATED

VI KAN BEHANDLA ÅNGEST ÄVEN OM SAKER SOM ÄR VERKLIGEN OBEHAGLIGA ELLER SMÄRTSAMMA

- Medical procedures really hurt, sounds really startle, losing feels badly
- While we can't eliminate the actual discomfort,
  - we can greatly reduce the emotional distress around it,
  - how it is anticipated and experienced
  - for example, ***vi kan minska rädslan för ljud***
- And this in turn often reduces although doesn't eliminate experience of discomfort.

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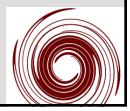

ANXIETY CONSIDERED DEVELOPMENTALLY

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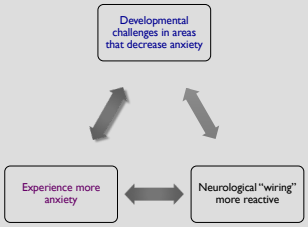
WHY IS ANXIETY SO PREVALENT IN PEOPLE WITH DD? A (HYPOTHETICAL) NEURO-DEVELOPMENTAL MODEL:



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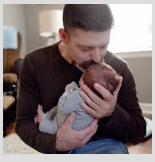
WE CAN THINK OF BABIES AS BUNDLES OF ANXIETY: SELF-REGULATION AND CO-REGULATION SOOTHES



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INFANTS WITH DEVELOPMENTAL DIFFERENCES OFTEN MORE VULNERABLE 'WIRING'

- Kids with WS probably have genetic neurologic wiring that causes anxiety
- Many have sensory processing challenges
- May be more easily 'jangled', more reactive overall, harder to settle, neurologically

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TYPICALLY DEVELOPING INFANTS AND TODDLERS LEARN TO MODULATE, LEARN WHAT IS/ISN'T AN ACTUAL THREAT' BY READING ADULT NONVERBAL CUES

- Infants learn new, increasingly regulated patterns, from social cues that are…
- *directed to the infant* – co-regulation efforts of caregivers (calming soothing parent holding infant)
- *And from incidental observed cues*

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YOUNG CHILDREN PRACTICE SCARY EVENTS THROUGH PRETEND PLAY ***SMÅ BARN ÖVAR LÄSKIGA UPPLEVELSER GENOM ATT LÅTSAS SPELA***

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THESE TOOLS, EARLY SOCIAL - COMMUNICATION, EXPERIENCE BASED PRETEND PLAY ARE LATER TO DEVELOP IN MANY CHILDREN WITH WS (IN ALL CHILDREN WITH ASD) ***SOCIAL KOMMUNIKATION, SPRÅK OCH LÅTSAS BRUKAR UTVECKLAS SENARE***

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TREATMENT DESIGNED FOR KIDS WITH WS…

- Recognizes and does depend on child having strong skills in social cue reading, communication or pretend play areas of difficulty
- Incorporates these skills, using them with scaffolding
- Often incidentally teaches skills in these areas

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HOW DOES A PHOBIA DEVELOP AND EVOLVE? **HUR BÖRJAR EN FOBI**

- Often there was some event or many events that were truly frightening/startling/unpleasant (may not know what) ***något skrämmande eller häpnadsväckande hände***
- Dread it happening again
- Fear ripples ***to things associated with it happening*** (fear of clouds in the sky as that could mean thunderstorm) ***rädsla sprider till saker som är associerade med vad barnet fruktar***

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FROM FEAR ***DURING*** THUNDERSTORM TO FEAR OF CLOUDS THAT ***MIGHT MEAN*** THUNDER TO FEAR OF CLOUDS ***IN WEATHER REPORT FOR NEXT WEEK TO CHECKING WEATHER REPORT MANY XS/HOUR***

- The fear ripples to anticipating the event '*anticipatory anxiety*'
- Then ripples to *anticipating* anticipating – *fear of fear… of fear*

SO IN THE FACE OF THIS CYCLE WHAT DOES A PERSON NATURALLY DO?

- Avoid
- Anticipate with dread
- vi hjälper naturligtvis barnet att undvika
- Power through in great distress when necessary
- Child may never gets to experience just the event without the anxiety in order to
  - ***Re-learn a new emotional response***
  - ***Bilda ett nytt emotionellt minne***
  - ***Revise ones thoughts, cognitions, feelings about the event***

IDEALLY THE CHILD COULD MAGICALLY…

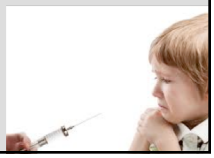
- …experience trigger without fear a few times - > CURED!

Treatment creates this, stepwise

I bästa fall,

i behandlingsprocessen barnet upplever den fruktade händelsen

i små mängder



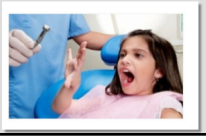
TYPICAL MODEL FOR TREATING PHOBIAS (AND MELTDOWN TRIGGERS) IN TYPICALLY DEVELOPING KIDS

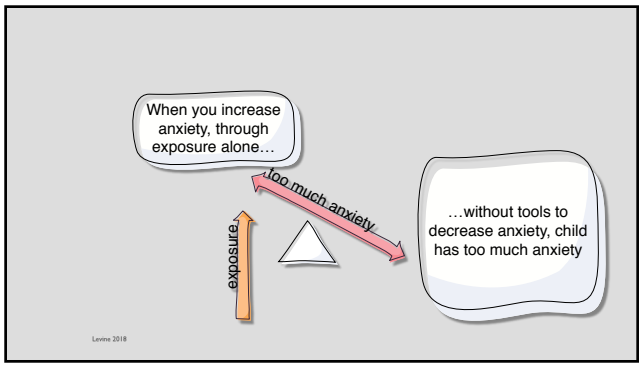
- CBT Cognitive Behavioral Therapy
  - ***Kognitiv Beteende-Terapi***
- ERP (Exposure with Response Prevention)
- Collaborative process done *with* the child

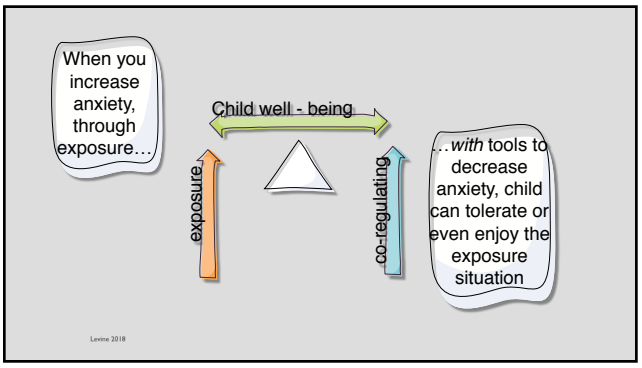
CBT BASED IN LOVELY COLLABORATIVE WORK BUT REQUIRES ADVANCED LANGUAGE AND META-COGNITIVE AND EXECUTIVE FUNCTIONING SKILLS

TYPICAL MODEL FOR TREATING PHOBIAS IN KIDS WITH ID/ASD: BEHAVIORAL W/OUT MUCH ATTENTION TO AFFECT, DEVELOPMENT, INTERACTION

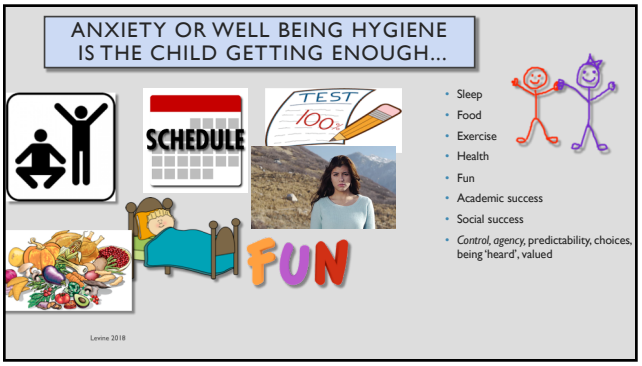
- ERP (Exposure with response prevention)
  - Gradually increasing exposure with some means to increase motivation and/or decrease distress
    - Distraction
    - Rewards
    - Escape Prevention







TREATING GENERALIZED ANXIETY



RELATIONSHIPS BETWEEN SENSORY AND EMOTIONAL SYSTEMS

- Sensory overload can cause anxiety, and some people are more vulnerable to this
- Emotional overload including anxiety can cause heightened sensory sensitivity
  - Reducing sensory overload may reduce anxiety
  - Reducing emotional overload/anxiety often reduces sensory sensitivity
    - In a moment in time
    - As a new baseline

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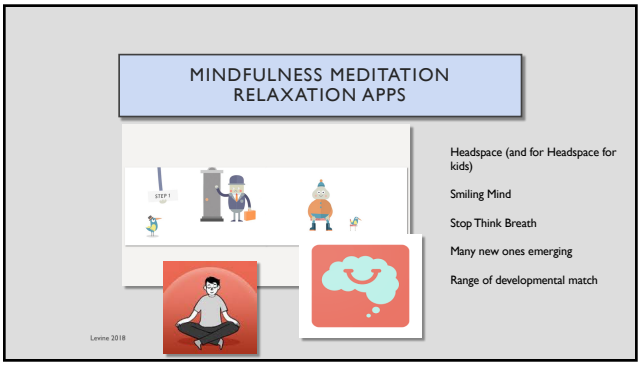

THE RIGHT MUSIC CAN BE VERY CALMING FOR MOST CHILDREN WITH WS

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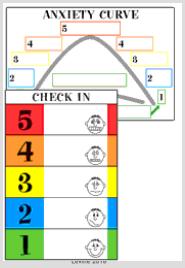
THE "INCREDIBLE 5-POINT SCALE" BY KARI DUNN



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IMPORTANCE OF DESIGNING AND STOPPING EXPOSURE BASED ON CHILD'S AFFECT

- Often unfortunately a pre-determined time or number of exposures is set in a plan
- Child control or basing in child's affect (for children who can't tell you verbally) -
  - Eliminates or greatly reduces child distress
  - Decreases anxiety so child can tolerate more
  - Increases potential for fun/child motivation to participate

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TREATMENT FOR PHOBIAS
BEHAVIORAL PLAY THERAPY (BPT)
OR ***REPLAYS***
BETEENDE -LEK TERAPI
(LEVINE, CHEDD AND KLEIN-TASMAN)

A child oriented individualized play based variation of components of CBT

En barnorienterad individualiserad spelbaserad variation av komponenter i CBT

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REPLAYS OR BPT
BEHAVIORAL PLAY THERAPY

OUR DEVELOPMENTAL, AFFECTIVE, RELATIONSHIP BASED BEHAVIORAL MODEL
TO TREAT PHOBIAS IN YOUNG CHILDREN

- Based on the principal of Gradual Exposure PLUS something to decrease anxiety
- It's the SOMETHING that is unique in this therapy
- Emphasis on using co-regulation, engagement, humor, playfulness to decrease child's anxiety during gradual exposure

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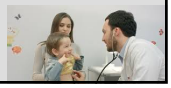
CHANGE A CHILD'S ***EMOTIONAL STATE***
FROM *ANXIOUS-WITHDRAWN*
TO *HAPPY-ENGAGED*
THEY WILL BE ABLE TO TOLERATE MUCH MORE OF ANXIETY PROVOKING SITUATIONS

HJÄLPA ETT BARN ATT VARA GLAD, MED LEKFULLHET, INTE OROLIG, OCH DE KAN TOLERERA MER AV DEN RÄDDA HÄNDELSEN



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REPLAYS OR BPT
BEHAVIORAL PLAY THERAPY CONT'D

- In BPT, the adult engages the child in re-enactment of all or parts of the trigger event including a version of the child's intense fearful responding
  - Adult tinkers with the play to both *maximize the child's* interest and pleasure while *gradually increasing exposure to the fear*
    - Vuxen arbetar för att maximera roligt samtidigt som exponeringen för den fruktade situationen ökar

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THE ADULT VARIES THE PLAY ALONG THESE DIMENSIONS DEPENDING ON THE CHILD'S RESPONSES

- pretend <-> realistic
- Intense affect <-> mild affect
- Slow <–> fast paced
- playful funny <–> serious lekfull till allvarlig

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INTERACTIVE PLAY/ENGAGEMENT INTEGRATED WITH GRADUAL EXPOSURE TO TINY INCREASING AMOUNTS OF THE PHOBIA OR ITS ELEMENTS

- Interactive Play as the medium for levels of gradual exposure of the fear trigger
- And, gradual exposure to distress - fear response
  - construct and modify based on child's affect
- The adult scaffolds interaction so child can participate in the social, affective play experiences that lead to greater coping capacity, just as TD children naturally engage in

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4 STEP CONCEPTUALIZATION OF PHOBIA TREATMENT

Step 1: Figure out key "trigger components" of the feared issue –

"*Unbundle*" the phobia

Step 2: Design levels of *gradually increasing exposure* (fear ladders) for each component

Step 3: Determine *activities, to reduce the person's anxiety (often interactive humor)*

Step 4: Go through each Level from Step 2, combined with anxiety reducing strategies from Step 3

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HUMOR/PLAYFULNESS…
HUMOR OCH LEKFULLHET

- Creates alliance with child
- A shared positive affective state diminishes anxiety
- ***en lekfull stämning minskar ångest***
- Creates new affective experience, and then positive memory
- ***skapar en ny känslomässig upplevelse och sedan nytt emotionellt minne***
- In playful mode, child feels more capable, more in charge of feared trigger
- Can remove anticipatory anxiety
- Optimal state for gradual exposure practice

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UNBUNDLING PHOBIAS

- May be more important to do for kids with less capacity to self regulate, inhibit, meta communication
- Unbundling allows exposure to proceed very gradually with child and adult working on single "strands" at a time so process can be pleasant

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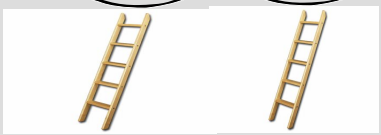
CONSTRUCT GRADUAL EXPOSURES (FEAR LADDER) FOR EACH UNBUNDLED COMPONENT

Fear of the sound of thunder

Fear of the surprise startle element



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FEAR LADDER FOR FEAR OF THE ACTUAL SOUND OF THUNDER

- Watch youtube clip together, announce just before the sound is coming (eliminate surprise element), and keep volume as low as possible
- With child's OK, do this many time gradually increasing volume
- Do this with multiple clips

- WHILE doing child specific things to reduce the child's anxiety
  - Making it fun and with familiar person
  - Can incorporate activities the child likes (Minecraft; favorite music etc)
  - Could be relaxation exercises, breathing, yoga

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FEAR LADDER FOR STARTLE/SURPRISE OF THUNDER SOUND

- Play youtube clips together with first very small and then gradually increasing 'window' of when the thunder might start
- Low volume then higher, combining elements

- WHILE doing child specific things to reduce the child's anxiety
  - Making it fun and with familiar person
  - Can incorporate activities the child likes (Minecraft; favorite music etc)
  - Relaxation strategies

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Components of the fear

Fear of thunderstorms

Fear of the actual sound of thunder

Fear of the Surprise element of the sound

Other possibilities: Fear of the sudden dark of lightening, heavy rain of others' anxious actions

Fear of fear Dreading feeling afraid

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SOMETIMES I ADD A 'LET'S SURPRISE EACH OTHER' GAME

- I'll close my eyes and you play the thunder.
- I pretend to be afraid.
- Now you close your eyes and I'll surprise you.

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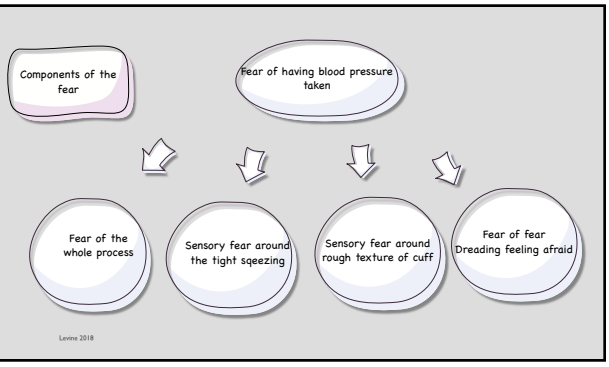
"THUNDER TUBE" TOY

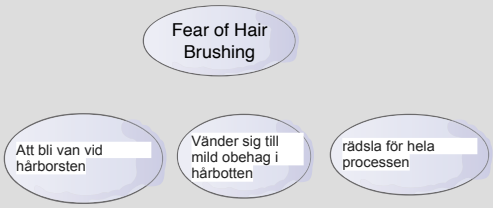
EVENTUALLY ADD MORE REALITY

- Play these activities outside, at night or in the dark inside
- Add intense rain audio
- Use big audio speakers so the sound is more realistic
- Storm exhibits at museum if accessible

UNBUNDLING PHOBIAS (DO GRADUAL EXPOSURE IN PLAY TO EACH ELEMENT)

- May be more important to do for kids with less capacity to self regulate and communicate
  - Can also be challenging to think up
  - Unbundling allows exposure to proceed very gradually with child and adult working on single "strands" at a time so process can be pleasant





HUMOR/PLAYFULNESS…

- Creates alliance with child
- A shared positive affective state diminishes anxiety
- Creates new affective experience
- In playful mode, child feels more capable, more in charge of feared trigger
- Can remove anticipatory anxiety
- Optimal state for gradual exposure practice
- Pacing, content, style, based on the child's unique make-up

WHERE DOES TREATMENT TEND TO GO AWRY *VILKEN TYP AV PROBLEM HAR VI OFTA MED ATT GÖRA DETTA?*

- Adults run out of 'in-between' steps to try
- ***springer ut ur steg på stegen för att lägga till inkrementella komponenter***
  - Consider range of home-made video (sibling or classmate doing the feared thing, modeling playful fear)
  - Ways of using role play/pretend more and more realistic
  - Re-look at unbundling – are there more subcomonents?

PROBLEMS, FORTSATT

- Adults trying to engage the child in fear play accidentally scare the child - ***oavsiktligt skrämma barnet***
  - Use many 'signals of play', monitor child's affect, *baby steps*
  - Can always repair!
- Real event (e.g. shots; storms; separation) arise before child is ready, sets process back

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THIS TREATMENT MODEL CAN BE USED -

- In clinics - across disciplines, mental health treaters, SLP, OT
- In schools – classrooms
  - Teachers
  - Assistants / Paraprofessionals with guidance
  - OT, SLP
  - Counselors
- Can be done as a group with common fears (shots; separation)
- By parents at home –
- At home with parents and EI or other home therapists

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ADJUST AS YOU PROCEED WITH THE EXPOSURE PROCESS

- Based on the child's response
  - Afraid enough so the process is getting at the anxiety
  - Not too afraid to cope and want to continue
- Adjust the ladder 'rungs' and the strands
  - New components may emerge
- Adjust the mechanisms to reduce anxiety

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ADAPTING, CREATING AND MONITORING HOW ONE IS WORKING TO HELP A CHILD

- Need for highly individualized approach within sensible tried and true frameworks
- More experiential focus
- More focus on use of favorite activities, unique humor, and relationship (co-regulating) to decrease anxiety while doing gradual exposure
- More focus on *unbundling* to create small enough components of anxiety to be tolerable

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SUMMARY

- Anxiety is very common in people with WS
- And it can have huge negative impact ***but***
- Phobias are often quite treatable
- Can be a very positive treatment experience for all involved

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