

From Me to You

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Meet Jane: Jane was born with a complex medical profile including hydrocephalus aqueduct stenosis which required shunting, septo otic nerve dysplasia and a profound hearing loss. Jane is deafblind. She has epilepsy, and significant constipation and sleep issues. Jane is now over 4 years old, but we met her when she was 2 and half on an outreach trip. Her rural home meant she qualified for the Vidkids project. This project, funded by the department of social services enabled a regular early intervention program to be provided to Jane and her family via videoconferencing.

Today's presentation will reflect on how the Active Learning approach can be effectively implemented via videoconferencing with children with multiple impairments, like Jane, who traditionally may not have been involved in video-therapy.

Our approach with Jane was based around three main theoretical frameworks:

Firstly, a family centered approach- this recognises that Jane is a part of an extended family and it is their day to day interactions that provide the key to her development

Secondly, intensive interaction- drawing on the work of Dr Dave Hewett we supported the family with Jane's permission to enter her world, share her experiences and follow her lead

And last and what we are primarily discussing today, Active Learning – established by Dr Lilli Nielsen, it is a developmental approach based on the premise that nearly all children can learn and do so through their own activity. The focus of Active Learning is two fold:

- Firstly – Lilli states, “The integrated skills that a learner has achieved while being self active become part of ones self perception and self identification; an understanding and appreciation of oneself to be a separate person with particular skills and qualities...an own personality. Jane is on a continuing journey of developing self identity.
 - o Prior to our intervention over videoconferencing, Jane's identity basically consisted of:
 - I am the one who lies in my cot on my back
 - I am the one who can cry to communicate my displeasure
- The second component of Active Learning is the use of the Functional Scheme. The Functional Scheme is an assessment tool specifically designed to assess where a child is functioning across all developmental domains. The functional scheme is ideal for this population as it breaks down skills into 3 month brackets which allows the smallest gains to be recognized and celebrated, which can be very significant for families. Based around play, it is holistic and looks at all domains in relation to play, which of course is what children do, and how they learn. The Functional Scheme was used with Jane to assess her developmental level, form achievable and meaningful goals and monitor her progress.

Based on the Functional Scheme, when we first met Jane;

- Her communication was in the 0-3 month level, Jane was able to cry in varied tones, to indicate displeasure or pain and perform mass movements to express joy and contentment
- Socially and Emotionally Jane was not meeting skills in the 0-3 month, level. She was not responding to familiar people and was not able to be comforted by them.
- Jane's Play Skills were at the 3-6 month level. She was able to play with her feet; push objects away from herself, scratch surfaces and hold onto her pillow.

- Jane's spatial perception was back at the 0-3 month level, with the only space she really understood being her cot
- Jane's Gross motor Skills were at the 3-6 month level. She did have some postural control and movement on her back but was reluctant or had a lack of experience to perform other gross motor movement, including moving in space.

In order for Jane to learn to explore her world we identified 3 primary considerations, all of which were able to be enhanced through videoconferencing. These included, the necessity to be consistent, the importance of developing (through attachment) meaningful communicative interactions between Jane and her primary carer's, and the philosophy of Active Learning as a means of Jane learning to be self active and establishing her identity.

For children with a vision impairment and especially if they have additional impairments, like Jane, consistency is crucial – from environment to handling, to communication, without consistency it was impossible for Jane to learn and construct her world.

From our experiences, children with additional needs, such as Jane, are often more susceptible to poor health. Delivering service via videoconferencing enabled more regularity of service. Jane had frequent ear infections and seizures, naturally increasing her irritability, and reducing her willingness to be active. Typically this would mean missed therapy sessions and prolonged periods without any intervention. However with videoconferencing we were still able to link with Jane's family, as there was no need for Jane to leave the house. We could be flexible with the timing of the session to work with Jane within her limits. This allowed for a continuity of service giving more options to the family than previously possible.

Utilising Jane's natural environment (Demiris, Shigaki, and Schapp 2008) and working within family routines (McWilliam, 2009) also played a significant role in our endeavor to develop consistency for Jane. Providing therapy in Jane's natural environment was even more relevant in her case, as she would become extremely defensive in unfamiliar environments, resulting in no therapeutic benefit. Through videoconferencing we were able to target routines as they occurred in real time.

Video – Jane feeding self

This video is from a mealtime session. Prior to this video we had already provided some coaching to her mum. Notice that the bowl is in front of Jane, allowing her opportunity to explore the food and understand where it is coming from. Jane also has a couple of spoons so she can practice using the spoon if she wants to. Jane has her feet touching the adult so she is aware of where the adult is in relation to herself. Through further coaching we were able to make mealtimes more meaningful by adding in some body signs and positioning the adult to the side so that Jane could feel the action required to use the spoon.

Video – Hair brushing

- This second video shows a hairdressing session which was a particularly difficult routine for Jane. Previously this activity took place with the Jane sitting on the adults lap. As Jane was familiar with her high chair we suggested she use it for hair brushing. Notice that the adult is removing the dummy from Jane and signing 'stop' on her hand. This has been a successful communication sequence used with Jane in a number of settings to assist her to self calm.

Our second consideration was the development of attachment and meaningful communication. Jane's deafblindness, along with significant environmental factors, meant that at 2 and a half years of age, she still had no real attachment with anyone or anything, beyond her cot, pillow and dummy. Jane became very defensive both emotionally and tactily if removed from her little comfort zone. Jane demonstrated this by withdrawing her hands and crying incessantly. Ultimately this affected her play as she would not touch or manipulate any other objects.

Attachment theory (John Bowlby and Mary Ainsworth) suggests that a child needs to develop a secure relationship with at least one primary caregiver for ongoing social and emotional development. Dr Lilli Nielsen likewise proposed that 'a child, particularly a child with disabilities, will only progress cognitively as far as they have developed emotionally and socially'. Thus, attachment creates a secure base for a child to explore the world.

Given the constraints of the availability of therapists in Australia, and the move towards a consultative approach, there is no way we as the therapist can form an appropriate relationship with such a child for them to trust us to interact with them and handle them. Over videoconferencing, we were able to leave Jane in her natural environment and work with the few people who it was relevant for Jane to establish attachment. Through this medium Jane's family were able to have their first meaningful interactions with Jane, and we all realized the potential of working in this way with children like Jane. We were able to guide the adult in interactions in real time to extend Jane's communicative interactions, without imposing on Jane.

Video-

This video shows Jane lying on her mum. This activity not only provided an excellent opportunity for tummy time which Jane was previously resistant to, more importantly it allowed safe close contact for Jane to 'be' with someone, playing back and forth kissing game and Jane exploring her mother's face and hair which is normal for a baby. Attachment enabled Jane to extend her world to include others which led to the beginnings for interactive play.

Drawing on the natural instincts of Jane's mother and with coaching from the therapist, a variety of interactive games were introduced and incorporated into Jane's day. Over time some of these games were able to be played by others in the family as well as ourselves as you will see in the following two videos during a one off face to face visit.

This first video shows a variation of peek a boo, using a scarf to provide light touch. Jane originally played game this by covering her eyes with her hands and removing them to allow the adult to kiss or blow on her face.

This second video shows the 'blowing game', an interactive turn taking game which was very meaningful to Jane as she enjoyed the feel of the air on her face and lifted her face towards the therapist to indicate that she wanted the game to continue.

Our third consideration in our therapeutic approach with Jane was the Philosophy of Active Learning. As noted earlier Jane's defensiveness caused her to be highly selective with her choice of objects she was willing to manipulate. And it was imperative that Jane further her play skills to explore objects and in so doing establish her knowledge of concepts, the foundation for further learning. Active Learning promotes a child to be self – active and without this self generated exploratory play it is difficult to develop an understanding of

concepts and without concepts it is difficult to develop meaningful communication (Space and Self, Dr Lilli Nielsen, 2003)

Using the Active Learning approach we were able to set up varied play environments and materials that were developmentally matched to Jane's level of functioning. Dr Nielsen states, 'if the environments and materials are not varied the child can become habituated or patterns of play stereotypic'. This video demonstrates how we set Jane up, again in her safe place, her high chair with a bowl positioned beside the tray to allow the easy retrieval of objects. It also provides an example of some of the everyday objects we offered to Jane to progress her play and encourage her to extend her world. For example, you may not be able to see on Jane's tray, but there are 2 whisks, one with a hard ball and the other with a soft ball inside for a comparison in weight, density and vibration.

The final key focus of therapy sessions was assisting Jane to develop a willingness to be self active, in movement and play, to become an active learner. Jane did not have significant musculoskeletal or neurological imbalances sufficient to explain her inability, or better described aversion, to move from her back. So my focus moved to a different contributor to movement – motivation. We cannot underestimate the motivation for movement provided by visual and auditory stimuli. Babies as young as 60 hours old are able to orient themselves toward a source of visual stimulation and can follow a moving object by correctly orientating the head (Bullinger, 1981). Studies suggest that blind babies show this early visual motor coordination, but it disappears after a few weeks. This is where the full impact of Jane's condition became apparent: one, she had a lack of body and spatial awareness to know she could move and influence her surrounds and position in her surrounds, and two, she received so little feedback from her environment or actions to encourage further movement, that she simply did not move. It was too scary to 'move to nothing' and there was no reason or reward for doing so.

To overcome this, firstly we worked on Jane's own body awareness (or her proprioceptive system) through a few mediums, including massage, tickle games, and particularly play with a peanut ball.

Video – This video shows Jane being assisted in play on her peanut ball by myself during our face to face visit. As she rocks back and forth on the ball, Jane is getting feedback through her proprioceptive system, about where she is through her tummy, hands and feet, as well as her vestibular system through the movement. She is also strengthening her body and developing her protective reactions. Once again encouraging Jane's initiation in the game was a focus, I would sign more on her back, and she would push off again. Jane actually progressed to playing this game on her own.

As Jane learnt about her body, the next step was understanding where she was in space. Understanding spatial relation is defined as 'a component of achieving object concept and object permanence, and knowing the relationship between oneself and the objects and events in one's environment.' Research from Dr Lilli Nielsen shows that setting up small spaces with boundaries and specific objects to optimize feedback increases self-activity and she found the main reason for this was a development of spatial awareness and subsequent self-identity. Dr Nielsen discusses how a new born baby experience little spaces of the cot, their parent's arms and pram where they can push against the borders with their body to gain feedback. As Jane was still developmentally at this early infant level, creating little spaces was paramount for her to ever develop spatial perception.

As you can see on the screen, some of the little spaces we guided Jane's parents to set up included a tent, a small blow up swimming pool, her cushion pile, and of course a Little Room. Over videoconferencing we were able to observe Jane in these spaces and suggest modifications and new places without us being intrusive to the spaces. We gradually saw these spaces become places of significance for Jane, and her understanding of them became clear as when Jane was put in these places she would calm and play.

As Jane began to learn about the space around her she was able to develop self-initiated explorative play. Part of this involved joining little places together to form a larger map or extending the perceptual field. For a typically developing 0-8month old, their perceptual field is only with reach while lying down, but for a 9-10month old it develops vertically as well as horizontally, ie. Sitting up. As children tend to play higher functioning games when sitting upright, and there is more opportunity for communication in the position, our goal became for Jane to sit upright as her preferred position to play. Introducing Jane to these positions, and of most importance, teaching Jane to transition between positions, involved much education of her family, around handling and how to use positions in play. I remember one whole video session where we had developed a sign for roll, and were playing a game of Jane rolling down her mum's legs ending in sidelye, where she would be helped to transition to sitting, and the game repeated if she indicated she would like it to.

After 1 year of being involved in videoconferencing, Jane relocated and was no longer eligible for Vidkids. Jane had progressed from her initial assessment, where she predominantly functioned at the 3-6 month level. She now demonstrated skills across most areas at the 6-9 month level, with some emerging higher level skills.

As we mentioned at the beginning of this presentation, the purpose of Active Learning is ultimately for a child to develop self-identity – to become 'the person who can'.

Jane's identity progressed from being the one who would only lie on her back and cry to communicate displeasure to:

- I am the one who lies in my cot to sleep
- I am the one who likes to be cuddled by a familiar person and give cuddles back
- I am the one who can understand and communicate
- I am the one who has arms and legs, and can make objects move with them
- I am the one who can feed myself sometimes
- I am the one who can play by myself and with others
- I am the one who can sit to play
- I am the one who can explore and move myself between my places
- I am the one who can make choices
- I am the one who can love and be loved

Videoconferencing put us in a unique position where we were forced to take a 'hands off' approach, and it was perfect for working with Jane. Conversely, Jane's family had to become more involved in sessions and the more they discovered they could interact with Jane, the more empowered they became, and so too did Jane transform as her motivation to move, play and explore increased. We were present but unimposing in Jane's environment where she became comfortable to be active, and we could guide her trusted capacity person assisting with the session how to better handle or alter the interaction for a particular result

From our work with Jane, I think there are 2 points which I hope you can consider for the future.

- Firstly, videoconferencing is an effective medium to move forward with from traditional therapy approaches for providing services to all children but especially those with additional needs. Validating our experiences as an evidence based treatment method in this population is certainly a potential future research prospect.
- Secondly, using the Active Learning approach through videoconferencing does enable a child to become self-active, so that they can establish their own unique skills and qualities, their identity, which they can bring as they discover the world.

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